

STAKEHOLDER ENGAGEMENT IN PEDIATRIC DISABILITY RESEARCH: WHY AND HOW TO DO IT

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ECHO

Environmental influences
on Child Health Outcomes

A program supported by the NIH



**CEREBRAL
PALSYP
FOUNDATION**



Children's
Healthcare of Atlanta



EMORY
UNIVERSITY
SCHOOL OF
MEDICINE

OVERVIEW

Health, disability and participation in research – Why do it & How to do it &

Stakeholder engagement in CP research – What results can you get

Example of ECHO 301 cohort work

DISABILITY

The Convention on the Rights of Persons with Disabilities defines living with a disability as *having a long-term physical, mental, intellectual or sensory impairment that – in interaction with the environment – hinders one’s participation in society on an equal basis with others.*

United Nations 2006



DISABILITY STATS

- 15% of the world's population have some form of disability, whether present at birth or acquired later in life.
- Nearly 240 million of them are children.
- In the US, 1 in 6 children have a developmental disability.
- 7.5 million US students (15%) received special education services under IDEA.



UNICEF Annual 2023

“The current research paradigm envisions disability primarily as an outcome to prevent or treat, leaving gaps in evidence regarding how to maximize health “

Swenor, NEJM 2022



ECHO

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ECHO 301- J. Aschner PI

Goal: Enhance inclusivity of
children with disabilities in ECHO
pediatric and pregnancy cohorts



ECHO

Environmental influences
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ECHO 301

Goal: Enhance pediatric and pregnancy research cohorts with disabilities in ECHO

Engaging parents and individuals in the disability community as stakeholders in ECHO to improve generalizability and future hypothesis generating

Focus on the primary outcome of positive health as defined in ECHO



ECHO

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ECHO 301

Focus on the primary
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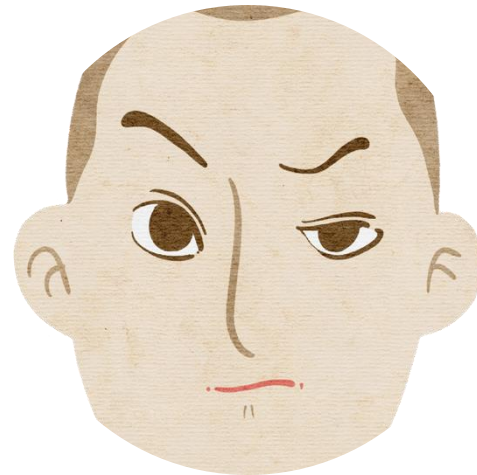
Aim 3 involves engaging the
disabilities community as
stakeholders in ECHO to
improve generalizability and
hypothesis validity

BARRIERS TO PARTICIPATION IN RESEARCH FOR ALL



Burden

Time, cost, transportation,
childcare



**Distrust of
Researchers**

History of misconduct



**Lack of
Understanding**

Importance, informed
consent, protections

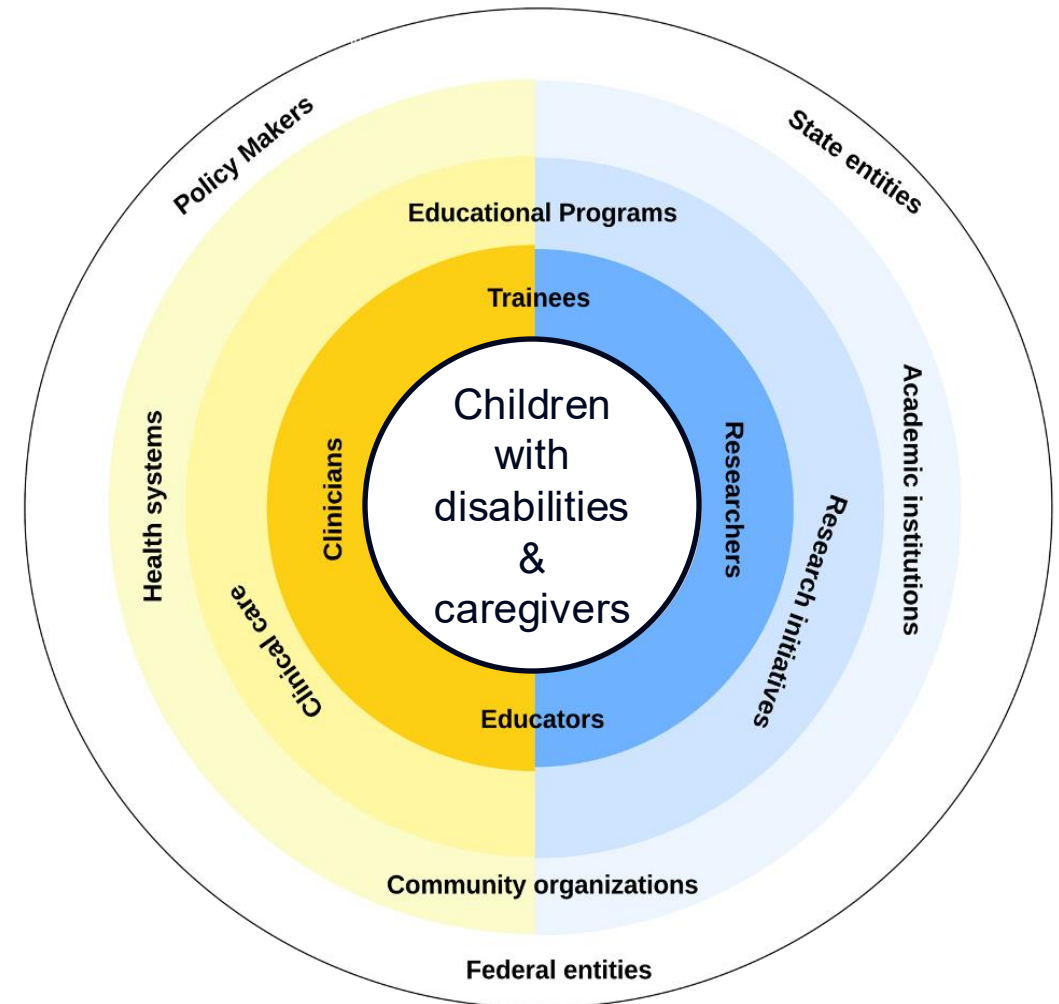


Fear

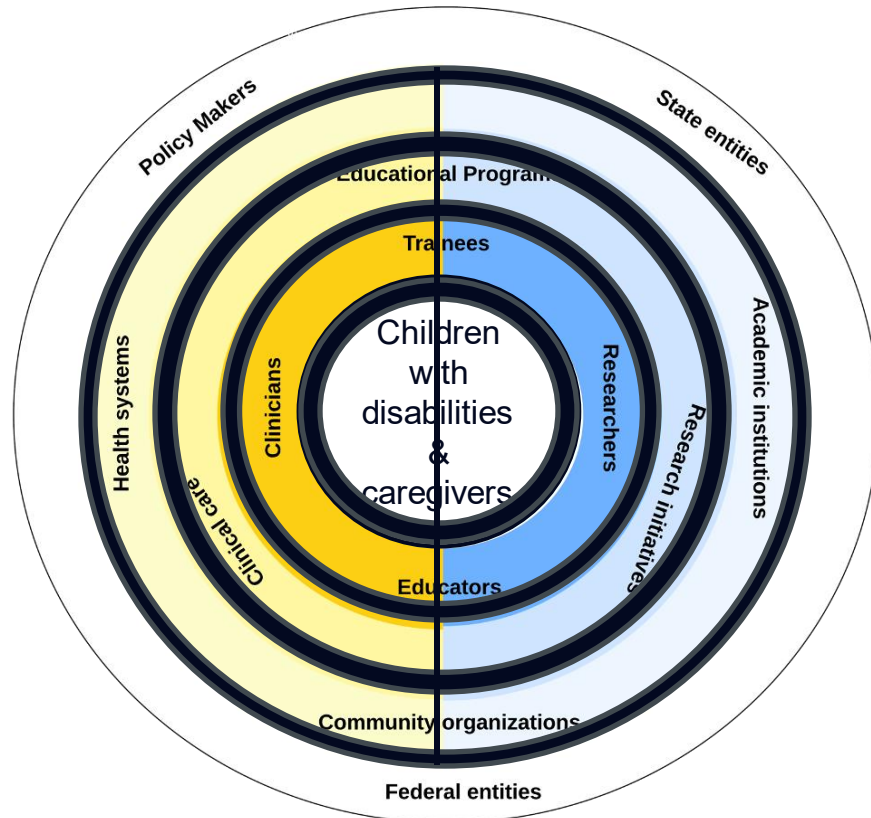
Risk real or perceived

INTEGRATION BETWEEN STAKEHOLDERS WITH DISABILITIES AND RESEARCH

- Cycle 1 ECHO: <10% of cohorts obtained data on identifying factors and function in children with disabilities since birth.
- Result: number and function in daily of children with disabilities in Cycle 1 is uncertain.
- New child medical forms based on the Washington Group/UNICEF Child Functioning Module will help.

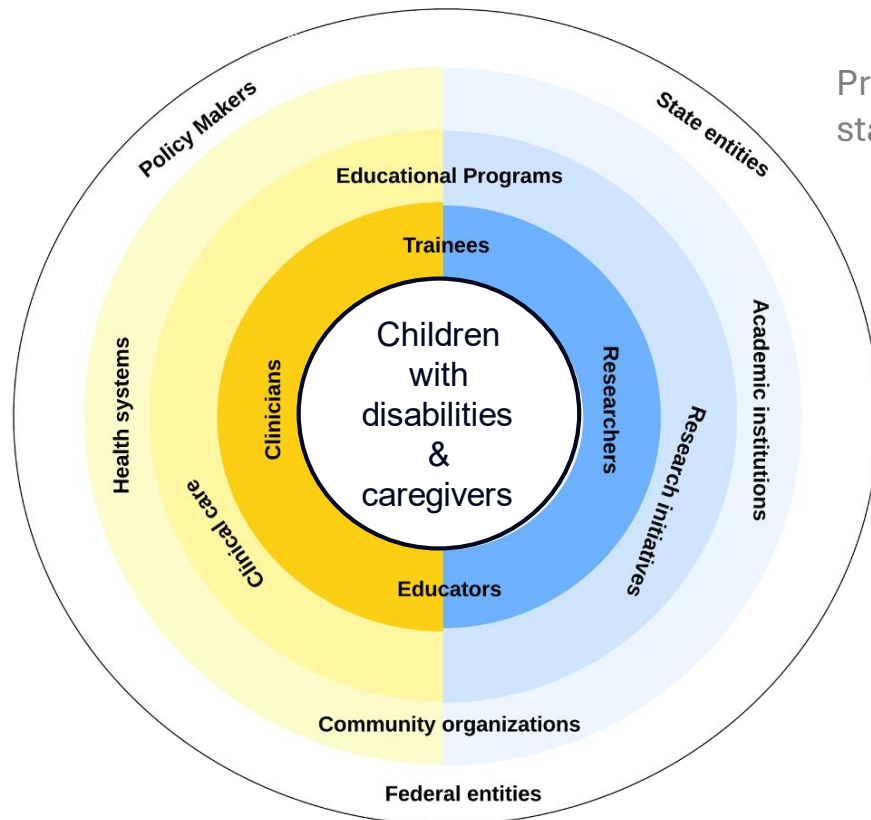


RESEARCHING DISABILITY AND HEALTH



Problem: the system is not integrated, with silos between and within levels - starting with the critical barrier isolating the individuals we are trying to help

RESEARCHING DISABILITY AND HEALTH



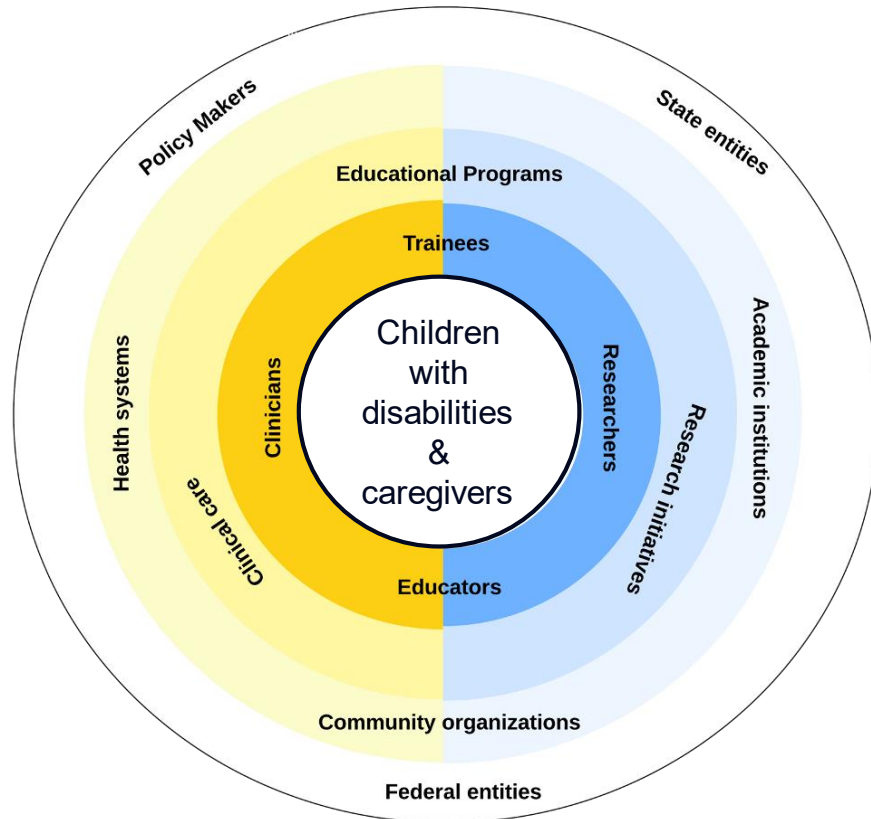
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Solution: Community Based Participatory Research - inquiry with the participation of those affected by an issue for the purpose of education and action for effecting change

Wallerstein & Duran
Viswanathan
Green et al.

RESEARCHING DISABILITY AND HEALTH

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Solution: Community Based Participatory Research - inquiry with the participation of those affected by an issue for the purpose of education and action for effecting change

Phases: Engagement & Issue Identification, Research Planning, Action Implementation, Reflection & reassessment

Wallerstein & Duran
Viswanathan
Green et al.

ONLINE SURVEYS



Advantages

Disadvantages

Quick to create and deploy for any size group

Low burden to complete

Many programs will automatically summarize results

Numerical & open-ended data collection possible

Response rates can be low

Response bias

Hard to interpret meaning behind response

Not personal

SEMI-STRUCTURED/STRUCTURED INTERVIEWS



Advantages

Disadvantages

Open-ended responses

Explore thoughts, feelings, beliefs

Time consuming to collect

Analysis required effort and skill

Delve deeply into sensitive issues

Relationship building

Difficult to quickly abstract information about a group

DeJonckheere & Vaughn (2019)



WORLD CAFÉ/FOCUS GROUPS



Advantages

Open-ended responses

Explore thoughts, feelings, beliefs

Relationship building

Delve deeply into sensitive issues

Empowering of community

Disadvantages

Time consuming for organizers and participants

Requires skilled facilitation

Lots of data collected

Requires skilled data analysis

<https://theworldcafe.com/key-concepts-resources/world-cafe-method/>

PHOTOVOICE



Advantages

Disadvantages

**Empowers
community**

**Accessible to
wide range of
participants**

**Time
consuming to
collect**

**Caution
needed to
protect
privacy/confide
ntiality**

**Captures
everyday
realities**

DeJonckheere & Vaughn
(2019)



EXAMPLE 1:
RESEARCH TO PREPARE FOR
CEREBRAL PALSY TRIALS ACROSS
THE STATE OF GEORGIA

"BARRIERS" DEPEND UPON WHO IS ASKED



n = 19
Child w CP age 0-3y
High School – college+
Survey & focus group

**PEOPLE WITH CP &
CAREGIVERS**



n = 66
CP-focused research
World Cafe

RESEARCHERS



n = 102
Clinical providers for 0-5y
Survey

CLINICIANS



Trainees: **n = 17**
Allied health
Focus group

Educators: **n = 8**
Allied health
Interview

TRAINEES & EDUCATORS

ALIGNED PERSPECTIVES



DISCREPANT PERSPECTIVES

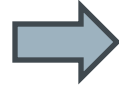


Caregivers needs



Perceived caregiver needs

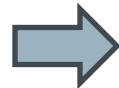
Involvement



Specific benefit to & info about their child/family

Info about general topics

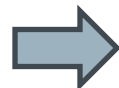
Connection



Connection with other families

Research-initiated interaction with community

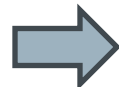
Approach



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Trust in research & research meeting community needs

Funding



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DISCREPANT PERSPECTIVES

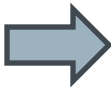


Clinicians need



Perceived clinician needs

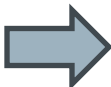
Involvement



Results summaries, info on research benefits for clinical care & research designs

Info on active studies & results

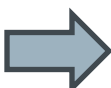
Connection



To be active part of study development & research team

Collaborations

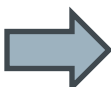
Approach



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Funding



Protected time for research

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DISCREPANT PERSPECTIVES ABOUT RESEARCH

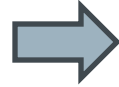


Trainees/ Educators need



Perceived trainee needs

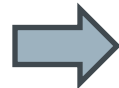
Involvement



Info about specialty areas & content, research methods

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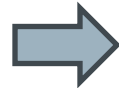
Connection



Communication pathways to increase professional & community connections

Collaborations

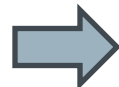
Approach



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Funding



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EXAMPLE 2:

RESEARCH FOR ECHO 301 (AIM 3)



ECHO 301 PRIMARY OUTCOME: POSITIVE HEALTH

1. A state 'far beyond a mere absence of disease'
2. Wellbeing
3. Resilience
4. A reserve in capacities (how much you have in your cup to share with others)

ECHO 301 AIM 3 APPROACH

Objectives

- 1- Discuss barriers and facilitators to obtaining research outcomes for children with disabilities in ECHO
- 2- Review the primary outcome of ECHO 310 for completeness and relevance to individuals and caregivers of children with disabilities

Methods

Series of focus groups with SAB individuals from the 2 ECHO cohort areas, **not** ECHO participants (14)

Written exercises/homework

Inductive thematic analyses of transcribed and collated data with 3 coders (>90% reliability)

Synthesis and translation

Series of focus groups for discussion and confirmation of results

Reframe: Reconceptualize positive health to be inclusive of people with impairments that lead to disability

- a. assess changes in psychosocial & physical adaptation to adversity over time
- b. measure environmental support & risk factors associated with adversity

Learn: Educate investigators, research teams, and community about disability

- a. Listen to perspectives of disability community regarding health & development
- b. Learn about ableism (negative actions, beliefs, & prejudices about disability), its impact on disability community, & strategies for unlearning ableist beliefs & practices



Empower: Increase community capacity to participate in and inform research

- a. reduce burden of research by providing individualized support with access needs, information, resources, & financial compensation for time & effort
- b. screen and address psychological & social needs of caregivers & families
- c. remove or mitigate logistical barriers to participation
- d. provide a point of contact for questions & support navigating the healthcare system

Connect: Strengthen social connection among families/individuals participating in research and increase opportunities for researcher-family partnership

- a. create an inclusive and accessible "people with disabilities research network" to connect disability community & disseminate research findings
- b. build researcher-community partnerships through stakeholder advisory boards to inform research priorities & dissemination strategies



Disability Reframes Research Definitions of Positive Health



REFRAME

Current Research Outcome	Transforming Idea	Disability Inclusive Outcome
A state 'far beyond a mere absence of disease'	Impairments in child-onset disability are lifelong	"absence" of disease may mean "a lack of co-occurring conditions"
Wellbeing	Caregiver and child/adult wellbeing are reciprocal - more dependency occurs due to impairment	Wellbeing of the family unit is intrinsic to <u>child</u> positive health
Resilience	Resilience is an expectation of the world outside disability & can lead to burdens undermining positive health	Resilience is value-add but not obligatory for positive health in disability
A reserve in capacity	Baseline capacity is lower due to limitations imposed by internal (biology) & external (environment) factors	Any capacity is positive, even if not in reserve

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