Autism & Under-resourced Communities: Opportunities for Change

Dr. Aubyn Stahmer & Vanessa Avila-Pons, LMFT
University of California-Davis MIND Institute
8th July 2021
Moderator: Dr. Nicholas Fears
Student & Trainee Committee Chair: Dr. Alana McVey

INSAR
International Society for Autism Research

Autism & Under-resourced Communities:
Opportunities for Change

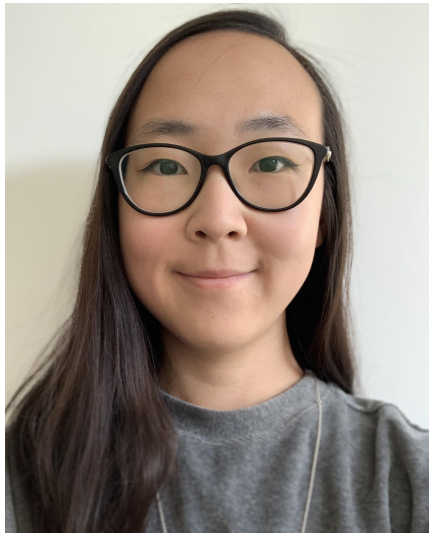
Working Group

Dr. Alana McVey

University of British Columbia, Canada

Fathima Muhsina Kodakkadan

Anglia Ruskin University, UK



Dr. Jiedi Lei

King's College London, UK

To Join INSAR Visit: http://autism-insar.org/membership

INSAR
International Society for Autism Research

Autism & Under-resourced Communities: Opportunities for Change

Speaker

Dr. Aubyn Stahmer

Professor, Department of Psychiatry, UC-Davis Medical Center

Speaker

Vanessa Avila-Pons, LMFT

Treatment & Training Manager, Collaborative Start Lab, UC-Davis MIND Institute

To Join INSAR Visit: http://autism-insar.org/membership

INSAR
International Society for Autism Research

Partners – Partners - Partners

Research Institutions

UC San Diego School of Medicine

CASRC child and adolescent services research center

Drexel University A.J. Drexel Autism Institute

UCLA

San Diego State University

Community Partner Examples

- School Districts
- Mental Health
- Part C
- Family Rsc Ctrs
- Children & families
- Autistic people
- Providers & leaders

BRIDGE SoCal BRIDGE COLLABORATIVE

CAPTAIN California Autism Professional Training and Information Network

AIR-B Autism Intervention Research Network on Behavioral Health

Researchers (examples)

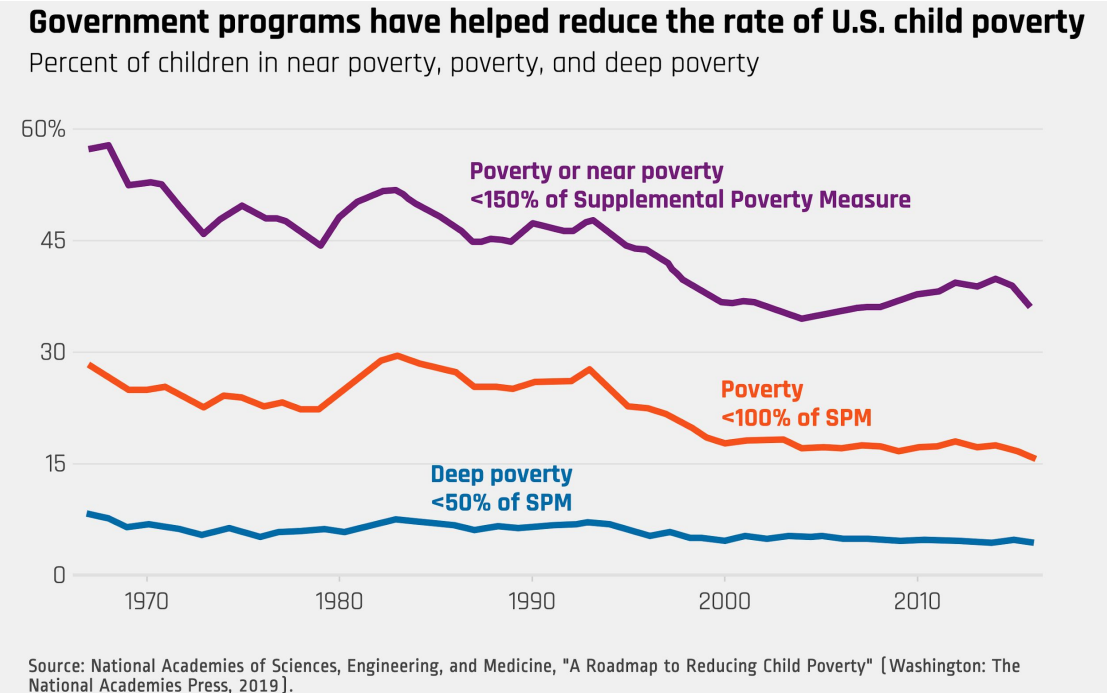
Greg Aarons
Lauren Brookman-Frazee
Connie Kasari
Sarah Rieth
Diana Robins
Jessica Suhrheinrich
Postdoctoral Fellows
Graduate Students
Research Coordinators
Data Team
IDDRC
CTSA

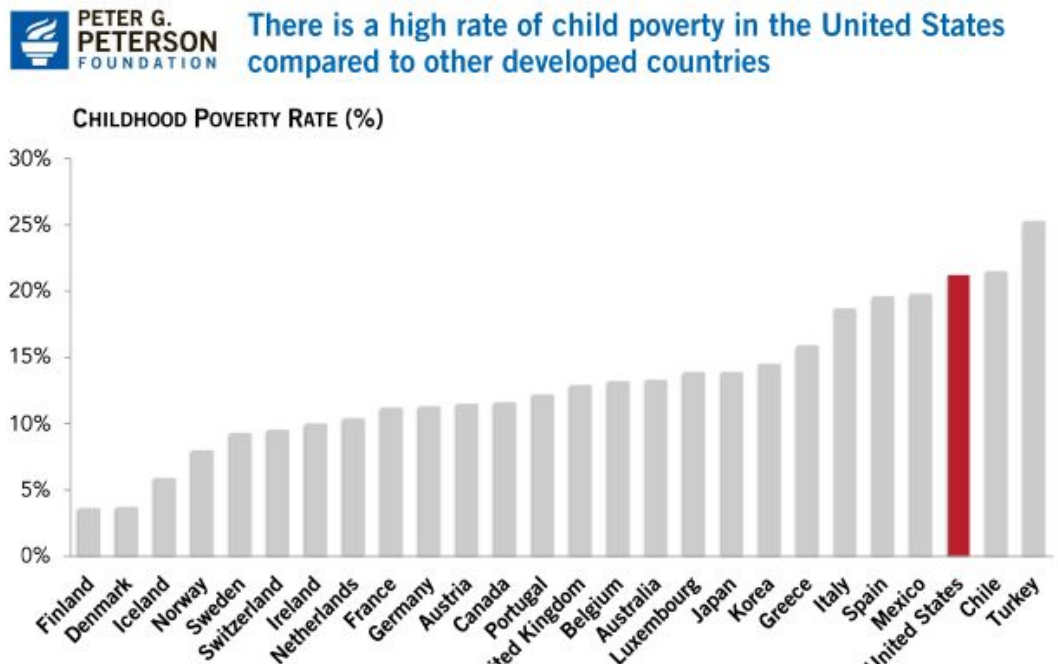
Funders

- NIMH
- IES
- Autism Speaks
- NIDDR
- NICHD
- HRSA
- WT Grant

Defining Poverty

- In U.S. – an individual with an income less than $36/day
- Family of 4 living on less than $72/day ($26,280/yr)
- Do not vary geographically
- Updated annually for inflation





Poverty Rates

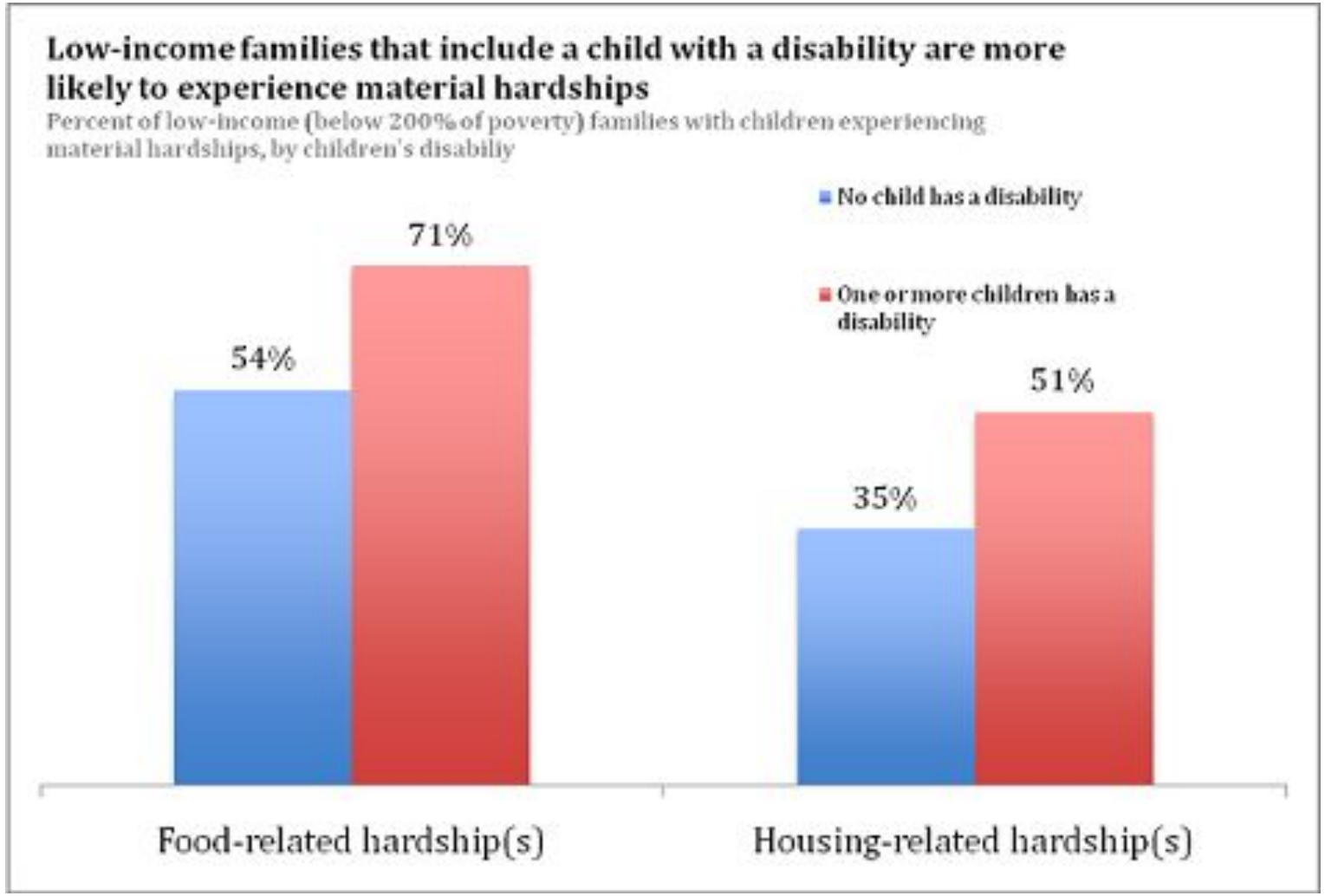
Poverty and the Developing Brain

"The brain is not destiny. And if a child's brain can be changed, then anything is possible. "

—Kimberly Noble

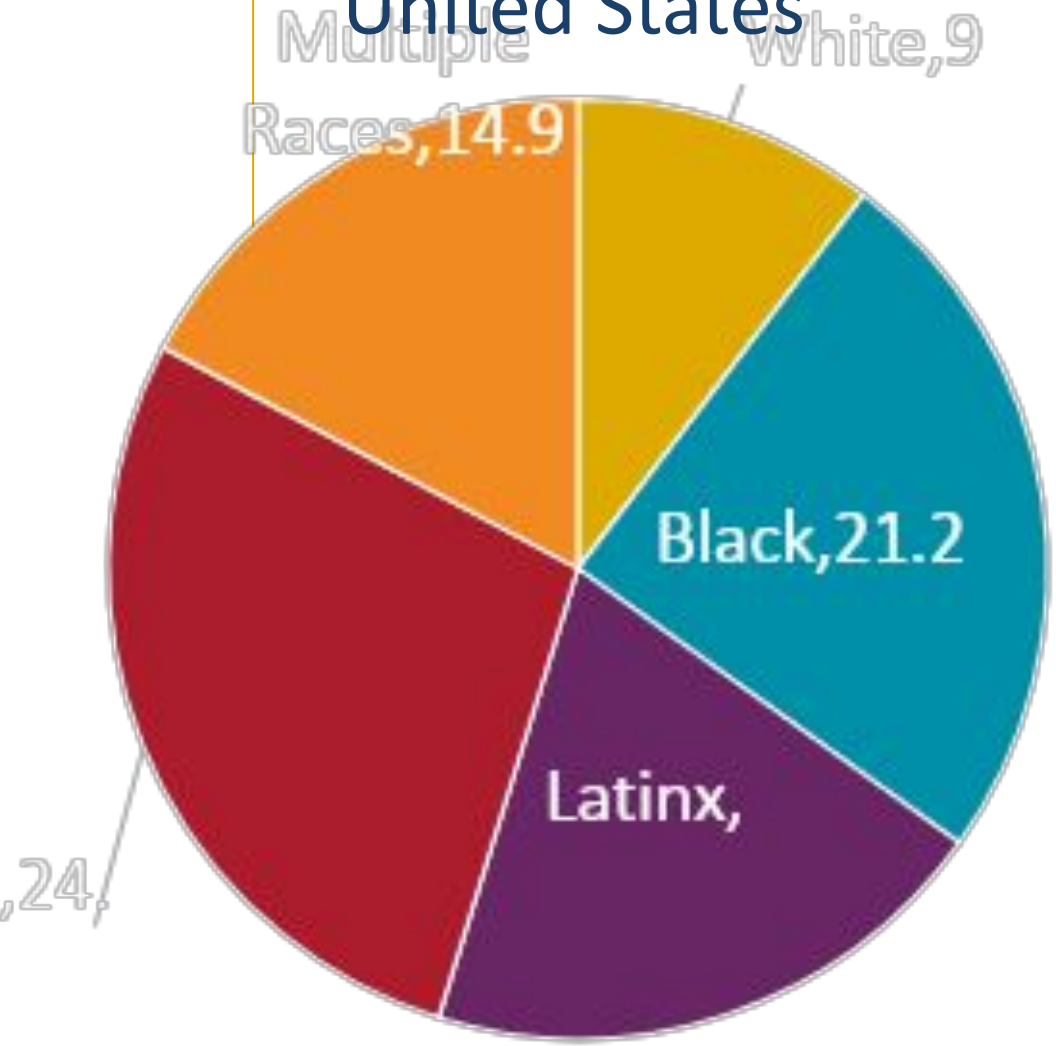
- Increase in NDD in low income families
- Malnutrition, environ toxins, poor access to health care, familial stress. low birthweight, fetal distress

Poverty and Disability

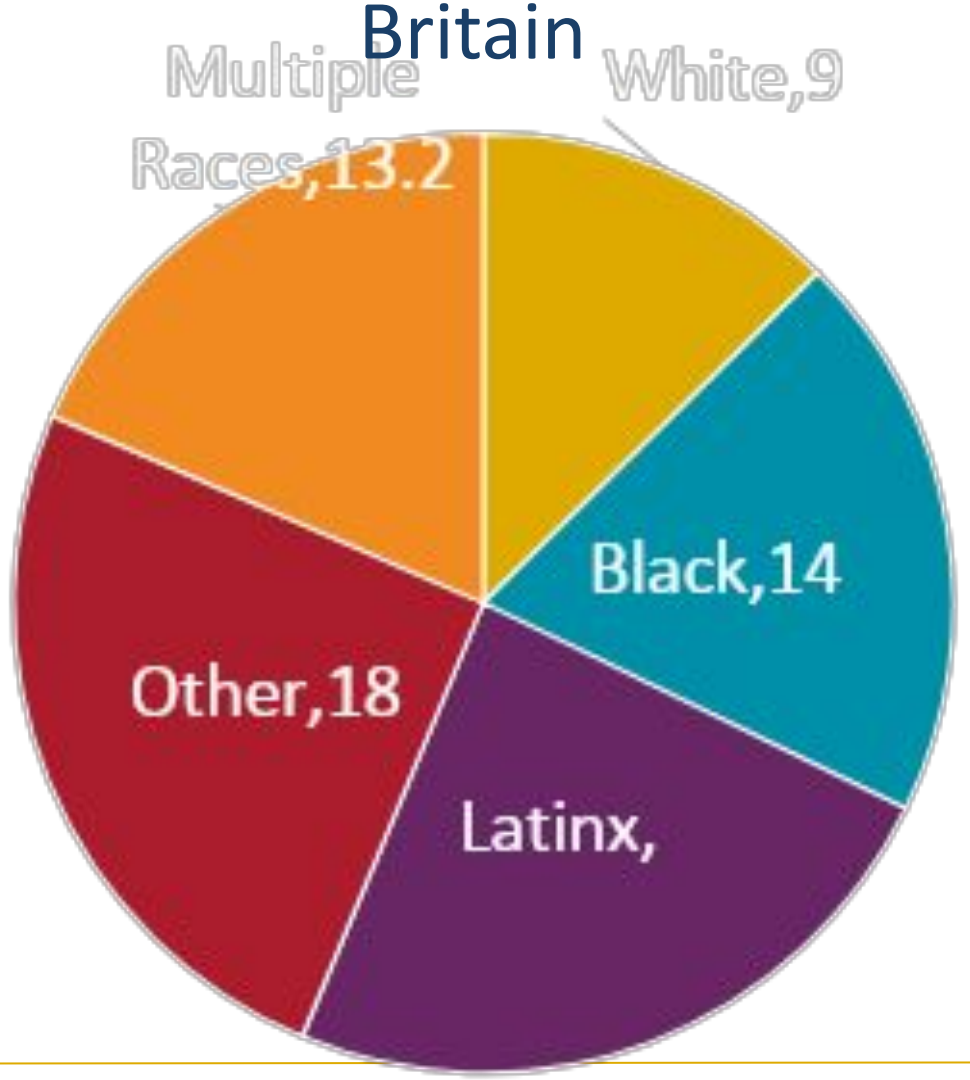


Poverty and Race/Ethnicity

United States

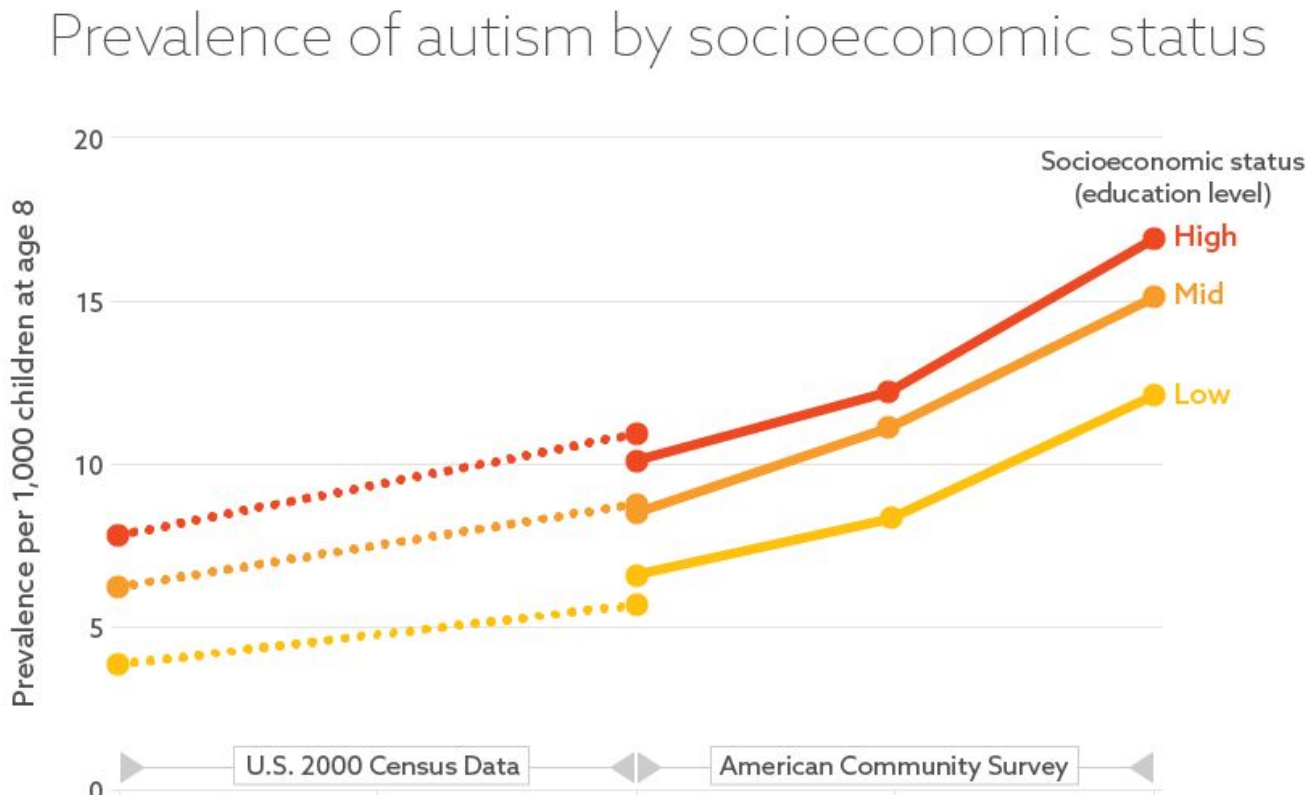


Britain



Delays in Autism Identification

In the US and the UK low income is associated with later autism diagnosis



Disparities in Autism Care (Smith et al., 2020 review)

Socioeconomic status

Service Use

- Poorer access to care (all types)
- Less likely to have primary care doctor
- Less likely to enroll in ABA and OT

Quality of Care

- Consistently lower quality of care

Intervention Effectiveness

- **No studies examining differences in intervention effectiveness based on socioeconomic status**

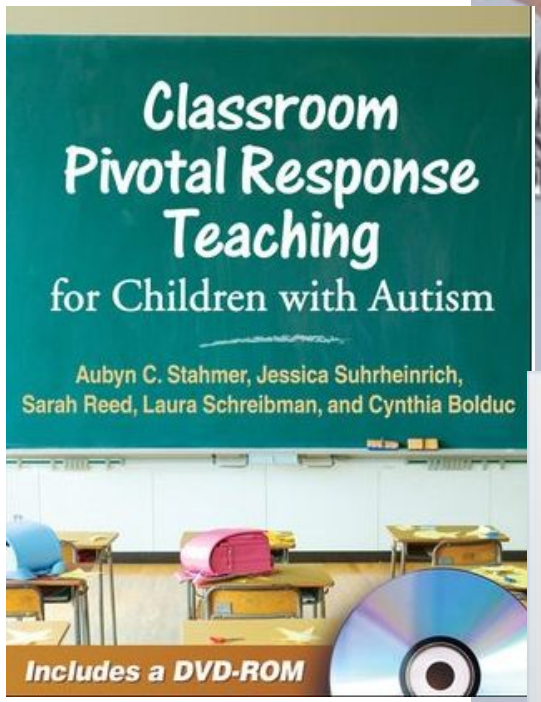
Poverty and autism in schools

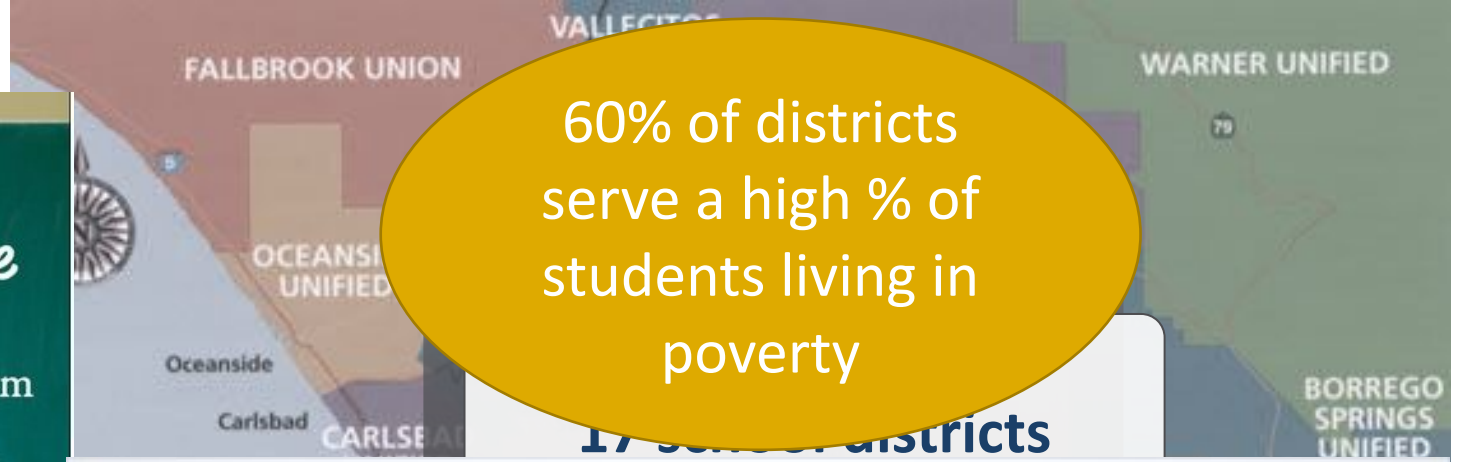
Poverty & School Research

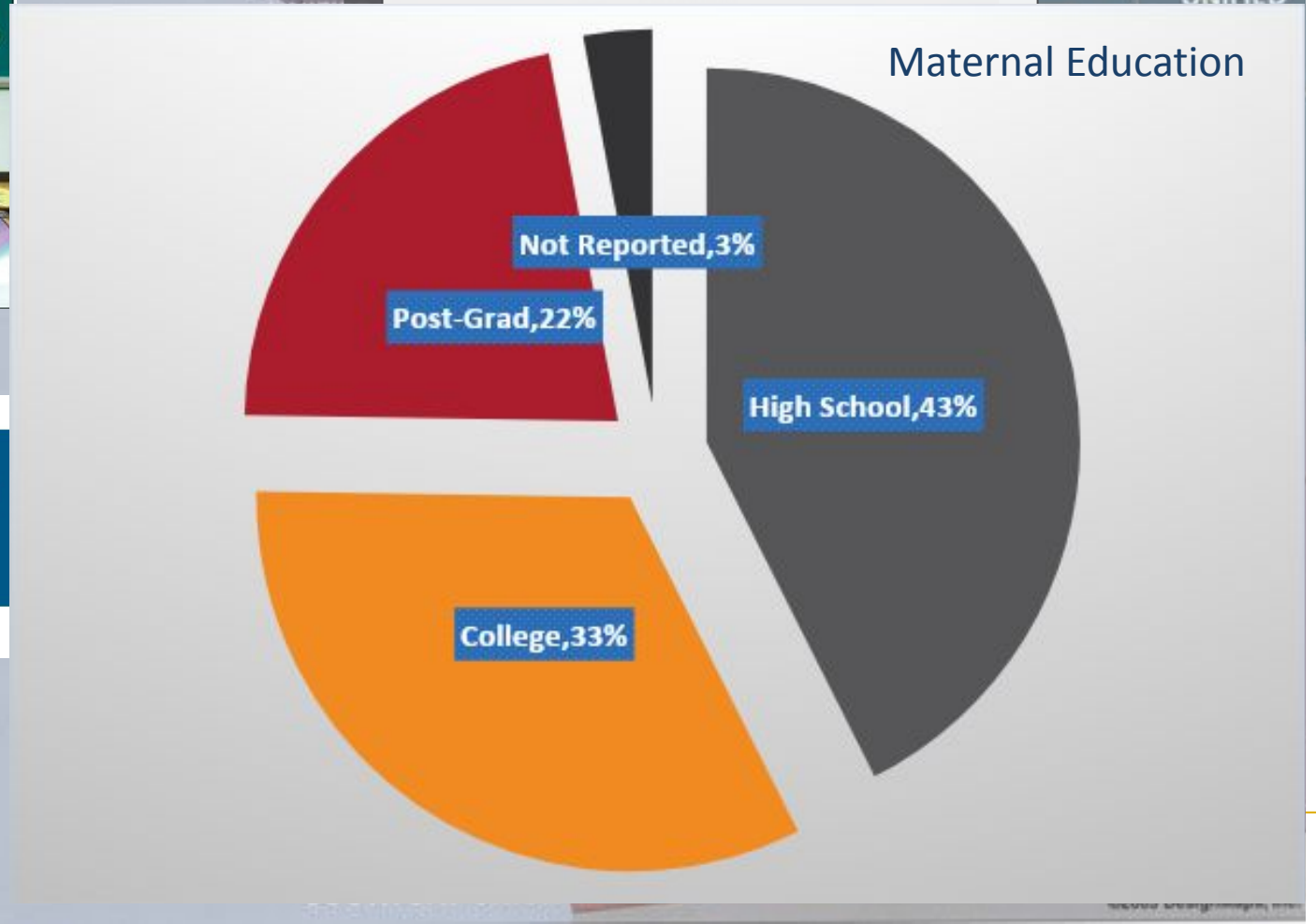
In high poverty schools:

- Lower quality special and general education (Surcher et al., 2019)
- Teachers are less qualified & have fewer professional development opportunities (Bettini & Park, 2021)
- Higher teacher turnover (Carver-Thomas et al., 2017)
- Limited leadership support (Garcia & Weiss, 2019)

Literature review by Dr. Kelsey Oliver







Co-Investigators:
Jessica Suhrheinrich
Sarah R Rieth

Data Analysis:
Scott Roesch
Allison Nahmias
Sarah Vejnoska

Funding:
Institute for Education Sciences

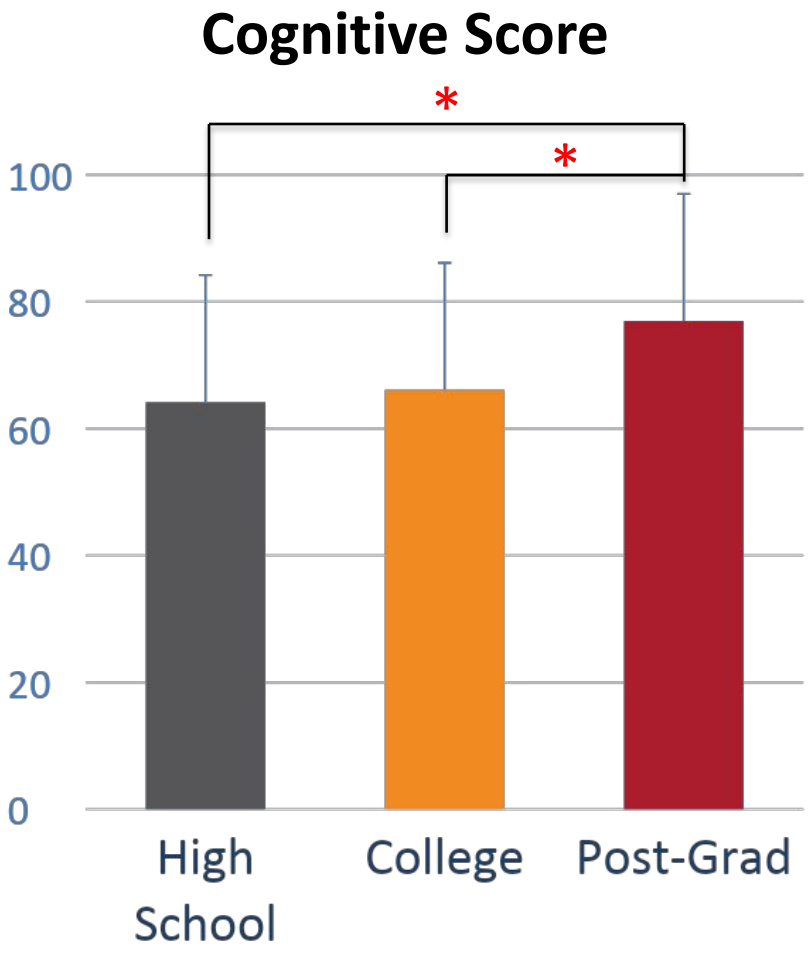
Poverty and ASD Identification

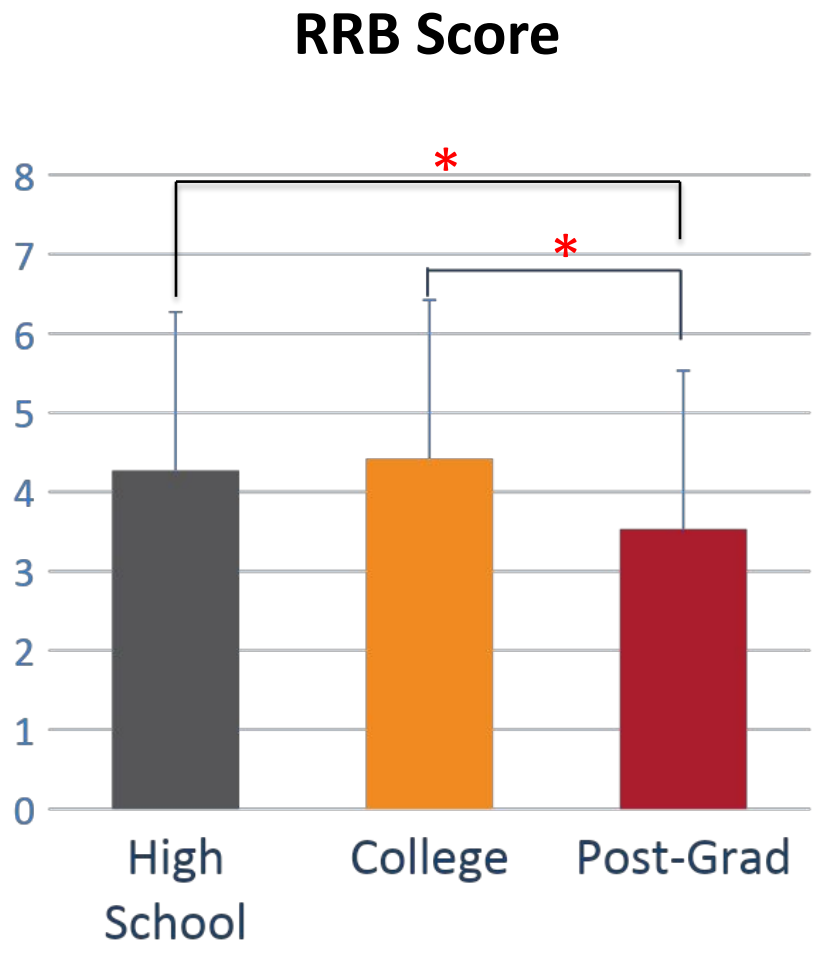
Identify specific areas of disparity in student characteristics by socio-economic status (SES).

- Examine cognitive and adaptive functioning scores and ratings of autism symptoms by maternal education.

Study led by S. Vejnoska

SES Results


Cognitive Score
*
*
100
80
60
40
20
0
High School
College
Post-Grad


RRB Score
*
*
8
7
6
5
4
3
2
1
0
High School
College
Post-Grad

CPRT Fidelity and Student Outcomes

Teacher fidelity to CPRT predicted student outcomes:

- Better progress on educational goals
- Higher student engagement in the lesson
- Fewer challenging behaviors during the lesson
- Improved social and communication scores on standardized assessments

Poverty, Classroom Quality & EBP Use

Overall classroom quality lower for schools serving a higher percentage of students in poverty

MIND THE Gap

Co-PIs
Connie Kasari (AIRB Network PI)
David Mandell; Suzanna Iadarola; Elizabeth Hassrick

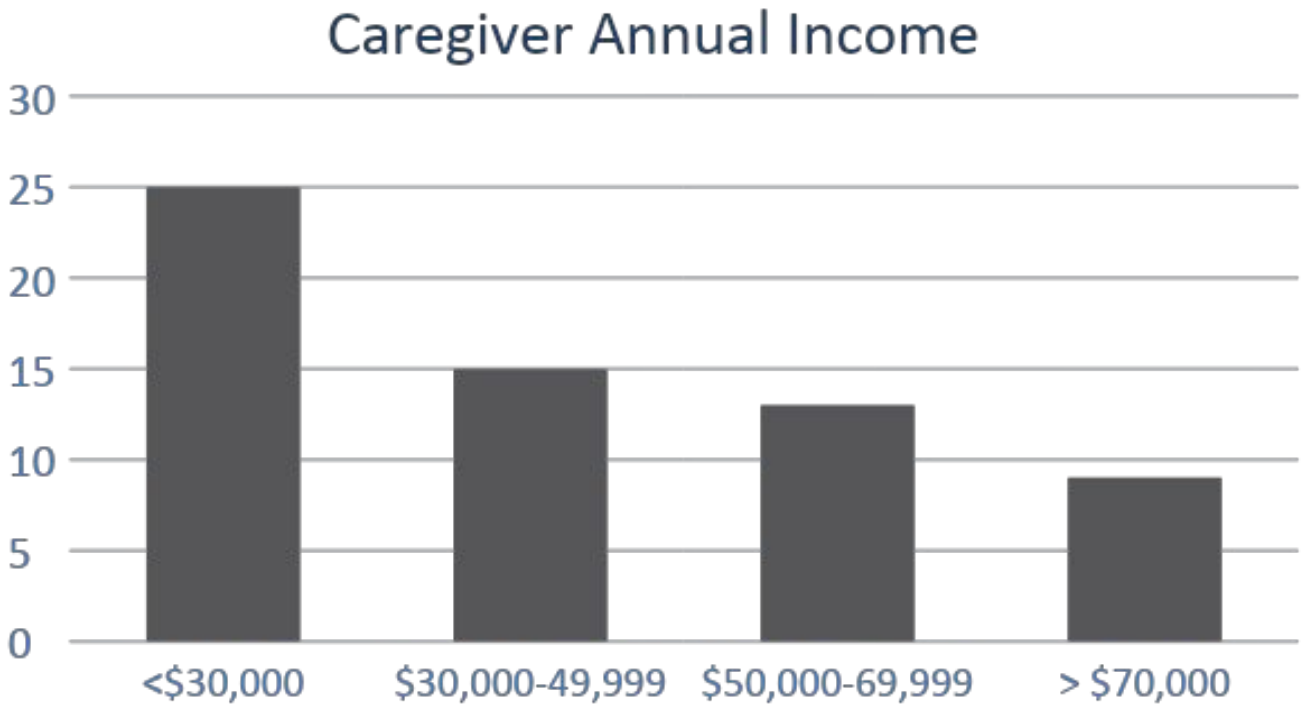
Data Preparation:
Elizabeth Holliday Morgan
Sarah Vejnoska

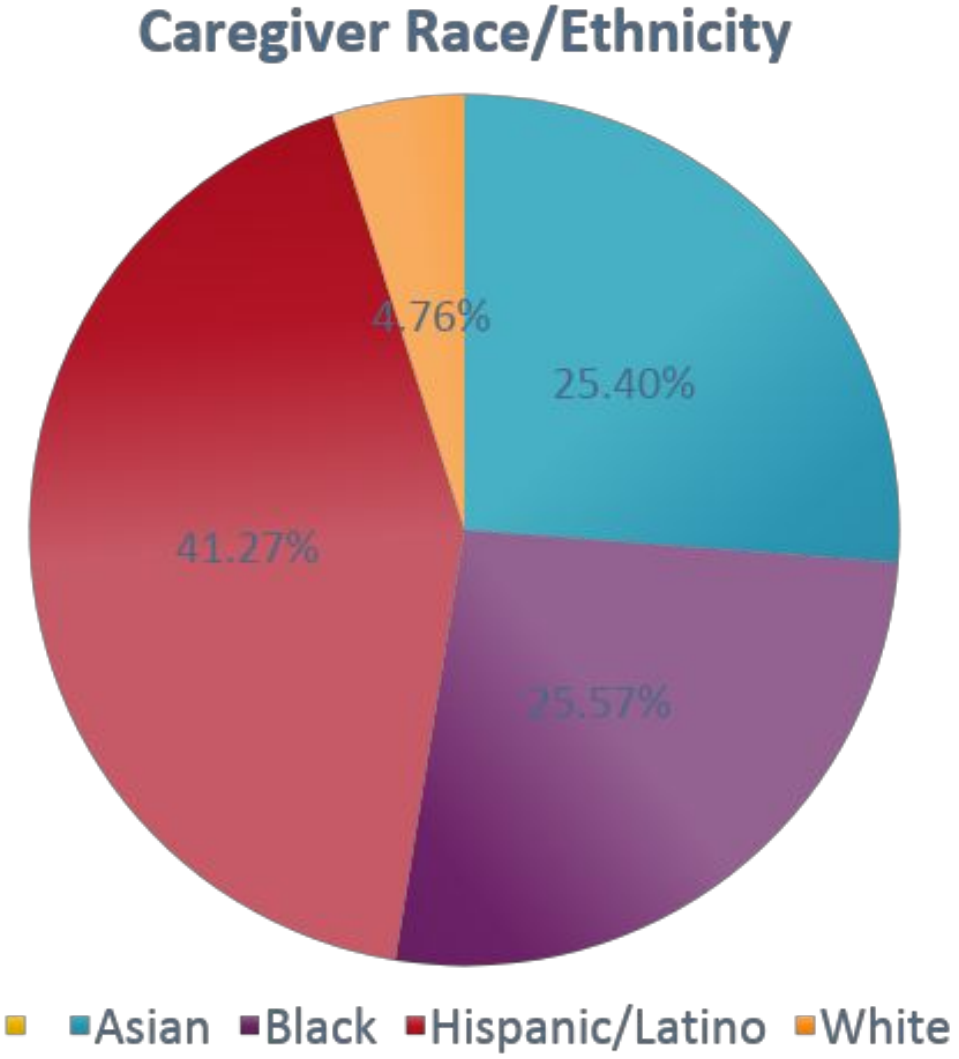
Stahmer, A.C., Vejnoska, S., Iadarola, S., Straiton, D., Segovia, F., Luelmo, P., Morgan, E.H., Lee, H.S., Javid, A., Bronstein, B., Hochheimer, S., Cho, E., Aranbarri, A., Mandell, D., McGhee Hassrick, E., Smith, T., & Kasari, C. (2019). Caregiver voices: Cross cultural input on improving access to autism services. *Journal of Racial and Ethnic Health Disparities, 6,* 752-773.

Funding:
HRSA

Penn University of Pennsylvania | Drexel University | UCDAVIS HEALTH | MIND INSTITUTE | UCLA | 1850 MELIORA UR MEDICINE Medicine of the Highest Order

Caregiver Demographics (n=63)





Barriers

Diagnostic Barriers

So, when he was two, I was always track everything he did, write it down, and tell the doctors. And…they would say, "Oh, well, he's only two. That's a typical two-year-old. They're going through the terrible two stages. That's just them."

I feel like in my situation that because of the color of my skin or because of maybe the way I decide to use my words or my tone or in my pitch or I use my hands a lot that I've been judged and treated poorly…throughout the whole entire process. So I think a barrier for me would be race.

Access to Resources

I'm a single mom with three kids, and I cannot come or go anywhere if nobody is providing any services. So I'm still juggling because I don't know who to choose for care for my special kid because I cannot call anyone to help.

I had to switch off my jobs very quickly because you know after some time I feel that they want me to go out of the workplace. They don't want moms who have young kids. They don't understand that. They will make adjustments to others but they don't feel sympathy of any kind for a working mom.

Facilitators

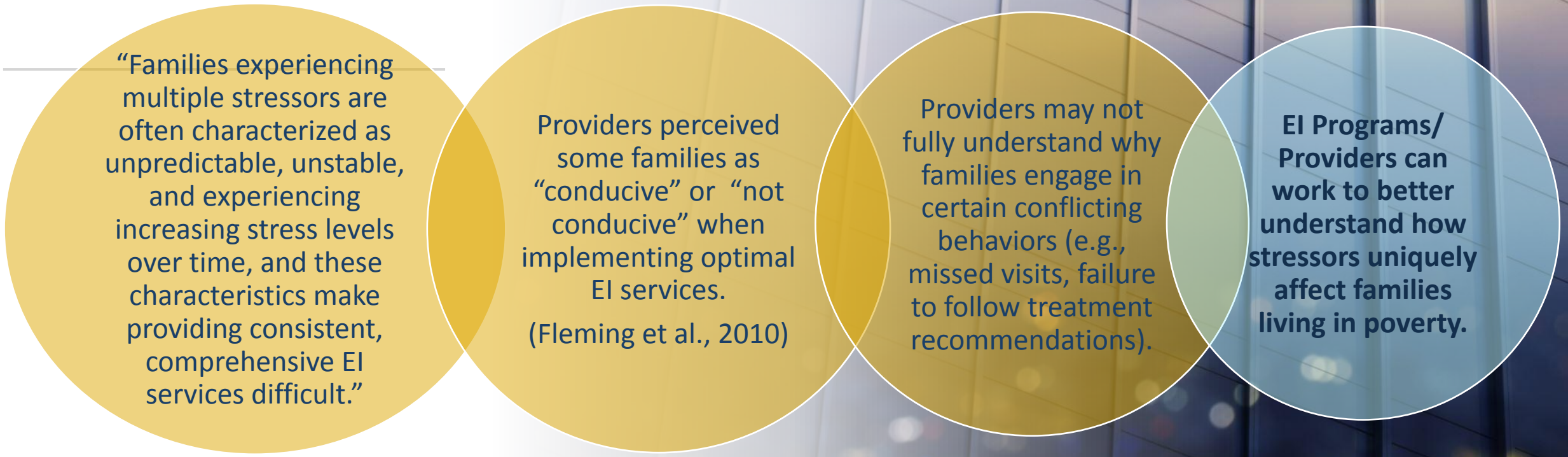
Provider Relationships

"When I saw their willingness to tell me certain things then I just put my guard down…And that's when I was okay I let everything go, humbled myself. Then I could be open. I was ready to be taught. And so they showed me things. They opened up a whole new world for me."

Poverty and ASD treatment

Picture: @OppCulture

Perceptions of Families in Poverty



(Guralnick, 1998; Peterson, Mayer, Summers, & Luze, 2010)

(Corr et. al, 2016)

Four Components of EI work Bruder (2010)

- Family centered
- Natural learning environments
- Collaborative team processes
- Service integration

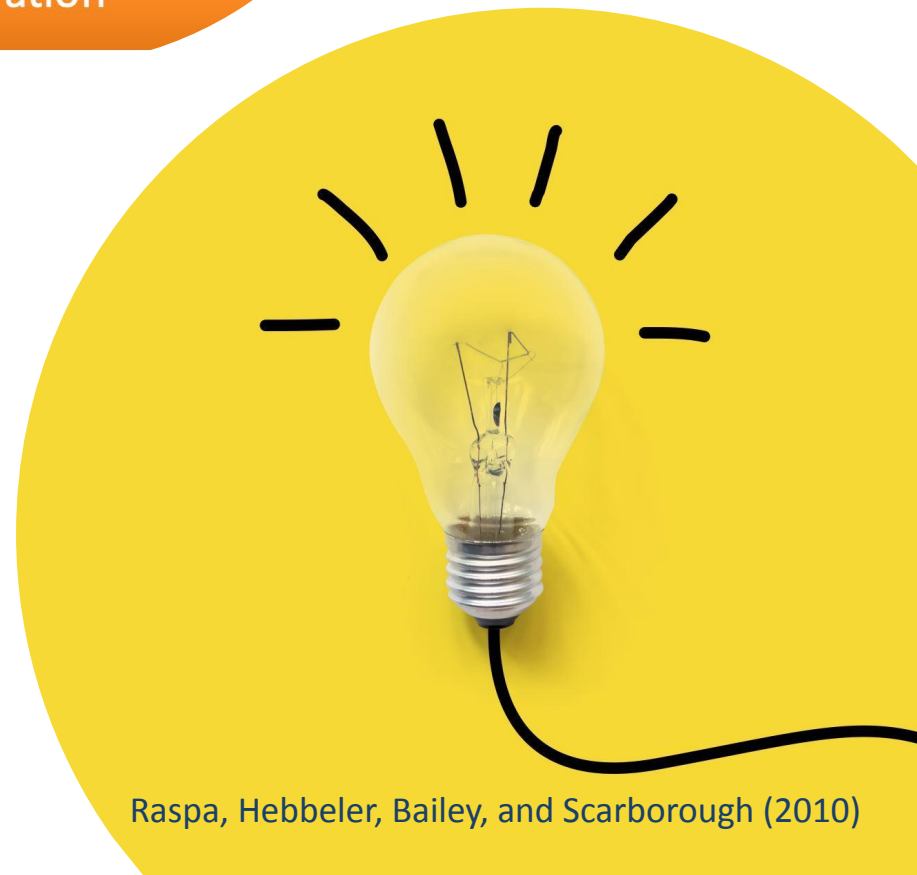
Challenges to EI Components

- **Multiple stressors (e.g., child's development + Housing)**
- **Lack of knowledge/ use of participation-based practices**
- **Disrupted daily routines (lack of consistent shelter, Access to food)**
- **Under utilizing services based on income**
- **Complicated Informal and formal routes to services**

Corr et. al (2016)

Facilitators to EI Components

- **Building on family's strengths**
- **Work with family on problem solving strategies for all stressors**
- **Consider how home environment needs may affect services (e.g., safety of neighborhood, limited resources)**
- **Individualize ways to manage/ coordinate services based on child + family's needs.**
- **High degree of knowledge in child development+ family services (housing assistance, food programs).**



Raspa, Hebbeler, Bailey, and Scarborough (2010)

Participants and Families

Treatment in Real Life

Co-PIs
Diana L Robins (ACE Network PI)
Deb Fein
Investigators:
Giacomo Vivanti
Sarah Dufek
Meghan Talbott
Data Preparation:
Leslie McClure, Director, Data Coordinating Center
Sherira Fernandes
Vanessa Avila-Pons
Rachel Balitsky
Chinelo Emekanwonovo
Funding:
NICHD

Treatment in Real Life

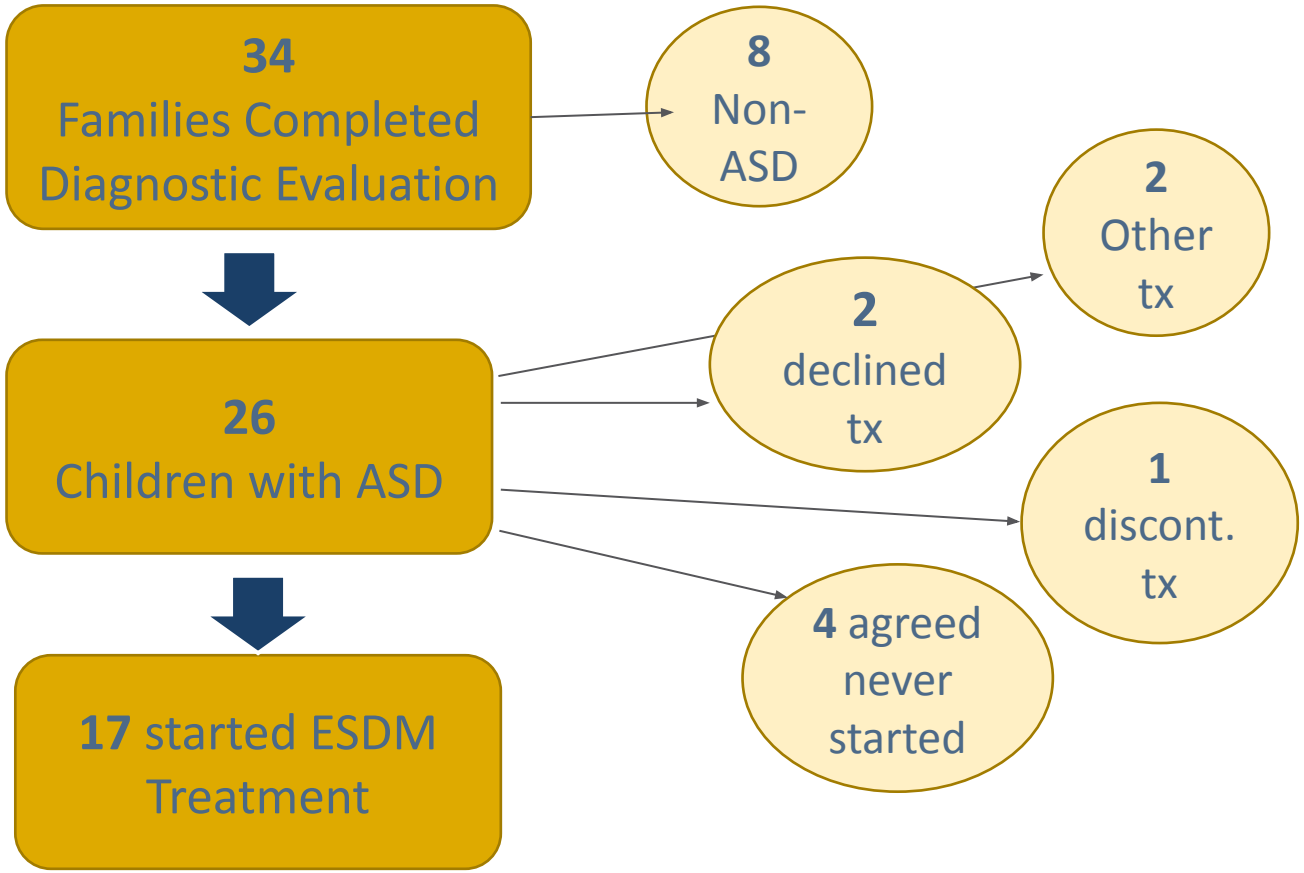
Universal Screening

Timely Evaluation

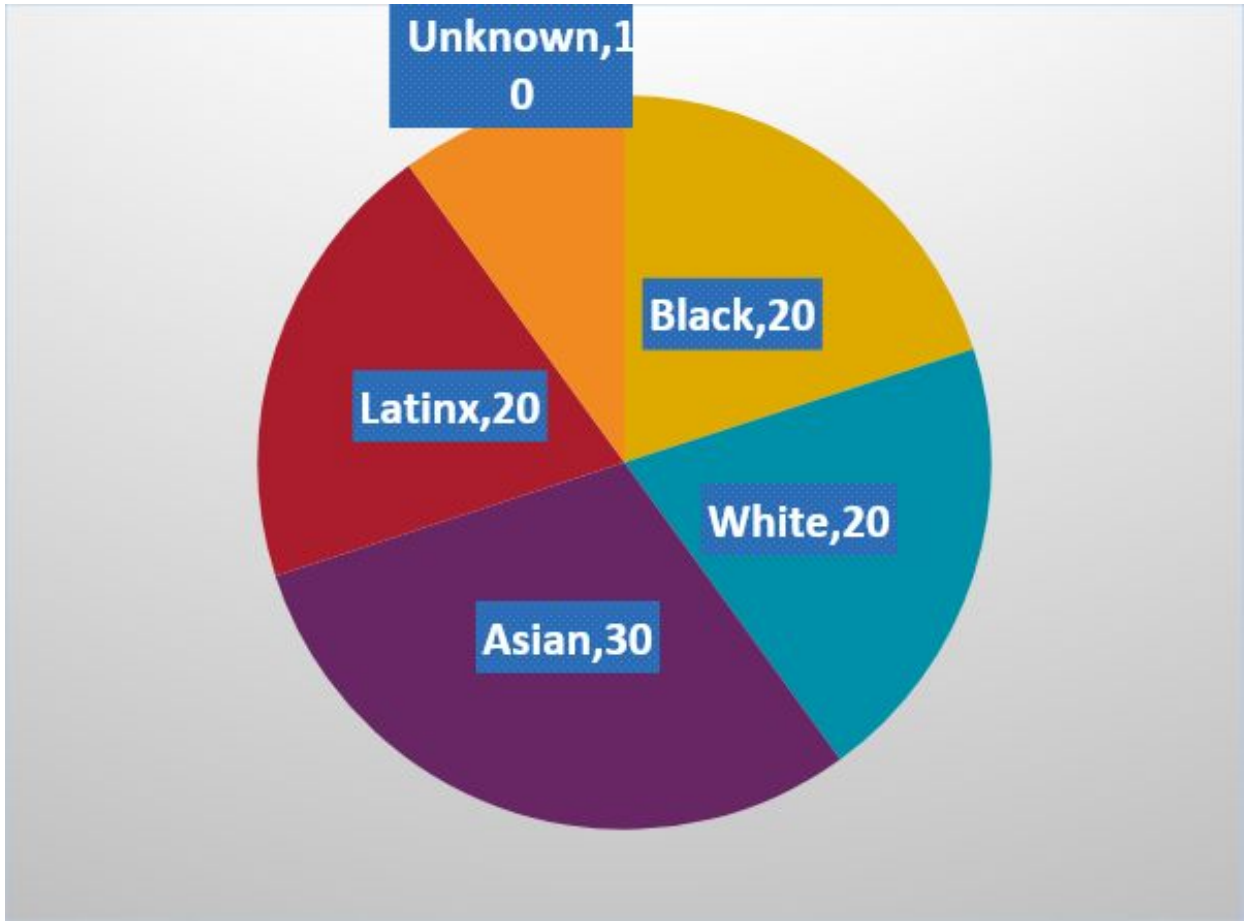
Quality Treatment Access

- 20 hours/week, 1-on-1
- Parent coaching twice a month

UC Davis Treatment Population



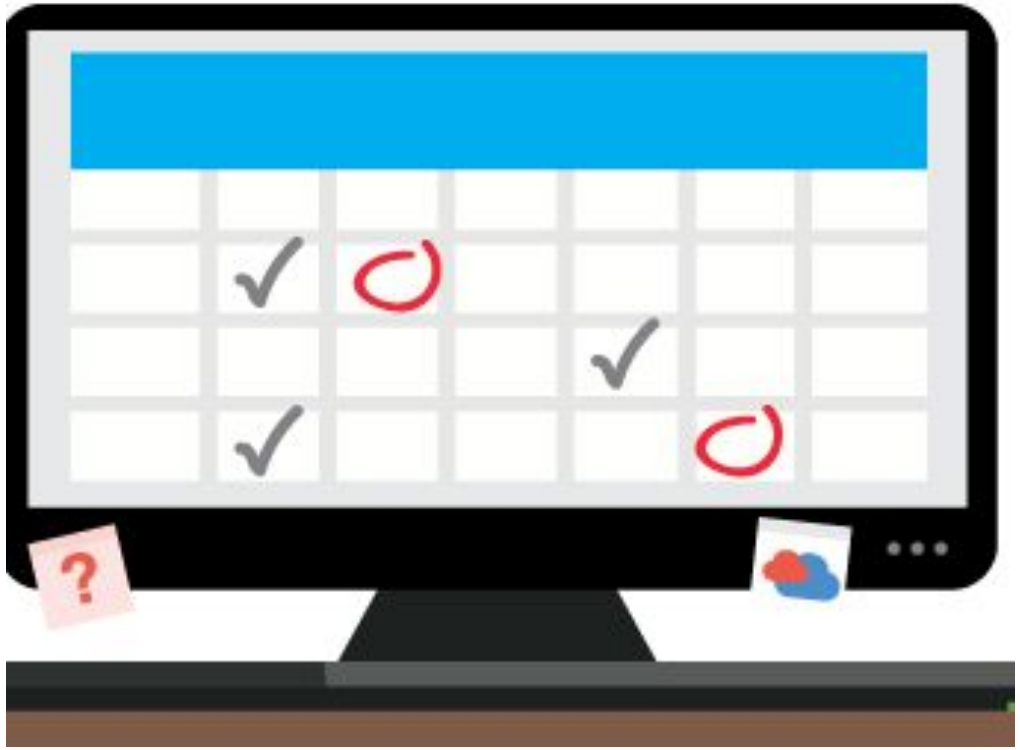
Demographics: Children Enrolled in Treatment



- 50% with income below $36,000/yr
- 40% single parent household

Adaptations

- Attendance and cancellations
- Additional non-ASD related resources requested by families
- Treatment modifications to support participation in treatment sessions



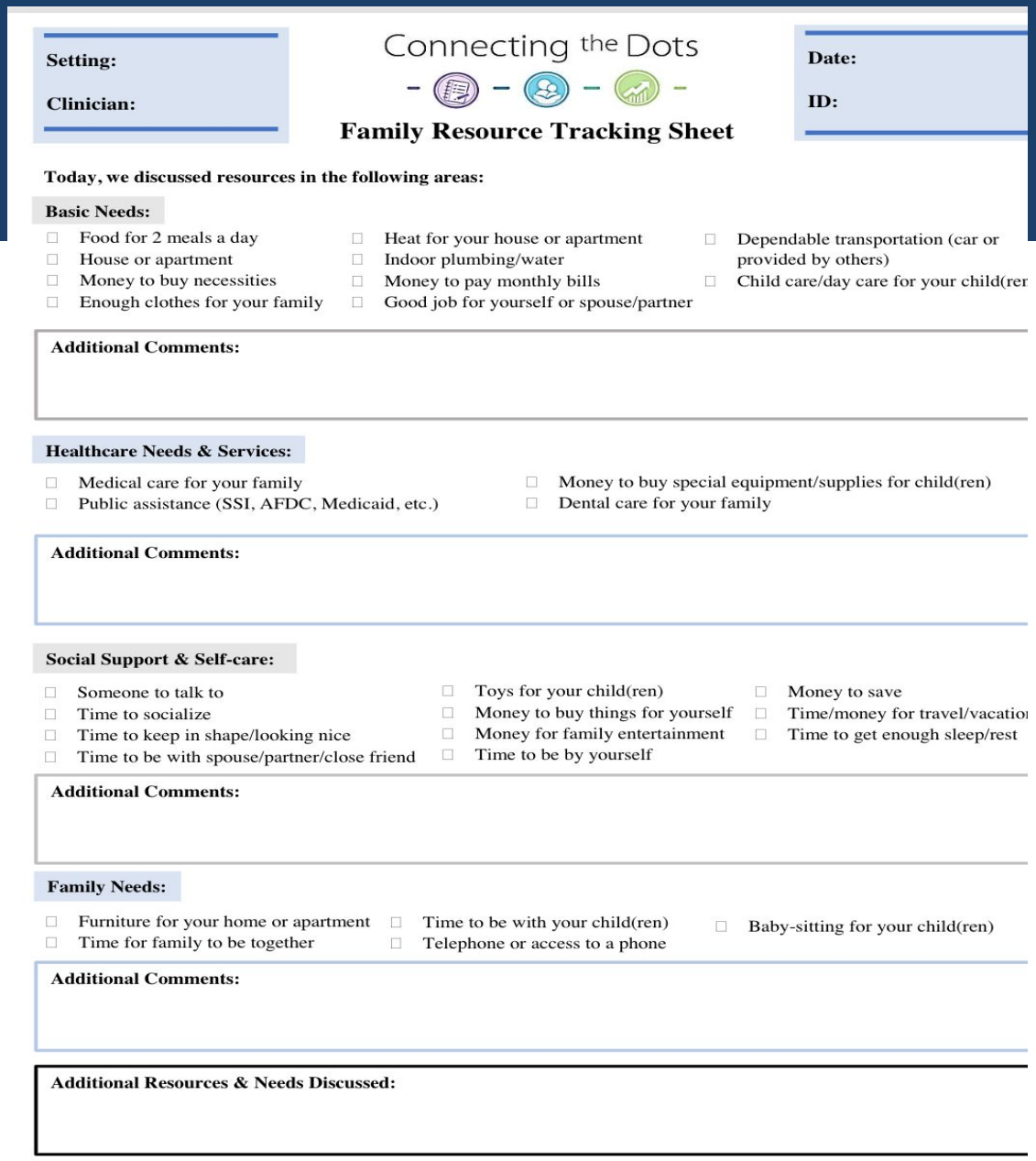
Resource Tracking

Basic needs (food, housing, utilities, car)

Healthcare

Social support/ self-care

Family (child-care)



Setting:

Clinician:

Connecting the Dots

Family Resource Tracking Sheet

Date:

ID:

Today, we discussed resources in the following areas:

Basic Needs:

- ☐ Food for 2 meals a day
- ☐ House or apartment
- ☐ Money to buy necessities
- ☐ Enough clothes for your family
- ☐ Heat for your house or apartment
- ☐ Indoor plumbing/water
- ☐ Money to pay monthly bills
- ☐ Good job for yourself or spouse/partner
- ☐ Dependable transportation (car or provided by others)
- ☐ Child care/day care for your child(ren

Additional Comments:

Healthcare Needs & Services:

- ☐ Medical care for your family
- ☐ Public assistance (SSI, AFDC, Medicaid, etc.)
- ☐ Money to buy special equipment/supplies for child(ren)
- ☐ Dental care for your family

Additional Comments:

Social Support & Self-care:

- ☐ Someone to talk to
- ☐ Time to socialize
- ☐ Time to keep in shape/looking nice
- ☐ Time to be with spouse/partner/close friend
- ☐ Toys for your child(ren)
- ☐ Money to buy things for yourself
- ☐ Money for family entertainment
- ☐ Time to be by yourself
- ☐ Money to save
- ☐ Time/money for travel/vacatio
- ☐ Time to get enough sleep/rest

Additional Comments:

Family Needs:

- ☐ Furniture for your home or apartment
- ☐ Time for family to be together
- ☐ Time to be with your child(ren)
- ☐ Telephone or access to a phone
- ☐ Baby-sitting for your child(ren)

Additional Comments:

Additional Resources & Needs Discussed:

Basic Needs

- Many families did not have their basic needs met.
- Resources provided:
  - Free diaper pick up locations
  - Accessing public assistance (SSI; Cash Aid; Medical care)
  - Accessing respite care
  - Parent support group
  - Mental health resources (counseling; therapy)
  - Translation services
- Additional Support
  - Budgeting (to ensure food and diapers last the month)
  - Communication with other providers
  - Paperwork completion
  - Session set up

Modification: Number of Contacts

- Increase number of calls
- Increase duration of attempts to contact (2 months)
- Allow a longer period for decision regarding evaluation (4 weeks) or treatment (6 months)

Treatment Modifications

Flexibility in treatment location (e.g., grandma's house, daycare)

Family meeting/ coaching with other important caregivers

Parent matched communication method

- phone call
- zoom call
- video call (no video)

Various parent contact methods

- Phone, email, text

Flexibility with scheduling

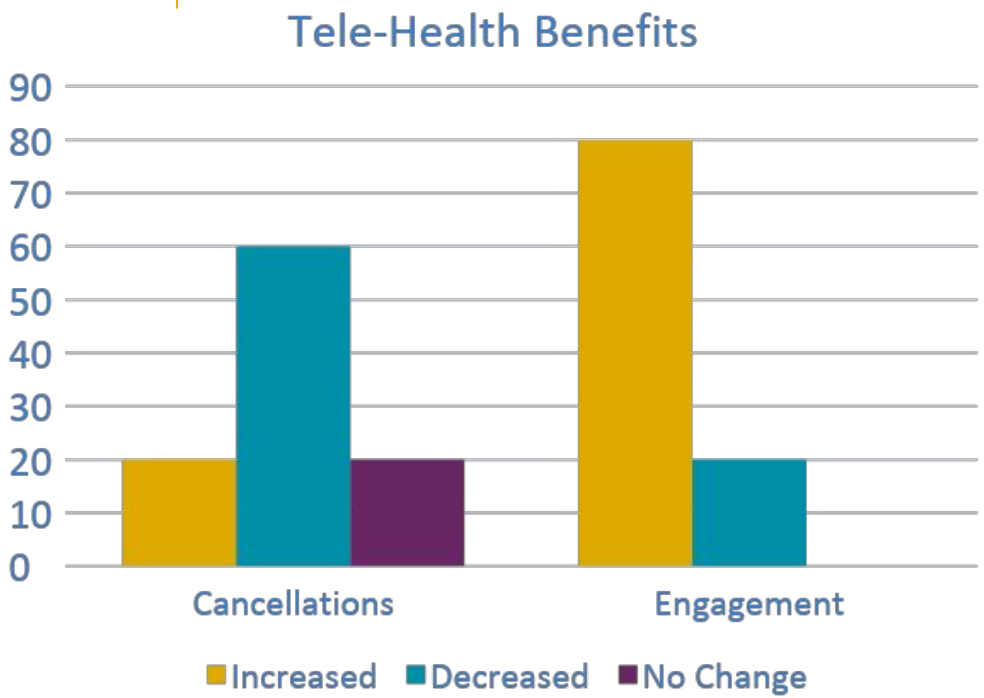
- Same week parent meetings
- Same day calls
- Non-comital schedules

Treatment Modification

- Goal: 20 hours per week
- Average: 8-12 hours per week
  - Parents requesting reduced treatment hours
    - Work schedules
    - Schedules of other children / household members
- Cancellations
  - Average = 5.3 hours / month
  - Range = 1 – 9 hours per month
  - 70% of families cancelled over 5 hours/mo
  - 30% of families took > 1 mo “break” from treatment

COVID-19 Service Modifications

- Move to telehealth for all families
  - Parent Coaching offered weekly



Benefits	Barriers
• Increased flexibility and ease of telehealth • Increases interaction with children during coaching • Both parents can participate	• Technology Challenges -Using video software -Limited internet access • Other children at home • Working from home

Next steps as a provider?

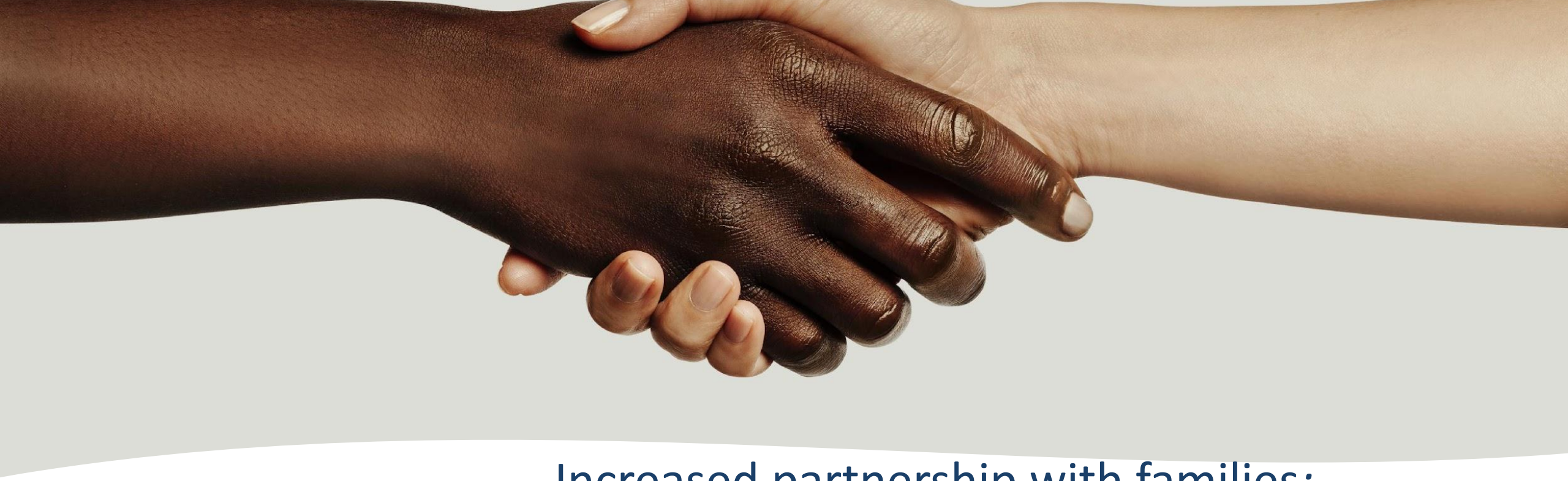
- Be aware of biases based on family characteristics and how that influences care.
- Practice cultural humility (Tervalon & Murray-Garcia, 1998).
- Become well versed in ALL areas of family support (e.g., housing services, food programs). Learn about resources in your area.
- Engage in multifaceted development activities to address perceived family barriers and build mastery of participatory practices.

(Fleming et. al 2011)

Making EBP Work for ALL Families

Increased <u>partnership</u> with families

- Provide time for decision making
- Shared goals for evaluation and intervention
- Shared development of treatment intensity, scheduling, expectations
- Assistance meeting basic needs prior to and during treatment
- Increased coordination between service agencies even during research



Making EBP Work for ALL Families

Increased partnership with families:

https://youtu.be/G3TPavXCzr4?t=2035

(starts around 33:55) From: Caregiver Coaching through Telehealth: Benefits, Challenges and Opportunities (AUCD Network)

Thank you!

astahmer@ucdavis.edu & vmavilapons@ucdavis.edu

Autism & Under-resourced Communities: Opportunities for Change

Questions and Answers

Dr. Aubyn Stahmer
Professor, Department of Psychiatry, UC-Davis Medical Center

Vanessa Avila-Pons, LMFT
Treatment & Training Manager, Collaborative Start Lab, UC-Davis MIND Institute

Nicholas Fears, PhD
University of Michigan, USA

To Join INSAR Visit: http://autism-insar.org/membership

INSAR
International Society for Autism Research

INSAR
International Society for Autism Research

INSAR INSTITUTE 2021
AUTISM & INTERSECTIONALITY
JUNE 17 - JULY 21, 2021

Autism & Race: Engaging Racially and Ethnically Diverse Communities in Autism Research *Sarah Dababnah, Yetta Myrick, & Charina Reyes*
Thursday, July 15th 10:00 am EDT

Central Elements between Intersectionality, Autism & Gender: The Research in 2021
Wenn Lawson & Jac Den Houting
Monday, July 19th, 6:00 PM EDT

Autism & Neurodiversity: Intersectionality and Social Justice
Steven Kapp & TC Waisman with Christina Nicolaidis
Thursday, July 22nd, 2:00 PM EDT