



# Meeting of the Interagency Autism Coordinating Committee

Wednesday, July 24, 2019

**Hilton Washington DC/Rockville Hotel & Executive  
Meeting Center**

1750 Rockville Pike  
Rockville, MD 20852

**Conference Call Access:**

Phone: 800-857-5010

Participant Passcode: 2327297

# Meeting of the IACC



## Morning Agenda

**9:00 AM**

**Welcome, Introductions, Roll Call, and Approval of Minutes**

**Joshua Gordon, M.D., Ph.D.**

Director, National Institute of Mental Health (NIMH) and Chair, IACC

**Susan Daniels, Ph.D.**

Director, Office of Autism Research Coordination, NIMH and Executive Secretary, IACC

**9:20**

**Report from the HHS National Autism Coordinator**

**Ann Wagner, Ph.D.**

HHS National Autism Coordinator  
National Institute of Mental Health

# Meeting of the IACC



## Morning Agenda

**9:25**

**Panel Presentation: Using Innovation and Collaboration to Develop a Community Continuum of Care Model – Baton Rouge, Louisiana**

**Representative Franklin Foil**

Louisiana House of Representatives  
Louisiana State Legislature

**9:40**

**Lauren Crapanzano Jumonville, M.B.A.**  
Director, Civic Leadership Initiatives  
Baton Rouge Area Foundation

**9:55**

**Traci Olivier, Psy.D.**  
Pediatric Neuropsychologist  
Our Lady of the Lake Physician Group

# Meeting of the IACC



## Morning Agenda

10:10 **Melissa Juneau, CCC-SLP**  
Former CEO, The Emerge Center for Communication,  
Behavior, and Development

10:25 **Stephen Whitlow, J.D.**  
Executive Director of Transition Services, Merakey Gateway

11:10 **Morning Break**

11:25 **Committee Business**

**Susan Daniels, Ph.D.**  
Director, Office of Autism Research Coordination, NIMH  
and Executive Secretary, IACC

**Joshua Gordon, M.D., Ph.D.**  
Director, NIMH and Chair, IACC

12:00 PM **Lunch**



# Welcome

# Introductions

# Roll Call

# Approval of Minutes

**Joshua Gordon, M.D., Ph.D.**  
Director, National Institute of Mental Health  
Chair, IACC

**Susan Daniels, Ph.D.**  
Director, Office of Autism Research  
Coordination, NIMH and  
Executive Secretary, IACC



# Report from the HHS National Autism Coordinator



**Ann Wagner, Ph.D.**

HHS National Autism Coordinator  
National Institute of Mental Health

# Panel Presentation: Using Innovation and Collaboration to Develop a Community Continuum of Care Model – Baton Rouge, Louisiana



**Representative Franklin Foil**  
**Lauren Crapanzano Jumonville, M.B.A.**  
**Traci Olivier, Psy.D.**  
**Melissa Juneau, CC-SLP**  
**Stephen Whitlow, J.D.**

# **USING INNOVATION AND COLLABORATION TO DEVELOP A COMMUNITY CONTINUUM OF CARE MODEL**

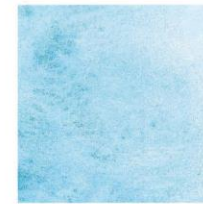
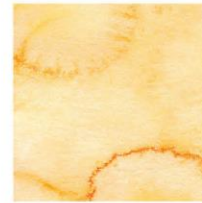
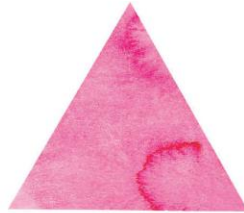
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**BATON ROUGE, LA**

***Interagency Autism Coordinating Council  
July 24, 2019***

*Baton Rouge  
Area Foundation*

A dark blue, stylized flourish or underline that spans the width of the text above it, featuring a central dip and pointed ends.



2016

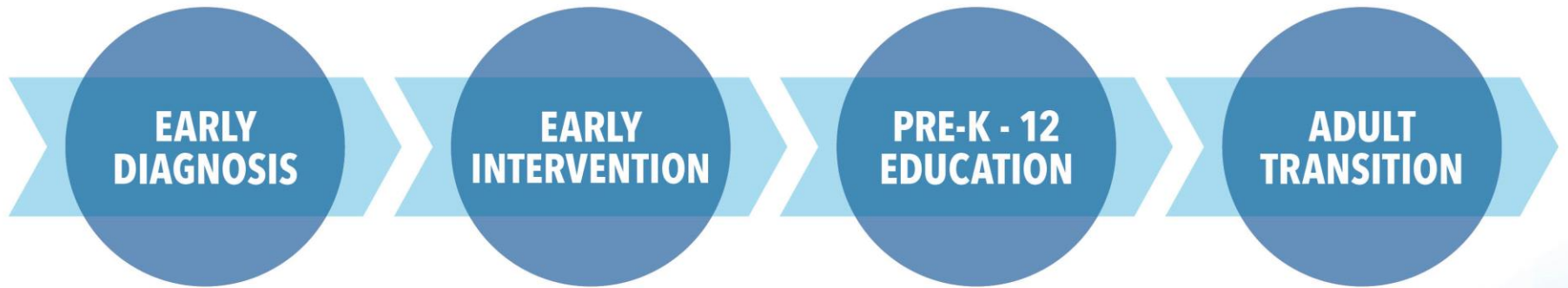
Comprehensive Study of

**AUTISM SPECTRUM DISORDER (ASD)**

Resources in the Capital Region



# A LIFETIME OF TRANSITIONS





# CAPITAL AREA AUTISM NETWORK



*for communication, behavior, and development*



OUR LADY OF THE LAKE  
CHILDREN'S HEALTH


PEDIATRIC DEVELOPMENT & THERAPY CENTER



• It's who we are. It's what we do. •



# TASK FORCES

- I. **Services for Individuals and Families**
  - II. **Family/public awareness and family support**
  - III. **Transition and workforce development opportunities**
  - IV. **Development of the professional workforce**
  - V. **Advancement of educational opportunities**
- 

Free, easy-to-use resources.

Find the best benefits and services in **Louisiana** for children and young adults with disabilities.



**Here's what you can do.**

Click on a choice here to tell us what you need:

✦ My child has autism and I'm not sure what to do.

✦ I'm worried about my baby or young child's development.

✦ I want help with special education services in my child's school.

✦ I want to learn about benefits, like SSI or in-home support.

✦ I want to learn how to support my older child or adult family member.

The **Guides** show you what to do and how to apply for benefits, services and support...

- SSI, Waivers, Health Insurance
- EarlySteps, Special Education or ESS
- What to do when your child seems different



[Start A How-To Guide](#)

The **Resource Directory** helps you find therapists, programs and support services near you...

- Therapies like ABA, speech, OT and PT
- Parent and caregiver support
- Vocational programs

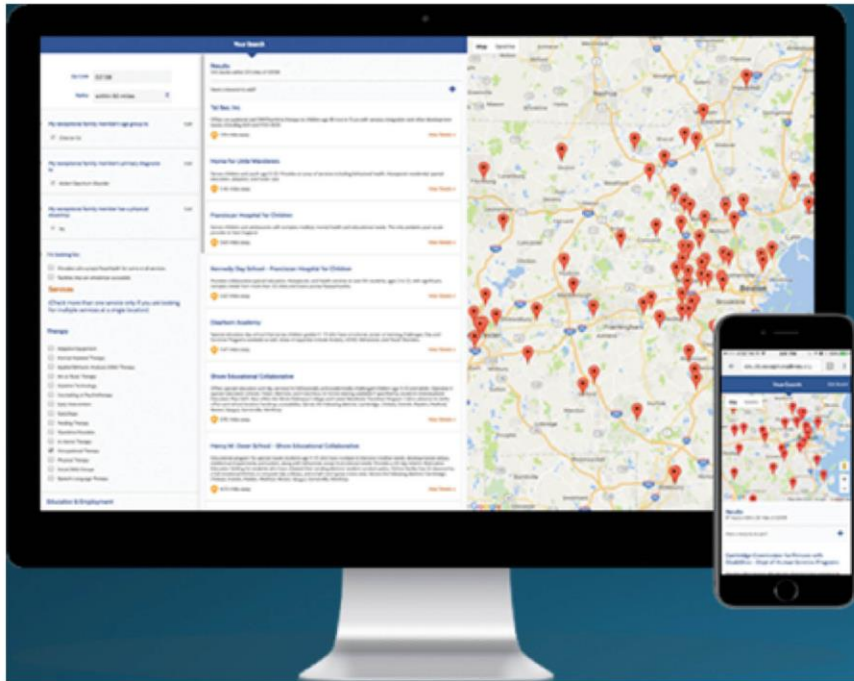


[Find A Resource](#)

# EXCEPTIONAL LIVES GUIDES

- **When you Think Your Child May be Different**
  - **Autism**
  - **EarlySteps**
  - **Special Education Services**
  - **Medicaid Waivers**
  - **Health Insurance**
  - **Transition to Adulthood**
  - **Employment**
  - **Supported Living and Housing**
  - **Decision Making for Adult Children**
  - **SSI Benefits**
- 

# CURATED RESOURCE DIRECTORY

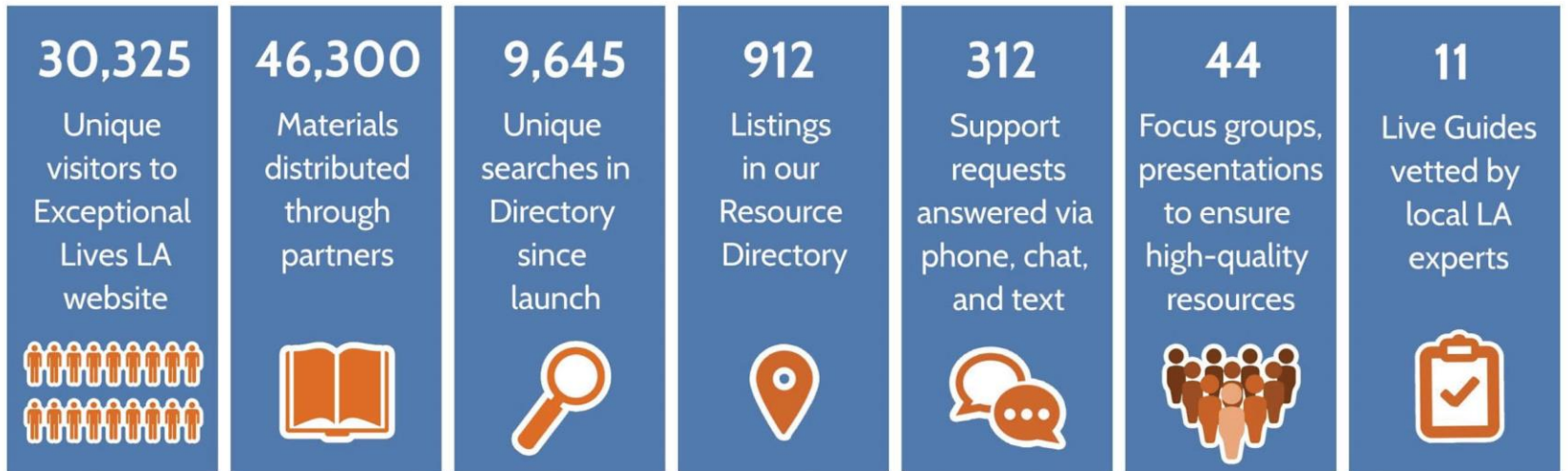


- Search by zip code and 50+ filters
- Visual mapping, directions, printing capabilities
- Descriptions for each entry written in plain language
- Constantly reviewed by ELI data specialists to ensure accuracy
- Available in Spanish

# LOUISIANA IMPACT



Data from Launch 8/2017 - Present





# EXCEPTIONAL LIVES IMPACT

*“I learned things I did not know even after 27 years of living this experience!”*





# OUR LADY OF THE LAKE CHILDREN'S HEALTH


*Developing*  
Innovative Approaches  
to Care for Everyone

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**PEDIATRIC DEVELOPMENT & THERAPY CENTER (PDTC)**

# OUTLINE

- Introduction to Our Lady of the Lake Children's Health (OLOL/FMOLHS)
  - Developing programming to complement medical facility and partnerships with community organizations
  - Development of the Capital Area Autism Network (CAAN) and role of a major medical facility
  - CAAN: Future directions and ongoing collaboration
- 



# FRANCISCAN MISSIONARIES OF OUR LADY HEALTH SYSTEM (FMOLHS)

- Faith-based, mission-driven non-profit organization
- One of Louisiana's largest health systems
- Seven hospitals across Louisiana and Mississippi



# FRANCISCAN MISSIONARIES OF OUR LADY HEALTH SYSTEM (FMOLHS)

## Our Lady of the Lake Regional Medical Center

- Largest private (non-profit) hospital in the state of Louisiana
- First freestanding children's hospital in the capital city
- 80 pediatric specialists in 30 subspecialties



# PEDIATRIC DEVELOPMENT & THERAPY CENTER

**Interdisciplinary team** of professionals who **specialize** in **diagnostic** and **therapeutic services** for children with **developmental concerns**

- Developmental Pediatrics
- Behavior Psychology
- Neuropsychology
- Physical Therapy
- Occupational Therapy
- Speech Language Pathology
- Social Work



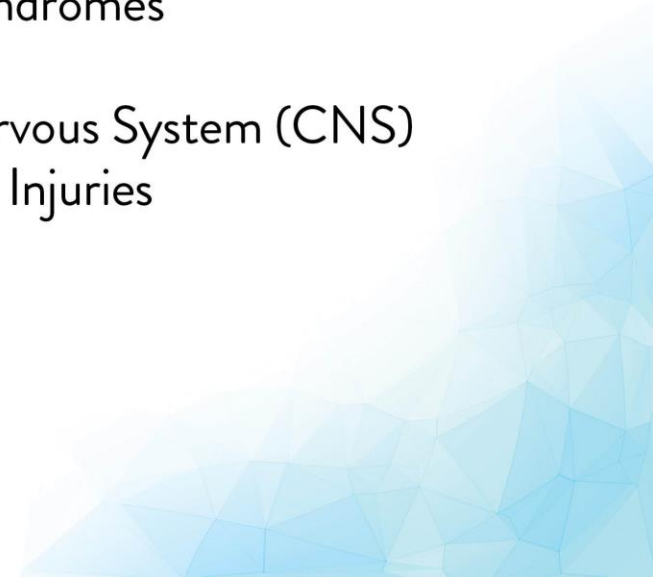


# PEDIATRIC DEVELOPMENT & THERAPY CENTER

- Diagnostic evaluation and therapy
- Interdisciplinary approach to coordinated and individualized treatment
- Specialty clinics and discipline-specific referrals
- **Address medical needs for children with ASD and other developmental concerns**




# PEDIATRIC DEVELOPMENT & THERAPY CENTER

- Autism Spectrum Disorder (ASD)
  - Developmental Delay
  - Behavioral Difficulties
  - Attention Deficit Hyperactivity Disorder (ADHD)
  - Down Syndrome
  - Spina Bifida
  - Cerebral Palsy
  - Pediatric Feeding Difficulties
  - Learning & Intellectual Disabilities
  - Genetic Syndromes
  - Central Nervous System (CNS) Cancer and Injuries
- 

# PEDIATRIC DEVELOPMENT & THERAPY CENTER

## Social Engagement Clinic (SEC)

- **Interdisciplinary, team approach**
    - Developmental Medicine
    - Psychology
    - Speech Language Pathology
    - Occupational Therapy
  - **Diagnosis**
  - **Treatment**
  - **Ongoing follow-up**
- 

# COMMUNITY PARTNERSHIPS

- **Mission-driven purpose (serve those most in need)**
- **Louisiana – low resource, high need**
- **Collaboration is essential due to the need**
  - **PDTC serves 46 of the 64 parishes in Louisiana and four surrounding states**
    - Mississippi
    - Arkansas
    - Alabama
    - Texas

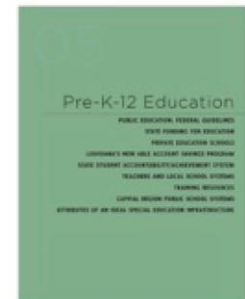
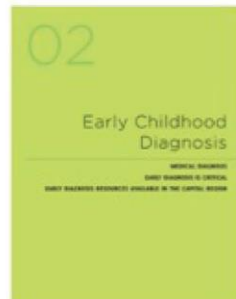
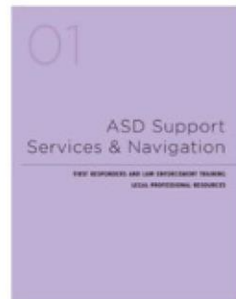
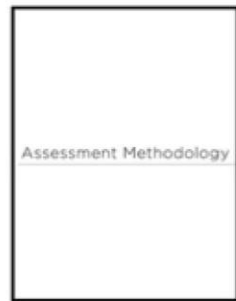
# COMMUNITY PARTNERSHIPS

- **Mission-driven purpose (serve those most in need)**
  - **Telemedicine**
  - **Merakey**
  - **McMains Children's Developmental Center**
  - **St. Lillian Academy**
  - **Referrals to local centers**
    - The Emerge Center, Abilities, Launch, ABC, CARD, Butterfly Effects



# DEVELOPING A NETWORK

## 2016 Comprehensive Study of ASD Resources in the Capital Region



# CAPITAL AREA AUTISM NETWORK (CAAN)

- **Implementation Committee**

- **Steven Felix, MD**, *PDTC Medical Director*
- **Bethany Robichaux**, *Director of Special Education, Catholic Diocese*
- **Jamie Tindle**, *Executive Director, Families Helping Families*
- **Teresa Harlan**, *Program Director (Resource Center for ASD), Families Helping Families*

- **Purpose**

- **Set goals to direct overall group**
- **Work with five task forces to implement goals**
- **Facilitate communication between task forces**
- **Coordinate interdisciplinary/interagency efforts**

# CAPITAL AREA AUTISM NETWORK (CAAN)

## Implementation Committee Task Forces

- **Services for Individuals/Families with ASD**
  - Build network of pediatric physician specialists and psychologists in Capital Area
  - Expand current early childhood intervention services capacity
- **Family/Public Awareness & Family Support**
  - Continued support and promotion for Louisiana Exceptional Lives
  - Routine screening at well-child visits (9, 18, 24+ months)
- **Transition & Workforce Development for Individuals with ASD**
  - Facilitating access to post-secondary education, housing, transportation, job readiness, legal assistance, etc.


# CAPITAL AREA AUTISM NETWORK (CAAN)

## Implementation Committee Task Forces

- **Workforce Development: Professionals Serving People with ASD**
  - Establish post-secondary career training programs
  - Form a working group to pursue alternative funding options for Louisiana Rehabilitation Services programs in light of budget constraints
- **National & State Policy Education**
  - Work with policymakers to ensure opportunities for exceptional students are maximized and included in state accountability system
  - Require new educators to be trained to look for “red flags” associated with ASD



# AUTISM STAKEHOLDERS GROUP

- **Approximately 65 individual participants**
  - **Semi-annual meetings**
    - **Discuss current initiatives**
    - **Elicit feedback to refine processes**
    - **Inform community of ongoing work**
    - **Establish future directions**
  - **Annual Town Hall meetings**
    - **Community-based**
    - **Feedback loop**
- 

# CELEBRATING SUCCESSES

- **Decreasing silos and fostering collaboration**
  - Understanding contributions of other community groups
  - Facilitating communication in the Capital Area
  - Finding ways to work together to serve those most in need
- **Office for Citizens with Developmental Disabilities (OCDD) Waiver Program**
  - Community-based services and supports through community-based waiver programs
  - CAAN is actively working to decrease wait list/wait times for waivers

# CELEBRATING SUCCESSES

- **Increasing awareness and safety**
  - **Police Training**
    - Increase awareness of ASD
    - Provide education on working with individuals with ASD
  - **Louisiana Driver's License identification of ASD**

# CELEBRATING SUCCESSES


- **Franciscan University (Fran U) Board Certified Assistant Behavior Analyst (BCaBA) program**
  - Only BCABA program in the State of Louisiana
  - Offers another level of service delivery and outreach
- **Ongoing collaborations between OLOL/PDTC and community groups**
  - McMains Children's Developmental Center
  - St. Lilian Academy



# CELEBRATING SUCCESSES

- **Franciscan University (Fran U) Board Certified Assistant Behavior Analyst (BCaBA) program**
  - **OLOL leveraged 2016 Report findings to secure \$800,000.00 in grant funds for expansion of behavioral services**
  - **Additional grant funds awarded for clinician training of gold-standard assessment of ASD (Autism Diagnostic Observation Schedule)**
  - **Dr. Eliana Pizarro joining in the Summer of 2019**
  - **Program will expand services in the Capital Area and offer training**
    - **Doctoral-level Louisiana State University (LSU) students**
    - **Fran U bachelor's-level students**

# MORE WORK TO DO...

- Further refine goals to meet changing needs
  - Work with private partnerships to improve services
  - Work with public authorities to improve reimbursement
    - Medicaid – interdisciplinary care initiatives
  - Establish CAAN as an independent, 501(c)(3) organization
  - Develop staff and professional workforce to further the work of the committee
- 



the  
**emerge**  
CENTER

*for communication, behavior, and development*

# ANSWERING THE CALL TO SERVE

**MISSION:** The Emerge Center empowers children with autism and individuals with communication challenges to achieve independence through innovative and family-centered therapies.

**VISION:** A world where all *individuals* are able to maximize their potential.





# ROOTED IN THE COMMUNITY

- 1960: Baton Rouge Speech and Hearing Foundation (BRSHF) began
- 2014: BRSHF moved into its new, state-of-the-art facility (The Emerge Center)
- We are an independent, 501c3 striving to fulfill the individual needs of families challenged by communication, behavioral and developmental issues.
- We offer an unique one of kind interdisciplinary program provided by a team of professional evaluators and therapists under one roof.







# THE EMERGE CENTER

*State-of-the-art facility, 26,000 square feet composed of:*

- 2 state-of-the-art Audiology testing booths, 2 hearing consultation rooms, plus hearing aid repair lab
- An Indoor Sensory/Occupational Therapy gym
- Outdoor Therapeutic Playground
- A parent resource room/lending library
- A large conference and training center
- A cafeteria and outdoor dining patio
- 7 Group Therapy Classrooms, with parent observation rooms
- 2 Kindergarten-level classrooms
- 1 Therapeutic Pre-school classroom
- 1 OT classroom
- 11 rooms for Applied Behavior Analysis, one-on-one therapy
- 7 offices for individual therapy, evaluations and psychological services

# OUR PROGRAMS

## CHILDREN'S DEVELOPMENT CENTER

- Individual speech-language therapy
- Group speech-language therapy
- Occupational therapy
- Applied Behavior Analysis (ABA)
- Assistive technology implementation

## PEDIATRIC BEHAVIORAL HEALTH

- Assessment Services
- Treatment Services
- Feeding Intervention

## AUDIOLOGY

- Bloom
- Kindergarten

## SCHOOL READINESS

- Hearing Aids
- Cochlear Implants troubleshooting
- Auditory Processing Disorder testing

## FAMILY SUPPORT

- Case management services
- Family Education



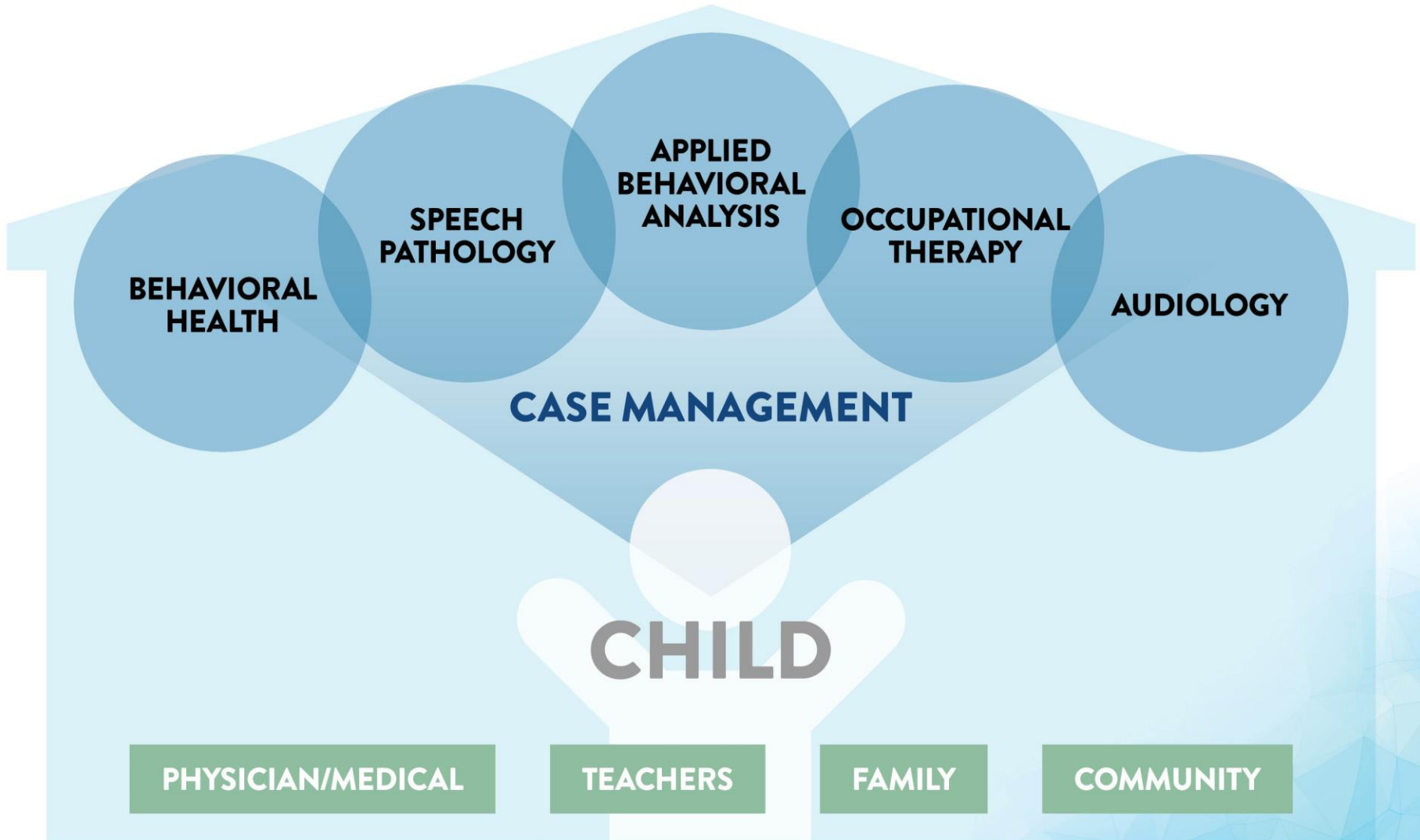
# OUR TEAM:

**+ 75 PROFESSIONALS  
+ 30 UNIVERSITY STUDENTS**



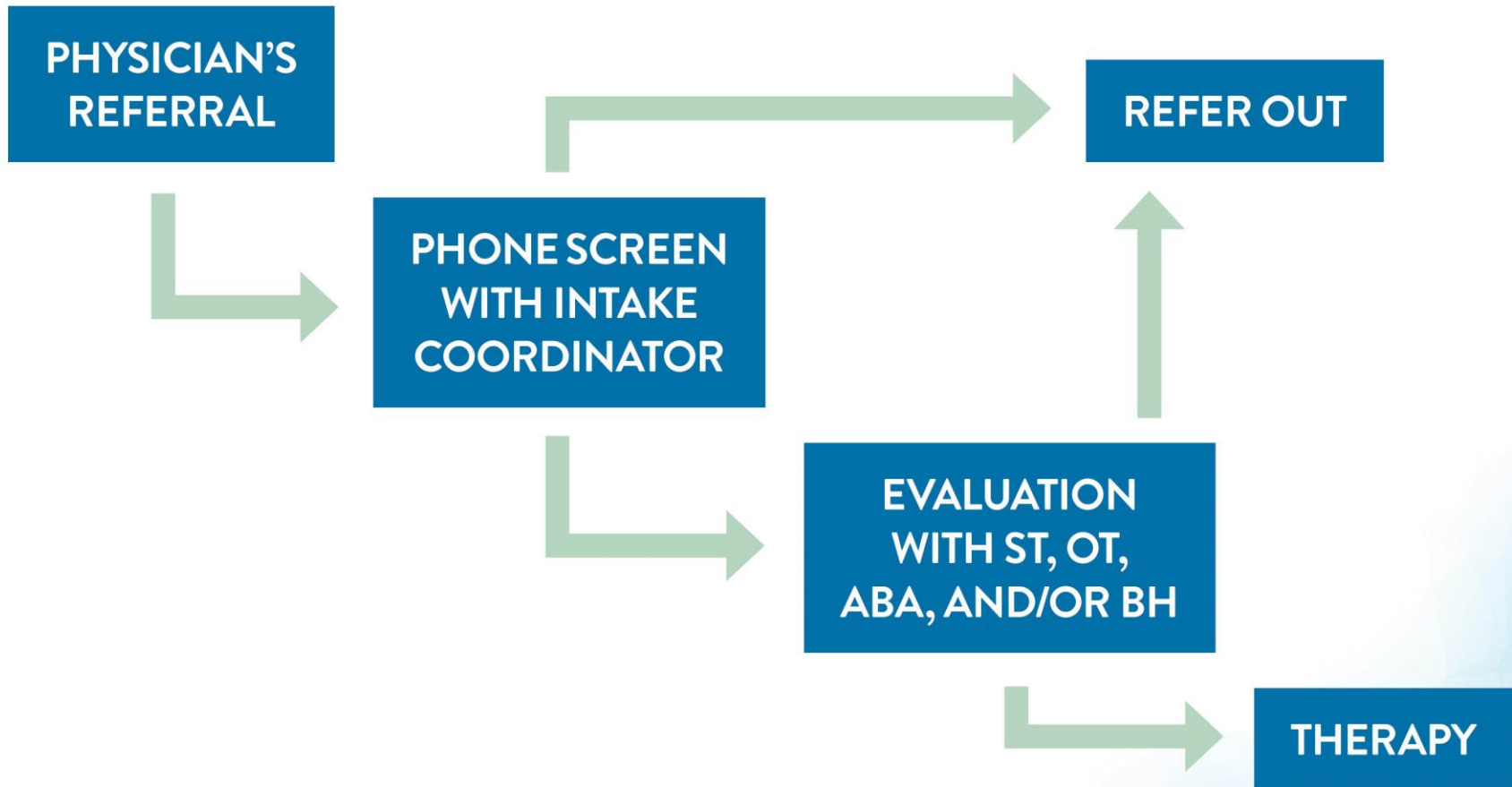
# THE EMERGE DIFFERENCE

COLLABORATIVE • INTERDISCIPLINARY • UNDER ONE ROOF





# HOW DO FAMILIES ACCESS OUR SERVICES?



# WHO WE SERVE



# OUR IMPACT

3,431

PHYSICIAN REFERRALS  
RECEIVED

1,593

PHONE SCREENS  
COMPLETED





# OUR IMPACT

**900** CHILDREN SERVED  
IN THE CDC FOR A TOTAL OF  
**64,386** THERAPY HOURS



**746** CHILDREN RECEIVED  
ST SERVICES FOR A TOTAL OF  
**29,256** THERAPY HOURS



# OUR IMPACT

**216** CHILDREN RECEIVED  
OT SERVICES FOR A TOTAL OF  
**4,109** HOURS

**87** CHILDREN RECEIVED  
ABA THERAPY FOR A TOTAL OF  
**31,021** HOURS





# OUR IMPACT

399

**CHILDREN RECEIVED  
BEHAVIORAL HEALTH SERVICES**

81

**ASD EVALUATIONS COMPLETED**



# OUR IMPACT

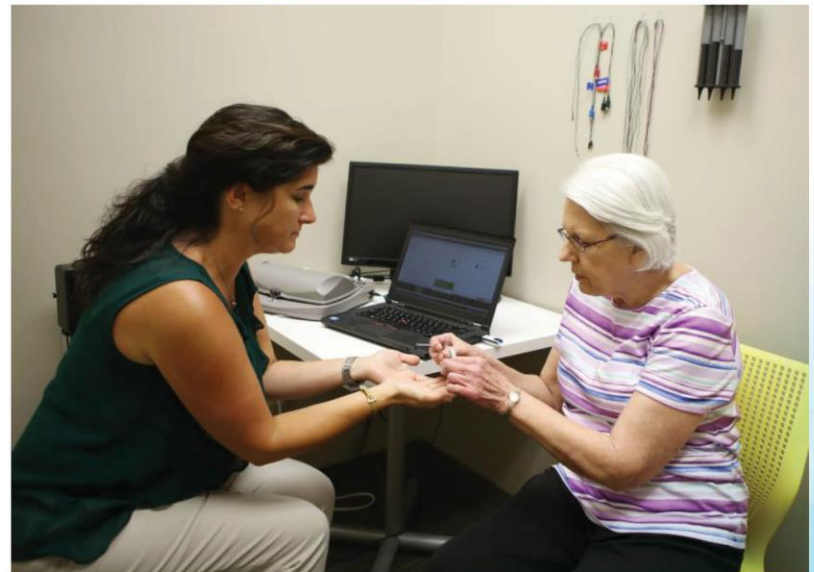
# 31

**CHILDREN ENROLLED  
IN SCHOOL READINESS  
PROGRAMS**



# 894

**CHILDREN & ADULTS  
RECEIVED AUDIOLOGY  
SERVICES**





# FAMILY FOCUSED FUN

- Family Day
- Book Fair
- Movie Day
- Holiday Feasts
- Grandparent's Day
- Muffins with Mom
- Donuts with Dad
- Mardi Gras Parade



# ON THE EMERGE HORIZON

- 1 Advocacy:** Executive Board of the Louisiana Access for Autism Services Coalition
- 2 Research:** Established a designated position at Emerge as the Director of Research and Design – currently have 5 research projects running through Emerge Center.
- 3 Medical Community:** Provides community learning opportunities to 20 OLOL Pediatric Residents and BR General Family Medicine Residents in 2017.
- 4 Mentorship:** Working with local university partners on both establishing an ABA Masters Level training program
- 5 Expansion:** Exploring opportunities and feasibility of expansion in both homebased in this and other regions in the state
- 6 Drum roll.....**  
The Emerge School for Autism

# THE EMERGE SCHOOL FOR AUTISM

*The expansion will provide 20 classrooms, expand clinical services, and be a school for 140 children through age eleven.*

**MISSION:** To educate students with Autism Spectrum Disorder using therapeutically focused strategies grounded in the principles of Applied Behavior Analysis (ABA) and Universal Design for Learning (UDL) enabling our children to reach their fullest potential.

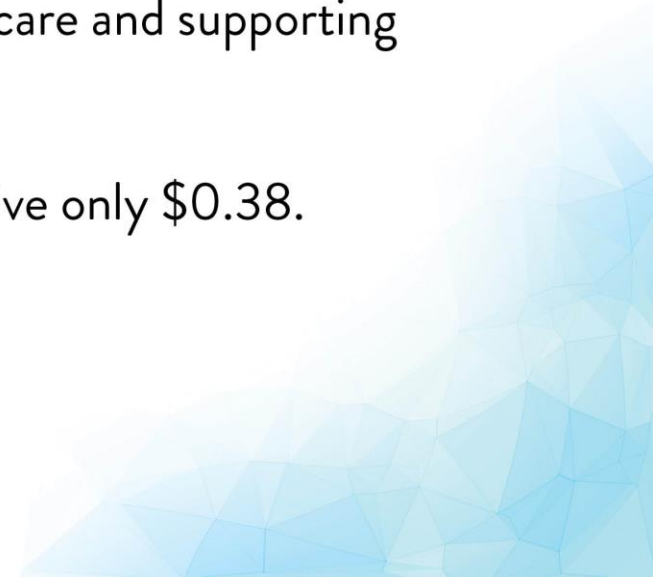
**VISION:** To transform the lives of children with ASD through innovative educational experiences focused on communication, social and behavioral goals through evidence based practice to close learning gaps and prepare our students for successful lives.

**GOAL:** To open the first tuition-free charter school in Louisiana focused on the education and therapy needs for children with autism grades K-5.

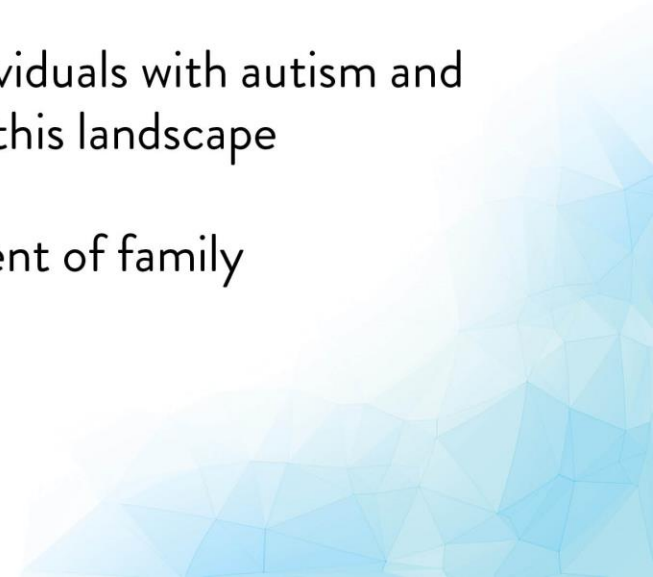
**FALL 2018: SCHOOL OPENED**



# THE EMERGE FOUNDATION

- Philanthropic investments in our mission make our work possible.
  - We strive to be a community resource, accessible to all.
  - More than two-thirds of our clients are on Medicaid or require financial assistance.
  - The invaluable time our therapists spend coordinating care and supporting parents cannot be billed.
  - For every \$1 submitted to insurance, we typically receive only \$0.38.
- 

# IT TAKES A VILLAGE: EMERGE'S PARTICIPATION IN CAAN

- CAAN is a direct result of the 2014 Comprehensive Study on Autism Services in the Greater Baton Rouge Area
  - The study identified key issues- the community did not know one another therefore the system was factored
  - In order to assure there is a continuum of care for individuals with autism and their families, CAAN is becoming integral to building this landscape
  - CAAN is a forum for an ongoing community assessment of family needs, community services breaking down silos
- 


# ADULT SERVICES

*The BRAF & Wilson report identified transition and adult services  
as an area of need in the community.*

# AREAS OF CONCENTRATION

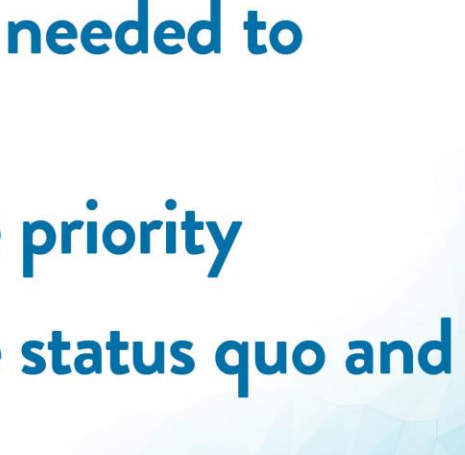
- **Transition Services**
  - **Housing**
  - **Transportation**
  - **Employment**
- 

# CAAN PARTNERS

- **Baton Rouge Community College**
  - **The Arc of Baton Rouge**
  - **Capital Area Transit Services**
  - **Governor's Office for Disability Affairs**
  - **Moran Construction**
- 



# LESSONS LEARNED

- **Study provided a basis for common mission**
  - **Cooperation between agencies requires common mission**
  - **Frank discussion is required to understand the boundaries of cooperation**
  - **Relationship and communication is needed to achieve mission**
  - **The needs of the families must take priority**
  - **We must be willing to challenge the status quo and seek new**
- 



## Gateway Transition Programs

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2019

# MISSION ORIENTED. VISION DRIVEN.

## MISSION

We respect the inherent dignity of every individual. We enrich lives by providing exceptional transition services through an individualized approach.

## VISION

Creating communities where everyone is empowered to take meaningful steps toward reaching their fullest potential.





# INNOVATIVE, AFFORDABLE, SCALE-ABLE SOLUTIONS

Gateway Transition Programs were adopted by Merakey in August 2018.

The program is designed to compliment the continuum of care that Merakey Autism & Education Division offers to individuals with Autism Spectrum Disorder as they approach and navigate the complexities of adulthood.

It is also our hope that the model brings a scale-able model to the larger community.







# GROUP SKILLS PROGRAM

- Classroom based learning covering Money Management, Social Skills, Career Exploration and Independent Living Skills
  - Weekly volunteer opportunities in the community to explore varied work environments
  - Employment Opportunities in our onsite screen print shop to gain transferable job skills
  - Opportunities for community involvement and social interaction.
  - 3 days per week
  - Semester based service
  - Private pay service
- 

# INDEPENDENCE COACHING


- One-on-one training
- Can accommodate an extremely wide skill level
- Includes work experience in the screen print shop
- Typically clients meet once per week with a skill coach
- Can include job application, placement and coaching
- An individual plan is created to meet the needs of the client
- Most clients work on vocational exploration and job readiness skills

## Volunteer and Community Outings

- Merakey Gateway is committed to teaching good citizenship to our young adults during this independent living transition period.
- Opportunities are available to them to give back through volunteer work- which also contributes to career exploration and experience their community settings in a fun supportive atmosphere.

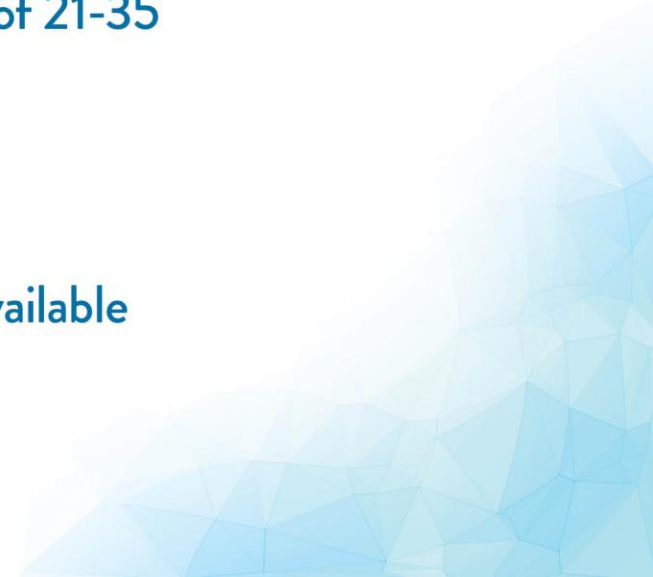


# GATEWAY INK


- Provides job training for young adults with autism.
  - Participants have the opportunity to earn a real pay check in a supported environment while developing transferable social skills.
  - Employment Opportunities in our onsite screen print shop to gain transferable job skills.
  - Over all goal is to lay the foundation for future employment by providing work experience and training based on the wants and needs of each participant.
  - Also a fully operating screen print shop that takes orders from within the community.
  - The income from shirt sales helps provide the funds to offset the cost of providing training to our participants.
  - The competitive nature of the screen printing business helps to reflect environments that our participants will face upon entering the work force.
- 



# RESIDENTIAL TRAINING PROGRAM

- Under development
  - Not a group home
  - Not a long-term housing solution
  - Designed to teach practical independent living skills
  - Available to young adults with ASD between the ages of 21-35
  - Pre-screening, application to program.
  - Development of self-sufficiency
  - Onsite transition courses and independent coaching available
- 

# EMPLOYMENT COALITION

- It is estimated that less than 20% of adults with autism are employed
  - These individuals could be employed with proper training and support
  - Network of Employers and Non-profits focused on providing employment opportunities for adults with autism
  - Create database of available jobs and positions
  - Create training plans for jobs and positions for willing employers
  - Communicate with employers to prepare them to accommodate employees
  - Identify a “Champion” within organizations to serve as mentor to employee
- 

# PARTNERSHIPS



**ROBINSON BROTHERS FORD**



**LOUISIANA SOCCER ASSOCIATION**



**GAITWAY THERAPEUTIC HORSEMANSHIP**



**THEATRE OF BATON ROUGE**



**ELIZA RESTAURANT**



# Discussion





**Break**

# Meeting of the IACC



## Morning Agenda

**11:25**

**Committee Business**

**Susan Daniels, Ph.D.**

Director, Office of Autism Research Coordination, NIMH  
and Executive Secretary, IACC

**Joshua Gordon, M.D., Ph.D.**

Director, NIMH and Chair, IACC

**12:00 PM**

**Lunch**

# IACC Committee Business

IACC Full Committee Meeting  
July 24, 2019



**Susan A. Daniels, Ph.D.**  
Director, Office of Autism Research Coordination  
Executive Secretary, IACC  
National Institute of Mental Health

# Thank you to OARC Staff



**Susan Daniels, Ph.D.**  
Director

**Oni Celestin, Ph.D.**  
Science Policy Analyst

**Rebecca Martin, M.P.H**  
Public Health Analyst

**Angelice Mitrakas, B.A.**  
Management Analyst

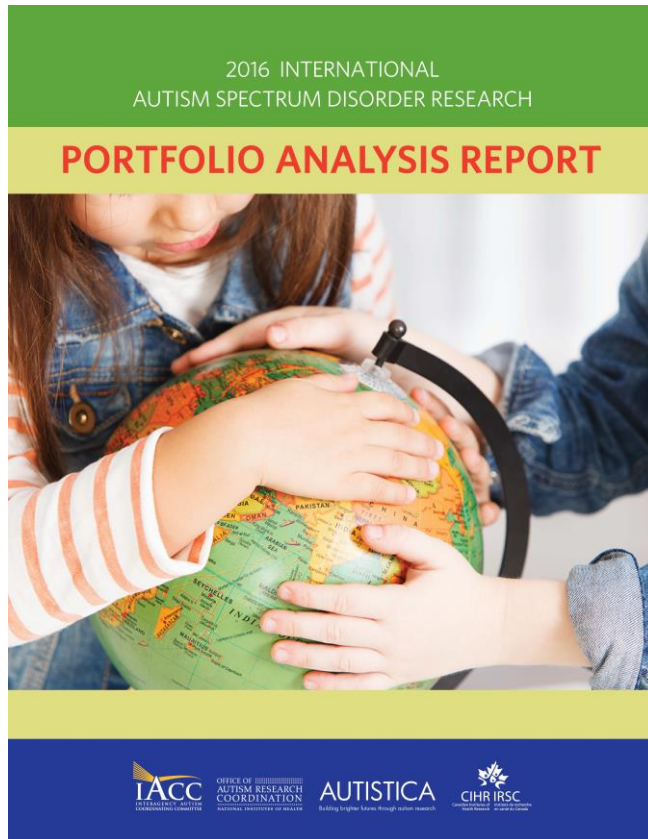
**Julianna Rava, M.P.H.**  
Science Policy Analyst

**Matthew Vilnit, M.B.A.**  
Operations Coordinator

**Jeff Wiegand, B.S.**  
Web Development and Outreach Manager



# 2016 International Portfolio Analysis Report – Coming Soon!



- The first *International Portfolio Analysis Report* collected ASD research funding data from four countries: United States, United Kingdom, Canada, and Australia.
- Collaborators included OARC, Autistica/UK, CIHR/Canada, Macquarie University/Australia.
- The comparison of portfolios revealed areas of emphasis, similarities, differences, and gaps across the portfolios.
- The analysis fostered international collaboration and identified global trends in ASD research funding.

**Coming Soon!**

# 2016 International Portfolio Analysis Report: Highlights



- Data was collected by collaborators from 34 government and private funders across the US, UK, Canada, and Australia.
- In 2016, there were 1,552 ASD research projects totaling \$395.8 million.

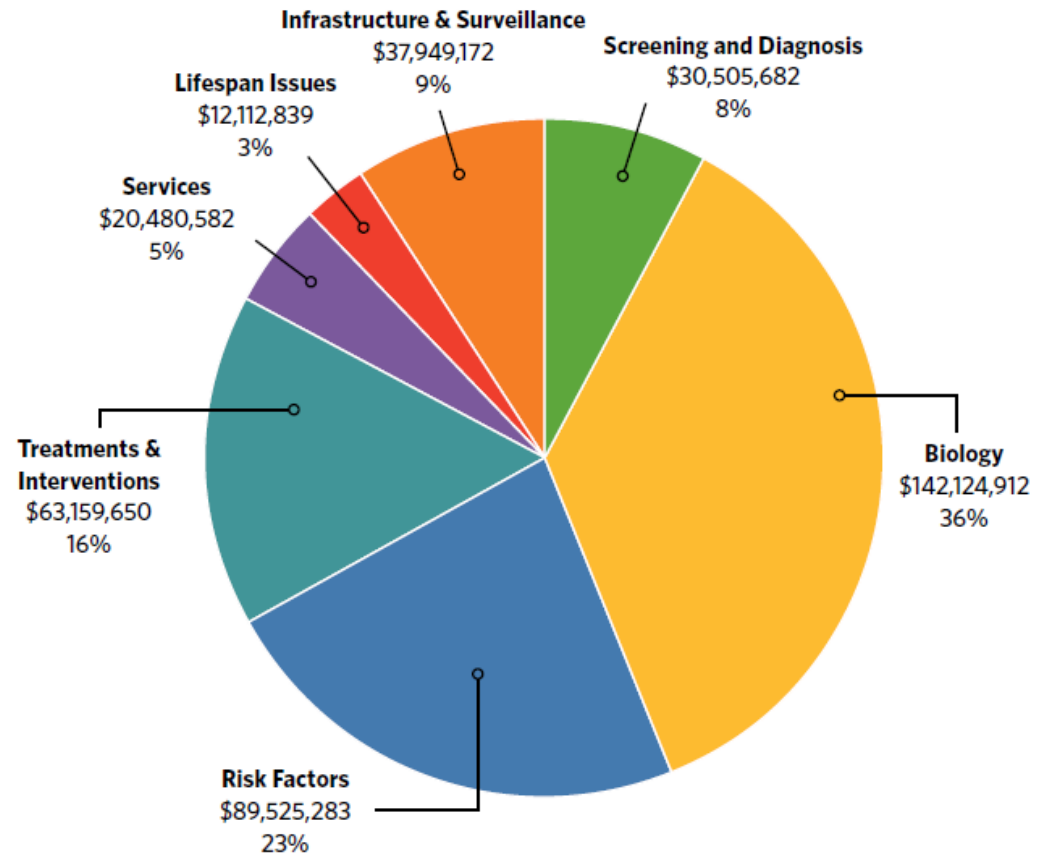
<b>2016 ASD Research Total Funding and Project Counts by Country</b>		
<b>Country</b>	<b>Funding Amount in U.S. Dollars (Percentage of total funding)</b>	<b>Project Count (Percentage of total project count)</b>
United States	\$364,435,254 (92%)	1360 (88%)
United Kingdom	\$14,848,929 (4%)	59 (4%)
Canada	\$10,719,396 (3%)	74 (5%)
Australia	\$5,854,451 (1%)	59 (4%)
<b>Grand Total</b>	<b>\$395,858,120</b>	<b>1552</b>

# 2016 International Portfolio Analysis Report: Highlights



- ASD research projects were aligned with the seven research priority areas in the *IACC Strategic Plan*.
- All of the countries had large investments investigating the underlying biology of ASD as well as investigating and developing ASD treatments and interventions.

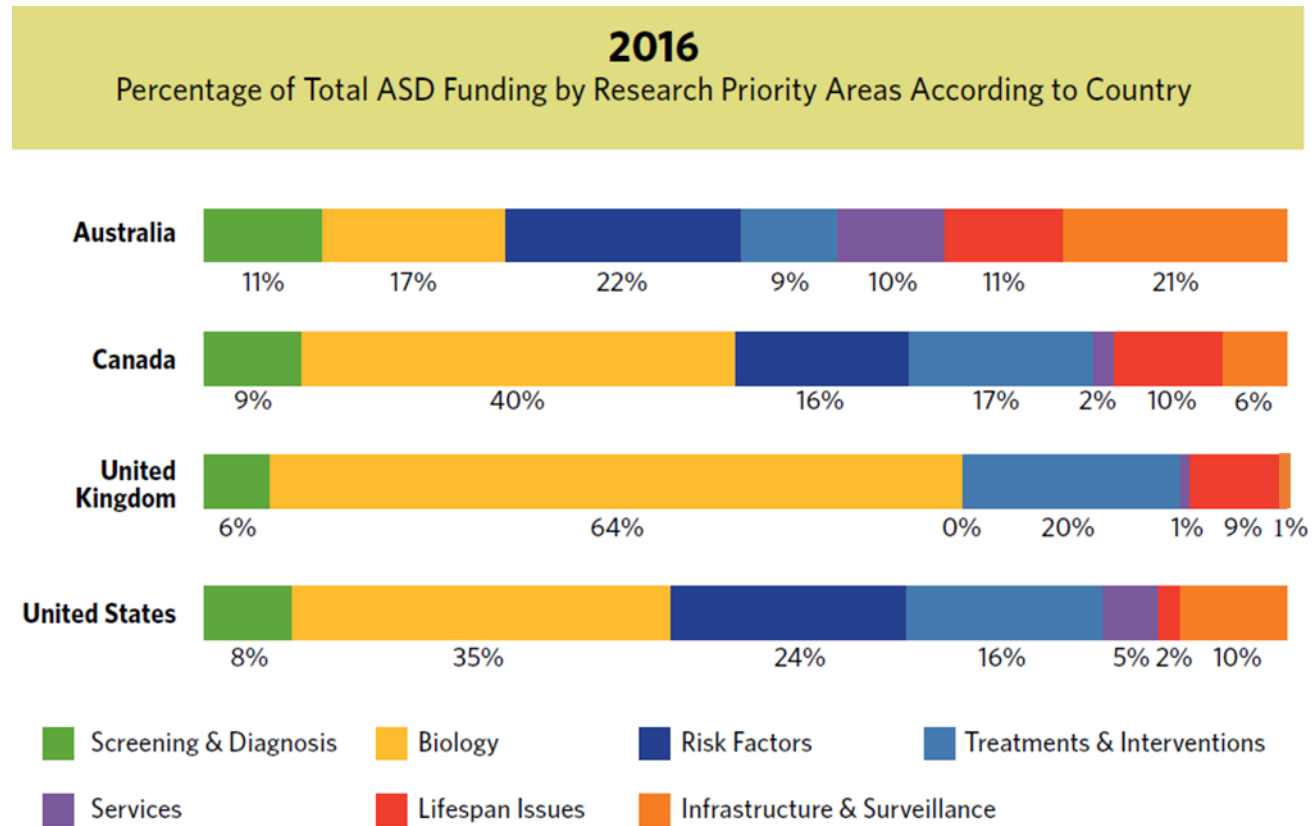
**2016**  
Combined International ASD Research Funding by Research Priority Areas  
Total Funding Amount: \$395,858,120



# 2016 International Portfolio Analysis Report: Highlights



- Due to significant differences in the size of each country's portfolio, the proportion of each country's portfolio devoted to each the seven research areas was compared.
- Details about ASD research initiatives in each country are included in the report.





# 2016 International Portfolio Analysis Report: Highlights



U.S. Department of Health & Human Services | Contact IACC | About Database

**IACC** | **AUTISM RESEARCH DATABASE** | OFFICE OF AUTISM RESEARCH COORDINATION | NATIONAL INSTITUTES OF HEALTH

United States Data | **International Data**

Select Fiscal Year: 2016 | Search Projects by Keyword: [ ] | Search

Strategic Plan Questions | Funders | Government vs Private Funding | Countries

Home / 2016 / Strategic Plan Questions

### Strategic Plan Questions

Download all 2016 projects

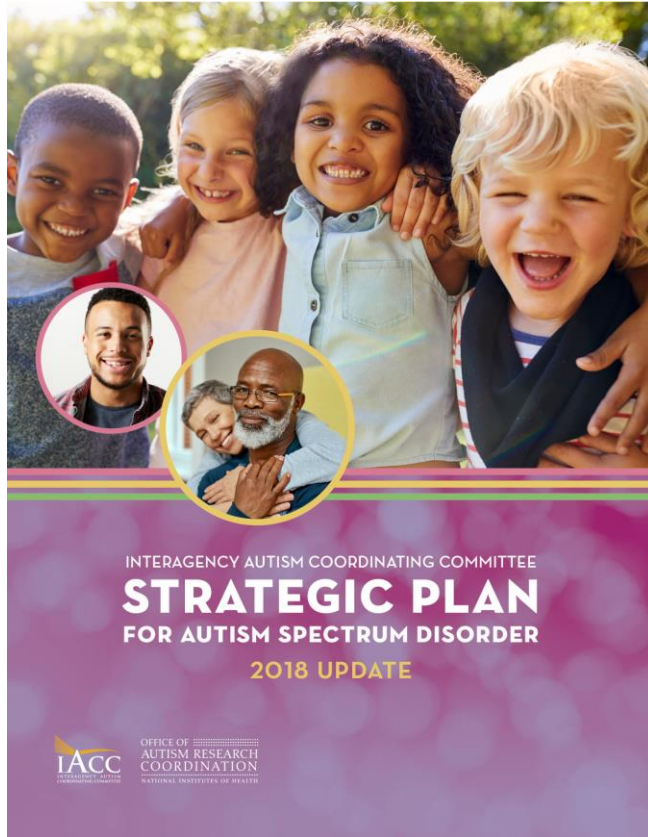
Strategic Plan Questions	Number of Projects	Total Funding	% of Total Funding
Question 1: How Can I Recognize the Signs of ASD, and Why is Early Detection So Important? (Screening and Diagnosis)	123 projects	\$30,505,682	8%
Question 2: What is the Biology Underlying ASD? (Biology)	558 projects	\$142,124,912	36%
Question 3: What Causes ASD, and Can Disabling Aspects of ASD be Prevented or Preempted? (Risk Factors)	256 projects	\$89,525,283	23%
Question 4: Which Treatments and Interventions Will Help? (Treatments and Interventions)	293 projects	\$63,159,650	16%
Question 5: What Kinds of Services and Supports are Needed to Maximize Quality of Life for People on the Autism Spectrum? (Services)	103 projects	\$20,480,582	5%
Question 6: How Can We Meet the Needs of People with ASD as They Progress into and through Adulthood? (Lifespan Issues)	68 projects	\$12,112,839	3%
Question 7: How Do We Continue to Build, Expand, and Enhance the Infrastructure System to Meet the Needs of the ASD Community? (Infrastructure and Surveillance)	151 projects	\$37,949,172	9%
<b>Total:</b>	<b>1552</b>	<b>\$395,858,120</b>	<b>100%</b>

ASD Research Funding by Strategic Plan Questions, 2016  
Total Funding: \$395,858,120.00

Strategic Plan Question	Percentage of Total Funding
Question 1: (Screening and Diagnosis)	8%
Question 2: (Biology)	36%
Question 3: (Risk Factors)	23%
Question 4: (Treatments and Interventions)	16%
Question 5: (Services)	5%
Question 6: (Lifespan Issues)	3%
Question 7: (Infrastructure and Surveillance)	9%

- To accompany the report, detailed 2016 international project data will be available in the [Autism Research Database \(ARD\)](#), accessible via the IACC website.

# IACC Strategic Plan 2018-2019 Update



- The *2018-2019 IACC Strategic Plan Update* will provide a summary of the IACC's recent activities and progress related to the *Strategic Plan*, including:
  - Summary of Health Outcomes working group and workshops
  - Summary of Housing working group and workshop
  - Summary of *2016 IACC Portfolio Analysis Report*
  - Summary of Autism CARES Act *Report to Congress*
- Committee members will receive draft for final approval in September 2019

# Update on IACC Health Outcomes Working Group



- The IACC convened a working group on health and wellness issues for individuals with ASD
- Co-chairs: Dr. David Amaral and Dr. Julie Taylor
- Scope
  - Health and general wellness for people with ASD
  - Co-occurring physical and mental health conditions
  - Premature mortality
  - Patient-provider interactions (including medical practitioner training)
  - Parental/family mental health



# IACC Health Outcomes Working Group: Activities



- Conference calls:
  - September 5, 2018
  - December 17, 2018
- Workshops:
  - Physical Health - September 27, 2018
  - Mental Health - May 21, 2019
- Meeting summaries for each workshop
- A written document providing an update on issues (pending)
- Future work and activities may be planned by the next IACC



# Health Outcomes Working Group Workshops



- Addressing the Physical Health Needs of People on the Autism Spectrum (September 2018)
  - Health Epidemiology
  - Co-occurring conditions: epilepsy, gastrointestinal disorders, and sleep disturbances
  - Improving patient-provider interactions
- Addressing the Mental Health Needs of People on the Autism Spectrum (May 2019)
  - Personal Perspectives
  - Anxiety and OCD
  - Depression and Suicide
  - Self-Injurious Behaviors (SIB) and Aggression
  - Mental Health Services

# Update on IACC Housing Working Group



- In 2019 the IACC convened a working group on housing issues for individuals with ASD.
- Scope
  - Research and best practices on housing
  - Implementation of current federal regulations
  - Housing issues faced by autistic individuals with more severe disabilities
- Chair: Alison Singer, IACC Member



# IACC Housing Working Group Activities



- Conference Call – June 20, 2019
- Workshop: Addressing the Housing Needs of People on the Autism Spectrum – July 23, 2019
- Full Committee Discussion – July 24, 2019
- Workshop Summary – Fall 2019
- Future work and activities may be planned by the next IACC

# IACC Reauthorization Update



- The IACC is authorized by the Autism CARES Act of 2014.
- The Autism CARES Act of 2014 will expire on September 30, 2019. Current IACC members will serve through that date.
- Next steps:
  - When reauthorizing legislation is passed by Congress and signed by the President, the Secretary of HHS will issue a call for nominations of new committee members.
  - This nomination call will be posted in the Federal Register, on the IACC website, and distributed by email to the OARC mailing list.
  - Current draft legislation limits individuals (public members) to two terms on the committee.
  - Nominations will be considered and approved by the HHS Secretary and a new committee will be convened.



# Autism CARES Act Reauthorization Update

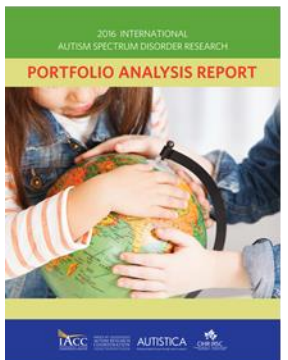
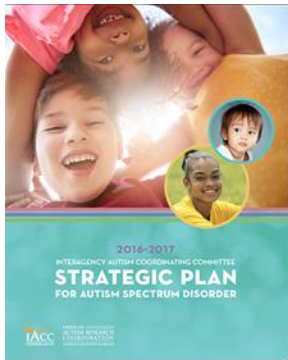


- The Health Subcommittee of the House Energy and Commerce Committee held a hearing to discuss the reauthorization of the Autism CARES Act on June 25, 2019  
Weblink: <https://energycommerce.house.gov/committee-activity/hearings/hearing-on-reauthorizing-vital-health-programs-for-american-families>
- On July 11, 2019, the Health Subcommittee of the House Energy and Commerce Committee voted to send the bill to the full committee.  
Weblink: <https://energycommerce.house.gov/committee-activity/markups/markup-of-hr-2781-hr-728-hr-1058-hr-2507-hr-776-hr-2035-hr-2296-hr-2328>
- On July 17, 2019, the House Energy and Commerce Full Committee passed the bill with amendments.  
Weblink: <https://energycommerce.house.gov/committee-activity/markups/markup-of-26-bills-full-committee-july-17-2019>

# IACC Accomplishments 2014-2019



- 2016-2017 *Strategic Plan* and 2018-2019 *Strategic Plan Update*
- 4 *Portfolio Analysis Reports*, covering 6 years of data
- 1 *International Portfolio Analysis Report*
- 5 *Summary of Advances* reports



# IACC Activities 2014-2019



- IACC accomplishments
  - 15 full committee meetings
  - 9 IACC working groups, 24 working group conference calls
  - 3 workshops





# Topics Addressed by the IACC 2014-2019



- Screening and Diagnosis
- ASD Biomarkers
- Co-occurring Physical Conditions
- Co-occurring Mental Health Conditions
- ASD in Women and Girls
- Self-Injurious Behaviors/Aggression
- Genetic and Environmental Risk Factors
- Treatments and Interventions
- Patient-Provider Interactions
- Youth and Adult Services
- Transition-age Youth and Young Adults
- Employment
- Wandering/Elopement
- Housing
- Adult Treatments
- Premature Mortality
- Suicide
- ASD Surveillance Programs
- Data Banks
- Federal Program Updates
- Advocacy Updates
- Legislation (e.g. ABLE Act, Kevin and Avonte's Law)

# IACC Members: Thank you for your service!





# IACC Members 2014-2019



## Federal Members

- National Institute of Mental Health
  - Joshua Gordon, M.D., Ph.D.
  - Bruce Cuthbert, Ph.D.
- Administration for Children and Families (ACF)
  - Linda Smith
  - Melinda Baldwin, Ph.D.
- Administration for Community Living (ACL)
  - Aaron Bishop, M.S.S.W.
  - Jennifer Johnson, Ed.D.
- Agency for Healthcare Research and Quality (AHRQ)
  - Elisabeth Kato, M.D., M.R.P.
  - Laura Pincock, Pharm.D., M.P.H.
- Centers for Disease Control and Prevention (CDC)
  - Cynthia Moore, M.D., Ph.D.
  - Stuart Shapira, M.D., Ph.D.
- Centers for Medicare and Medicaid Services (CMS)
  - Melissa Harris
- Department of Defense (DoD)
  - Nicole Williams, Ph.D.
- Department of Education (ED)
  - Larry Wexler, Ed.D.
- Environmental Protection Agency (EPA)
  - Ruth Etzel, M.D. Ph.D.
  - Elaine Cohen Hubal, Ph.D.
- Food and Drug Administration (FDA)
  - Tiffany Farchione, M.D.
- Health Resources and Services Administration (HRSA)
  - Laura Kavanagh, M.P.P.
- Indian Health Service (IHS)
  - Marcella Ronyak, Ph.D.

# IACC Members 2014-2019



## Federal Members

- National Institutes of Health (NIH)
  - Francis Collins, M.D., Ph.D.
  - Josephine Briggs, M.D. (alternate)
  - Carrie Wolinetz, Ph.D. (alternate)
- *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD)
  - Catherine Spong, M.D.
  - Diana Bianchi, M.D.
- National Institute on Deafness and Other Communication Disorders (NIDCD)
  - James Battey, M.D., Ph.D.
  - Judith Cooper, Ph.D.
- National Institute of Environmental Health Sciences (NIEHS)
  - Linda Birnbaum, Ph.D.
- National Institute of Neurological Disorders and Stroke (NINDS)
  - Walter Koroshetz, M.D.
- Social Security Administration (SSA)
  - Melissa Spencer
  - Cheryl Williams

# IACC Members 2014-2019



## Public Members

- David Amaral, Ph.D., University of California Davis
- James Ball, Ed.D., B.C.B.A.-D., JB Autism Consulting
- Samantha Crane, J.D., Autistic Self-Advocacy Network (ASAN)
- Geraldine Dawson, Ph.D., Duke University
- Amy Goodman, M.A.
- Shannon Haworth, M.A., Association of University Centers on Disabilities (AUCD)
- David Mandell, University of Pennsylvania
- Brian Parnell, M.S.W., C.S.W., Utah Department of Human Services
- Kevin Pelphrey, Ph.D., University of Virginia
- Edlyn Pena, Ph.D., California Lutheran University
- Louis Reichardt, Ph.D., Simons Foundation Autism Research Initiative
- Robert Ring, Ph.D., Kaerus Bioscience
- John Elder Robison, College of William and Mary
- Alison Tepper Singer, M.B.A., Autism Science Foundation (ASF)
- Julie Lounds Taylor, Ph.D., Vanderbilt University



# Lunch



# Meeting of the IACC



## Afternoon Agenda

**1:00**

### **Public Comment Session**

**Susan Daniels, Ph.D.**

Director, Office of Autism Research Coordination, NIMH  
and Executive Secretary, IACC

**Joshua Gordon, M.D., Ph.D.**

Director, NIMH and Chair, IACC

**Oni Celestin, Ph.D.**

Science Policy Analyst

Office of Autism Research Coordination, NIMH

# Meeting of the IACC



## Afternoon Agenda

**2:00**

**Panel Presentation: Racial and Ethnic Disparities in Autism**

**Detecting, Understanding, and Addressing Racial and Ethnic Disparities Among Children with ASD**

**Sandy Magaña, Ph.D., M.S.W.**

Professor in Autism and Neurodevelopmental Disabilities  
Steve Hicks School of Social Work  
University of Texas at Austin

**2:15**

**Disparity Up Close: Centering the Diverse Voices of the Autism Community in a Research Framework**

**Temple Lovelace, Ph.D., BCBA-D**

Associate Professor of Special Education, Department of Counseling, Psychology, and Special Education,  
Duquesne University

# Meeting of the IACC



## Afternoon Agenda

2:30 **Using Community-based Autism Research to Tackle Racial and Ethnic Disparities**

**Sarah Dababnah, Ph.D., M.P.H., M.S.W.**

Assistant Professor, University of Maryland, Baltimore

2:45 **The Color of Autism**

**Camille Proctor**

Founder, The Color of Autism Foundation

Founding Member, National African American Autism Community Network

# Meeting of the IACC



## Afternoon Agenda

3:00 **Addressing Disparities for Latino Families**

**Matiana M. Ovalle**

Grupo Salto

Chicago, Illinois

**Jose Luis Ovalle**

Regional Coordinator Region 1, The Autism Program of Illinois (TAP) Senior Advisor, Grupo SALTO

3:15 **Yetta Myrick – Invited Public Comment**

President and Founder, DC Autism Parents, CDC's Act Early Ambassador to the District of Columbia

3:45 **Afternoon Break**



# Meeting of the IACC



## Afternoon Agenda

**4:00**

**Department of Labor Apprenticeship Initiative**

**Scott Robertson, Ph.D.**

Office of Disability Employment Policy

U.S. Department of Labor

**4:15**

**Summary of Advances Discussion**

**Susan Daniels, Ph.D.**

Director, Office of Autism Research Coordination, NIMH and  
Executive Secretary, IACC

**Joshua Gordon, M.D., Ph.D.**

Director, NIMH and Chair, IACC

**4:35**

**Round Robin**

**5:00**

**Closing Remarks and Adjournment**

# Oral Public Comments



**Susan A. Daniels, Ph.D.**

Director, Office of Autism Research Coordination

Executive Secretary, IACC

National Institute of Mental Health

# Written Public Comments



**Oni Celestin, Ph.D.**

Science Policy Analyst

Office of Autism Research Coordination, NIMH

# Live Feedback





# Discussion





The University of Texas at Austin  
Steve Hicks School of Social Work

# **Detecting, Understanding and Addressing Racial and Ethnic Disparities among Children with ASD**

**Sandy Magaña, MSW, PhD**



# Overview of presentation

- Defining health disparities and health equity
- Disparities in diagnosis and services among children with ASD
- Understanding Reasons for Disparities; ADI Study
- Reducing disparities: Parents Taking Action
- Future research needed



# What are health disparities?

From Healthy People 2020

A health difference that is closely linked with economic, social or environmental advantage

- Adversely affects groups of people who have systematically experienced greater social or economic obstacles to health based on race/ethnicity, SES, gender, age, disability, sexual orientation, geographic location, etc.
- historically linked to discrimination or exclusion



# What is health equity? (Braveman, 2014)

- Commitment to reduce and eliminate health disparities
- Striving for the highest standard of health for all people
- Giving special attention to the needs of those at greater risk of poor health based on social conditions
- Health equity and health disparities are intertwined—health disparities are the metric and health equity means social justice in health

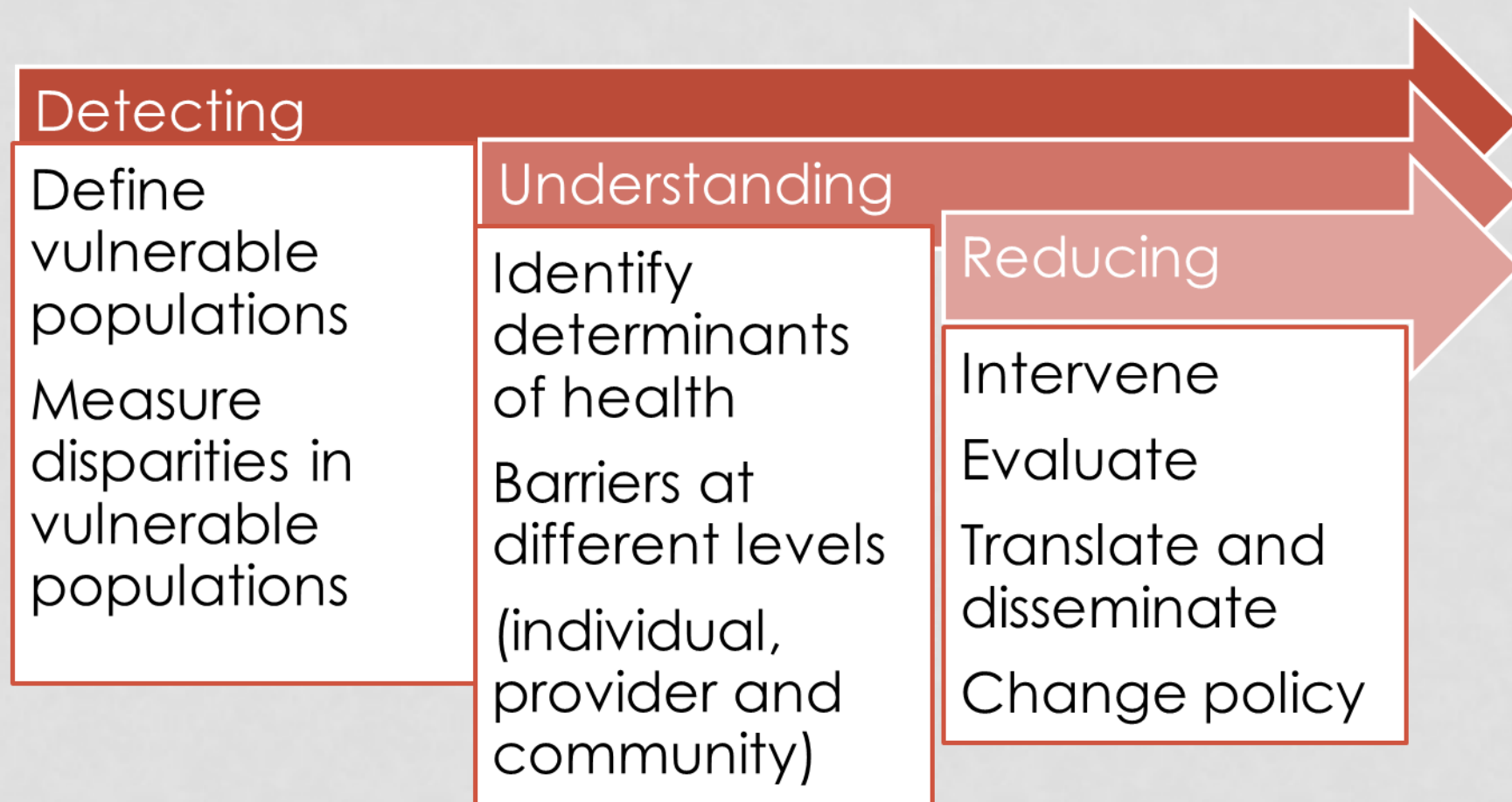


# Why are disparities important in autism

- Autism diagnosis, treatment and services are expanding to meet the growing need
  - While not all individuals and families are able to access these services, many are left out due to already established social inequalities
  - Important discoveries and treatments are being made, yet not all can benefit from them
  - How do we promote social justice in autism identification and supports?

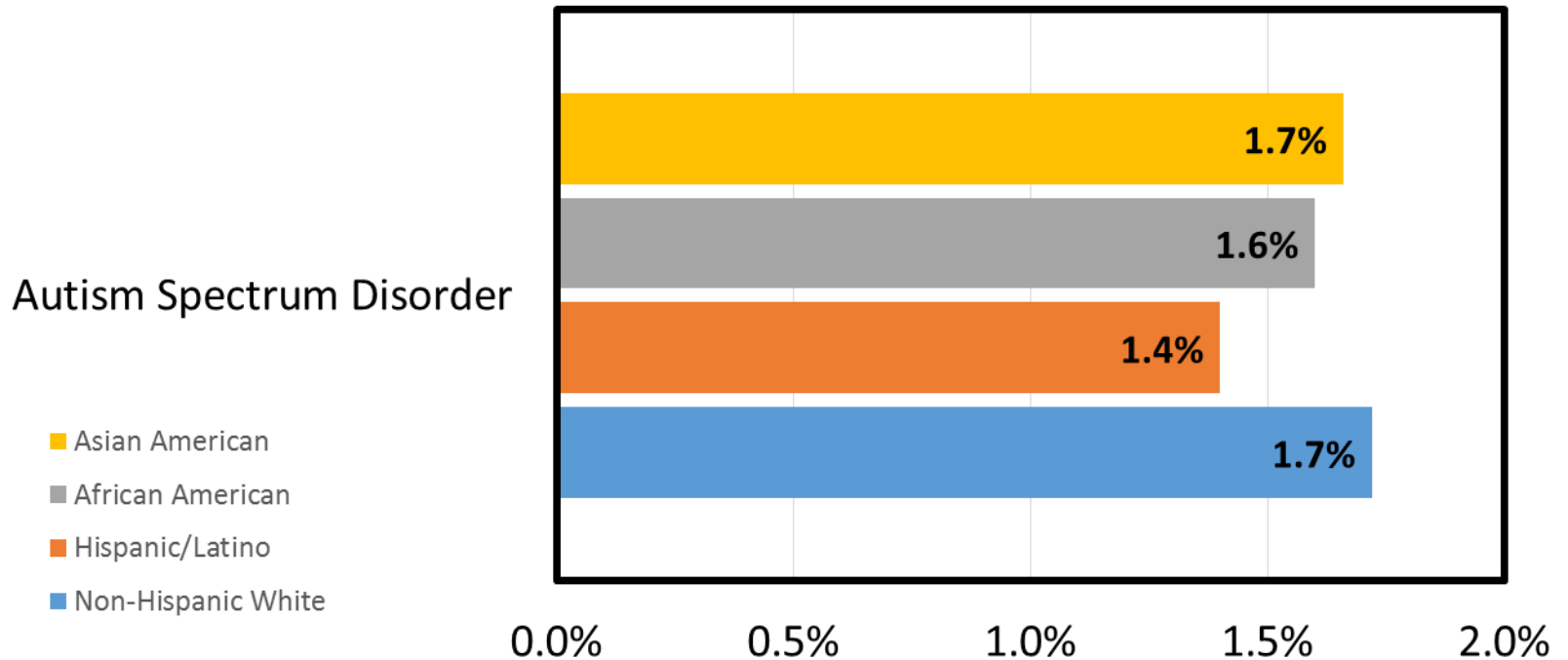


# FRAMEWORK FOR HEALTH DISPARITIES RESEARCH (KILBOURNE ET AL., 2006)



# Detecting: Prevalence of Neurodevelopmental Disorders Across Race/Ethnicity

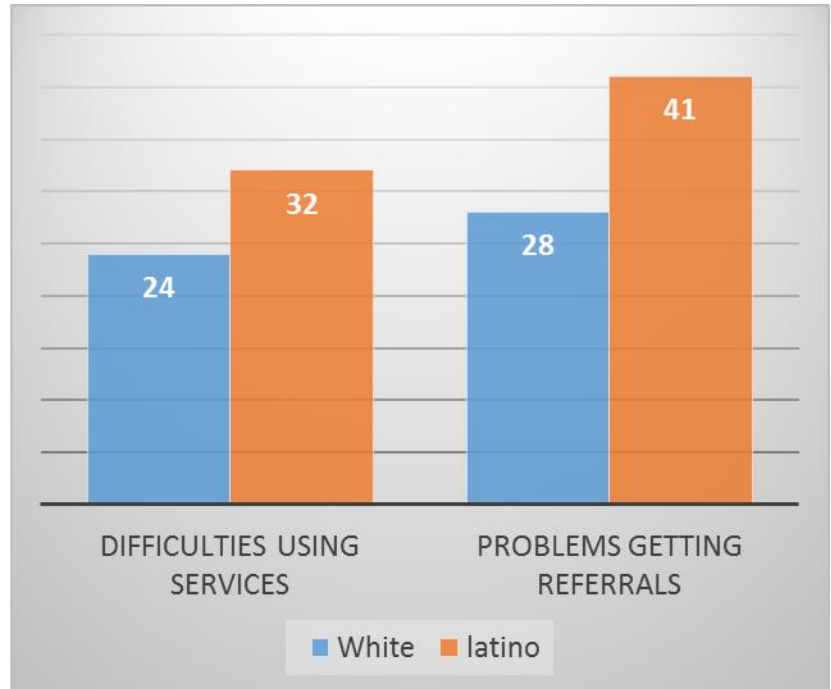
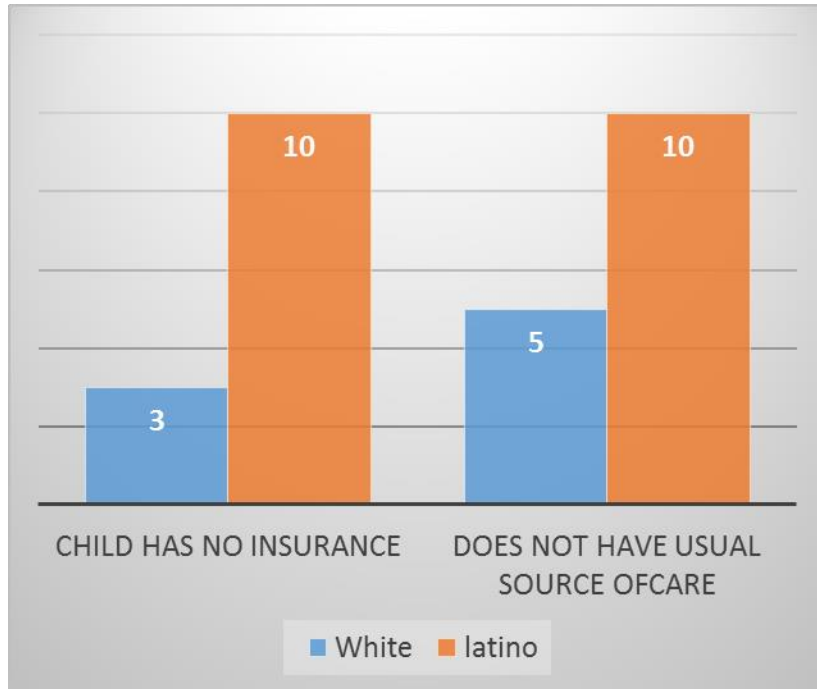
**CDC 2014 Prevalence Rates**



Autism Spectrum Disorder

- Asian American
- African American
- Hispanic/Latino
- Non-Hispanic White

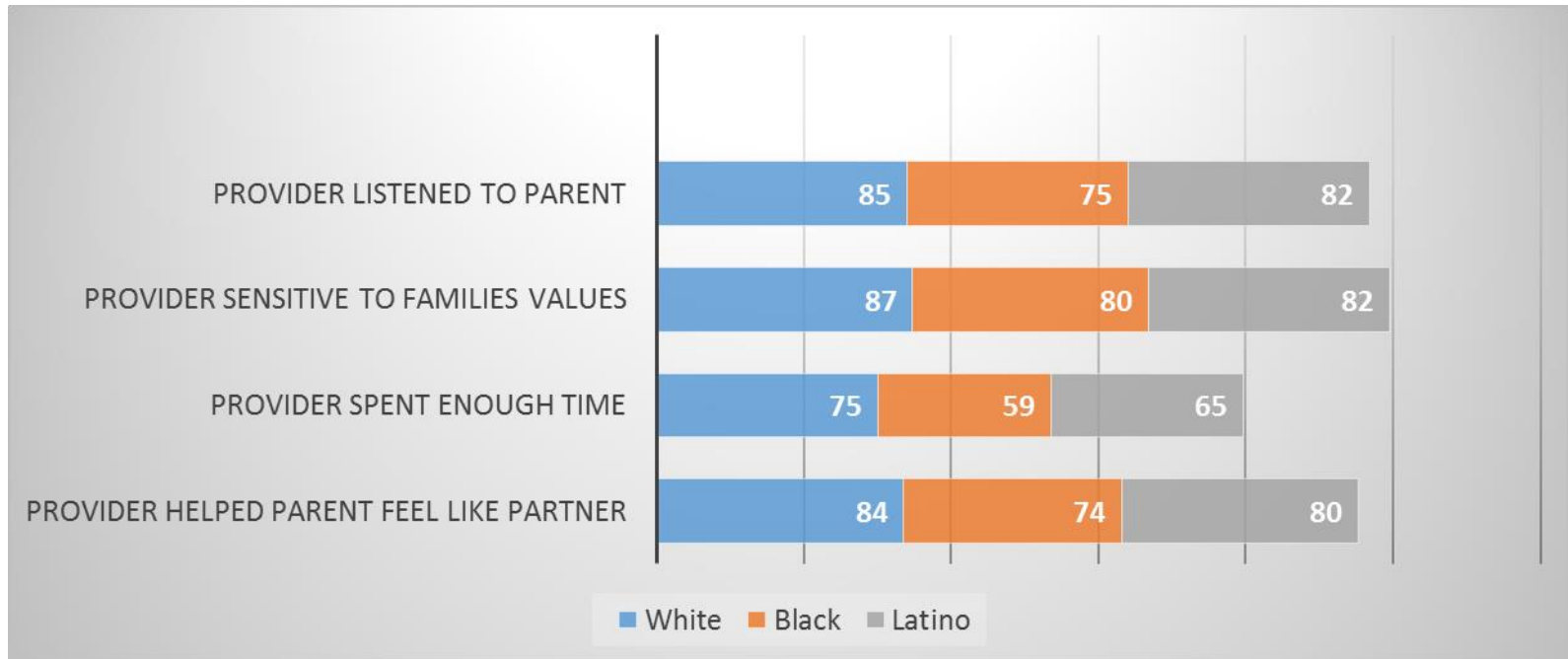
# Disparities in health care access and utilization, national survey of children with special health care needs, 2006 (Parish, Magaña, rose & Timberlake, 2012)



(MCHB/HRSA, Parish)

# Disparities in Health Care Quality

(National Survey of Children with Special Health Care Needs, 2010)



Magaña, Parish, & Son, 2015  
(MCHB/HRSA, Parish)



# Disparities in Specialty Services

- Less Access to ABA and other EB treatments
- Greater need does not equal more services
- Fewer therapy hours and more unmet therapy needs

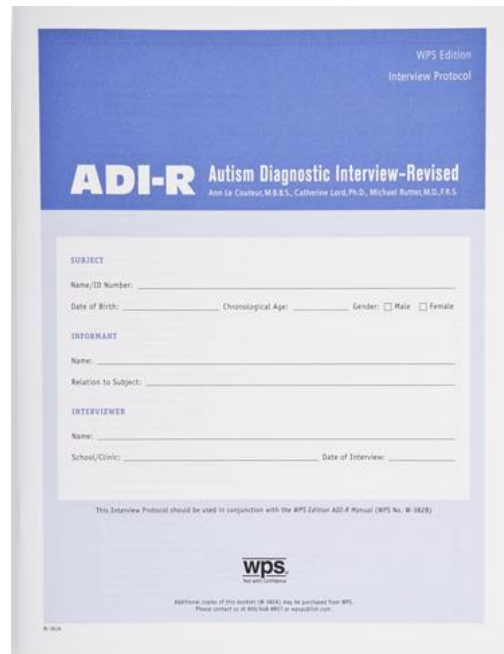


# Understanding Disparities

- Bias and lack of cultural training among providers/limited cultural tools
- Limited social capital of low income and racial and ethnic groups
- Specialized diagnostic and treatment services and lack of trained professionals
- Policy Barriers

# Determining cultural validity of instruments: ADI-R Study

- Study examined validity of the ADI-R with Spanish speaking families



WPS Edition  
Interview Protocol

**ADI-R** Autism Diagnostic Interview-Revised  
Ann Le Couteur, M.B.B.S., Catherine Lord, Ph.D., Michael Rutter, M.D., F.R.S.

**SUBJECT**  
Name/ID Number: \_\_\_\_\_  
Date of Birth: \_\_\_\_\_ Chronological Age: \_\_\_\_\_ Gender:  Male  Female

**INFORMANT**  
Name: \_\_\_\_\_  
Relation to Subject: \_\_\_\_\_

**INTERVIEWER**  
Name: \_\_\_\_\_  
School/Clinic: \_\_\_\_\_ Date of Interview: \_\_\_\_\_

This Interview Protocol should be used in conjunction with the WPS Edition ADI-R Manual (WPS No. W-1828)

**wps**  
Additional copies of this manual (W-1828) may be purchased from WPS.  
Please contact us at 767-344-8801 or [www.wps.com](http://www.wps.com)

A-1624

# Diagnosing children with ASD

- Gold Standard: Observations and Developmental History
  - Autism Diagnostic Observation Schedule 2 (ADOS 2)
  - Autism Diagnostic Interview-Revised (ADI-R)
- ADI-R is used worldwide
  - Translated in 17 different languages
    - Translation of text but not validation

# ADI-R Across Cultures

<b>Country</b>	<b>Sensitivity</b>	<b>Specificity</b>
<b>United States</b>	96%	92%
<b>Japan</b>	92%	89%
<b>Greece</b>	88%	69%
<b>Finland</b>	95%	74%

Lord et al. (1994); Tsuchiya et al. (2013); Papanikolaou et al. (2009); Lampi et al. (2010)

# Parent Characteristics

## Demographic Characteristics of Parents by ASD and DD Group

	ASD	DD
	n = 29	n = 21
Mean age (SD)	40.0 (6.3)	39.7 (5.5)
Married/living together (%)	79%	81%
High School or Less (%)	71%	86%
Less than \$30,000 (%)	61%	71%
Employed (%)	21%	33%
Foreign-born (%)	97%	95%
Mexican (%)	79%	95%
Good/excellent English (%)	11%	10%

Note: All p's > .05.



# Child Characteristics

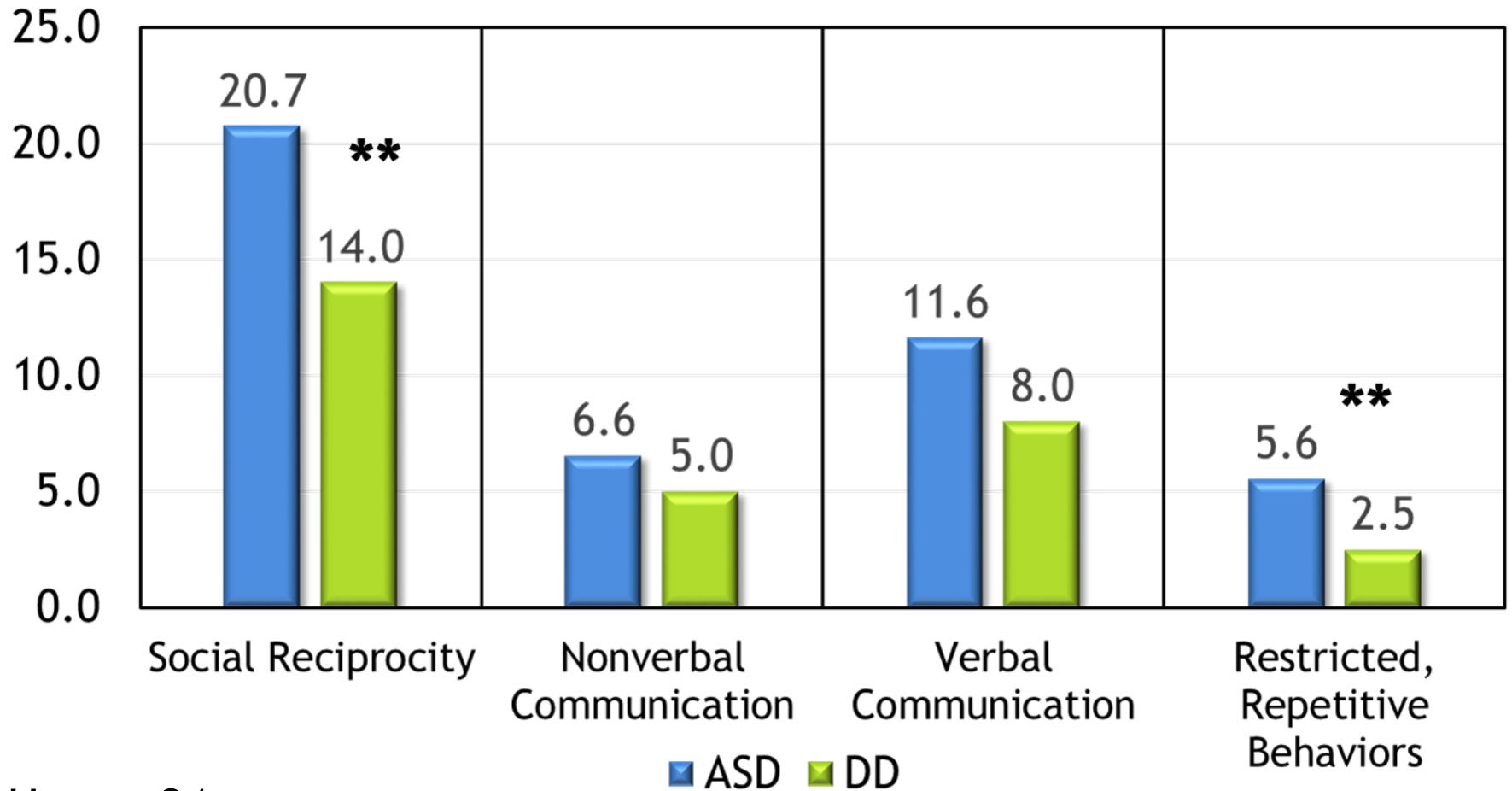
Demographic Characteristics of Children by ASD and DD Group

	ASD	DD
	n = 29	n = 21
Mean age (SD)	9.1 (3.4)	8.8 (3.5)
Male (%)	76%	81%
Born in United States (%)	100%	95%
Intellectual Disability (%)	21%	14%
Verbal (%)	66%	67%
Bilingual or more English (%)*	55%	48%

*Note:* \* based on who were verbal; All p's > .05.

Vanegas, Magaña, Morales, & McNamara, 2016

# Results: ADI-R Domain Scores



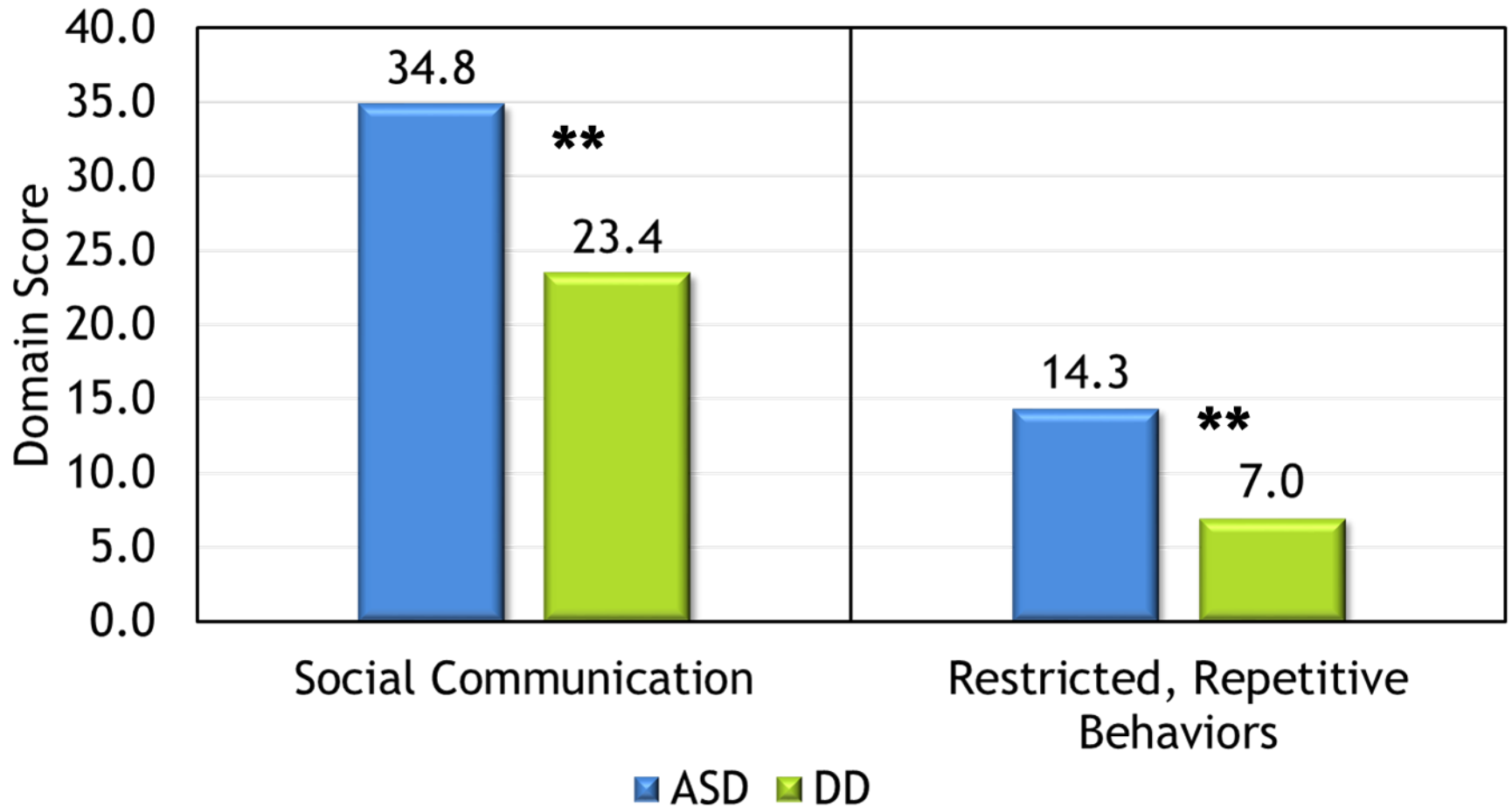
\*\*  $p < .01$

# Results: Clinical Validity

<b>Autism Spectrum Disorder</b>	<b>Sensitivity</b>	<b>Specificity</b>
All Domains + Age of Concern	69%	76%
Domain + Age of 1 <sup>st</sup> Concern		
Social Reciprocity	93%	38%
Communication	79%	52%
Restricted Interests, Repetitive Behaviors	79%	76%

English-language ADI-R: Sensitivity = 96%; Specificity = 92%

# DSM-5 Overall Criteria



\*\*  $p < .01$

# Clinical Validity: DSM-5 Criteria

<b>Autism Spectrum Disorder</b>	<b>Sensitivity</b>	<b>Specificity</b>
All Domains	79.3%	66.7%
Individual Domains		
Social Communication	82.8%	47.6%
Restricted Interests, Repetitive Behaviors	93.1%	47.6%

Magaña & Vanegas, 2017



# Factors that may influence Diagnostic Validity

- Language proficiencies
  - Possible mismatch between parent and child language
- Content validity issues, concepts may be difficult to convey across cultures
  - SES and literacy could impact
  - Direct translation not understood the same way
- INSAR student internship project- Liz Jaramillo
  - Examining items that do not distinguish
  - Conducting cognitive interviews on those items

# Addressing Disparities

- Culturally tailored interventions that help to reduce disparities on individual and family level
- Interventions that provide training to providers to reduce disparities
- Policy level interventions

## Example of culturally tailored intervention: Parents Taking Action

- Intervention created to address disparities for Latino immigrant parents of children with Autism
- Formed Advisory Committee ->
- Used Ecological Validity Framework ->
- Used Promotoras de Salud

# Curriculum

- **Psycho-education**
  - Understanding ASD
  - What are EB practices?
- **Advocacy & Parent Support**
  - Advocating for child
  - Reducing parental stress
- **EB Strategies**
  - Play
  - communication
  - Challenging behaviors



# The University of Texas at Austin Steve Hicks School of Social Work







# The University of Texas at Austin Steve Hicks School of Social Work





- Training of Promotoras
- Held in group format, 4 to 8 hour blocks
- Total of 32 hours of training
- Provided meals and compensated promotoras for training time





## Demographics

### Mom Characteristics

	Interv n=42	Cont n=54
Average Age	37.7	36.5
% married/partner	70.8	78.6
% High school + up	73.8	56
% < 40,000 income	76.9	85.8
% foreign born	88.1	90.7
% good/excellent health	55	64.8
% employed	23.8	35.2
% Chicago (vs. CA)	71.4	74.1

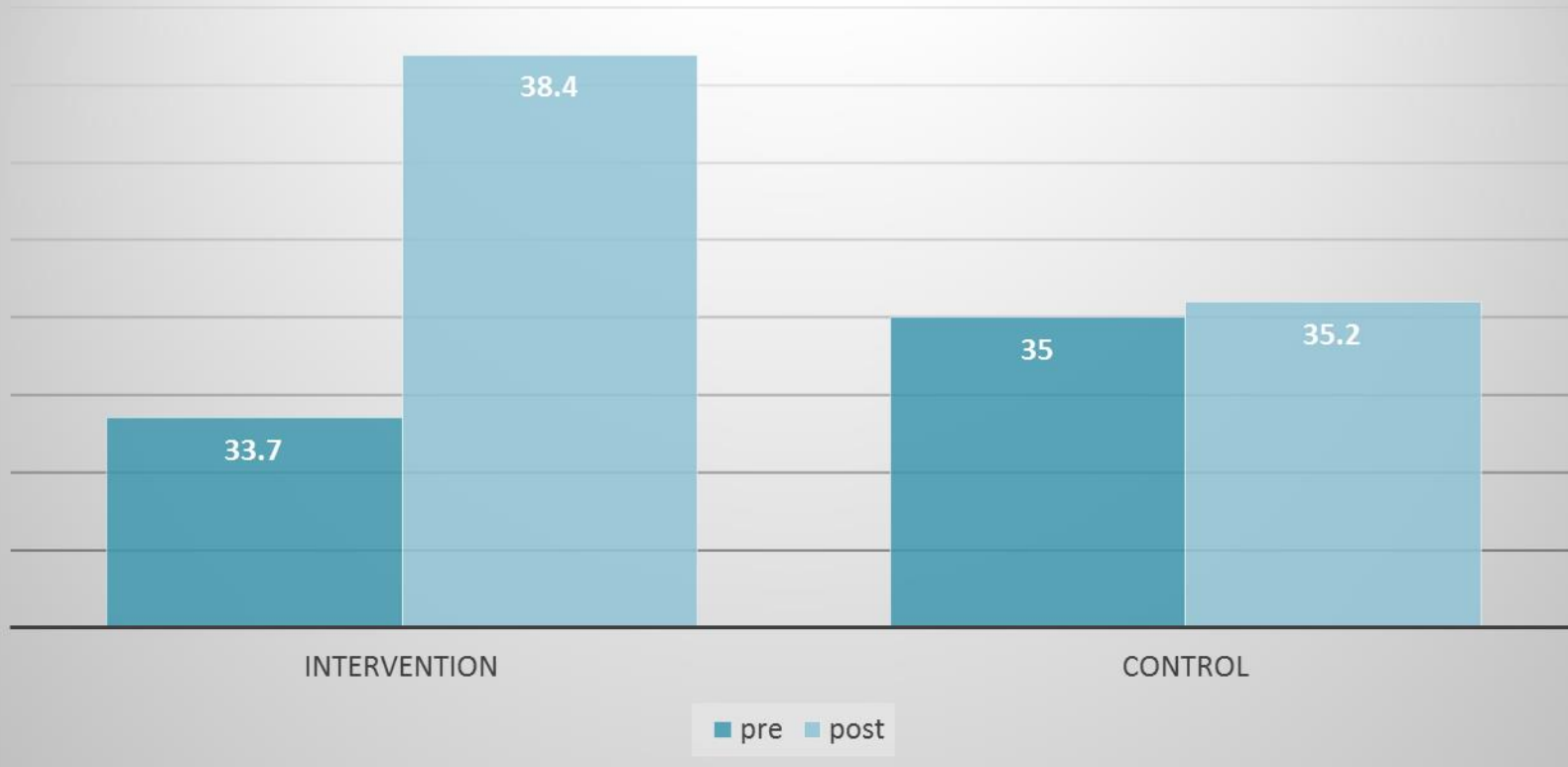
### Child Characteristics

	Interv n=53	Cont n=57
Average age	5.3	5.4
% male	87.7	89.5
% severe symptoms (CARS)	38.1	33.9



# Maternal Outcomes

## Efficacy in Use of Strategies

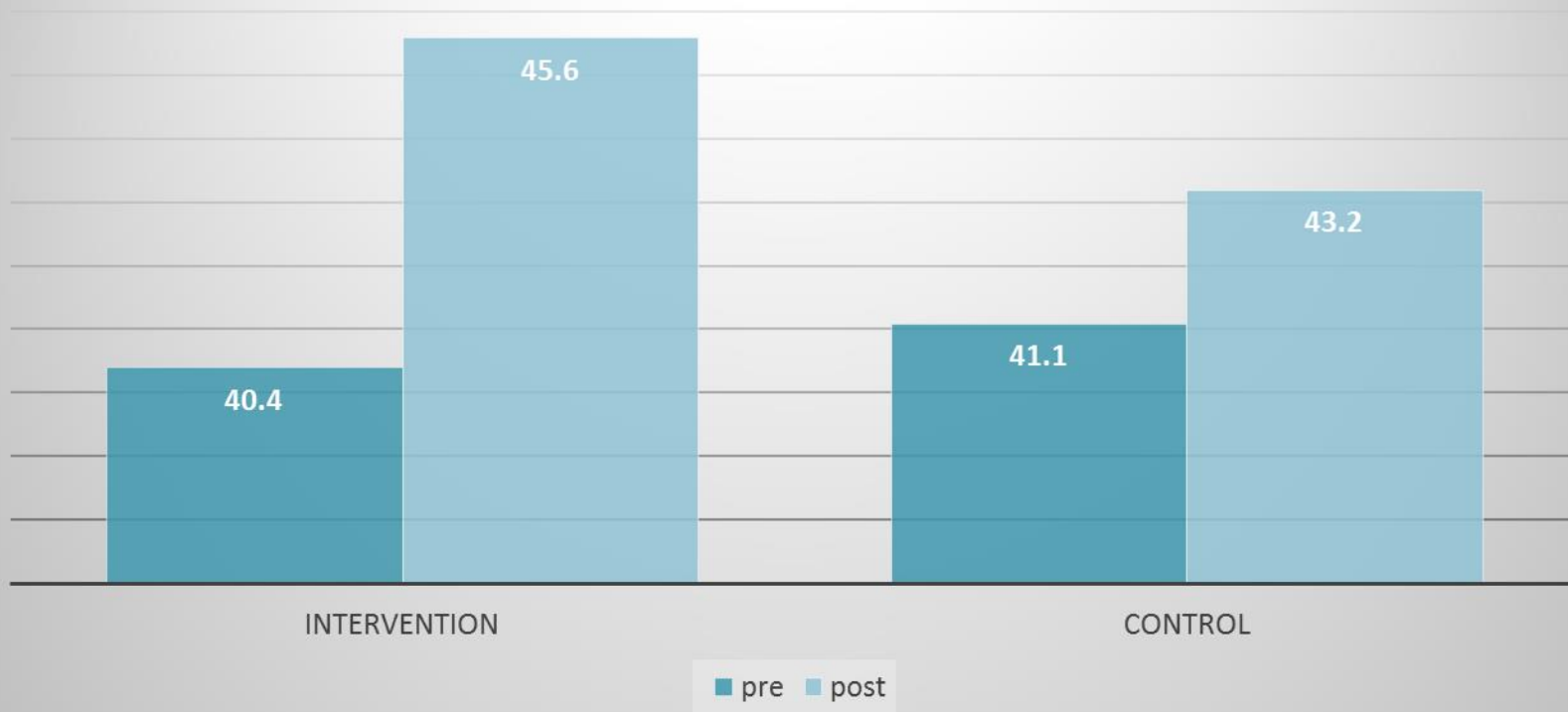






# Maternal Outcomes

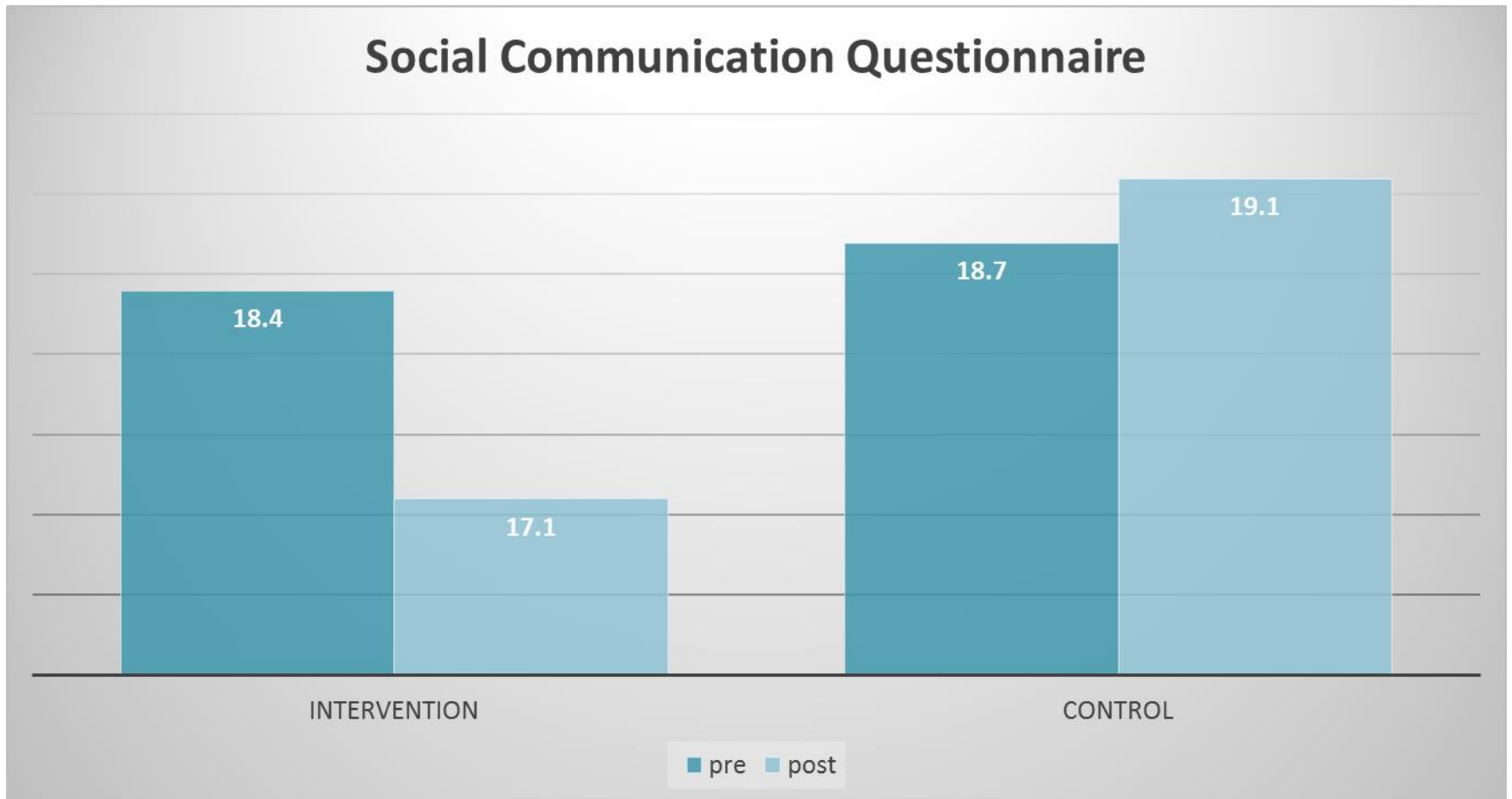
Frequency in Using Strategies





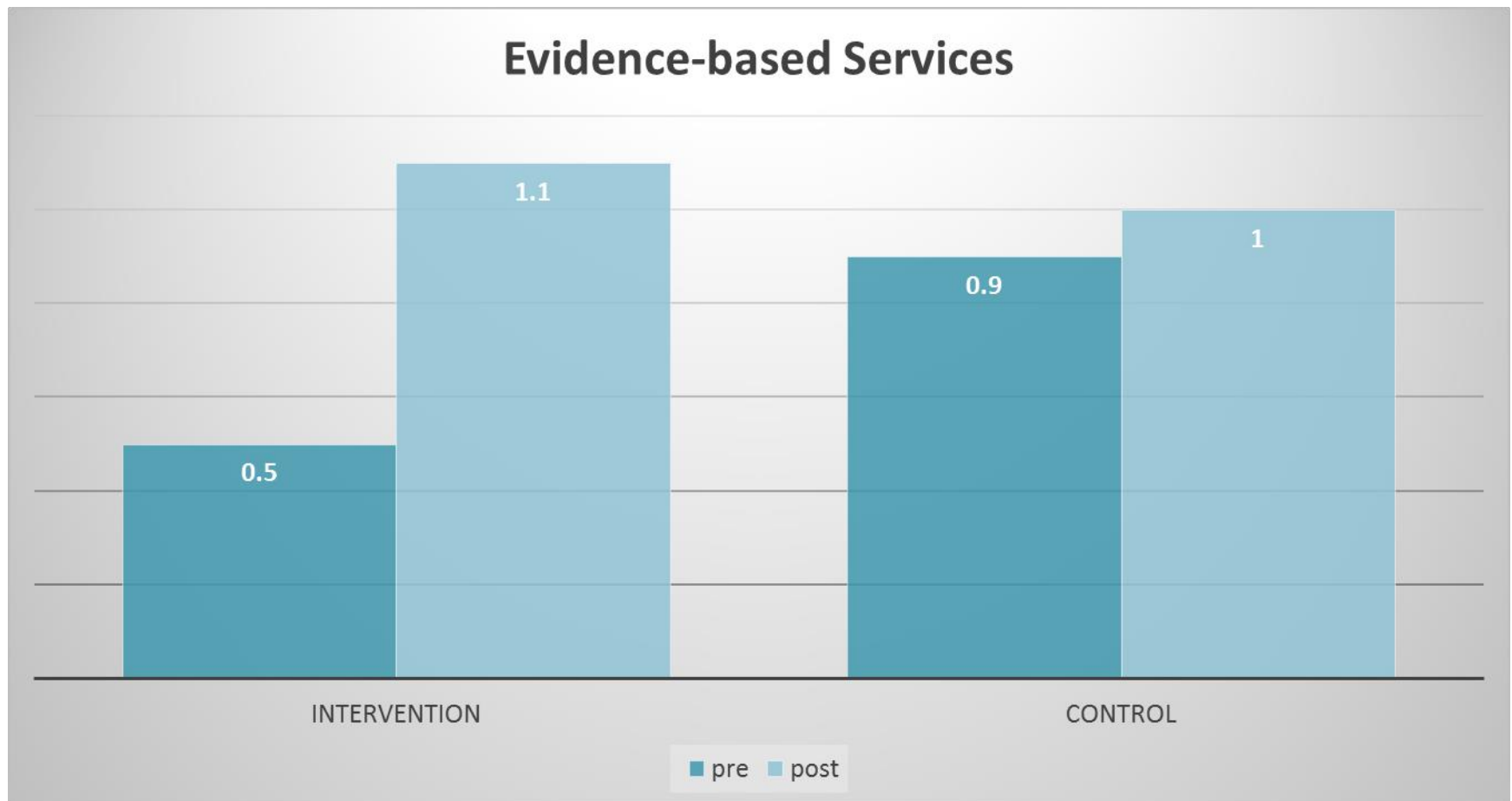


# Child Outcomes





# Child Outcomes





# Discussion

- Parents feeling more empowered >
- Parents using evidence-based strategies >
- - Children accessing more EB services
- Reduction in social communication problems

# Future Research Needed

- **Detecting-** need more research examining disparities in EB services and supports
- **Understanding-** need more research understanding barriers at different levels and for different populations
- **Addressing-** need funding towards development of culturally tailored interventions; Also on system-wide efforts to reduce disparities



# PTA Acknowledgements

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# **Disparity Personalized: Centering the African American Voices of the Autism Community in a Research Framework**

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# Objectives of Presentation

- Importance of Voice in a Quantitative World
- Autism Disparity Causal Loop Diagram
- Perspectives of Caregivers
- National Perspectives
- Recommendations

“A different way of looking at the social world that actively invites [us] to participate in dialogue... **multiple ways of seeing and hearing**, multiple ways of making sense of the social world, and multiple standpoints on what is important and to be valued and cherished.”

Greene (2007) p. 20

# NIH Current Priorities: Health Disparities

- basic research focused on health disparities experienced by racial and ethnic minorities, the rural and urban poor, and other medically underserved populations;
- population-specific community-based participatory research;
- enhancing capacity to conduct health disparities research;
- recruiting and retaining racial and ethnic minorities and other underrepresented groups into the scientific research workforce;
- establishing health education programs for special populations; and
- promoting the inclusion of women, minorities, and other medically underserved groups in clinical trials

- System Dynamics models the relationships between all the parts of a system and how those relationships influence the behavior of the system over time.

Richardson (2011)\*

- Created in the 1950s by Dr. Jay W. Forrester, system dynamics utilizes informal maps and formal models with computer simulation to uncover and understand the endogenous sources of system behavior.
- It is a computer-aided approach to policy analysis and design.

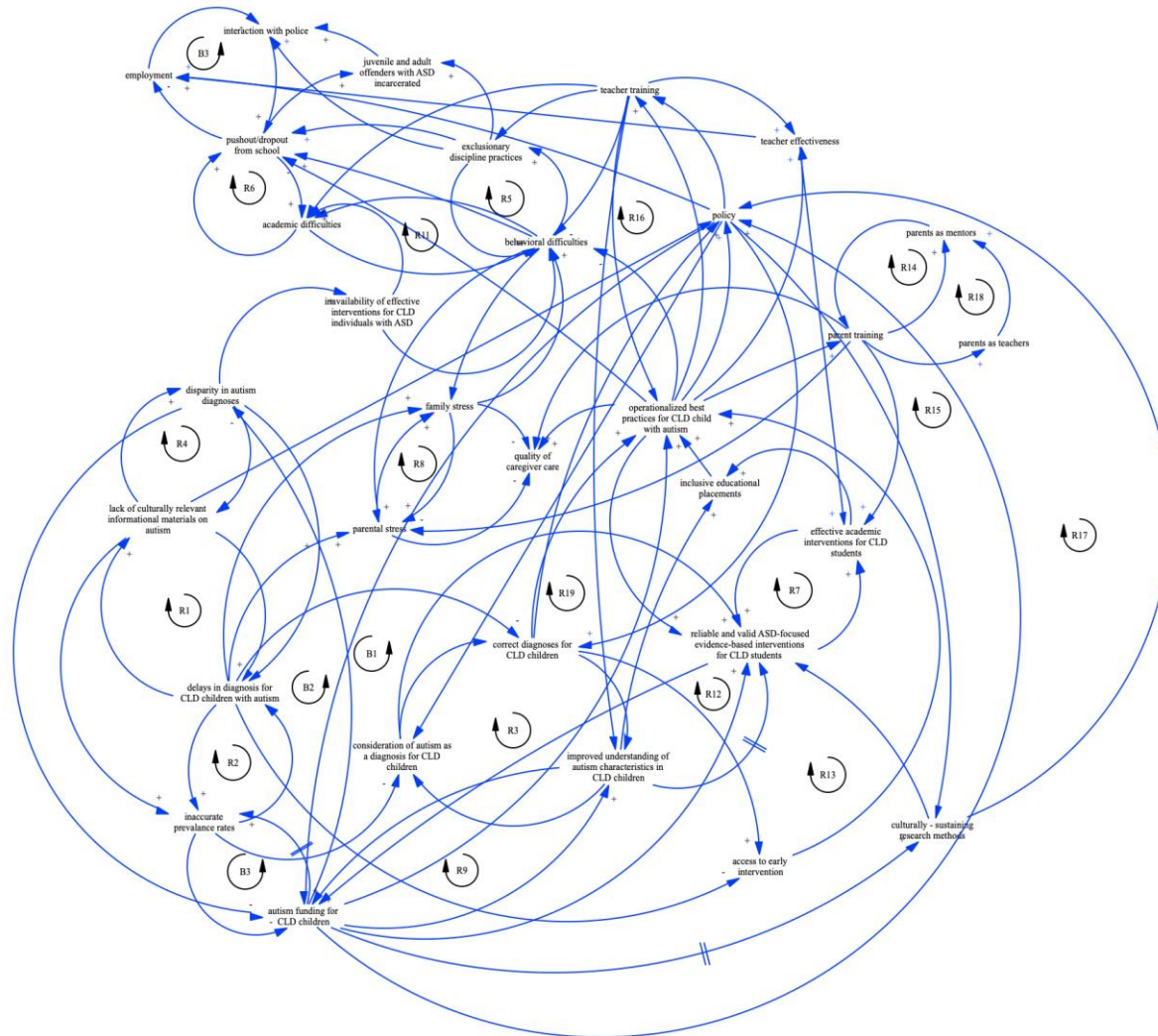
\*Full references available from author



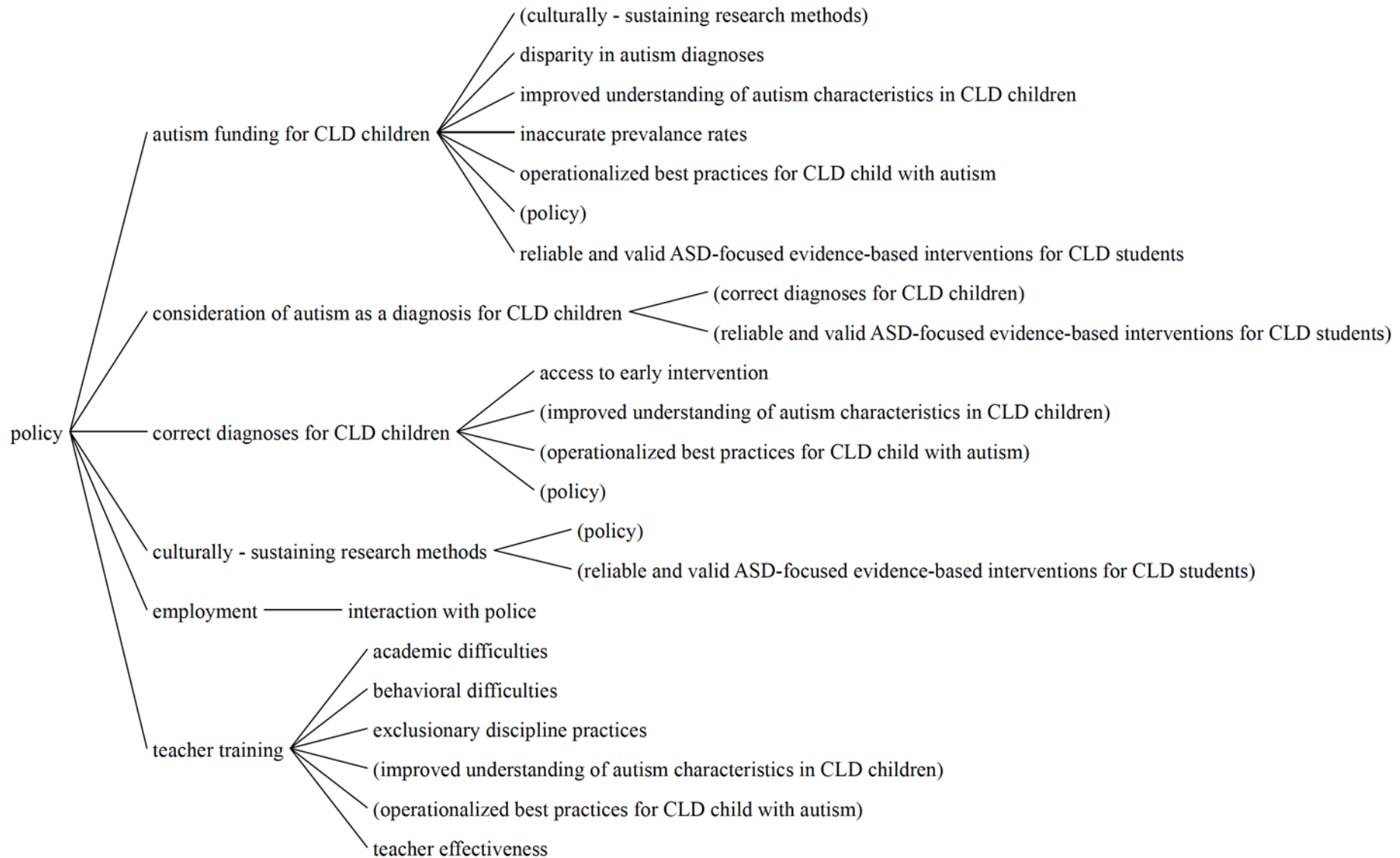
- Systems Dynamics focuses on intervention at the systems level that correlate with desirable change for the individual.
- Community-based system dynamics aims to understand the mechanisms driving dynamic behavior *through collaboration with the community* in identifying causal relationships, feedback loops, delays and unintended consequences.

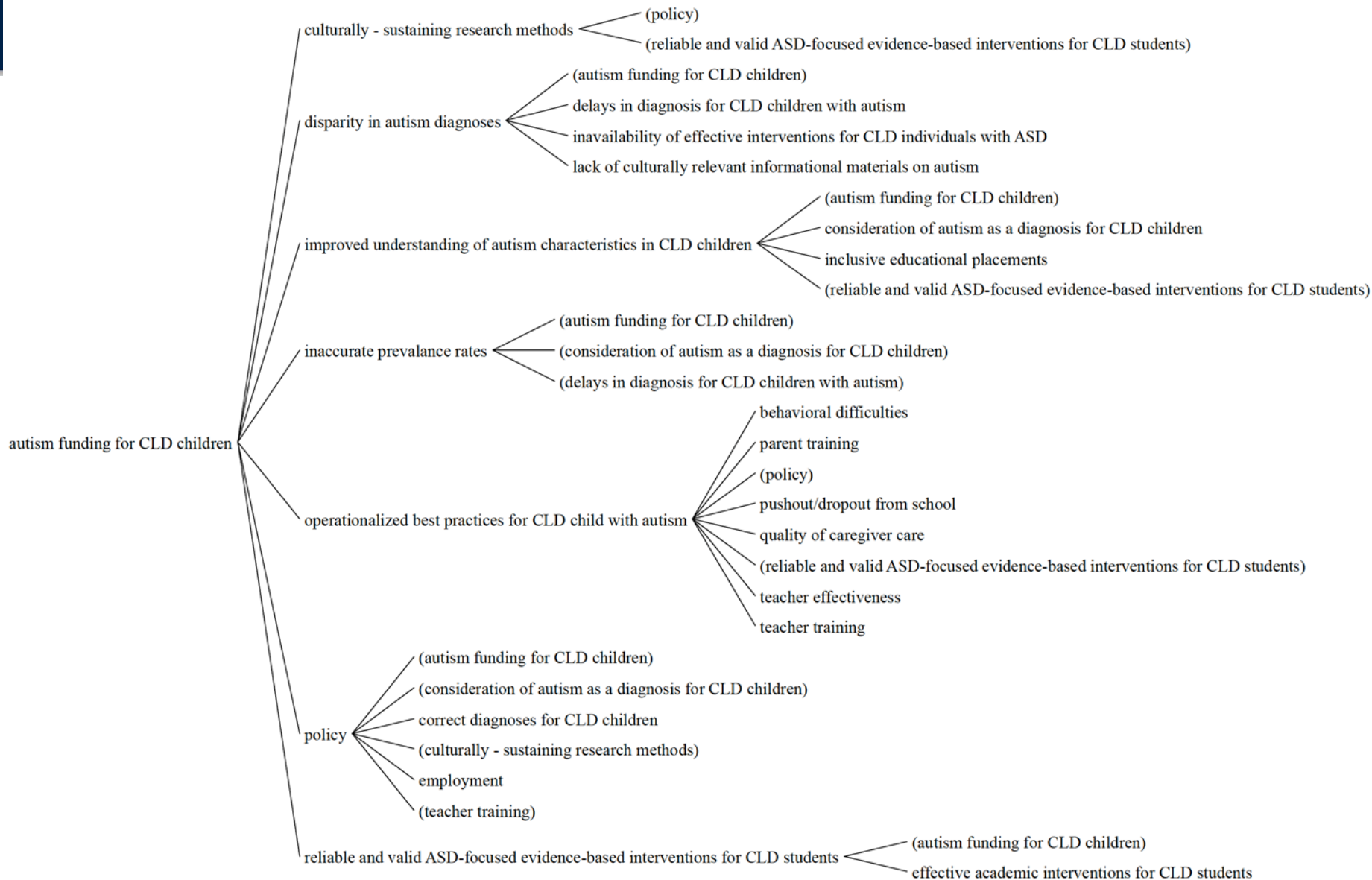
Hovmand 2014

# Autism Disparity Causal Loop



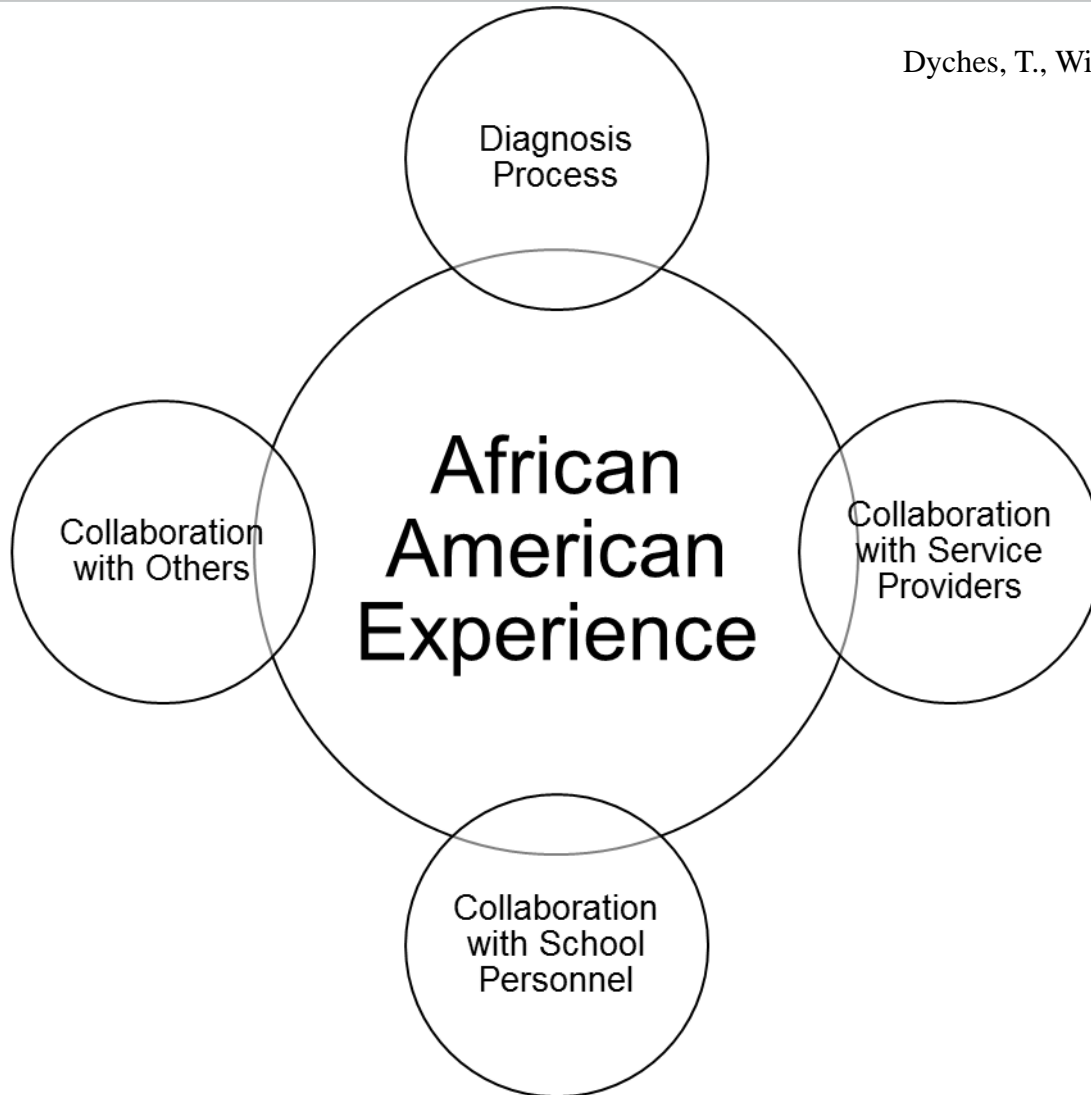








# Perspectives of African American Caregivers

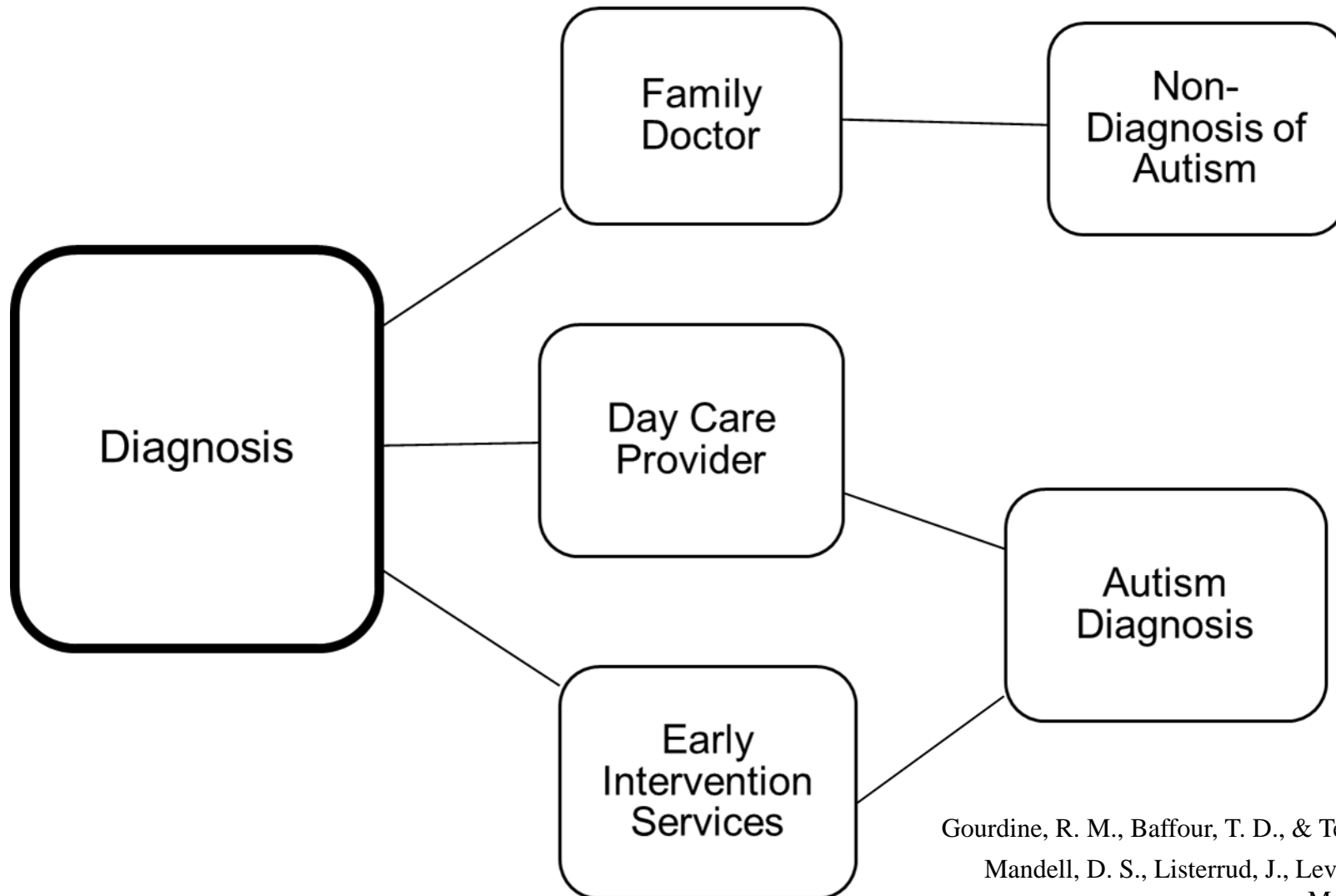


Dyches, T., Wilder, L., Sudweeks, R., Obiakor, F., & Algozzine, B. (2004)

Fox, L., Vaughn, B., Wyatte, M., & Dunlap, G. (2002)

Pruchno, R., Hicks Patrick, J., & Burant, C. J. (1997)

# Diagnosis



Gourdine, R. M., Baffour, T. D., & Teasley, M. (2011)

Mandell, D. S., Listerrud, J., Levy, S. E., & Pinto-Martin, J. A. (2002)

Pearson, J. N. & Meadan, H. (2018)

**“Yes, absolutely. It took longer to actually get a diagnosis.** Let’s say this politically correct, I don't want to offend, but, knowing... I knew by the time he was 2 or 3, I knew that this was autism, but **it took another 2 years to finally get a diagnosis because pediatricians kept writing it off.”**

**Viola**

**He showed signs as an infant, but by the time he was 1, he was completely nonverbal and he wasn't responding to his outside environment at all.** That went on for about a year, and at 2 he started to regain a few skills, but he always had a huge delay as far as communication and social skills. **So we started seeing obvious signs at age 1, but you get brushed off, you get brushed off.**

**And by the time age 3 hit and no one could understand what he was saying, I knew, this was autism,** it just is, there is nothing else that can describe this. He is purposefully injuring himself everyday and so, I knew by the time age 3..."

## Collaboration w/ Service Providers

Positive Experiences

Negative Experiences

Patronization

Assumptions about Home Environment

Denial of Services

Location of Services

Blanchett, W. J., Klingner, J. K., & Harry, B. (2009)

Gourdine, R., Baffour, T., & Teasley, M. (2011)



“He still talks about certain TSS's, he had 3 that stood out, I've had lots. I had, one African American TSS, in aaalll (emphasized) the different agencies that i have been involved with, and the 3 they were nice women. **They worked with him, they had expectations that matched mines, just they were willing to do things with my other son too, they didn't exclude him.**”

**Latisha**

**“I guess Cory was just "too autistic" and with this program I could have gotten medical assistance, I could have gotten Access to pick him up drop him off, pick him up from school, take him to the program, and bring him home. They were like well, he sounds like he is to severely autistic. So, I said what you're telling me is, your autistic program only accepts certain types of autistic people? And she was like, "yea"...**

**Latisha**

**And I know the way that I speak, I don't "sound" like I'm an African American person.** I can speak just as prim and proper as anyone, you know as they want, but when I, **once I started saying, well, my son has this, and where I lived at, and people start doing the math and they're like "oh no no...**

**You hate to say it's because of your color. I hate to say that. I try to look at everything else and then when everything else doesn't all line up then you have to say maybe it was my color. Maybe it was because I was black."**

**Latisha**

“I also had a [therapeutic support specialist] who didn’t want to go out in the community, I said, ‘come on let’s walk to the farmers market,’ that’s a way you know community, social skills, things like that. **She didn’t want to go because at the time I lived in [urban community],** and I happened to live like on the [urban community] line, **I didn’t live right in the ‘shoot’em up central”**

**Latisha**

**...people will try to talk to me like I don't know what I'm talking about** and they will make suggestions and I'm looking at them like I've done that or I do that, and their like "oh" (sounding shocked)....**she was just very condescending when she spoke to me and I had to tell her, "with all do respect, this does not work with my child, I've tried this."**

**Latisha**

## Collaboration with School Personnel

- **Perceptions**
  - **Knowledge about Services**
  - **Knowledge about Needs**
  - **Knowledge about School's Responsibility**
- Placement
  - Incorrect Placement based on PLOP
  - No basis for Placement Decision
- IEP
  - Frequent Revisions
  - Intimidation
- Class/Home Work
  - Not Getting Accommodations
  - Incorrect work for Skill Level



It was very difficult trying to find research, or really where to go or what to do, **I felt kind of lost.**

**Viola**

**I had to educate myself, I had to read up on autism, I went to the appeal center and got parent advocate certified because I needed to know what to do that for my child.**

**Latisha**

## Collaboration with School Personnel

- Perceptions
  - Knowledge about Services
  - Knowledge about Needs
  - Knowledge about School's Responsibility
- **Placement**
  - **Incorrect Placement based on PLOP**
  - **No basis for Placement Decision**
- IEP
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  - Incorrect work for Skill Level

“I don’t want to say that it’s a racial thing. **I don’t want to say that it has to do with him being African American but sometimes it is questionable where his placement is in school.**”

“**I’m not the kind of parent that just...don’t care...**my son comes absolutely first.”

**Tina**

“They don’t want him to go to an autistic support classroom because they said he’s too high functioning to go to an autistic support classroom. I’m okay with that. **I’m not okay with him just not being taught. We need more help. He does. He just needs more help.**”

**Viola**

## Collaboration with School Personnel

- Perceptions
  - Knowledge about Services
  - Knowledge about Needs
  - Knowledge about School's Responsibility
- Placement
  - Incorrect Placement based on PLOP
  - No basis for Placement Decision
- **IEP**
  - **Frequent Revisions**
  - **Intimidation**
- Class/Home Work
  - Not Getting Accommodations
  - Incorrect work for Skill Level

**“It was a struggle for me because I didn’t know how to go in there and say I’m not okay with this. I couldn’t breathe going into that meeting and then on top of that the meeting is the principal, the assistant principal and all of his teachers. You know **there’s 6, 7, 8 other women in the room with me.**”**

**Tina**



**This school year so far we have changed his IEP twice, and we have another meeting next month; his needs are not being met at all.**

**I've had to talk to his special education teacher several times and ask her please adjust this on his IEP...He's still not getting accommodations.**

**Viola**

## Collaboration with School Personnel

- Perceptions
  - Knowledge about Services
  - Knowledge about Needs
  - Knowledge about School's Responsibility
- Placement
  - Incorrect Placement based on PLOP
  - No basis for Placement Decision
- IEP
  - Frequent Revisions
  - Intimidation
- **Class/Home Work**
  - **Not Getting Accommodations**
  - **Incorrect work for Skill Level**

**He needs one-on-one teaching and he is not getting that.** He is in a typical/regular education classroom, but checking for comprehension is not occurring. **Any kind of re-teaching is not occurring at all, he has no sensory breaks,** he's now getting pulled out for help for spelling, but its not very beneficial to his grades because with math and language arts he is still having difficult time. **He will routinely come home from school and will not have any idea what to do for homework. It is as if he was gone for 7 hours for nothing.**

**Viola**

Sometimes they don't understand the culture. **Sometimes you know it's like is it prejudice or is it because they don't understand what's really going on.**

**Tracey**

# African American Experience

## **African American Experience**

### **Knowledge about Autism**

**Characteristics**

**Supports**

**Services**

### **Underrepresentation**

**Programs**

**Schools**

### Access to Services

Lack of Community-based Services

Inability to Access Services

**“...my family just assumed that it was something that I did wrong because Chance came out with autism; it was my fault. "You must have been drinking, or you must have been using drugs",** no, I didn't do anything. They didn't want to accept it.”

”They just didn't understand. It was like we never had anybody like this in the family before. I have a cousin who [has an intellectual disability] but we know why he [has a disability]. **They just could not understand that. I was educating everybody. Everybody in my circle started getting educated.**

**Latisha**



Some of them don't quite understand what autism is and trying to explain it to them it's pretty difficult. **They just don't understand it. It's difficult to try to explain why his behaviors are the way they are...**

**Viola**

**I think it's just a culture that they're just so used to. I mean my grandmother my mother on both sides for years they were like he does not need to be in all that therapy.** I'm like this is a new day. He does need help. There are things that I cannot **I don't know if it's a pride thing I really don't know what it is but I know that I'm not like them.**

Tina

# African American Experience

## African American Experience

Knowledge about Autism

Characteristics

Supports

Services

Underrepresentation

Programs

Schools

## Access to Services

**Lack of Community-based Services**

**Inability to Access Services**

**I just think the information needs to be out there more.**

Even if it's just like doctors that are good with children with autism. I had to change his pediatrician that he was with from a baby because she really wasn't there as much as I feel she should have been.

**Tina**

“Well a lot of times it's because **there was no place in my own community that I could go to so I was forced to go travel far out.** It does make things difficult if you don't have something close by to you.

**Latisha**

**“I think that early diagnosis and screening are one of the biggest issues that African Americans face, and I think that putting more knowledge out there specifically geared towards African American. Examples of African American that have children on the spectrum that are getting services, that are actually benefiting in some way, and encouraging them to be more involved in their child's services, and their child's education as well, it would really, really, really, really, really, help.”**

**Viola**

# NAAACN National Town Halls

- Detroit, MI
- Washington, DC
- Birmingham, AL

Surveys & Conversational Interviews  
+100 participants across the 3 town halls

Survey Results: Detroit & Washington (n=70)

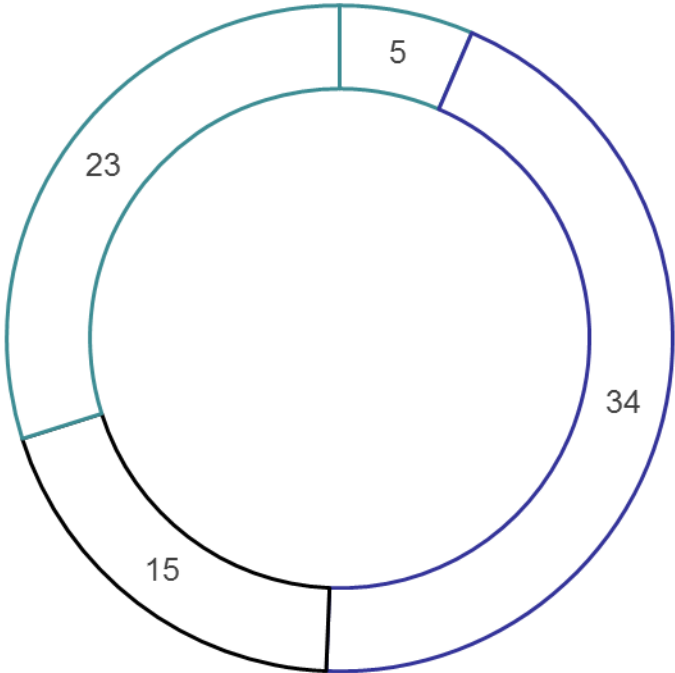


**N A A A C N**  
NATIONAL AFRICAN AMERICAN  
AUTISM COMMUNITY NETWORK



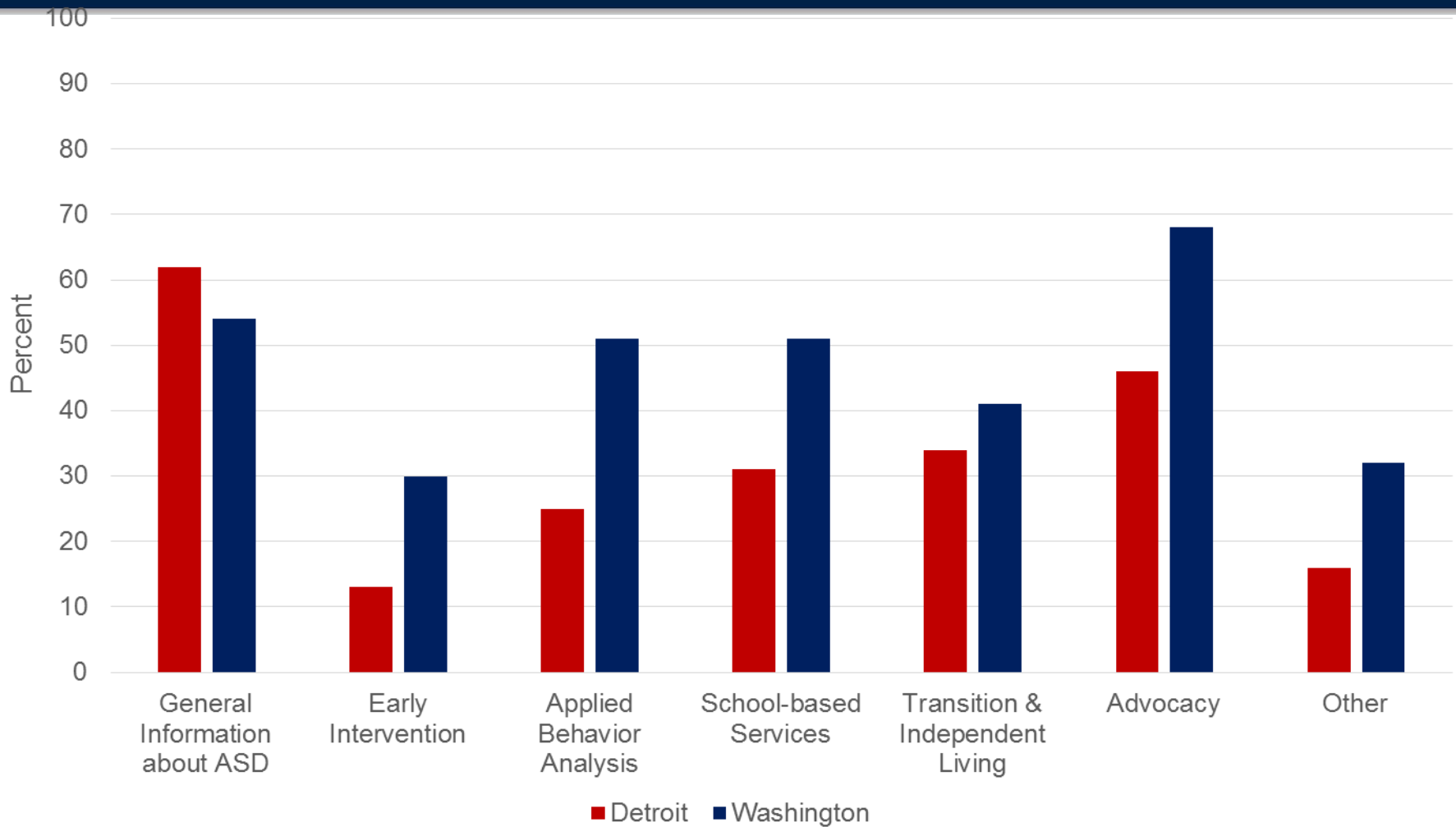
# Town Hall Attendants

### Town Hall Representation



Person w/ ASD   Parent   Family Member   Professional

# Town Hall – Information Needs



- Increased use of qualitative and mixed methods studies in order to improve an understanding of the *experiences* of racially and ethnically diverse individuals with autism spectrum disorders and their families.
- Increased multi-disciplinary collaboration to improve the *participation* of racially and ethnically diverse individuals with autism in developing solutions for the disparities in diagnosis, services, and support available to the African American community.
- Increased support of evidence-based practices created specifically for racially and ethnically diverse individuals with autism and their caregivers in order to decrease latency in effective intervention implementation.

# USING COMMUNITY-BASED RESEARCH TO TACKLE RACIAL & ETHNIC DISPARITIES

Sarah Dababnah, PhD, MPH, MSW

Interagency Autism Coordinating Committee Meeting

July 24, 2019

# AGENDA

- ▶ Note about language
- ▶ Parenting interventions for caregivers of young children with autism
- ▶ Using community-based family research to document and address racial and ethnic disparities
- ▶ Recommendations for research funding priorities



# EMPHASIZING THE IMPORTANCE OF FAMILIES IN AUTISM RESEARCH



- ▶ Parents as de facto “case managers”
- ▶ High levels of parenting stress & depression
- ▶ Family financial burden
- ▶ Relationship between parenting stress and child outcomes
- ▶ Importance of early intervention for both child AND family
- ▶ Few autism interventions exist that address parent/family outcomes



# IMPROVING CHILD & PARENT WELL-BEING THROUGH INTERVENTION RESEARCH

- ▶ Need to build on natural child and parent strengths and address autism-specific challenges
- ▶ Example: adapted empirically supported group-based intervention for parents of young children with autism (ages 2-6): *The Incredible Years* (Dababnah & Parish, 2016; Dababnah et al., 2019)
  - ▶ Significant reductions in parenting stress & improvements in child behavior challenges
  - ▶ Low attrition & high acceptability
  - ▶ Utilization of program supports (childcare, meals, transportation)
- ▶ So what about those parents who did not complete or never joined the program?

# DISENTANGLING POVERTY AND RACE IN TIMELY AUTISM SERVICE ACCESS

- ▶ Poverty and limited education are clear contributors to autism-related diagnostic and service disparities (e.g., Carr et al., 2016).
  - ▶ Important ongoing research to improve access to autism services in low-resource, ethnically and racially diverse communities (e.g., Stahmer & Brookman-Fraze, 2019)
- ▶ While Black caregivers with limited income and/or education are especially vulnerable to delayed diagnoses, racism and other service barriers persist for middle/high-income Black families (Dababnah, Shaia, et al., 2018):
  - ▶ Example quote from college-educated Black mother of child with autism: *“I would get this whole lip service with the doctor, “Well, you can’t do this with Medicaid.” I said, “I don’t even have Medicaid, I have private insurance.”...There are assumptions like...I’m just this person that has multiple kids. This is a Black woman. If you see my three kids, you assume I don’t have a husband.”*

# EXPANDING FOCUS TO OTHER U.S. RACIAL AND ETHNIC GROUPS

- ▶ Emerging information on the experiences of Latinx and Black families in the U.S.
- ▶ Limited literature focused on other ethnic and racial minority families
  - ▶ Studies of Korean-American (Kim & Dababnah, 2019) and Arab-American caregivers (Habayeb, Dababnah, et al., under review) underscore the complexity of “cultural stigma”:
    - ▶ Tension with traditional gender roles
    - ▶ Isolation from family and from ethnic community



# BUILDING COMMUNITY PARTNERSHIPS TO DOCUMENT & ADDRESS DISPARITIES



- ▶ Social Work Community Outreach Service
  - ▶ Work in West Baltimore for 25+ years
  - ▶ Executive Director: Wendy Shaia, EdD
- ▶ Community Advisory Board
  - ▶ Parents of children with autism in Baltimore
  - ▶ Providers from local service agencies
  - ▶ Local public school representatives
  - ▶ Legal advocate

# INCREASING BLACK FAMILIES' INVOLVEMENT IN AUTISM RESEARCH

## ▶ Barriers to research involvement (Shaia, Nichols, Dababnah, et al. 2019):

- ▶ Autism-related embarrassment and shame
- ▶ Distrust of research process
- ▶ Lack of time and/or interest
- ▶ Literacy issues/inaccessible research materials

## ▶ Facilitators to research involvement:

- ▶ Highlighting importance of research inclusive of Black communities
- ▶ Offering information and support for child and family
- ▶ Engaging with research team members from the local community



# TAILORING *PARENTS TAKING ACTION TO* BLACK FAMILIES IN BALTIMORE

- ▶ Developed by Sandy Magaña & collaborators for Latinx families
- ▶ 14-week program for parents of young Black children (ages 2-8 years old) with **or at-risk** for autism
- ▶ Parent Leaders (caregivers of children ages 9+ years old with autism) deliver program
- ▶ Parent Leaders and participating parent agree when and where to meet (e.g., at home on a Saturday)
- ▶ Focus: increasing autism knowledge; improving advocacy skills; building social support; managing child behavior





# CULTURALLY ADAPTING PTA WITH ADVISORS' RECOMMENDATIONS

- ▶ Major changes to *PTA* program manual
  - ▶ Modified first session to begin with a story of an individual with autism in Baltimore
  - ▶ Added photos of Black and African-American children and families
  - ▶ Recorded new video narrations
  - ▶ Included resources on police interactions
  - ▶ Revised manual with Baltimore-specific resources
- ▶ Recruitment approach
  - ▶ Warm hand-off when possible
  - ▶ Wide outreach through service providers, schools, faith communities, childcare centers, and other local organizations
  - ▶ Emphasize signs and symptoms of autism to reduce fear or avoidance of the “a” word in recruitment materials
  - ▶ Dedicate time to explaining purpose of project and research protections in place

# SUMMARIZING INITIAL PROGRAM BARRIERS



- ▶ Two Parent Leaders currently delivering PTA to 4 mothers
- ▶ Major recruitment and program delivery barriers
  - ▶ Life challenges such as homelessness, community violence
  - ▶ Home is not always best place to meet due to partner safety issues and/or child distractions
  - ▶ Two hours per week might be too long due to concentration/distractions due to material/immediate needs, literacy, etc.

# USING GLOBAL AUTISM RESEARCH TO INFORM LOCAL PROGRAMS

- ▶ Can we apply knowledge from research in countries where staff and resources are scarce, delays are common, and populations are hard-to-reach?
- ▶ Example: research with Syrian refugee families raising children with autism in Turkey (Dababnah, Habayeb, Bear & Hussein, 2019)
  - ▶ Engaging community liaisons to tailor intervention and recruitment to local context
  - ▶ Training parents and non-specialist workers to deliver interventions
  - ▶ Measuring dosage needed to achieve positive outcomes
  - ▶ Offering optional modules and different formats (e.g., hybrid: group + one-on-one; virtual) to accommodate diverse needs and schedules
  - ▶ Targeting multiple systems + policies
  - ▶ Incorporating content on both trauma and stigma

# MOVING FORWARD: RESEARCH IMPLICATIONS

- ▶ We cannot address racial and ethnic disparities without more intervention research that is:
  - ▶ Inclusive of families;
  - ▶ Culturally relevant;
  - ▶ Multilevel (e.g., involve schools/teachers, childcare providers, policymakers); and
  - ▶ Multidisciplinary.
- ▶ Community partners should not be an afterthought in research studies. They are essential to reaching the most underserved populations.
- ▶ Community-engaged intervention research takes time, particularly to build trust with an array of community partners; hire and train new staff; and reach those not already connected to services.
- ▶ Autism researchers need measures that are:
  - ▶ focused on child/family strengths and appropriate for diverse cultural groups.
  - ▶ include open-ended questions and other forms of data to provide fuller picture of outcomes of interest.
- ▶ Support for local (city/county/state/region) autism research consortiums could pool resources, reduce redundant services, share knowledge, and increase collaboration.



# Thank you!

For more information or to request publications, please contact:

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- The Duke Endowment
- Organization for Autism Research
- Society for Research in Child Development
- University of Maryland, Baltimore



# THE COLOR OF AUTISM

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CAMILLE PROCTOR



# CHILDREN OF COLOR

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The Autism and Developmental Disabilities Monitoring (ADDM) reports have consistently noted that more white children are identified with ASD than black or Hispanic children. Previous studies have shown that stigma, lack of access to healthcare services due to non-citizenship or low-income, and non-English primary language are potential barriers to identification of children with ASD especially among Hispanic children. A difference in identifying black and Hispanic children with ASD relative to white children means these children may not be getting the services they need to reach their full potential.

# IN THE BEGINNING

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In 2008 at the age of 2 my son Ari was diagnosed with autism spectrum disorder. Knowing a little about what autism, I thought the process of getting services and support would be easy. Unfortunately, that wasn't the case and our journey hit a few bumps along the way.

As I scrambled for resources I quickly learned that there was a disparity in the African American Community. Support groups didn't really understand the complexities of being a person of color and how it would affect every facet of my son's life. I remember attending a support group asking how can I protect my son from police brutality? If he wanders away and is approached by the police, he may not respond properly. What if he never understands what "yield" means? Everyone in the room assured me he would be just fine! Realizing that this group of all white parents didn't understand or even have a clue what people of color experience.



# FOUNDING AN ORGANIZATION

In 2009, I founded The Color of Autism Foundation to raise awareness in the African American Community about Autism Spectrum Disorders. To erase the negative stigma attached to Autism by helping families through the early intervention process and providing support. Our goal is to lessen the isolation associated with raising a child on the autism spectrum.

Creating a circle of care for communities of color that provides them with resources that they can use to become their child's best advocate. We also bring in the community into this circle so they can learn more about autism.



# A NETWORK OF ADVOCATES

In July 2017, organizations and advocates from various communities across the country met in New York and formed NAAACN (National African American Autism Community Network). NAAACN 's Mission is to empower and support African American Families affected by autism. Through our network of community partners, we advocate for increased awareness, screening, and treatment of autism in underserved communities.

Since 2018 NAAACN has hosted a series of townhalls in Detroit, D.C, and Birmingham, AL.





# CONCLUSION

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- Funding needs to be provided to organizations working within underserved communities, so they can create equitable solutions for individuals affected by autism. The days of observing from the outside and assuming what's needed on the inside must end!
- Building a strong infrastructure of support, training, and education within these communities. Structuring for equitable outcomes that close gaps and focus resources among populations and communities most in need. By committing to fair, equitable, and responsible investment of public funds, policymakers can play a significant role in building healthier and more equitable communities.





Addressing Disparities  
for Latino Families  
Grupo SALTO



# A Latino focus within autism: Grupo SALTO

- ▶ In 2003 in an effort to meet the void that many Latino families experienced, Grupo SALTO was co-founded by parents of children with autism (ASD), Dr. Elina R. Manghi (RIP) and the Latino program staff from the UIC Developmental Disabilities Family Clinics (DDFC). Dr. Manghi served as director of DD Family clinics and countless other health and human service agencies such as The Autism Program (TAP).
- ▶ Currently Grupo SALTO is a 501 (c) (3) non-profit organization dedicated to provide support for families who have children with a disability focusing on autism and whose primary language is Spanish. The main purpose of the group is to provide training, information, resources, education, and support for parents and their children.
- ▶ Grupo SALTO has no employees and relies on annual fundraising activities, such as a banquet, donations, grants, and membership fees to sustain its programming.



Grupo SALTO

# Grupo SALTO

## Mission:

- ▶ Provide each family member and their community with a vision of hope in all aspects of life
- ▶ Commit to offer in a culturally competent manner, the most up-to-date available information
- ▶ Offer support services that respond to the needs of families



Grupo SALTO

## A Latino emphasis within autism: Grupo SALTO

- ▶ In 2018, approximately 600 families were registered with GS, making it the largest organization for Latino families mostly with ASD in Illinois, and possibly the United States
- ▶ An average of 50 families attend each monthly session. Additionally, 35-45 children, adolescents, and adults, who participate in artistic programs, social groups for individuals with ASD and their siblings' group. The group also offers child care.
- ▶ Since its inception GS has enjoyed various collaborations and success stories with other organizations and individuals.



Grupo SALTO

# Monthly Educational Sessions



- ▶ Through collaboration with different individuals and organizations parents receive culturally and linguistically appropriate updated training and education on topics of interest. Parents share their own experience in an atmosphere of mutual support and understanding. This in return generates a network of parents with common growth and development as a family.



Grupo SALTO

# Monthly Educational Sessions

- ▶ With volunteer students from the IL Lend program, friends, family members, members of the Latino DD Family Clinics staff, and the support from TAP, every month GS creates a culturally embracing environment for the entire family. Relatives, teachers, and other professionals also learn about ASD education, leadership, how to cope and take care of their own selves, general advocacy, etc.



Grupo SALTO



Since its inception GS has enjoyed various collaborations and success stories with other organizations and individuals

Parents taking action



- ▶ Promotoras de Salud / Parents Taking Action: a research study conducted by Dr. Sandy Magana from the Department of Disability and Human Development at the University of Illinois Chicago first sponsored by TAP (The Autism Program), then by other grants. Is composed by mothers of children with ASD who were trained to mentor other mothers of children with similar conditions. The objective is assisting other parents to create a better system of intervention.



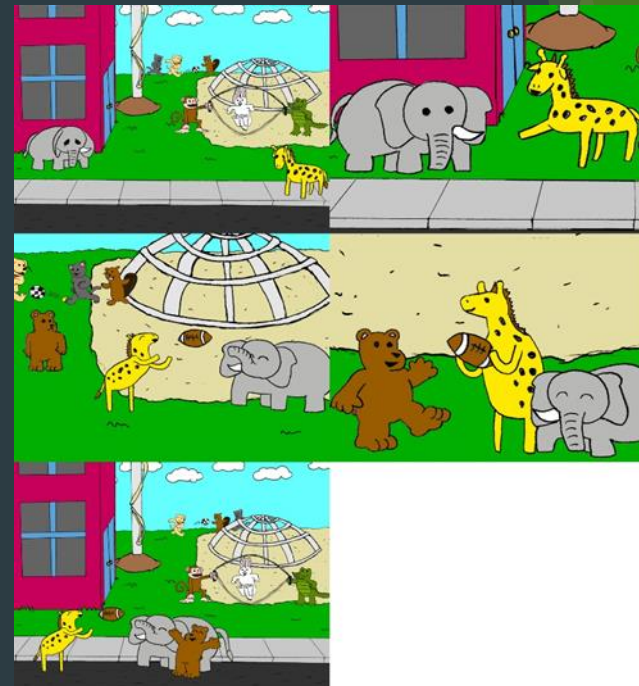
## Tu y Yo Child to Child

- ▶ Tu Y Yo is Grupo Salto's peer mentorship, composed of a group of college/university self-advocate graduates with autism helping adolescents and adults in the Chicagoland area.
- ▶ Tu y Yo (Child to Child international concept) Program was initially implemented thanks to a grant from The Autism Program of Illinois (TAP).
- ▶ Everyone wants to be accepted and virtually every kid has been hurt by bullying. Under the philosophy of 'young kids learn well from big kids', Tu y Yo members learned games and techniques to help children discuss bullying. Tu y Yo learned to conduct a problem-tree analysis as a creative form of identifying a problem, the roots or cause of the problem, and devising a solution to the problem.



# Tu Y Yo Child to Child: Projects

- ▶ “Myths and Facts about Autism” Tu y Yo members present the information that they think is most important to understanding Autism based on their experience at sites that range from Chicago Public Schools, Libraries to community centers such as the YMCA.
- ▶ A storyboard designed to engage elementary school students in discussing visible/invisible differences and bullying.



# My journey with Autism- Virginia Murray

- I was diagnosed with autism in 2005 (age ten).
- Since then, things have improved a lot with therapy (occupational and psychotherapy) and support.
- Although I have a degree and two jobs, I still face many challenges.
- I believe things have been harder for me because I am a women with autism, but I have faith that with education everyone can thrive

# Civic Engagement and Parent Leadership Support Project by Dr. Meghan Burke

## Leadership skills learned as shared by parents:

"I learned the importance of educating myself. Because I didn't know how to help my children in their education. I also learned how to negotiate and to confidently ask the school for services ... to have confidence in me, that the responsibility is mine and I have the mission to find and seek the best education for my children. Thank you for everything. "

"I learned the great power of being informed to make the most appropriate decisions in the education of our children"

"I learned to understand and comprehend what to do when I attend an IEP meeting and what rights my child has as a student and I as a parent to request appropriate services."



Grupo SALTO

# Latino Parents Participating in Retreats



Grupo La Esperanza

- ▶ With the support from DD Family Clinics Latino staff, parents of GS attend an all day retreat called *La Esperanza: Creciendo y Mirando Hacia Adelante* (Growing and Looking Forward with Hope).
- ▶ The group has provided new opportunities to learn more about ASD and self-care. The open-question environment included activities to facilitate sharing individual experiences.



Grupo SALTO

# Advocacy

Illinois did not have a budget for more than two years. The administration proposed more than once to cut state spending on universities, health care, human services, local government allocations and pensions for state employees. Grupo SALTO traveled to the state capital advocating for the services to be retained or restored.

April 2 2015: Tu Yo Yo members attended a press conference to support The Autism Program of Illinois (TAP) . TAP is the autism network in th state, supporting services for individuals with ASD. TAP provided a grant for Grupo Salto to launch the Tu Y Yo program. ABC Chicago News anchorman Ravi Baichwal included Tu Y Yo members in his prime-time segment about TAP.



Grupo SALTO



# ART, CRAFT, MUSIC and Mentoring Programs



July Picnic



December Family Party



Grupo SALTO

# I'm not sick, I just have a condition. I'm different functioning

- ▶ Myth - People with ASD prefer to be alone. Many people think people with ASD are just quiet, alone, and weird.
- ▶ Reality. - People with ASD have a hard time socializing. They have a hard time to talking and interacting at school, home, or any other place because they get so nervous and scared.
- ▶ Why? The reason why they prefer to be alone is because when they meet new people, they often get nervous or bullied by others.

Tu Y Yo's Dream Libraries Presentation

<https://www.youtube.com/watch?v=7XLgrMFyVc8&list=PLnTMLC7x8kJnltpLgANH2EYhgHXk8-EHu&index=16&t=0s>

# Conclusion

- ▶ With the help of parents, volunteers, DDFC/TAP (The Autism Program) staff, and IL LEND trainees, Grupo SALTO can move forward with its mission. The organization creates opportunities for parents of children with ASD in leadership trainings and ASD education, as well as opportunities for young adults with ASD to have a voice of their own.
- ▶ As Grupo SALTO grows, it will continue to lessen the void felt by many families in the Latino community upon learning someone in their family has ASD.
- ▶ Creating a culturally embracing environment with volunteers that care about providing much needed services is what Grupo Salto is all about.
- ▶ <http://gruposalto.org/docs/Lend-Brief-Winter-2015.pdf>

# Matie Ovalle

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# Jose L. Ovalle

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The Autism Program of Illinois

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# Yetta Myrick

Invited Public Comment  
President and Founder, DC Autism Parents  
CDC's Act Early Ambassador to the District of Columbia





# Discussion





**Break**

# Meeting of the IACC



## Afternoon Agenda

**4:00**

**Department of Labor Apprenticeship Initiative**

**Scott Robertson, Ph.D.**

Office of Disability Employment Policy

U.S. Department of Labor

**4:15**

**Summary of Advances Discussion**

**Susan Daniels, Ph.D.**

Director, Office of Autism Research Coordination, NIMH and  
Executive Secretary, IACC

**Joshua Gordon, M.D., Ph.D.**

Director, NIMH and Chair, IACC

**4:35**

**Round Robin**

**5:00**

**Closing Remarks and Adjournment**



# Expanding Inclusive Apprenticeship and Access for People on the Autism Spectrum: Apprenticeship Inclusion Models initiative

Interagency Autism Coordinating Committee  
July 24, 2019 Public Meeting | Rockville, MD

Scott Michael Robertson, PhD  
Policy Advisor,  
Employment-Related Supports Team

Carolyn Jones, MBA  
Senior Policy Advisor,  
Youth Team

Office of Disability Employment Policy (ODEP)  
U.S. Department of Labor (DOL)



# Outlining the Presentation

- ODEP's mission and vision
- Define Apprenticeship
- Apprenticeship Inclusion Models (AIM) initiative
- ODEP Resources and Initiatives



# ODEP Seeks to Increase Employment Access for Americans with Disabilities

Only non-regulatory federal agency that promotes policies and coordinates with employers and all levels of government to increase workplace success for people with disabilities

- **Mission:** Develop and influence policies that increase the number and quality of employment opportunities for people with disabilities
- **Vision:** A world in which people with disabilities have unlimited employment opportunities

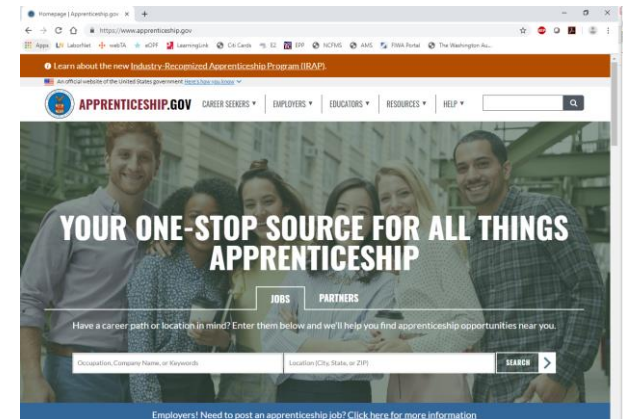


# Apprenticeship Means...

- Core facets of apprenticeship:
  - Advance the model of “earn while you learn” for work-based learning and job training
  - Combine on-the-job training with related instruction (not an internship)
  - Driven by employers and related organizations
- Find apprenticeship opportunities:

[www.apprenticeship.gov](http://www.apprenticeship.gov)

Local apprenticeship program  
finder (occupation + zip code)



Apprenticeship.gov

Driving Change ★ Creating Opportunity





# Apprenticeship Inclusion Models (AIM) Initiative Launched in FY2019

**Focus:** Expanding inclusive apprenticeship and piloting integrated apprentice/pre-apprenticeship training

**Context:** \$2 million, 2-year initiative of ODEP

- Alignment with the President's 2017 Executive Order
- Pilot (demonstration) project to enhance policy/practices for inclusive apprenticeship
- Run by SPR, Jobs for the Future (JFF), and Wheelhouse Group (in association with ODEP)

**AIM Website:** <http://www.spra.com/aim>



# AIM Initiative Integrates This Approach

- Research, test, and evaluate innovative pilot models
- Expand inclusive apprenticeship access for working-age youth and adults with disabilities
- Target high-growth, in-demand industries/sectors:
  - Information technology (IT)
  - Healthcare
  - Advanced manufacturing
- Foster connectivity to supportive services and accessible technology



# AIM Initiative Announced 4 Pilot Sites

- 4 AIM Pilot Sites:
  - Microsoft
  - Amazon
  - Healthcare Career Advancement Program (H-CAP)
  - Industrial Manufacturing Technician Apprenticeship program (IMT)
- Sign up for the Community of Practice (CoP) at:  
[https://docs.google.com/forms/d/1O8VA2YF8Dz2\\_2y05P7Qpr1jifas6N5yUdK\\_JgoZh06s/viewform?edit\\_requested=true](https://docs.google.com/forms/d/1O8VA2YF8Dz2_2y05P7Qpr1jifas6N5yUdK_JgoZh06s/viewform?edit_requested=true)



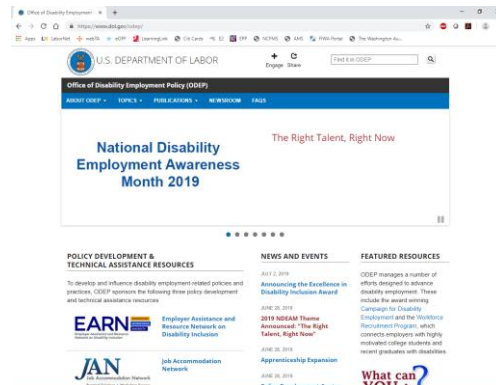
## 2 AIM Pilot Sites Include Autism Focuses

- Microsoft's AIM pilot site:
  - Intermediary: Apprenti ([apprenticareers.org](http://apprenticareers.org))
  - Building a connection to the Autism Hiring Program at MS
  - Focus: apprenticeships for software developers and other information technology positions
- H-CAP's AIM pilot site:
  - DOL's intermediary organization for Registered Apprenticeship programs in healthcare ([hcapinc.org](http://hcapinc.org))
  - Focus: apprenticeships for medical coders, community health workers, and central sterile processing technicians



# ODEP's Resources and Initiatives Include...

- Technical Assistance Centers:
  - EARN (employer engagement): [askearn.org](http://askearn.org)
  - Job Accommodation Network (JAN): [askjan.org](http://askjan.org)
  - Partnership on Employment & Accessible Technology (PEAT): [peatworks.org](http://peatworks.org)
- Initiative Websites:
  - Apprenticeship Inclusion Models initiative: [spra.com/aim](http://spra.com/aim)
  - Workforce Recruitment Program: [wrp.gov](http://wrp.gov)



ODEP's website



# Contact ODEP to request info or share your questions

- ODEP's website: <http://www.dol.gov/odep>
- ODEP's main email: [odep@dol.gov](mailto:odep@dol.gov)
- ODEP's main phone #: 866-ODEP-DOL
  
- ODEP's Topic Resource Webpage on Autism: <https://www.dol.gov/odep/topics/Autism.htm>





# 2019 Summary of Advances Discussion



**Joshua A. Gordon, M.D., Ph.D.**  
Director, National Institute of Mental Health  
Chair, IACC

**Susan A. Daniels, Ph.D.**  
Director, Office of Autism Research Coordination  
Executive Secretary, IACC  
National Institute of Mental Health

# 2019 Summary of Advances Procedure



- Current IACC members may continue to nominate articles by email through September 30, 2019.
- Once a new IACC is convened, new members will also have an opportunity to nominate any articles published in 2019.
- All nominations will be considered by the new IACC members and they will make the final selection of articles for inclusion in the *2019 IACC Summary of Advances*.

# 2019 Summary of Advances Nominations April – July 2019



**Joshua A. Gordon, M.D., Ph.D.**  
Director, National Institute of Mental Health  
Chair, IACC

# Question 1: Screening and Diagnosis



**JAMA** Pediatrics

Apr 2019

**Evaluation of the Diagnostic Stability of the Early Autism Spectrum Disorder Phenotype in the General Population Starting at 12 Months.**

Pierce K, Gazestani VH, Bacon E, Barnes CC, Cha D, Nalabolu S, Lopez L, Moore A, Pence-Stophaeros S, Courchesne E.

# Question 2: Underlying Biology



nature  
neuroscience

Jun 2019

## **Loss of nuclear UBE3A causes electrophysiological and behavioral deficits in mice and is associated with Angelman syndrome.**

Avagliano Trezza R, Sonzogni M, Bossuyt SNV, Zampeta FI, Punt AM, van den Berg M, Rotaru DC, Koene LMC, Munshi ST, Stedehouder J, Kros JM, Williams M, Heussler H, de Vrij FMS, Mientjes EJ, van Woerden GM, Kushner SA, Distel B, Elgersma Y.

JNeurosci  
THE JOURNAL OF NEUROSCIENCE

Jul 2019

## **Deletion of Autism Risk Gene Shank3 Disrupts Prefrontal Connectivity.**

Pagani M, Bertero A, Liska A, Galbusera A, Sabbioni M, Barsotti N, Colenbier N, Marinazzo D, Scattoni ML, Pasqualetti M, Gozzi A.

# Question 2: Underlying Biology



**Cell**

May 2019

## **Human Gut Microbiota from Autism Spectrum Disorder Promote Behavioral Symptoms in Mice.**

Sharon G, Cruz NJ, Kang DW, Gandal MJ, Wang B, Kim YM, Zink EM, Casey CP, Taylor BC, Lane CJ, Bramer LM, Isern NG, Hoyt DW, Noecker C, Sweredoski MJ, Moradian A, Borenstein E, Jansson JK, Knight R, Metz TO, Lois C, Geschwind DH, Krajmalnik-Brown R, Mazmanian SK.

**Science**  
AAAS

May 2019

## **Single-cell genomics identifies cell type-specific molecular changes in autism.**

Velmeshev D, Schirmer L, Jung D, Haeussler M, Perez Y, Mayer S, Bhaduri A, Goyal N, Rowitch DH, Kriegstein AR.



# Question 3: Risk Factors



## JAMA Psychiatry

Jul 2019

### **Association of Genetic and Environmental Factors With Autism in a 5-Country Cohort.**

Bai D, Yip BHK, Windham GC, Sourander A, Francis R, Yoffe R, Glasson E, Mahjani B, Suominen A, Leonard H, Gissler M, Buxbaum JD, Wong K, Schendel D, Kodesh A, Breshnahan M, Levine SZ, Parner ET, Hansen SN, Hultman C, Reichenberg A, Sandin S.

# Question 3: Risk Factors



nature  
genetics

Mar 2019

## **Identification of common genetic risk variants for autism spectrum disorder.**

Grove J, Ripke S, Als TD, Mattheisen M, Walters RK, Won H, Pallesen J, Agerbo E, Andreassen OA, Anney R, Awashti S, Belliveau R, Bettella F, Buxbaum JD, Bybjerg-Grauholm J, Bækvad-Hansen M, Cerrato F, Chambert K, Christensen JH, Churchhouse C, Dellenvall K, Demontis D, De Rubeis S, Devlin B, Djurovic S, Dumont AL, Goldstein JL, Hansen CS, Hauberg ME, Hollegaard MV, Hope S, Howrigan DP, Huang H, Hultman CM, Klei L, Maller J, Martin J, Martin AR, Moran JL, Nyegaard M, Nærland T, Palmer DS, Palotie A, Pedersen CB, Pedersen MG, dPoterba T, Poulsen JB, Pourcain BS, Qvist P, Rehnström K, Reichenberg A, Reichert J, Robinson EB, Roeder K, Roussos P, Saemundsen E, Sandin S, Satterstrom FK, Davey Smith G, Stefansson H, Steinberg S, Stevens CR, Sullivan PF, Turley P, Walters GB, Xu X; Autism Spectrum Disorder Working Group of the Psychiatric Genomics Consortium; BUPGEN; Major Depressive Disorder Working Group of the Psychiatric Genomics Consortium; 23andMe Research Team, Stefansson K, Geschwind DH, Nordentoft M, Hougaard DM, Werge T, Mors O, Mortensen PB, Neale BM, Daly MJ, Børglum AD.

# Question 4: Treatments and Interventions



The Journal of Child  
Psychology and Psychiatry

Jun 2019

**Effectiveness of community-based early intervention for children with autism spectrum disorder: a meta-analysis.**

Nahmias AS, Pellecchia M, Stahmer AC, Mandell DS.

*Journal of Autism  
and Developmental Disorders*

Feb 2019

**Disseminating Information on Evidence-Based Practices for Children and Youth with Autism Spectrum Disorder: AFIRM.**

Sam AM, Cox AW, Savage MN, Waters V, Odom SL.

# Question 5: Services



**PEDIATRICS**  
OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

Jun 2019

**State Mandate Laws for Autism Coverage and High-Deductible Health Plans.**  
Barry CL, Kennedy-Hendricks A, Mandell D, Epstein AJ, Candon M, Eisenberg M.

**JAMA Psychiatry**

Mar 2019

**Effectiveness of Training Therapists to Deliver An Individualized Mental Health Intervention for Children With ASD in Publicly Funded Mental Health Services: A Cluster Randomized Clinical Trial.**  
Brookman-Frazee L, Roesch S, Chlebowski C, Baker-Ericzen M, Ganger W.

# Question 5: Services



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**HSR** HEALTH SERVICES RESEARCH  
*Impacting Health Practice and Policy Through  
State-of-the-Art Research and Thinking*

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Aug 2019

**The effect of Medicaid waivers on ameliorating racial/ethnic disparities among children with autism.**

LaClair M, Mandell DS, Dick AW, Iskandarani K, Stein BD, Leslie DL.

# Question 6: Lifespan Issues



AUTISM  
RESEARCH January, 2017 | Volume 10 | Number 1

Apr 2019

## **Loss in Services Precedes High School Exit for Teens with Autism Spectrum Disorder: A Longitudinal Study.**

Laxman DJ, Taylor JL, DaWalt LS, Greenberg JS, Mailick MR.



# Question 7: Infrastructure and Surveillance



Mar 2019

Russell G, Mandy W, Elliott D, White R, Pittwood T, Ford T. **Selection bias on intellectual ability in autism research: a cross-sectional review and meta-analysis.**

# Round Robin





## Help us improve autism research for the entire community by participating in the Autism EXPECT Study!

The Autism EXPECT Study is an online survey coordinated by the Autism Science Foundation in partnership with the University of Pennsylvania. We want to hear from autism families and autistic adults about what influences them to participate in clinical research.

You will be asked questions about why you have or haven't participated in research and about what might make your next research experience better.

This survey takes 30 minutes to complete. Participation is completely voluntary.  
All participants will be entered for the chance to **WIN an iPad.**



We will use our findings to inform scientists about steps they can take to improve the research experience for members of the autism community.

Please take the survey at:  
**[bit.ly/EXPECTsurvey](http://bit.ly/EXPECTsurvey)**

Have questions? Contact us:  
[AutismExpectStudy@gmail.com](mailto:AutismExpectStudy@gmail.com)





# **Closing Remarks & Adjournment**