



Department of Defense's
Comprehensive Autism Care
Demonstration (ACD): Listening
Session Comments

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April 22, 2024

Mission

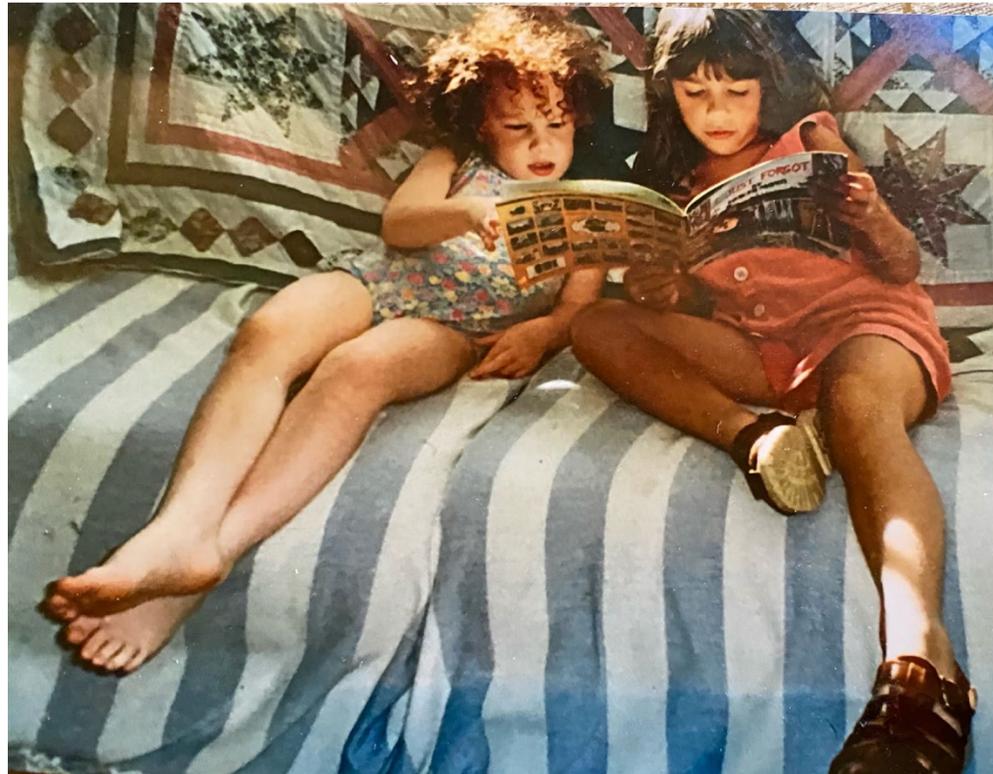
To conduct research that advances the health and well-being of neurodivergent and marginalized populations across the life course, leveraging principles of development & community -engaged methodologies

Vision

To disrupt the vicious cycle of inequitable research, practice, education, and policy for neurodivergent populations

Values

Embracing neurodiversity & its tenets combined with rigorous research methodologies



Conceptual frameworks

Neurodiversity

Neurological variations are a vital part of humanity, as much as variations in size, shape, skin color and personality.

Life Course Health Development

Individual & population health trajectories are determined by interactions between biological & environmental factors

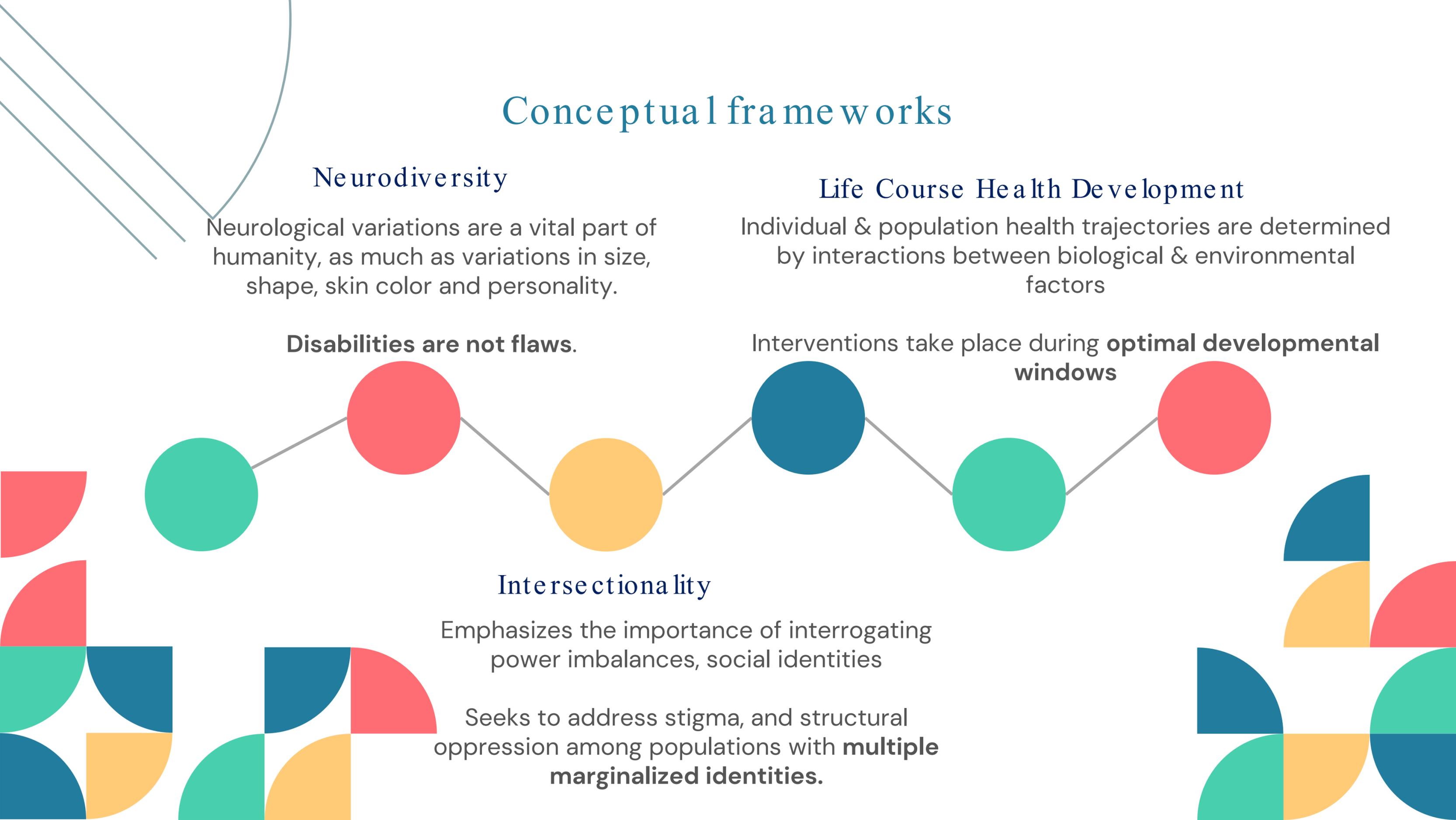
Disabilities are not flaws.

Interventions take place during **optimal developmental windows**

Intersectionality

Emphasizes the importance of interrogating power imbalances, social identities

Seeks to address stigma, and structural oppression among populations with **multiple marginalized identities.**



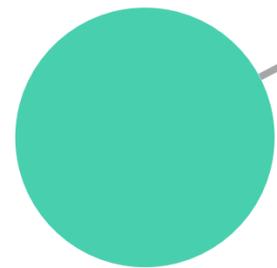
Methodological frameworks

Equity-driven methods

- Devising research questions that address the social determinants of health
 - **Stigma/ableism**

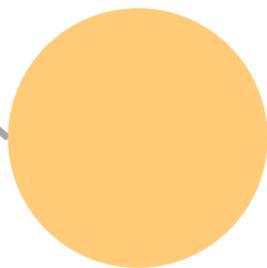
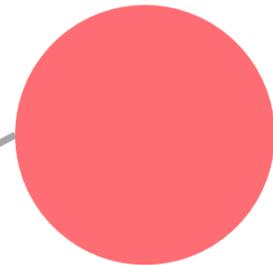
Action-oriented research

- Ensuring clear **translation** implications



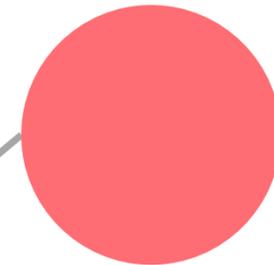
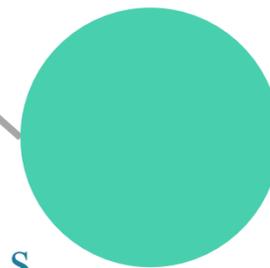
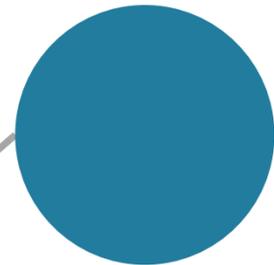
Participatory methods

- **Collaboration & co-design** at each stage in the research to ensure relevance & utility to the target population
 - CBPR
 - Human-Centered Design



Life course approaches

- The **timing** of exposure changes how a particular risk or protective factor affects health
 - Exposure to a particular type or quality of adversity/protective factor leads to **chains of risk/protective factors**
- The study of complex challenges requires analyses at **multiple levels**



Focal areas

1. An assessment of all methods used to assist in the assessment of domains related to autism spectrum disorder broadly, including a determination as to whether the Secretary is applying such methods appropriately under the demonstration project;
2. An assessment of the methods used under the demonstration project to measure the effectiveness of applied behavior analysis in the treatment of autism spectrum disorder;
3. A review of any guidelines or industry standards of care adhered to in the provision of applied behavior analysis services under the demonstration program, including parental involvement in applied behavior analysis treatment, as well as a review of the effects of such adherence with respect to dose-response or health outcomes for an individual who has received such services;
- 4. A review of health outcomes, including mental health outcomes, for individuals who have received applied behavior analysis treatments over time;**
5. An analysis of the increased utilization of the demonstration program from inception by beneficiaries under the TRICARE program, to improve understanding of such utilization;
6. Such other analyses to measure the cost effectiveness, program effectiveness, and clinical effectiveness of the demonstration program as may be determined appropriate by the National Academies;
7. An analysis on whether the incidence of autism is higher among the children of military families than in the general population;
8. An analysis on whether the diagnosis and treatment of autism is higher among the children of military families than in the general population;
9. The development of a list of recommendations related to the measurement, effectiveness, and increased understanding of the demonstration program and its effect on beneficiaries under the TRICARE program.

A neurodiversity-oriented approach to behavioral approaches

In 2022, the Autism Intervention Research Network on Physical Health (AIR-P) published its first Pediatrics Supplement



Called for a **neurodiversity-oriented approach** to care for autistic individuals.



In this approach:

- The physical environment, staff demographics, clinical interactions, and office culture within health clinics are:

Designed to be responsive to the diverse needs, experiences, and preferences of individuals across the life course

Focused on promoting health, well-being, and thriving, rather than on trying to “cure” or “normalize” autistic individuals.



Linking neurodiversity-oriented approaches with developmental principles

– Efforts to align practice with neurodiversity would also be aligned with **developmental principles**, in that they would be:

- **Proactive & strengths-based:** occurring before “problem behaviors” occur
- **Developmentally based:**
 - Aligned with developmental milestones
 - Focused on optimal transitions & turning points
 - Culturally tailored to families’ unique characteristics, circumstances & developmental goals for their children



Linking neurodiversity & developmental lenses

During **childhood**, interventions can focus on children & families' unique developmental and cultural goals and identify strategies to reduce stress

During **early adolescence**, interventions can target social-motivational learning that includes peer-mediated and teacher-mediated approaches that integrate special interests.

During **mid to later adolescence**, interventions can build off gains in social-motivational learning to scaffold successful transition to independence.



Perspectives of autistic adults

Despite the importance of centering autistic perspectives in educational decision-making for autistic children, few studies have directly assessed autistic perspectives on the social acceptability of early childhood practices.

This study conducted an online survey to recruit perspectives of autistic adults on educational practices typically employed with autistic children.

They also extended the survey to caregivers and early childhood practitioners.

Journal of Autism and Developmental Disorders
<https://doi.org/10.1007/s10803-024-06242-4>

ORIGINAL ARTICLE



Centering Autistic Perspectives: Social Acceptability of Goals, Learning Contexts, and Procedures for Young Autistic Children

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Accepted: 8 January 2024

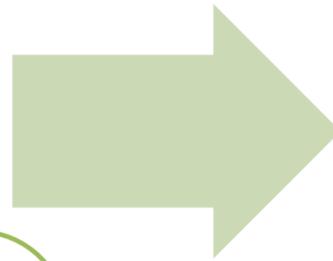
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Perspectives of autistic adults

They received responses from 660 individuals, 226 of whom identified as autistic. Respondents reported:

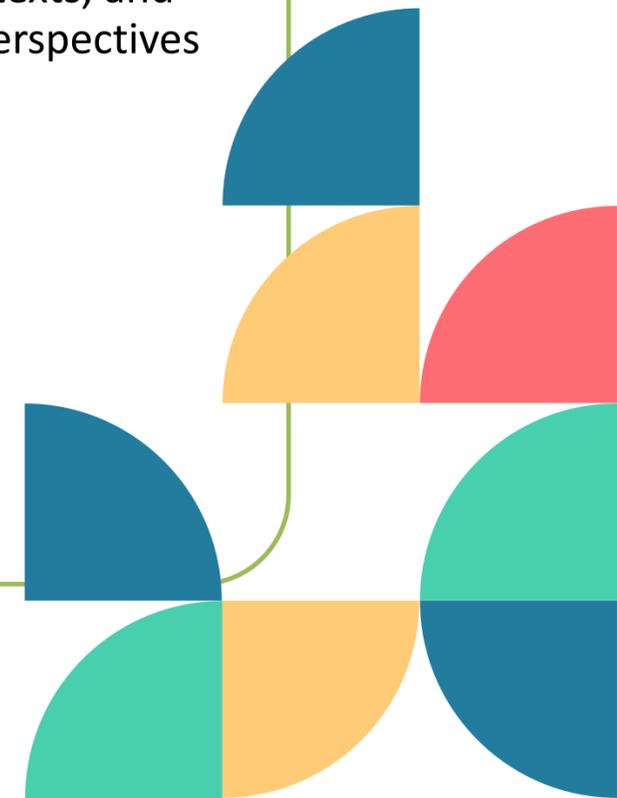
- **High acceptability for:**
 - Goals promoting **self-determination**
 - Spending more time in **child-led, inclusive environments with peers.**
 - **Antecedent interventions** (altering environment before concern occurs)
- **Low social validity for:**
 - Goals promoting **masking**
 - Some forms of **extinction***
- Appropriate learning environments are **highly context dependent**, varying with individual needs
- **The child is the most important shareholder in educational decision-making.**



The authors recommended:

- Respecting autistic culture and characteristics in selecting goals
- Considering social, emotional, and psychological needs in selecting procedures
- Individualizing goals, learning contexts, and procedures based on the child's perspectives and unique needs.

**"Procedures used should be trauma informed. When challenging behaviors occur, emphasis should be on co-regulation/de-escalation whereas procedures such as planned ignoring, hand over hand, restraints, and withholding often escalate the situation."*





Learning from autistic scholars

Parents often feel intense distress akin to grief after their child receives an autism diagnosis

This grief is further fueled by the ‘stories of autism’ crafted for families by both professionals and popular media.

The diagnosis of autism has been framed from a deficit-based perspective

Solely deficit-framed descriptions often miss the strengths that can be associated with autism.

Changing the story: How diagnosticians can support a neurodiversity perspective from the start (Brown, 2021)



Thank you!

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