Participatory Research:
Opportunities to Foster Influence and Belonging in Science

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Language

- People first

- Identify first

Learning Objectives

1. Describe the scientific and ethical motivations to promote influence over knowledge production

2. Discuss strategies for building relationships between scientists and people with developmental disabilities to collaborate in scientific pursuits

3. Identify approaches to conducting participatory research with people with developmental disabilities

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Research Uncovering Resilience

- Persistent frameworks of individual deficits and increased risk for poor outcomes

- Individuals with Down Syndrome show resilience (decreased risk) to some forms of cancer

- Science provides discoveries to nurture full inclusion, human rights, and belonging

- *Yet ...*

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Troubled History

- Willowbrook (1956 – 1971)

  – New York state institution for children with developmental disabilities

  – Studied the natural history of hepatitis

  – Infected children with hepatitis (fed with stool extracts; injections)

  – Families could bypass waitlist for admittance by agreeing to participate in the research

  – Parents not well informed of risks

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Troubled History

- "Participants'" belonging to marginalized groups (decreased social value)

- "Participants" embedded in coercive contexts

- "Participants" with limited capacity to understand information and act upon a decision

- Convenience samples

- Deception

- Little to no prospect of personal or social benefit, significant harm, injury and death

Troubled History

- Ethical and social dynamics contribute to:

    – people with developmental disabilities being **understudied (excluded, left out)**

    – people with developmental disabilities being at risk for **inappropriate inclusion**

    – **A mismatch of priorities** in science

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A Call to Action

- Adults with developmental disabilities experience significant **disparities**

- **New knowledge** is needed for social and health equity

- Emphasis on **direct representation** in research ("you belong")

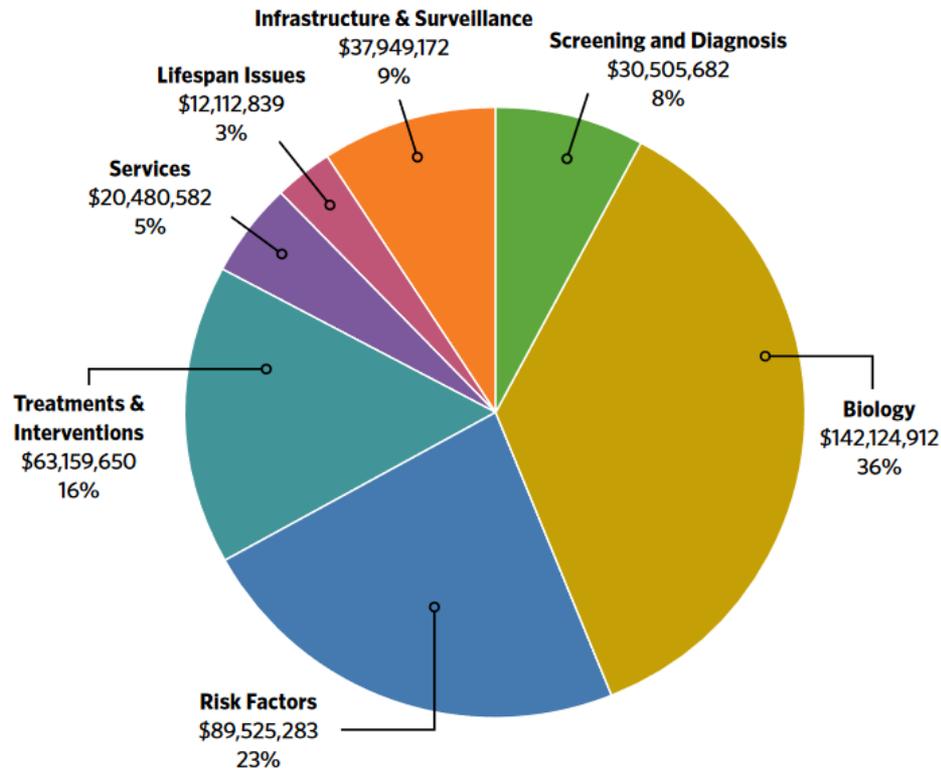**FALK** | Syracuse University

A Call to Action

- Whose interests are served by prevailing research agenda?

- Who stands to benefit or be harmed by specific research projects?

- Does the distribution of research funding match priorities of people with developmental disabilities?

- Do research agenda reflect deficits-based frameworks or human rights approaches (inc. environmental supports and factors)?

- Do research agenda seek to unearth protective factors that can help individuals fully belong and flourish?

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A Call to Action

2016
Combined International ASD Research Funding by Research Priority Areas
Total Funding Amount: $395,858,120 USD

Infrastructure & Surveillance
$37,949,172
9%

Lifespan Issues
$12,112,839
3%

Services
$20,480,582
5%

Screening and Diagnosis
$30,505,682
8%

Treatments & Interventions
$63,159,650
16%

Biology
$142,124,912
36%

Risk Factors
$89,525,283
23%

Figure 2. The combined total investment from the four countries in the seven research priority areas.

- Efforts to eradicate?

- Promote dehumanizing and harmful behavioral interventions (long-term)

- Lack of investment in community priorities

Office of Autism Research Coordination, National Institute of Mental Health, Autistica, Canadian Institutes of Health Research, and Macquarie University. 2016 International Autism Spectrum Disorder Research Portfolio Analysis Report. October 2019. Retrieved from the U.S. Department of Health and Human Services Interagency Autism Coordinating Committee website: https://iacc.hhs.gov/publications/international-portfolio-analysis/2016

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A Path Toward Belonging

- Direct participation in research only partially addresses the problem

- Disability rights requires *influence* over science as a hallmark of true belonging

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A Path Toward Belonging

- Authentic research partnerships
  - Community representatives as full members of research team
  - Equitable exchange of power and expertise
  - Can lead to better science, community capacitation, empowerment, improved knowledge translation
- Research funding bodies, ethical review boards, peer review process, trained scientists
- *Transform relationships*

Belonging in Science

- Science is inherently relational

- Scientists (without disabilities) must take responsibility for cultivating more positive relationships and earning the trust of people with developmental disabilities

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Advance Disability Justice within Science

1. **Become an ally and advocate for the full inclusion of people with developmental disabilities in science**

   - Develop a strong foundation in disability history, oppression, and disability rights

   - Read

   - Watch documentaries

   - Attend cultural and recreational events

   - Develop relationships with people with developmental disabilities

   - Advocate for change (Micah!)

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Advance Disability Justice within Science

2. Establish mutual, long-term relationships with people with developmental disabilities in science.

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Advance Disability Justice within Science

- Selection of community researchers
  - Shared values
  - Relevant life experiences
  - Ability to commit
  - Accessible selection processes

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Advance Disability Justice within Science

- Creating community among all research team members
  - Accessible video introductions
  - Accessible ice breakers
  - Check ins
  - Time outside of research activities

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Advance Disability Justice within Science

- Establishing and demonstrating trustworthiness
  - Transparency in decision-making
  - Shared decision-making
  - Consistent follow-through (act on preferences)
  - Clear, flexible, ongoing, accessible communication

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Advance Disability Justice within Science

- Be transparent about the continuum of power-sharing in research partnerships and take actions that reflect the selected participatory approach
  - Terms used
  - Resources (inc. time, accommodations)
  - Partnership through the end (action)

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Advance Disability Justice within Science

3. **Create structures that show respect and foster engagement, participation, and shared decision-making.**

- Compensation

- Transportation (costs)

- Guidelines for working together

- Accommodations

Advance Disability Justice within Science

4. **Reflective Practice.**

- Meeting check-outs
- Who did what?

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Implications:
Promoting Disability Justice in Science

- Right past wrongs, advance disability justice
- New knowledge poised to positively impact people with developmental disabilities
- Improves the quality of the research
    - Research questions reflect needed knowledge and lived realities
    - Data collection strategies are sensitive, accessible, and effective, thus engendering greater response rates and validity
    - Interpretation grounded in creative implications rooted in needs, preferences, and lived experiences
    - Knowledge translation is more viable and effective

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Implications:
Promoting Disability Justice in Science

- Capacity to engage in science grows

- Friendships form

- Social capital is increased

- Confidence and employment skills and opportunities grow

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