Autistic Parenting & Critical Disability Studies

A Brief Overview of Parenting on the Spectrum
Words about words – addressing the instability of language

• Person vs identity first language
  • Influences – government, activism, pathological and political legacies

• Word use
  • More: Autistic, Autistics, Autism, Disability, Disabled
  • Less: Person with Autism, Person with a disability, “ASD”
  • No: Euphemisms like “differently-abled,” “person with exceptionalities,” “special”

• Beyond words – discourse
  • Language isn’t just about words
  • Discourse is intertwined with research agendas and ideologies
  • “word swapping” really isn’t the goal
Critical Disability Studies: What is it?

Critical Disability Studies: What is it? (elevator pitch)

• A distinct field of study that is truly interdisciplinary
  • anthropology, sociology, social psychology, gender studies, education...

• Framework (20th & early 21st century):
  • Where is disability? + “Social Model of Disability”
  • “Impairment” (Feminist accounts, Tom Shakespeare)
    • Complex embodiment - intersectionality
    • Pathology, biology and the “predicament of impairment”
  • “Crip Theory”
    • Roots in queer theory
    • Compulsory able-bodiedness (compulsory neurotypical)
<table>
<thead>
<tr>
<th><strong>Medical(ish)</strong></th>
<th><strong>Social(ish)</strong></th>
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<tbody>
<tr>
<td>The Theory of Mind (Simon Baron-Cohen)</td>
<td>The Double Empathy Problem (Damian E.M. Milton)</td>
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<td>• Core deficit: lack of empathy</td>
<td>• Difference in processing information</td>
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<td>• Autistic strength derived from “splitting” and “systemizing”</td>
<td>• Autistic and neurotypical confusion when interacting</td>
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<td>• Preference/reliance on deductive logic versus inductive inference/logic</td>
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<td>• If/then rules vs “filling in the gaps”</td>
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<td>• “Interest model”</td>
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Many/Most autistic scholars reject “theory of mind”
See discourse on Spectrum 10k
Disabled people as “a people”

People: a body of persons that are united by a common culture, tradition, or sense of kinship, that typically have common language, institutions, and beliefs, and that often constitute a politically organized group

• Disability art, dance, literature (*Disability Cultural Studies*)
• Academics
• Political structures (*Disability Justice, Disability Rights*)
• Across borders, races, ethnicity, gender, political affiliations
If we consider “disability” as a people

• Like any people, disabled people will have experiences like most others
  • Consider the full lifespan: infancy, school, work, independence, love, marriage, children, later life, death

• Autism identity and the relationship to disability
  • Consider the full lifespan: infancy, school, work, independence, love, marriage, children, later life, death
Autism Research: A Life Span Timeline

HUMAN LIFE CYCLE
Enter your sub-headline here

- Fetus in the womb
- Baby/Infant (birth – 1 year)
- Toddler (1 – 3 years)
- Preschooler (3 – 5 years)
- Primary School Boy (5 – 12 years)
- Adolescent/Teenager (13 – 19 years)
- Adult (36 – 55 years)
- Old Person (65+ years)

Childhood
Adolescence
Adulthood
Autism Research (Money Matters)

Source Dr. K. Bortema-Beutel, Lynch School of Education and Development, Boston College October 2021
Autism Research (Money Matters)
Autism Research (Money Matters)

2% lifespan issues
Are we OK with this distribution?

• We typically research only a portion of the autistic lifecycle (ages -9 months to early adulthood)

• Uneven inquiry
  • If we consider Noninvasive prenatal testing (NIPT) the number skews dramatically
  • $136 million in biological research (USA, autism specific research)
  • 2% for lifespan issues (approx. $8 million)
Research independent of “cure”

• Critical Disability Studies brings a non-pathologized perspective

• Growing body of literature that resists historical research/treatment/therapies
  • AASPIRE – Academic Autism Spectrum Partnership in Research and Education
  • ASAN – Autism Self Advocacy Network
  • We’re Not Broken: Changing the Autism Conversation Eric Garcia (2021)
  • Brilliant Imperfection: Grappling with Cure, 2017.

• Research that isn’t focused on “masking” or camouflaging
  • Masking = the appearance of neurotypical

• Goal: “disability cultural competence” for autism and parenting (interactional expertise)
  • Support vs deficit that needs remedy
The danger of ignorance (Content Warning)

• Child Protection + Legal Interactions
  • Over representation of disability within CPS
  • Defaulting to the Grandparent? Foster care?
  • Autism and policing

• Issues of Reproductive Justice
  • Less utilization of family planning services
  • Lower cervical and breast screening rates

• Legacies of Sterilization

• Is reproduction being shaped? (Compulsory able-bodiedness?)
The “Wanted Pregnancy” Scenario

• Like any people, not all autistic people will want to be parents
  • Shedding any association with “Pro-life” (Not a debate about abortion)

• There is a population
  • There is gynecological research that outlines the population of autistic people who become pregnant
    • Dr. Jennifer Aimes, Autism Intervention Research Network on Physical Health (AIR-P),

• What do we do?
  • Do we need to do anything?
  • Neurotypical supports?
  • Custom tailored?
Stepping off Point: This is where research begins

• National Research Center for Parents with Disabilities (USA)
  • “Advice and information for professionals working with parents on the autism spectrum” (2017)
    • connected to robust support networks,
    • mental frameworks for approaching parenting
    • improve self-efficacy
    • knowledge on how to advocate for their children in professional settings

• AASPIRE – Community Based Participatory Research Principles
• Clues from OBGYN research
• Clues from lifespan initiatives
Methodology: Community Based Participatory Research

• The absence of any academic literature
  • Develop a framework from the ground up
• Community – differences when compared to other minority groups
• Balancing Power and the “Benefit gap” in research
Methodology: Community Based Participatory Research (AASPIRE)

**Community**
- Keeps research respectful, accessible, and socially relevant
  - Meets community priorities
  - Ensures accessible instruments
  - Publicizes findings

**Development**
- Focus of inquiry / problem definition
- Study design
- Funding
- Has scientific value
- Meets funder priorities

**Implementation**
- Recruit participants
- Collect data
- Analyze data
- Ensures safe & scientifically appropriate recruitment
- Ensures scientific rigor

**Dissemination**
- Draw conclusions
- Design interventions
- Translate findings
- Builds on theory
- Publishes findings

**CBPR Process**
From the AASPIRE Model – Development

• Focus of Inquiry – Lifespan: Parenting
• Problem definition
  • Absence of research,
  • little understanding of needs,
  • problematic interactions with governmental structures
  • The double empathy problem in the lives of autistic parents

- Developed from library science, adopted by AASPIRE
- Grounded Theory – theorize results of delphi boards, develop new questionnaires
  - research questions and potential hypotheses are not articulated at the outset;
  - gain familiarity with a research context, and only in later stages does the process become progressively more focused and targeted.
- Delphi method – structured interviews/questionnaires to experts and autistic folx
  - Questionnaires to evolve into semi-structured interviews
Methodology: Grounded Delphi Method

Round 1 questionnaire
- NRCPD AASPIRE frameworks

Round 2 questionnaire
- Theorize and collaborate
- Reflecting Round 1 results

Round 3 semi structured Interviews/Interviews
- Theorize and collaborate
- Based on Rounds 1 + 2

The process is refined each round (4-6 rounds is the goal)
Design

- Consultation: Delphi panels – Experts in the field + Lived Experience
- Authentic Inclusion – Co-production with autistic folx
  - Help keep research oriented to community needs

Questionnaires/Interviews Constructed with:
- AASPIRE accommodation tools
  - Diverse communication methods (accessible instruments)

Design articulated by Dr. Christina Nicolaidis: Inclusive Autism Research: Matching Theory to Practice (October 2021)
“Meeting on Inclusive Research on Autism” (1:46:56/3:35:51)
https://www.youtube.com/watch?v=ljx0ea_JZEl
www.asspire.org
Challenges

• Regional/Geographic Sourcing
• Communication requirements
  • Questionnaires, interviews, and focus groups must be accessible
  • Electronic communication “lag”
  • Managing large amounts of information – balancing overwhelming amount of information with transparency
• Group meetings
  • Regional/geographic limitations
  • Sensory accommodations
• Consent
Solutions

• Regional/Geographic
  • In the initial phases of research, difficult to assess

• Communication
  • Highly structured email and communication formats
  • Plain language use
  • Communication Review options (Zoom, face-to-face, an assistant)

• Group Meetings
  • Multiple media (slides, video, text, chat, close captioning)
  • Meeting preparation - material available in advance or pre-meetings

• Consent: Accessible Consent formats
  • Co-created with autistic partners
  • Simplified consent language
  • Visual aids
  • Extra time to consult with trusted person
One of Dr. Milton’s favourite quotes

“Grant me the dignity of meeting me on my own terms... Recognize that we are equally alien to each other, that my ways of being are not merely damaged versions of yours. Question your assumptions. Define your terms. Work with me to build bridges between us.” (Sinclair, 1993)
Autism


Disability


Parenting


Child Protection