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?

- Dan Goodley (2013) Dis/entangling critical disability studies, Disability & Society, 28:5, 631-644, DOI: 10.1080/09687599.2012.717884


vic finkelstein
key site
abled self
spastic colon
margrit shildrick
century disability study
materialist social model
strait islander community
franz fanon
impaired body
form of oppression
everyday life
others
disability issues
social model
dominant self
anita ghai
normative body
disabled body
crip theory
oppression
goodley
disability & society
queer body
way
campbell
smokie
helen meekosha
compulsory heterosexuality
people
ghai
impairment
self
twentieth century
tom shakespeare
income nation
queer theory
disabled people
disability study
disability
critical disability study
body
disability experience
corporeal standard
politics of disability
analysis of disability
human rights
contemporary state
contemporary life
contemporary society

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)

Disputed Territory – Autism "medical" vs "social"

Medical(ish)

- The Theory of Mind (Simon Baron-Cohen)
  - Core deficit: lack of empathy
  - Autistic strength derived from "splitting" and "systemizing"

Social(ish)

- The Double Empathy Problem (Damian E.M. Milton)
  - Difference in processing information
    - Autistic and neurotypical confusion when interacting
  - Preference/reliance on deductive logic versus inductive inference/logic
    - If/then rules vs "filling in the gaps"
  - "Interest model"

Many/Most autistic scholars <u>reject</u> "theory of mind"
See discourse on Spectrum 10k

Disabled people as “a people”

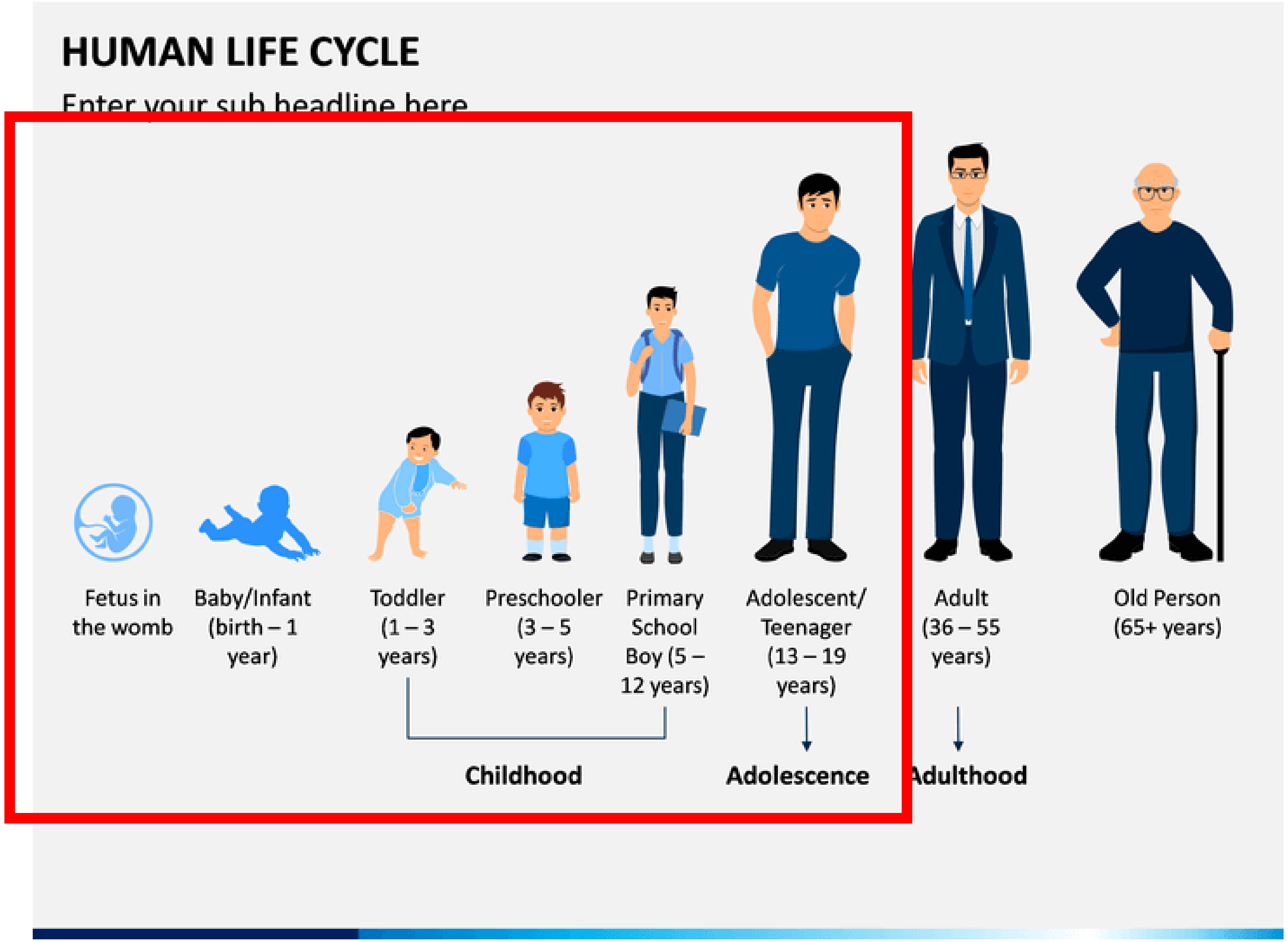
People: a body of persons that are united by a common culture, tradition, or sense of kinship, that typically have common language, institutions, and beliefs, and that often constitute a politically organized group

- Disability art, dance, literature *(Disability Cultural Studies)*
- Academics
- Political structures *(Disability Justice, Disability Rights)*
- Across borders, races, ethnicity, gender, political affiliations

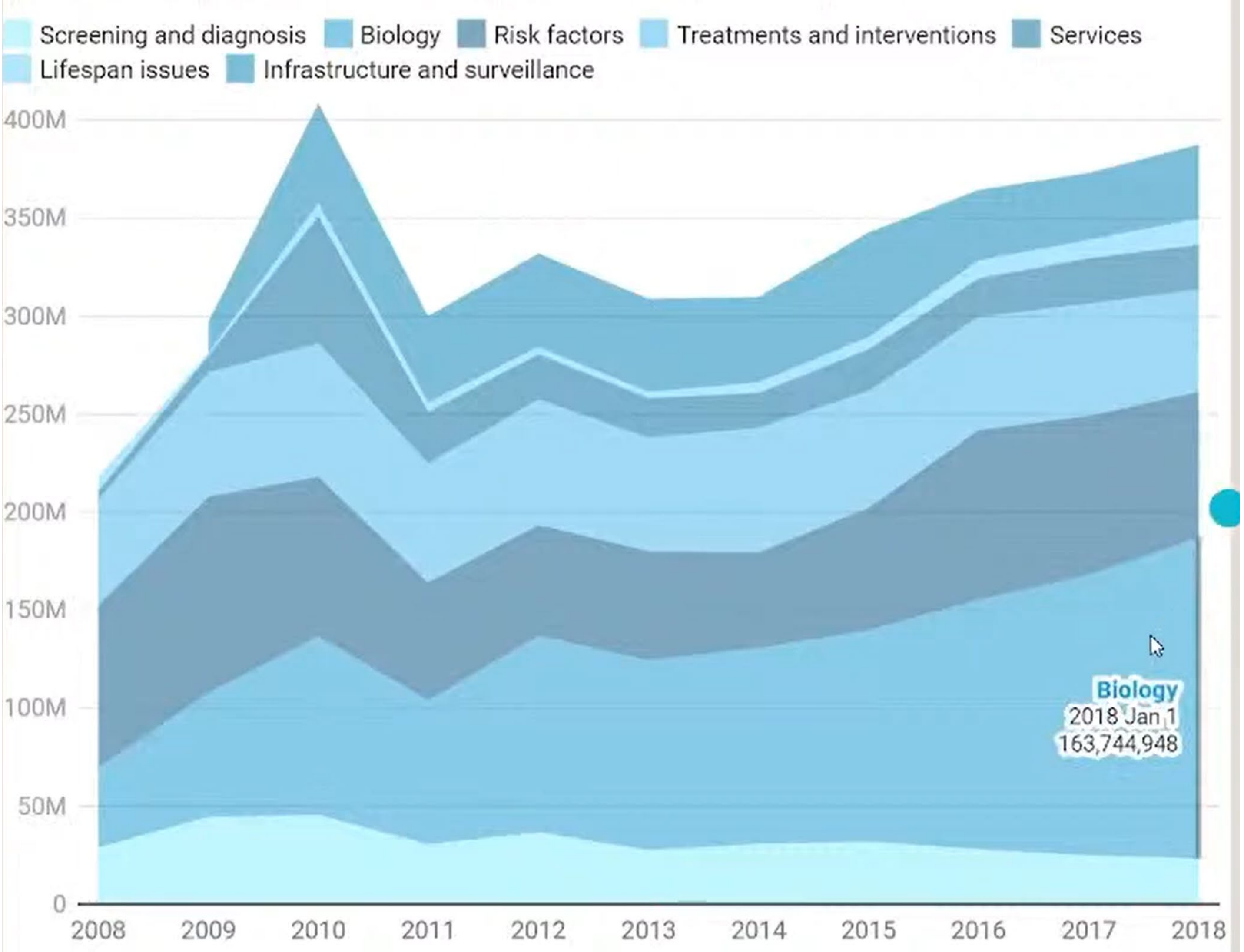
If we consider “disability” as a people

- 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

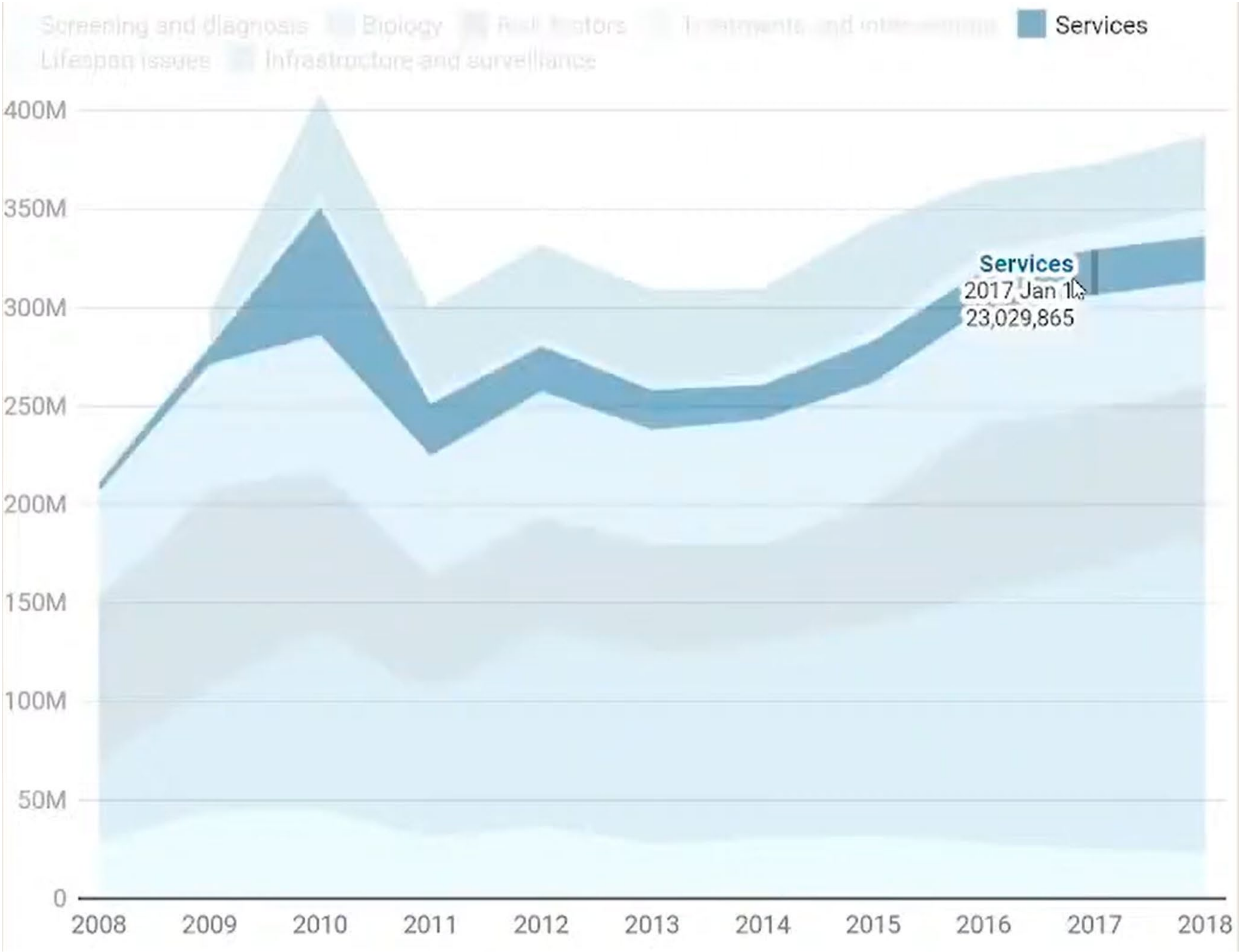


Autism Research (Money Matters)

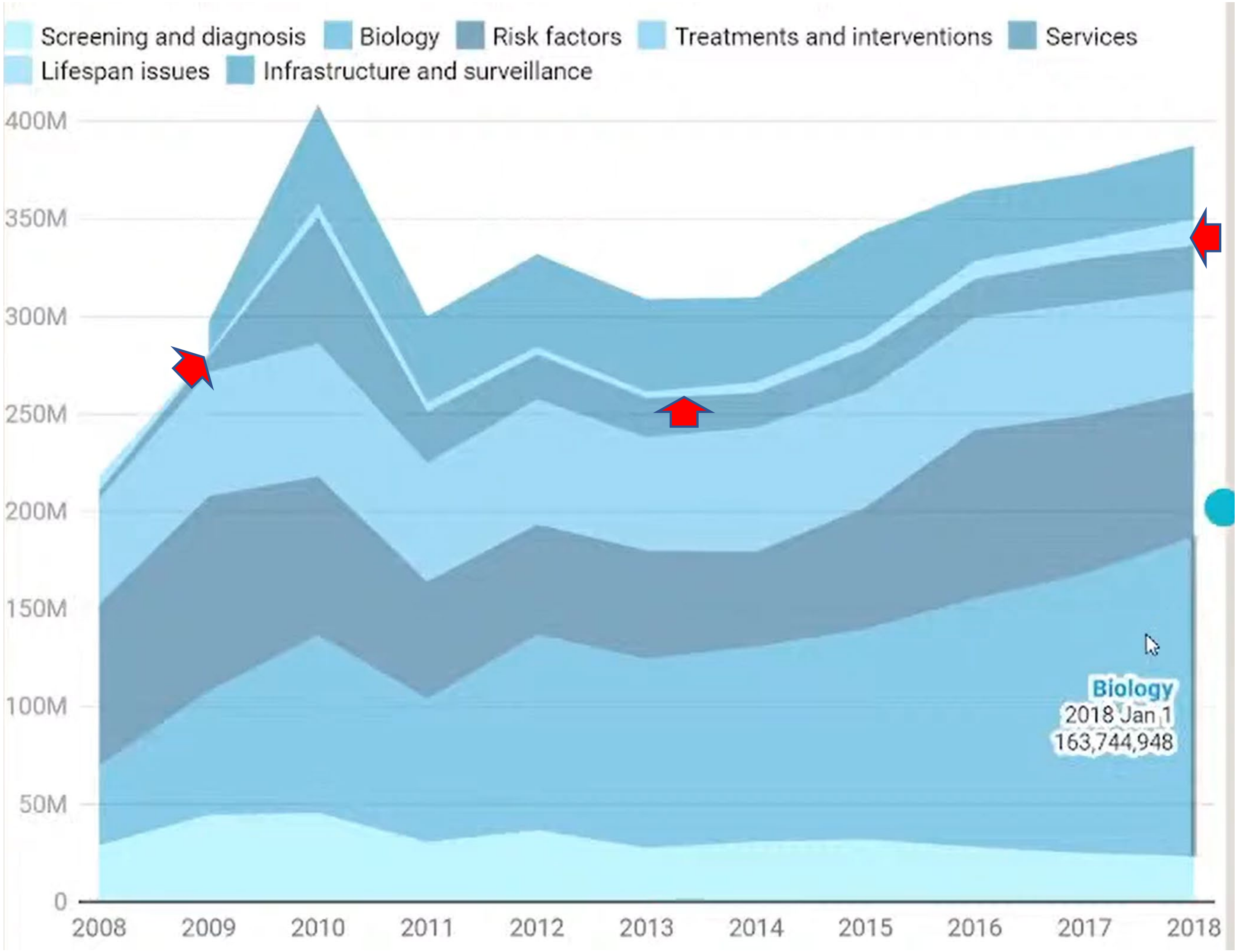


Source Dr. K. Bortema-Beutel, Lynch School of Education and Development, Boston College October 2021

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?

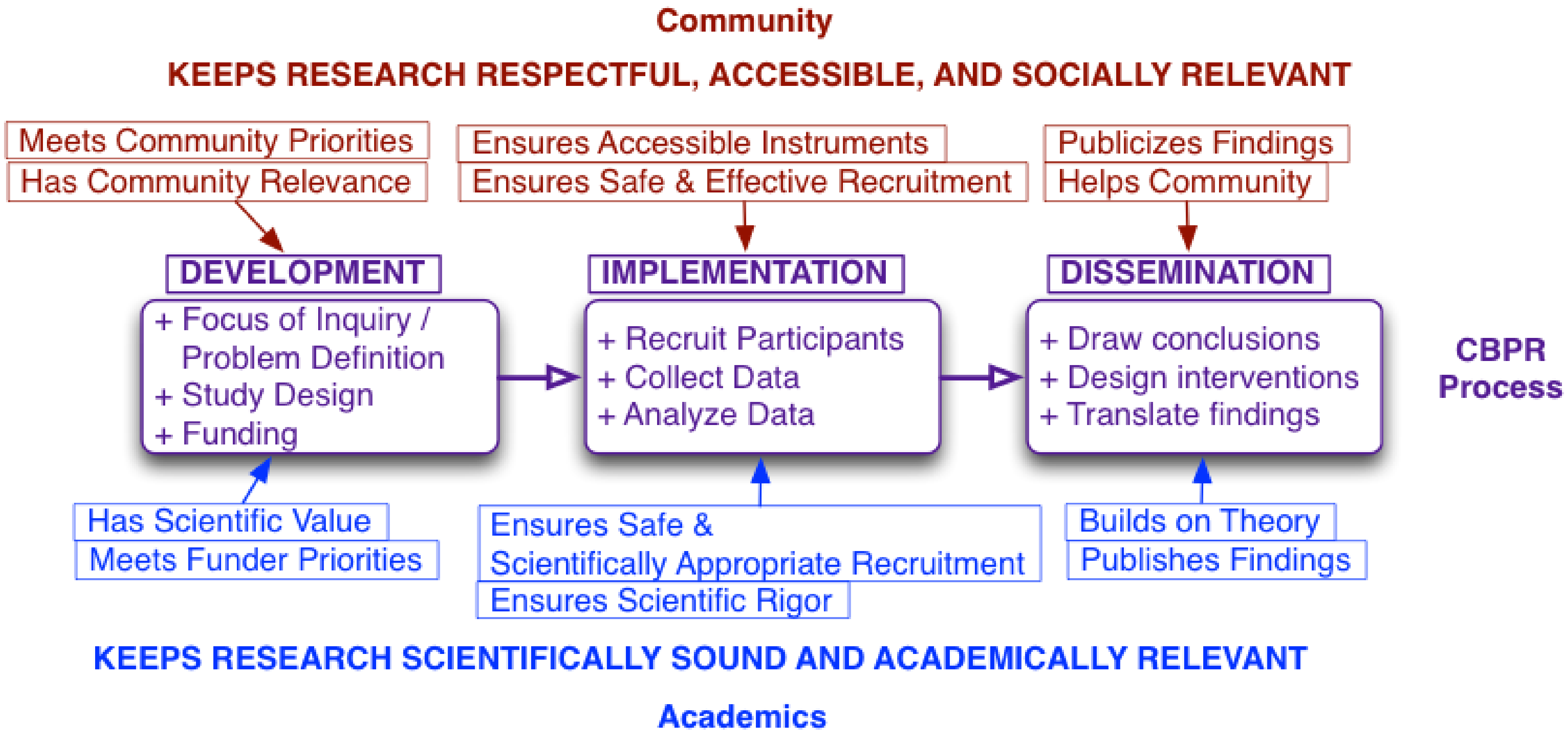
Stepping off Point: This is where research begins

- 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 initatives

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 the “Benefit gap” in research

Methodology: Community Based Participatory Research (AASPIRE)



Community

KEEPS RESEARCH RESPECTFUL, ACCESSIBLE, AND SOCIALLY RELEVANT

Meets Community Priorities
Has Community Relevance

Ensures Accessible Instruments
Ensures Safe & Effective Recruitment

Publicizes Findings
Helps Community

DEVELOPMENT
- Focus of Inquiry / Problem Definition
- Study Design
- Funding

IMPLEMENTATION
- Recruit Participants
- Collect Data
- Analyze Data

DISSEMINATION
- Draw conclusions
- Design interventions
- Translate findings

CBPR Process

Has Scientific Value
Meets Funder Priorities

Ensures Safe & Scientifically Appropriate Recruitment
Ensures Scientific Rigor

Builds on Theory
Publishes Findings

KEEPS RESEARCH SCIENTIFICALLY SOUND AND ACADEMICALLY RELEVANT

Academics

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

Study Design: Grounded Delphi Method

Higgins, Julianne M, et al. "Defining Autistic Burnout through Experts by Lived Experience: Grounded Delphi Method Investigating #AutisticBurnout." Autism : the International Journal of Research and Practice 25, no. 8 (2021): 2356–69.

- 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

Theorize and collaborate

Round 2 questionnaire

Reflecting Round 1 results

Theorize and collaborate

Round 3 semi structured Interviews/Interviews

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_JZEI

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)

Literature & Resources (see link in chat)

Autism

Milton, Damian (2013) ‘Filling in the gaps’: A micro-sociological analysis of autism. Autonomy, the Critical Journal of Interdisciplinary Autism Studies, 1 (2).

Nicolaidis, C., Raymaker, D. M., McDonald, K. E., Lund, E. M., Leotti, S., Kapp, S. K., … & Hunter, M. (2020). Creating accessible survey instruments for use with autistic adults and people with intellectual disability: Lessons learned and recommendations. Autism in Adulthood, 2(1), 61-76. https://doi.org/10.1089/aut.2019.0074

Nicolaidis, C. (2012). What can physicians learn from the neurodiversity movement?. AMA Journal of Ethics, 14(6), 503-510. http://doi.org/10.1001/virtualmentor.2012.14.6.oped1-1206

Raymaker, D. M. (2016). Intersections of critical systems thinking and community based participatory research: a learning organization example with the autistic community. Systemic Practice and Action Research, 29(5), 405-423. http://doi.org/10.1007/s11213-016-9376-5

Disability

Barnes, C., & Oliver, M. (2012). The new politics of disablement . Palgrave Macmillan.

Clare, Eli (2017) *Brilliant Imperfection*. North Carolina: Duke University Press.

Garland-Thomson. (2017). Disability Bioethics: From Theory to Practice. Kennedy Institute of Ethics Journal, 27(2), 323–339. https://doi.org/10.1353/ken.2017.0020

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Shakespeare, Tom (2014) *Disability Rights and Wrongs Revisited*. New York: Routledge.

Parenting

“Advice and information for professionals working with parents on the autism spectrum.” National Research Center for Parents with Disabilities,” (2017) accessed September 30, 2021. https://heller.brandeis.edu/parents-with-disabilities/info-resources-research-briefs/advice-for-professionals/advice-autism-spectrum.html

LaLiberte, Traci and Elizabeth Lightfoot (2013) “Parenting with a Disability, What do we Know?” in *The Intersection of Child Welfare and Disability: Focus on Parents*, edited by T. LaLiberte and T. Crudo, 4-5. Minneapolis: University of Minnesota Press.

Child Protection

DeZelar, Sharyn and Elizabeth Lightfoot (2018) “Use of Parental Disability as a Removal Reason for Children in Foster Care in the U.S.” *Children and Youth Services Review* 86 (2018): 128-134.