# Culture & Autism

# UCLA Tarjan Lecture Series

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# 3 "Learning objectives"

Provide some findings from social and cultural research on disability and autism

What methods from sociocultural research will help to understand autism and family responses

What might help to provide a culturally-aware or culturally-informed engagement with families and children with autism – examples from studies in India & Los Angeles

Imagine a young child in your mind's eye; now, add that this young child currently has (or will develop) ASD, ADHD, learning problems, or another serious developmental disability. What is arguably the single most important influence on the likely developmental pathway of that young child?

**If you could do one thing to influence the developmental pathway of that child … what would that be?**

From a sociocultural perspective, the answer would be the … place on earth where that child is going to grow up. Place means not only the geographic locale and ecology, but also includes *the family, local community, its resources, ways of life and shared beliefs about development and disability. Certainly diagnosis, services and biomedical interventions should be important, as will be community attitudes, family socialization and care along with many other features*.

What diagnostic categories, services, and interventions are available, accessible, and understood to be effective in that community? What beliefs about cause, treatment, care, and stigma are shared and contested? How is carework understood and accomplished?" What is the explanatory model for this illness?

What resources will the family / community have? Who will caregivers be; how is love, stimulation, attachment and security, sibling relations, and gender roles shown and managed?  What are marriage and inheritance systems, residence rules? What are the competing investments the family, community and state are facing?

# ANOTHER CONTEXT: THE ASD COMMUNITY AS A "CULTURE"

**The culture, or community support and recognition of and by, those with ASD. The ASD community as a culture, a supportive, interactive collective with shared beliefs, values, practices, resources, institutions, identities.**

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**Cultural Learning Environments: Culture is experienced as the characteristics of activity settings we engage with and give meaning, in our everyday routines of life**

Activities or practices of everyday life (bedtime; mealtime; homework; going to church; play; play dates; soccer practice; chores; …)
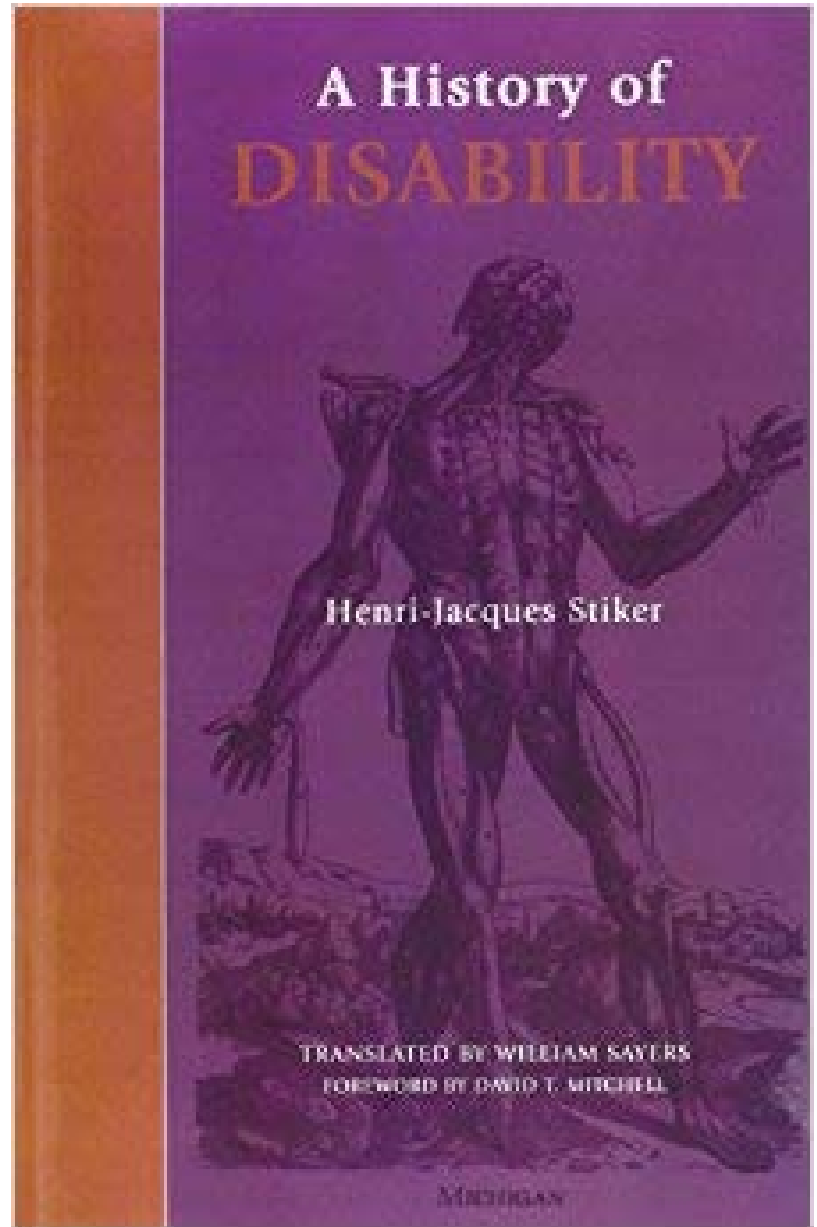
- *Scripts* or norms for conduct including *beliefs and social categories (including explanatory models for why things are they way they are)*
  - *Tasks* to be accomplished
  - *Values and goals* within belief systems
  - *Emotions and motives* experienced
  - *People and relationships* available and expected for support
  - *Resources* needed and available within a broader cultural ecology
  - *Predictability,* stability, routinization of a daily routine that is meaningful

# Some implications of having a sociocultural, or contextual, view of autism and disability more generally

# DIFFERENCE IS CONSTRUCTED BY CULTURE AND SOCIETY, AND ALSO IS A REAL FACT IN OUR BIOLOGY AND IN THE WORLD

- We expect similarity and basic competence yet always find diversity and highly varied levels of competence.

- Society "rehabilitates" at the same time as it monitors, supervises, & regulates.

- WHEN EVEN A CLEARLY IDENTIFIED BIOLOGICAL DISEASE (ASD) BECOMES AN ILLNESS AND DISABILITY, THE CULTURAL CONTEXT AFFECTS EVERY ASPECT OF THE CONDITION.
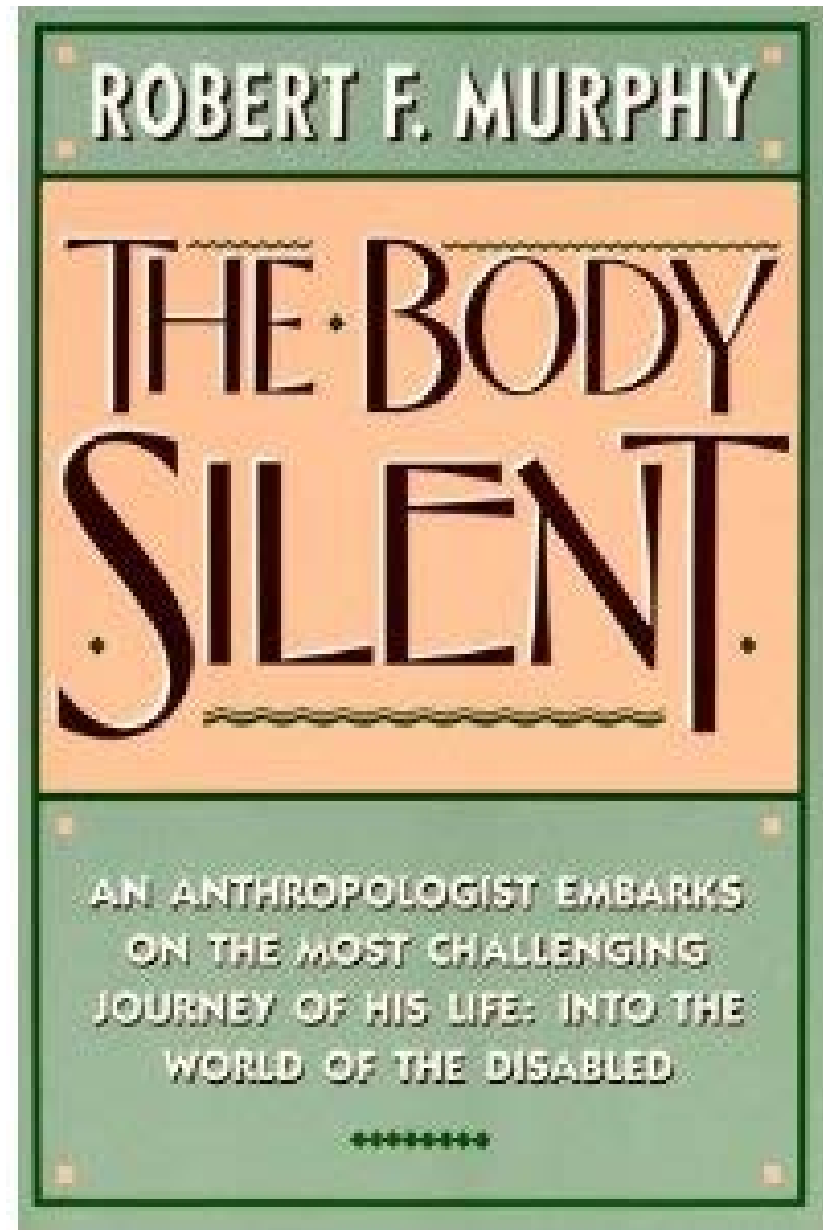
(Henri-Jacques Stiker (*A History of Disability*)



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**DISABILITY DEEPLY AFFECTS THOUGHT AND CONSCIOUSNESS. ITS <u>EXPERIENCE</u> IS CENTRAL TO UNDERSTANDING ITS MEANING AND ITS IMPACTS ON EACH PERSON**
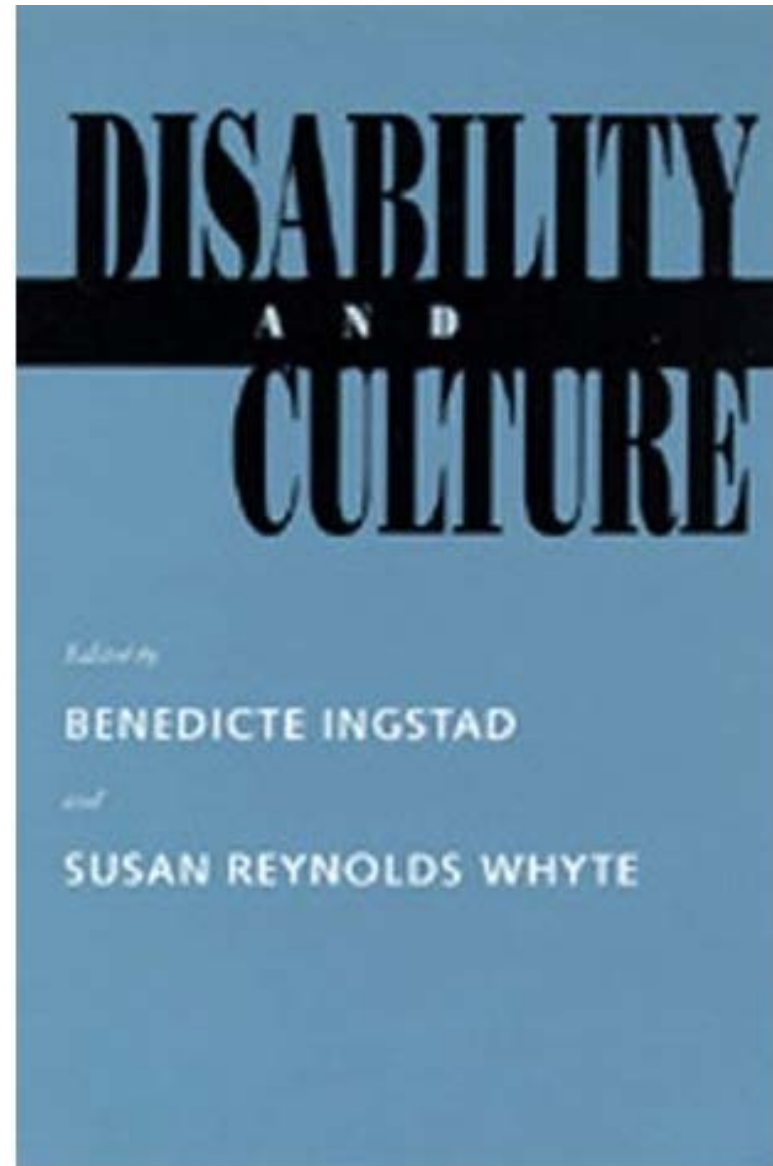
EXAMPLE: AN ANTHROPOLOGIST WHO WAS STRUCK BY AN INOPERABLE SPINAL TUMOR AT THE HEIGHT OF HIS SUCCESS, WHICH GRADUALLY AFFECTED ALL HIS ABILITIES AND KILLED HIM

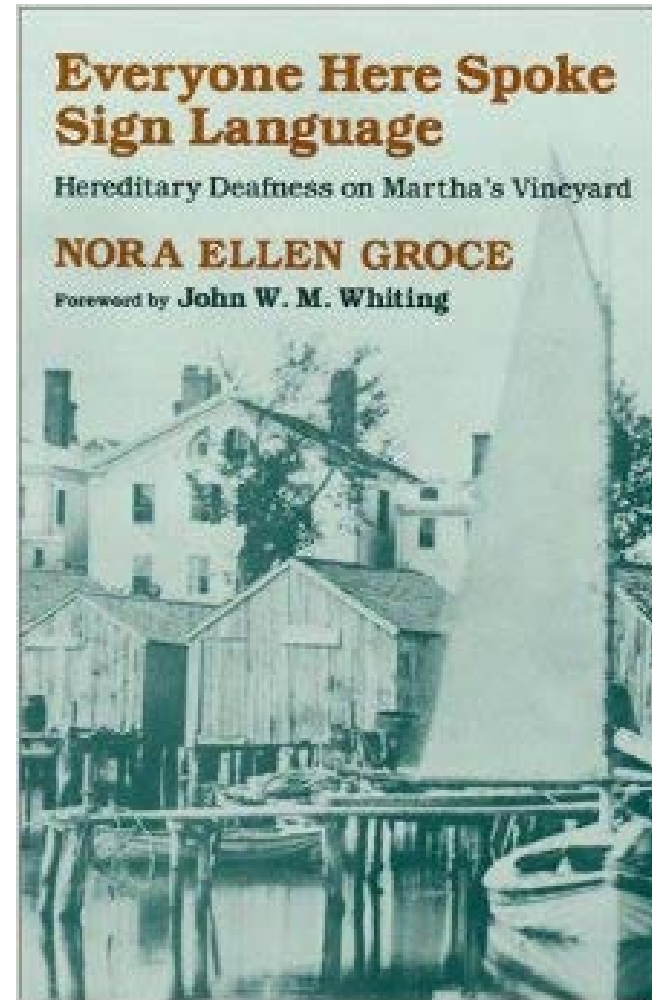ROBERT MURPHY, *THE BODY SILENT*



ROBERT F. MURPHY
THE·BODY·SILENT·
AN ANTHROPOLOGIST EMBARKS ON THE MOST CHALLENGING JOURNEY OF HIS LIFE: INTO THE WORLD OF THE DISABLED

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# DISABILITY IS CONNECTED TO OTHER DIFFERENCES IN SOCIETY

- DISABILITY IS RECOGNIZED UNIVERSALLY IN ALL KNOWN COMMUNITIES.  IT'S FORMS AND RESPONSES VARY WIDELY HOWEVER...

  - *DEPRIVATION, EXCLUSION & VULNERABILITY (DEV)* AFFECT EVERY ASPECT OF DISABILITY IN ALL KNOWN COMMUNITIES.

- **POVERTY, GENDER, CLASS AND CASTE, RELIGION, ETHNICITY – ALL THESE ARE INTERTWINED WITH DISABILITY AND MENTAL ILLNESS**
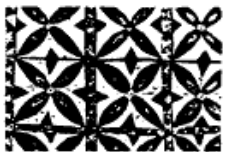
INGSTAD & WHYTE, *DISABILITY & CULTURE*



DISABILITY AND CULTURE

Edited by

BENEDICTE INGSTAD

and

SUSAN REYNOLDS WHYTE

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**HOW A PERSON IS TYPICALLY EXPECTED TO FUNCTION <u>AS A SOCIAL ACTOR IN THEIR COMMUNITY</u> (HOW WE ARE EXPECTED TO ACT AS A PERSON) IMPACTS CULTURAL RESPONSES TO DISABILITIES**

- EXPECTATIONS FOR VERBAL COMMUNICATION, PHYSICAL ACTIVITY, OR UNUSUAL BEHAVIORS CAN BE MORE TOLERANT.  BUT THERE ALWAYS WILL BE EXPECTATIONS.

- SOCIAL PRACTICES CAN CHANGE TO MAKE IT EASIER (EXAMPLE OF USE OF SIGN LANGUAGE)

- HOWEVER: SOME EXPECTATIONS ARE NOT FLEXIBLE CROSS-CULTURALLY, SUCH AS PHYSICAL VIOLENCE & THREATS, SEXUAL BEHAVIORS, COMMUNICATION, SOME OTHERS….

**Everyone Here Spoke Sign Language**
Hereditary Deafness on Martha's Vineyard
**NORA ELLEN GROCE**
Foreword by **John W. M. Whiting**

PROBLEMATIZING IMPAIRMENT: CULTURAL COMPETENCE IN THE CAROLINES[1]
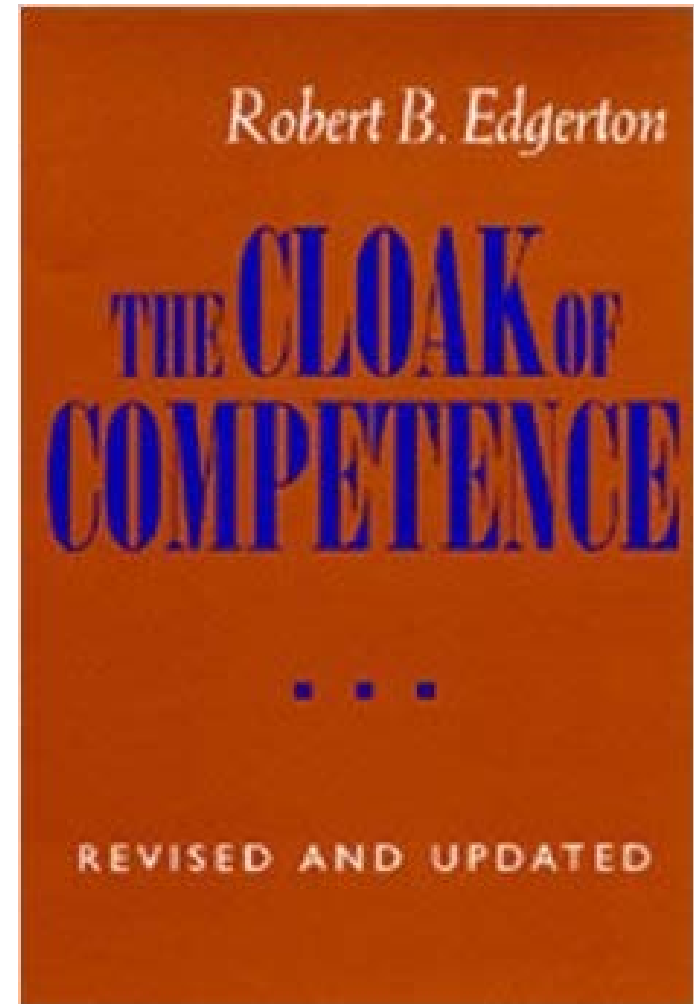
Mac Marshall
University of Iowa

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**WEARING A CULTURAL "CLOAK OF COMPETENCE" – BEING ABLE TO FUNCTION, OR "PASS" IN THE EVERYDAY WORLD -- IS A DIFFICULT PROJECT FOR PERSONS WITH DISABILITIES.**

BUT IT IS ALSO DIFFICULT FOR TYPICALLY-DEVELOPING PEOPLE AS WELL. IT IS DIFFICULT FOR ALL OF US IN SOME WAYS, TO SOME DEGREE.

WE *ALL* RELY ON OTHERS FOR HELP AND SUPPORT. SELECTIVE SUPPORT, LEAVING OTHER ASPECTS TO THE PERSON TO DO THEMSELVES, LEADS TO MORE SOCIAL INTEGRATION. **BENEFACTORS**.

Robert B. Edgerton

THE **CLOAK** OF **COMPETENCE**

. . .

REVISED AND UPDATED

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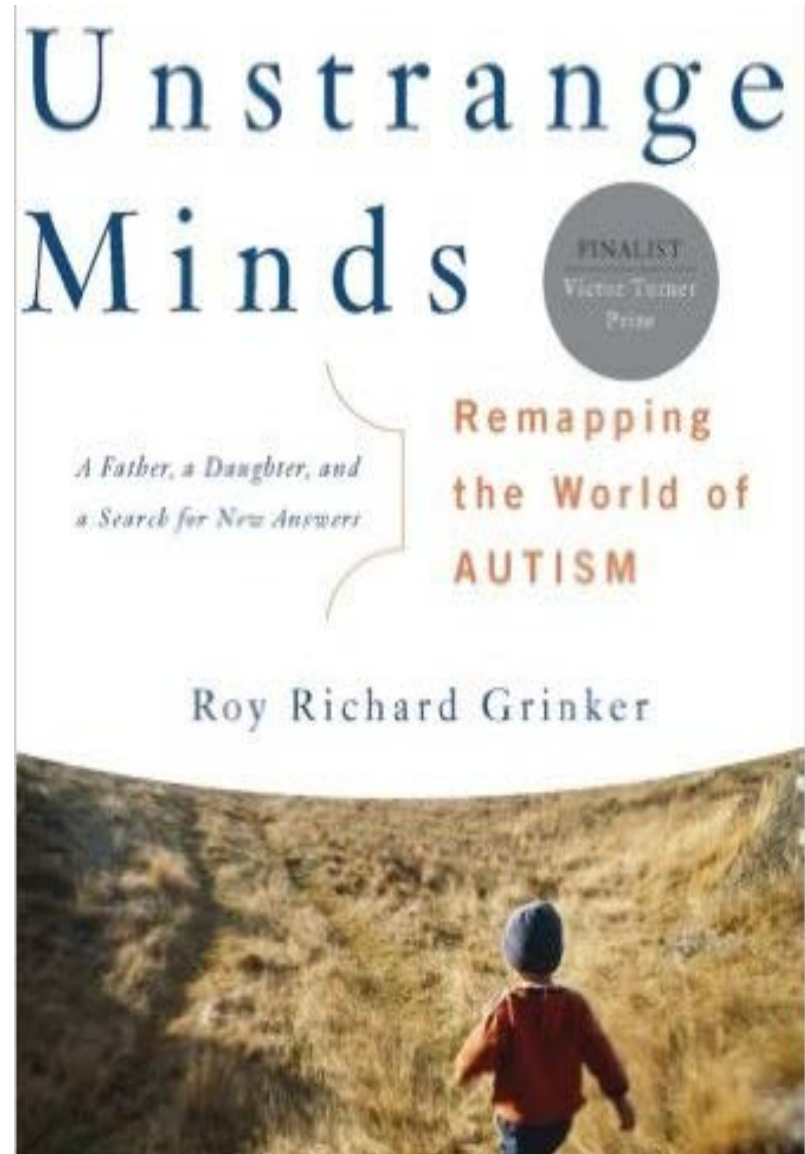Program for Culture, Brain,
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**-Awareness of ASD is widespread; but prevalence studies, diagnostic systems, treatment and support systems are very few globally.**

**-Increased diagnosis is due to awareness and shifts in diagnostic categories.**

Grinker's daughter Isabel has ASD.

SIX COUNTRIES' EXPERIENCES WITH ASD: INDIA, SOUTH KOREA, SOUTH AFRICA, PERU, FRANCE, US (+ OTHERS).



Unstrange Minds

FINALIST
Victor Turner
Prize

Remapping the World of AUTISM

A Father, a Daughter, and a Search for New Answers

Roy Richard Grinker

Discovering Successful Pathways
in Children's Development

Mixed Methods in the Study of Childhood and Family Life

Edited by Thomas S. Weisner

Mixed methods and interdisciplinary, holistic

Integration of qualitative & quantitative methods

Multiple research designs

Community, family, institutional & intervention studies

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# EXAMPLES

- CULTURE, BRAIN, DEVELOPMENT AND MENTAL HEALTH (CBDMH) PROJECT:  PARENT-CHILD TRAINING PROGRAM IN INDIA.  THE ACTION FOR AUTISM NGO IN NEW DELHI
  - *Evaluation of AFA parent-child training program*
  - *Narratives of parents before & after treatment*
  - *Self-descriptions*
  - *Daily lives of adults with ASD*
  - *Partnership research model*

- THE UCLA STUDY OF CHILDREN WITH DEVELOPMENTAL DELAYS IN LOS ANGELES
  - **Teen understanding of self and identity**
  - **Friendships**

# CBDMH Action for Autism (AFA) India Partnership

- The AFA team (from rt.)
  - Nidhi Singhal
  - Merry Barua
  - Tamara Daley
  - Indrani Basu
  - (tall guy on the left)
- Collaborative: MOU
- Joint projects
- Research assistants in Delhi & UCLA

Rachel Brezis, FPR postdoc



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# CBDMH & Center for Culture & Health, UCLA, & Foundation for Psychocultural Research.
## Culture & Disability: Autism Spectrum Disorder in India

- Action for Autism (AFA) NGO ***partnership & collaboration*** in New Delhi (Weisner, Daley, Barua, Singhal)

- Two Research studies:
  - *Parent-Child Training Program (PCTP) at AFA (Daley, Singhal, Weisner, Barua)*
  - *Parent narratives about their child before and after PCTP (Brezis, Weisner)*

# The AFA India Research Team

# UCLA TEAM

# Acknowledgments (UCLA - AFA partnership)

Project leaders:
- Tom Weisner
- Tamara Daley
- Nidhi Singhal
- Merry Barua

UCLA Coding team:
- Navjot Sandhu
- Shreya Chollera
- Avani Bedagkar

AFA Research Team:
- Deepali Taneja
- Sachita Suryanarayan
- Simi Sunny
- Nidhi Singhal
- Rubina Pradhan
- Tanvi Behl

PCTP leader: Indrani Basu

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# Stated goals of the AFA Parent Child Training Program (PCTP)

PCTP uses Western autism-training methods (such as TEACCH, Applied Behavioral Analysis, and Floortime) with cultural adaptations

Increase:

- Parent's *acceptance* of the child
- Parent's *understanding* of autism
- Parent's *teaching* skills
- Parent's sense of *empowerment*
- Child's *functioning* improves

Decrease parental *stress*

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# Evaluation of the PCTP: Overview

- Three cohorts of 13-15 mother-child dyads in each
- Upper income and education; Hindu; joint & conjugal households; ADOS child assessments
- Families are evaluated pre- and post the 3-month treatment program; as well as at 6-month and 12-month follow-ups.
- <u>Blend of measures</u>:
    1. use of Western measures adapted for Indian context,
    2. use of Western methods (not adapted); and
    3. novel measures created specifically for Indian context
- <u>Mixed-methods</u>: combining standardized, quantitative measures with qualitative observational measures and coded interviews

# Findings: Overview

- Mothers report increased empowerment, acceptance, skills

- Somewhat reduced stress

- Only scattered changes in children's behaviors however

- ***Many gains still present at 18 months post-program !***

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# Parental narratives about their child

- Mothers and fathers interviewed using the Five Minute Speech Sample (FMSS) before and after PCTP program

- Parents' own narratives about their child and ASD

- N=40; 3 cohorts of training courses; parents in top 10% of income distribution in India

-  Reliable coding of narratives

Brezis, Weisner, et al. 2015. Parenting a Child with Autism in India: Narratives Before and After a Parent–Child Intervention Program. Culture, Medicine & Psychiatry."

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# Topics mentioned by parents (% mentions)

- **Child's behavior   100  SEE NEXT SLIDE!**
- **Growth and change in parent or child   69**
- **Parent (self-reflection)   63**
- **The parent–child relationship   62**
- **Other people and children   58**
- **Spouse   54**
- **Other treatments and diagnoses   54**
- **PCTP Program   53**
- **Autism terminology   53**
- **Future   42**
- **Family   36**
- **Siblings   22**
- **Religion   11**
- **After parent's death   10**
- **Society/community   8**
- **Child as teacher   5**
- **Parent display of emotion   4**

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# Child behaviors mentioned by parents (% mentions)

- **Social relationships and play skills   77**
- **Cognitive skills, academic skills, learning ability   65**
- **Communication skills   61**
- **Self-help, independent living skills 56**
- **Challenging behaviors   44**
- **Comparisons to normality   34**
- **Attention and activity   34**
- **Positive emotions   27**
- **Following directions   26**
- **Restricted interests and routinized behavior 12**
- **Sensory interests or sensitivity  9**

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# Results

-- Parents who spoke in Hindi, came from relatively lower income families, and who were living in larger, joint households, were significantly more likely to mention their child's independent skills; to speak about their concerns for what would happen to their child after their death; to make references to religion; and to cry during the 5-minute narrative period.

-- Parents who spoke in English, and who came from smaller, nuclear families, with a higher income, were more likely to reflect about their own role as a parent; to speak about the broader society and community; and to view their child as, at times, their teacher. Higher income parents either focused more on academic achievement—or explicitly rejected such goals.

-- There is a greater focus of parents from nuclear families (vs. joint families) on their child's cognitive skills.

Brezis, Weisner, et al. 2015. Parenting a Child with Autism in India: Narratives Before and After a Parent–Child Intervention Program. Culture, Medicine & Psychiatry."

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# Results, con't

-- After participating in the PCTP, parents were significantly less likely to mention other people and children and the child's siblings, or compare their child to 'normal' standards; at the same time, they were more likely to reflect on the past and future.

-- There was no significant change in parents' mentions of any particular child behavior before and after the program; however, there is a significant decrease in parents' mentions of normality.

-- Mothers were more likely than fathers to speak about their relationships with their child, and to reflect on their roles within the relationship, while fathers were more likely to speak about their spouses' roles.

Brezis, Weisner, et al. 2015. Parenting a Child with Autism in India: Narratives Before and After a Parent–Child Intervention Program. Culture, Medicine & Psychiatry."

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# TWO CHILD PROJECT STUDIES

- YOUTH'S EXPLANATORY MODELS OF DISABILITY (UCLA Los Angeles disability study)

- FRIENDSHIP AND PEER RELATIONSHIPS (UCLA Los Angeles disability study)

- 102 families with developmental disabilities of uncertain etiology followed from age 3-4 to 16-18. 1984 -2002. Mixed methods. Center focus on family circumstances, accommodations, and adaptations, and child developmental trajectory.

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# CHILD Project Acknowledgements

- National Institute of Child Health and Human Development

UCLA Colleagues:

- Barbara Keogh
- Kazuo Nihira
- Ronald Gallimore
- Robert Edgerton
- Cindy Bernheimer
- Donald Guthrie
- …many more!...

# *"I Speak a Different Dialect"*

## Teen Explanatory Models
of Difference and Disability

Tamara Daley
(Westat & UCLA)

Tom Weisner
(UCLA)

# Explanatory Models

- The person's own assessment of illness beliefs

- Conceptions of illness held by patient (and/or others such as parents and family members and others) consequential for recognition, treatment, and outcomes of illness and suffering.

- Explanatory models are usually studied using open-ended, semi-structured interviews

- Used both clinically and for research
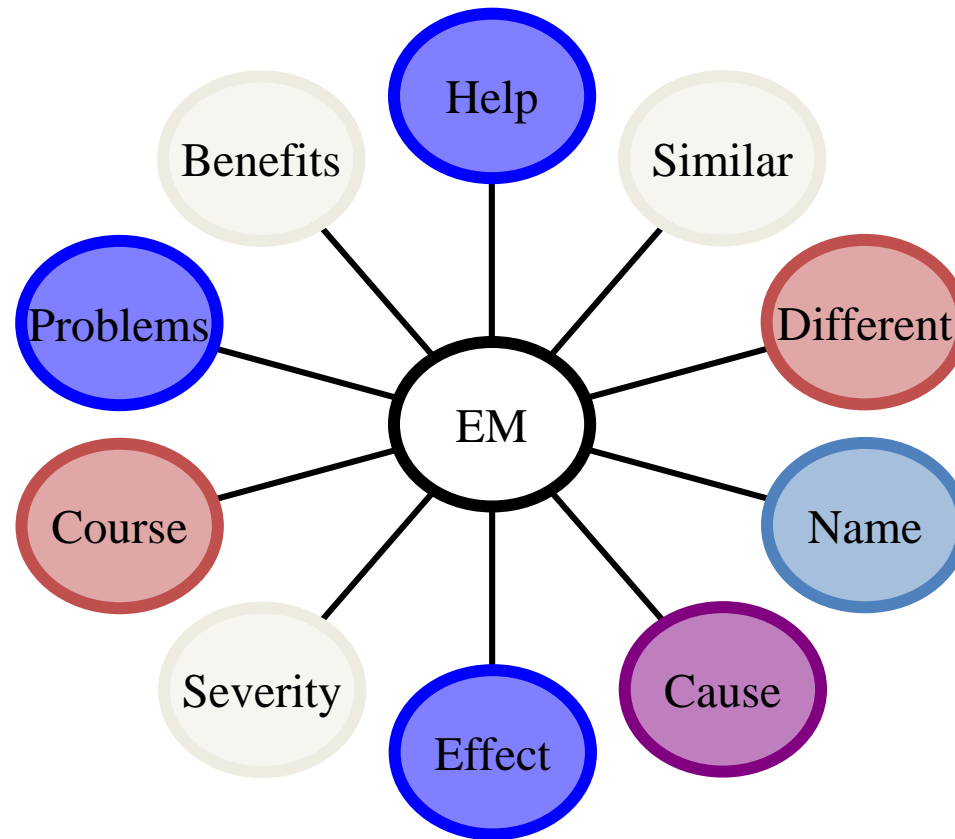
Arthur Kleinman (1980), Weiss (1994)

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## Table 2
## Teen interview questions.

1. What makes you similar and different from other kids you know?
2. What do you call your difference/problem/teen's word? What name does it have?
3. What do you think caused you to be different/have this problem/teen's word? Why do you think it started when it did?
4. How severe is it? Will it always be there?
5. What does your difference/problem/teen's word do to you? How does it work?
6. What are the main problems that being/having _____ have caused for you?
7. What are the good parts/benefits ofbeing having _____ ?
8. What kind of help/treatment do you thinkk you should receive.

Daley, Tamara, & Weisner, Thomas S. (2003). "I Speak a Different Dialect": Teen Explanatory Models of Difference and Disability. Medical Anthropology Quarterly 17 (1): 25 – 48.

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# Explanatory Model Questions

# Conclusions

- About half the Adolescents with disabilities were able to provide a coherent, fairly full explanatory model (EM). Even lower functioning teens able to respond at least partially (23/30)

- Discussions of their disability situations definitely do appear – but emerge later in adolescents' explanatory models:  Is this a sign of a cloak of competence?

- Self-concepts of adolescents & their EM much broader than is covered by measures of "self-esteem".  Use of "self-esteem scales" misses what matters about identity, self-construal and personhood! Well-being – type comments common

- Wide range of responses found; *there was no standard EM across the disability sample*

- *Parents and others often unaware of the extent of and depth of the teen's Explanatory Models*

- There is an emphasis (in the USA at least) to use only "positive language" & a "no-labeling" ethos (don't even use terms like "autism" or "disability").  This can lead to not even discussing EM or self-construal with those affected. Youth are then unprepared to engage in this topic with others

- Adolescents themselves thought EM's were very important to them

# A Good Friend is Hard to Find: Meanings and Consequences of Friendship Among Adolescents with Disabilities

Catherine C. Matheson & Rebecca J. Olsen & Thomas S. Weisner

University of California, Los Angeles

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# PARENTS' AND TEENS' FRIENDSHIP ACCOUNTS

Parents had more complex definitions and thus expectations, both for themselves and their teens, than teens had, and often described their children as having no friends, or only "acquaintanceships" rather than true friendships.

The teens seemed to prefer a more contextual, concrete model which appeared to be based on their actual experiences with peers, rather than a more conceptually-driven definition. Youth did describe "friends" but as THEY thought about friends

The parents were often looking toward the future; the teens were aware of their current daily activities, their here and now.

The most stable friendships seem to be among peers who, in addition to social skills, have gone through the same special education classes or other programs together, sometimes for many years. Done activities together.

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# Imagine again?!

Imagine a young child in your mind's eye; now, add that this young child currently has (or will develop) ASD, ADHD, learning problems, or another serious developmental disability. What is arguably the single most important influence on the likely developmental pathway of that young child?

**If you could do one thing to influence the developmental pathway of that child … what would that be?**

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# Questions and Conversation

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