



Re-Thinking Autism: Identity, not Disease

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1



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2

- Identity first vs. Person first
 - "on the spectrum" is acceptable
- Autism as an identity as opposed to a "disease" or "disorder"
- "High-functioning" vs. "Asperger syndrome" vs. without an intellectual disability
- Neurodivergent vs. neurodiverse
- "Normal" vs. "Typical" vs. non-autistic

A NOTE ON TERMINOLOGY

- April 2022 *Pediatrics* supplement from the Autism Intervention Research Network on Physical Health (AIR-P)
 - April is Autism Acceptance month



3

UCLA Study



2012: UCLA was a site for an autism case confirmation formative research project for the National Children's Study



parents/caregivers of 25 young children (24-45 months) identified as autistic were interviewed about identification/diagnostic process



Semi-structured interviews 60-90 min in length



Also filled out Knowledge of Infant Development Inventory (KIDI), Parenting Daily Hassles (PDH), measures from the National Survey of Early Childhood Health (NSECH), and Autism Services Inventory (ASI)

4

Quote



• *"Our son was always so sweet and calm and didn't require much, it seemed like he was content that way. He never really fussed, he liked going down to bed. Up until my son was 14 months old, I thought everything was fine."*

5

Quote



• *"First you need to go to your pediatrician and the pediatrician has to make the referral to a specialist, and after you see the specialist, that's when you get the diagnosis added. But that takes a while. The only thing I get very, very mad about is the process to get everything done takes so long. Like for my son, I had to wait months to get just a hearing evaluation and I think it's just wasting time. And you can't get the services during that time, because you don't have the evaluations yet."*

6

A I R P


Quote

- *“When you feel like a child has their own personality, you don't really want to change it. Every child has their own personality and I thought my son's autism was his personality. So me trying to break into that world was something I was apprehensive to do.”*

7


Quote

- *“It was intimidating to have someone tell you how to parent. It was a challenge... it is the biggest blessing and the scariest thing at the same time... It is really exposing, you know, how vulnerable and blessed we can feel at the same time.”*



8

Lessons Learned



- Gaining an autism identity is a *process* for everyone in the family
 - Many parents commented on feeling of “ticking time bomb” or “being behind from the moment of getting the diagnosis”
- Family support has been woefully neglected in this process by service providers
- Families need to create communities of support around them to help each member of the family
- PCPs can support and guide families through this process

9

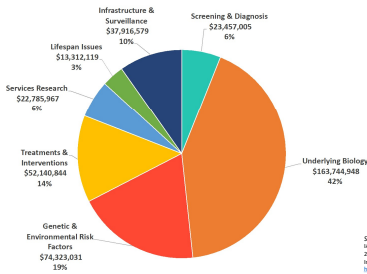
Family Support is Key



10

Current Research Investments

2018
ASD Research Funding by IACC Strategic Plan Question
Total Funding: \$387,680,492

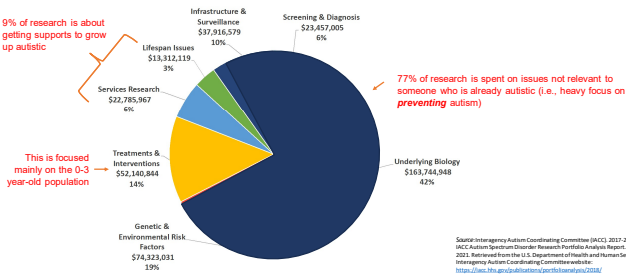


Source: Interagency Autism Coordinating Committee (IACC), 2017-2018 IACC Action Spectrum Disorder Research Portfolio Analysis Report, April 2021. Retrieved from the U.S. Department of Health and Human Services Interagency Autism Coordinating Committee website. <https://www.hhs.gov/substance-abuse/iaac/reports/2021/>

11

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12

A New Wave of Autism Research

- The mission of the AIR-P is to develop a robust research infrastructure that will foster measurable improvements in optimal physical health and well-being of autistic individuals and their families across the lifespan.

IDENTIFY

- Identify the needs, experiences, priorities of autistic individuals and their families.

TRANSLATE

- Facilitate the translation of intervention research to policy and practice.

IMPLEMENT

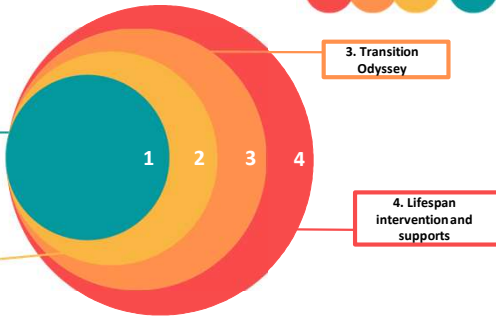
- Implement multi-site data collection and create a centralized data repository.

TRAIN

- Facilitate the training and mentorship of diverse early career investigators in physical health and autism.

13

Reimagining the Investments



14

Health and lifespan inequities for autistic individuals



- Autistic individuals experience:**
 - Disproportionate negative health outcomes across the life course
 - On average, a 16-year-lower life expectancy, relative to non-autistic individuals
 - Untreated cardiovascular disease, unidentified or late-identified cancers and mental health (i.e., suicidality, substance use) are main reasons
- Autism doesn't shorten life expectancy, being autistic does**
 - This is due to factors such as:
 - Barriers to high-quality healthcare services and supports
 - High administrative burden and resulting service fragmentation
 - Persistent exposure to implicit and explicit stigma and stress across interpersonal, educational, healthcare, and other contexts

The AIR-P addresses these key factors

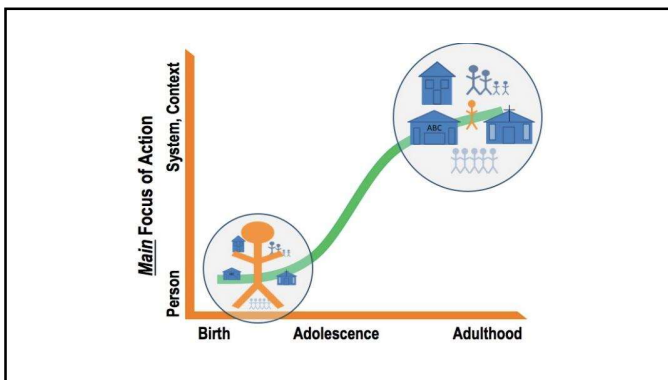
15

A I R P

Video: Zack



16



17

Eye on the Prize

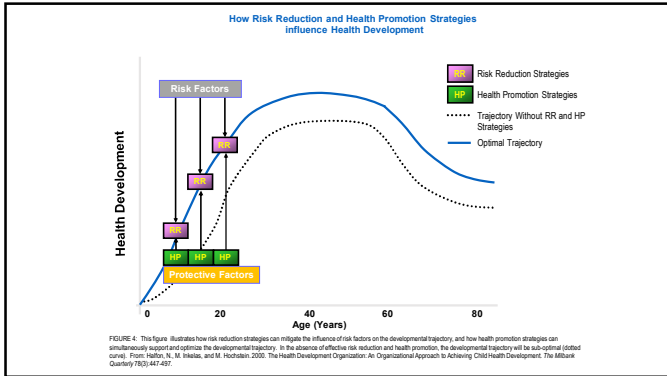
A human is a child for 18 years and an adult for 60+ years

Childhood is the preparation for adult life

Fighting for the services in school is an attempt to maximize a protective factor—keep it in perspective

We should be maximizing other protective factors

18



19

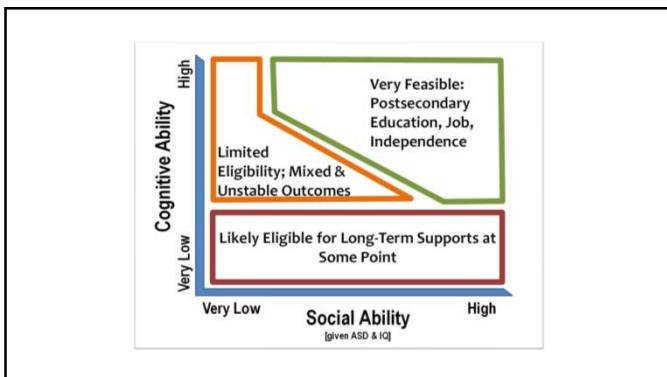
What Matters Most

Maximizing adult potential

Think Freud

- Work
- Love

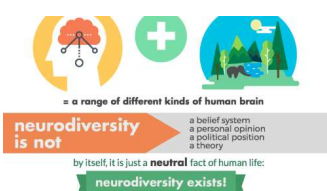
20



21

Neurodiversity

- The idea that neurological differences like autism and ADHD are the result of normal, natural variation in the human genome
- Strong Disability Rights focus
- "Nothing about us without us"
- Slippery slope
 - can start to see variation in "normal" behavior everywhere



= a range of different kinds of human brain

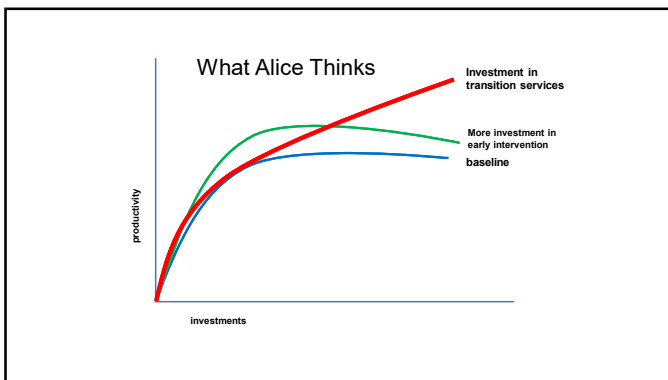
neurodiversity is not

- a belief system
- a personal opinion
- a political position
- a theory

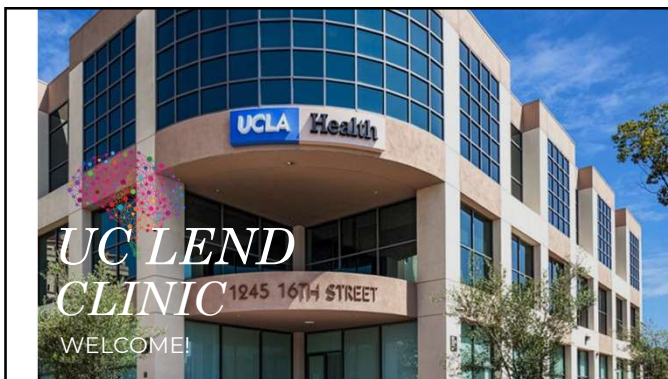
by itself, it is just a **neutral** fact of human life:

neurodiversity exists!


22




23



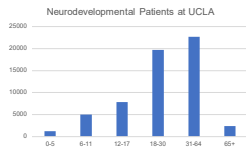
24



Importance of Primary Care



- UC-LEND is embedded in med-peds primary care at UCLA
- Of all PCPs, 1.3% are med-peds, but we see up to 18% of neurodevelopmental patients of all ages at UCLA
- Neurodevelopmental = autism, intellectual disability, ADHD, learning disability
- n = 58,784 (7.3% patient population at UCLA)
- **24% pediatrics, 72% adults (18-64), 4% seniors**



Age Group	Number of Patients
0-5	~1,000
6-11	~4,000
12-17	~8,000
18-30	~19,000
31-64	~22,000
65+	~2,000


25

WHAT WE DO

Diagnostic Clarity <ul style="list-style-type: none"> •Assessment referrals •Interpretation of evaluations 	Service Coordination <ul style="list-style-type: none"> •Care team communication •Quality of care 	Patient Services <ul style="list-style-type: none"> •Mental health •Transition planning •Goal setting
Parent Support <ul style="list-style-type: none"> •Parental activation •Mental health •Placement planning 	Behavioral Management/Parent Training <ul style="list-style-type: none"> •Skill building 	IEP Advocacy <ul style="list-style-type: none"> •Attending IEPs •Helping parents with preparation



26



What We Are Doing at UCLA Health

We have 800,000 patients in over 50 primary care offices throughout Southern California



27



Autism-related Services

- Number of neurodevelopmental patients seen in 12 months (May 2022 to April 2023): 32,494
 - 25% are children
- Current wait lists for DBP or child psych around 2 years
- Needle Anxiety Program—launched Summer 2020
- LEND Champion in every primary care office
 - Identification of neurodivergent patients in electronic medical record
 - Training of clinicians to work with neurodivergent patients
 - Expansion of clinical services for this population
- **Overall goal is to decrease the health inequity leading to poorer health outcomes, poorer quality of life, and shorter life expectancy for autistic patients**



28

UCLA LEND Champions

- 48-hour LEND PCP training
 - Combo of video lectures + clinical precepting in multi-disciplinary LEND clinic (which post-pandemic is now completely virtual)
 - Emphasize clinical diagnoses of autism (which post-pandemic schools are accepting)
- UCLA system-wide ECHO model
 - Monthly case conference led by Dr. Lekha Rao, pediatric neurologist and Dr. Kashaia Rosenau, developmental psychologist
- Goal is to see any patient with a developmental/behavioral concern within **2 months** of parent/patient wanting appointment
 - Work through the 1-2 year wait list for DBP and neuropsych clinics

29

Practice/Research Reflections

- Practice informs research and vice versa
- These experiences inform our AIR-P research agenda
- Research findings can be implemented into clinical practice changes relatively quickly
- Goal is for UCLA Health to be our learning lab for improving care for autistic patients

30

AIR-P Node Research Areas - What are we researching?




-  **Primary Care Services and Quality:** Addressing health services and health care quality for neurodevelopmental patients
-  **Community-based Lifestyle Interventions:** Translating clinical interventions for application in the community setting
-  **Gender, Sexuality, and Reproductive Health:** Understanding how autistic people experience gender, sexuality and reproductive health and how to improve care
-  **Health Systems and Services:** Using large datasets to identify health care disparities for autistic populations
-  **Neurology:** Interventional studies to improve/mitigate neurological issues in autistic patients
-  **Genetics:** Improving genetic registries

31


Authentic Voices

The Autistic Researcher Review Board (ARRB) served as a valuable autistic advisory board within the Network (2020-2022)

- Made progress towards integrating autistic voices in research yet were siloed in decision-making
- ARRB accolades: <https://airpnetwork.ucla.edu/about/arrb-accolades>
- There was, however, a need for autistic researchers to be more centralized within the AIR-P




Autism Intervention Research Network on Physical Health







32

Autistic and Neurodivergent Scholars Working for Equity in Research (ANSWER)



- Recently established as a significant investment from the AIR-P
- Led by Dr. Heather Brown, Zack Williams, & Dr. Emily Hotez
- **Currently forming to serve as an innovative model for how autistic and non-autistic autism researchers can effectively work together in meaningful & authentic collaboration**
- <https://airpnetwork.ucla.edu/about/answer-call-for-applications>

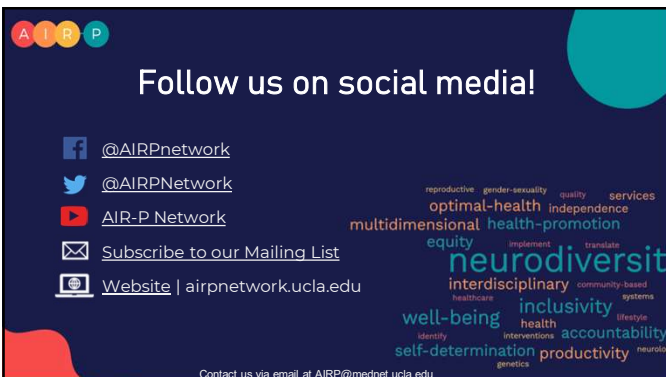
33



34



35



36

Dr. Alice Kuo, M.D, Ph.D
Biography

Dr. Alice Kuo is Professor and Chief of Medicine-Pediatrics and Preventive Medicine at the David Geffen School of Medicine at UCLA and Health Policy and Management at the UCLA Fielding School of Public Health. Her research interests include access to and delivery of developmental services, health disparities in marginalized populations, transitions to adulthood for children with special health care needs, and services for children and adults with autism and other neurodevelopmental disabilities.

Dr. Kuo is the Principal Investigator of the Autism Intervention Research Network on Physical Health and Director of the University of California Leadership Education in Neurodevelopmental Disabilities (UC-LEND) program. She is Medical Director of the UC-LEND Clinic and has a primary care practice for neurodevelopmental patients of all ages in Santa Monica and Redondo Beach.

Dr. Kuo received a B.A. in biology from Harvard University, her M.D. degree from UCLA, and her Ph.D. in educational psychology, also from UCLA. In 2017, she received an M.B.A. in healthcare administration from the Isenberg School of Management at the University of Massachusetts, Amherst.