

# Welcome to the 2024 Autism CARES Virtual Series

*Strengthening the MCH Workforce and System of Care: Using Innovative Methods to Measure and  
Demonstrate Program Impact*



Monday, July 29<sup>th</sup>





**Jackie Czyzia, MPH**

Director, MCH Engagement

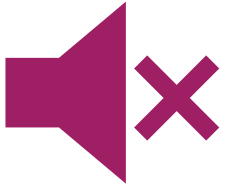
Association of University Centers on  
Disabilities (AUCD)



# Interdisciplinary Technical Assistance Center (ITAC) on Autism and Developmental Disabilities



# Housekeeping Items



- Ensure your name is displayed correctly in the participant list. You may also include program/org and preferred pronouns, if desired
  - Example: Jackie Czyzia (she/her), AUCD
  - Hover over your name in the “Participants” box and select “More” → “Rename”
- Please keep yourself on mute when not speaking
- State your name prior to speaking
- Captioning is available
- If you need tech or accommodation support, please email [itac@aucd.org](mailto:itac@aucd.org)
- Introduce yourself in the chat (name, program, role)



# *Westat Presents: Autism CARES Evaluation Update*

**Carla Bozzolo**, Project Director, Westat

**Elizabeth Taylor**, Deputy Project Director, Westat





# Autism CARES Evaluation FY22 Project Updates

**2024 Autism CARES Virtual Meeting Series**

July 29, 2024



- 
- Evaluation Objectives
  - Evaluation Timeline
  - Data Sources
  - Preliminary Findings by Program Area
  - Summary and Evaluation Next Steps

# Evaluation Domains

## Research

interdisciplinary, empirical, and applied research on effective interventions and guidelines

## Awareness

the dissemination of information related to effective interventions, guidelines, supports, access, and addressing wellbeing across the lifespan

## Systems of Care

increased access to coordinated and integrated care and the development of statewide systems of care and innovation

## Equity

including populations that have been historically underserved or marginalized in program activities

## Transition/Lifespan

improving transition to adulthood across various systems and improve care across the lifespan

## Resource Centers

providing technical assistance and support to Training and State Systems awardees

## Covid-19

identifying changes made by CARES programs because of COVID-19 that affect systems of care

# Evaluation Timeline

**FY21**

- Secondary data analysis only
- FY21 Annual Report
- Data Placemats

**FY22**

- Primary data analysis
- Secondary data analysis
- FY21 Annual Report
- Data Placemats

**FY23**

- Secondary data analysis
- FY21 Annual Report
- Data Placemats
- Bibliometric Analysis
- Cumulative 3-year report

**Calendar Year  
2023**

**Calendar Year  
2024**

**Calendar Year  
2025**



# Data Sources by Program Area

Primary data includes FY21 and FY22, and secondary data covers FY22.

Data Sources	Research	Training	ITAC	State Systems	SPHARC
<b>DGIS</b>	<b>X</b>	<b>X</b>	<b>X</b>	<b>X</b>	<b>X</b>
<b>NIRS</b>		<b>X</b>			
<b>Progress Reports</b>	<b>X</b>	<b>X</b>	<b>X</b>	<b>X</b>	<b>X</b>
<b>Survey</b>	<b>X</b>			<b>X</b>	
<b>Interviews</b>	<b>X</b>	<b>X</b>	<b>X</b>	<b>X</b>	<b>X</b>



# **Preliminary Findings from FY22 Data Collection:**

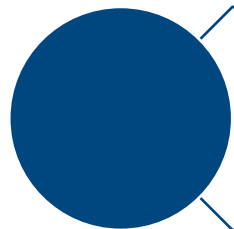
## Training Programs

## Findings include data from:

- 60 LEND programs
- 11 DBP programs
- The Interdisciplinary Technical Assistance Resource Center (ITAC)



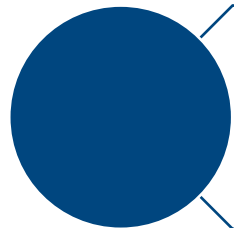
# Training Programs: Research Activities



## Trainee Involvement



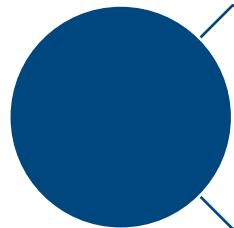
Trainees participate in scholarly activity including research, leadership, or capstone projects, and QI initiatives.



## Research Conducted



Faculty conduct a wide array of research in which fellows and trainees can participate. Example topics include screening and diagnosis, community inclusion of individuals with autism and DD, and transition to adulthood.

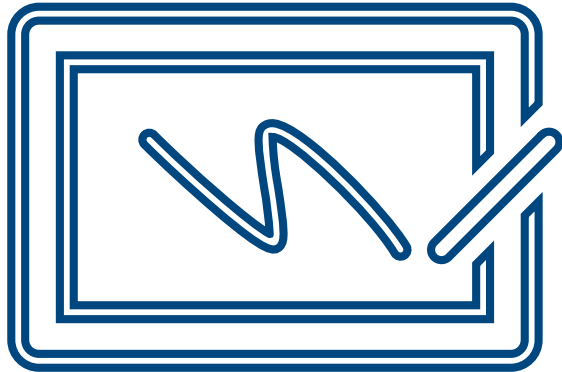


## Dissemination of Research Products



Programs present findings in journals, at conferences, or within resources provided to the community (e.g., infographic) DGIS data show that LEND programs had **1,997** and DBP programs had **271** publications in press or published in FY22.

# Training Programs: Awareness



**LEND programs developed 5,919 total products and DBP developed 630 as part of their awareness activities.**

## **Programs' awareness activities include:**

- Promoting and raising awareness within their university and/or hospital
- Developing and disseminating community-based products.
- Providing training opportunities
- Initiating community-based, sensory-friendly initiatives
- Educating policymakers

# Training Programs: Systems of Care

Findings discuss the system of care as it relates to changes in access, gaps in care, innovative solutions to address challenges, key collaborations and partnerships, and continuing education/technical assistance initiatives.

<p>Changes in access included <b>increased waitlists, workforce shortage, and increased use of telehealth</b></p>	<p>Gaps in care were attributed to <b>workforce shortage and access to general health care services</b></p>	<p>Innovative solutions included <b>examining clinical models, providing training to primary care providers, and providing caregiver training</b></p>	<p>Collaboration activities with Title V agencies: <b>2,934</b> LEND and <b>249</b> DBP Training</p> <p>Other MCH related programs: <b>2,800</b> LEND and <b>203</b> DBP Training</p>	<p>LEND conducted <b>3,940</b> CE events across <b>382,203</b> participants. DBP Training conducted <b>529</b> events across <b>39,046</b> participants.</p> <p>LEND provided <b>3,781</b> TA/collaboration activities to <b>95,858</b> participants. DBP Training provided <b>275</b> activities to <b>15,975</b> participants</p>
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# Training Programs: Equity

## Programs supported and promoted DEIA through training curricula, recruitment, and providing service to historically underserved populations.

- Programs infused DEIA and equity concepts into their curriculum.
- Programs discussed strategies to recruit diverse trainees (e.g., racial/ethnicity, family, self-advocate) including hiring diverse staff and developing pathways with HBCUs and MSI.
- Programs experienced challenges with recruiting diverse trainees and faculty including university hiring processes and state level policies.
- Training programs used innovative strategies and provided services to historically underserved areas to reduce disparities.
- **3,708** LEND and **342** DBP training faculty and fellows provided care in historically underserved areas in FY22.

	LEND LTTs (1,647)	LEND Faculty (1,084)	DBP Training LTTs (59)	DBP Training Faculty (169)
<b>American Indian or Alaska Native</b>	<b>10</b> (0.6%)	<b>7</b> (0.6%)	<b>0</b>	<b>1</b> (0.6%)
<b>Asian</b>	<b>174</b> (10.6%)	<b>56</b> (5.2%)	<b>14</b> (23.7%)	<b>26</b> (15.4%)
<b>Black or African American</b>	<b>194</b> (11.8%)	<b>73</b> (6.7%)	<b>2</b> (3.4%)	<b>2</b> (1.2%)
<b>Native Hawaiian or Pacific Islander</b>	<b>2</b> (0.1%)	N/A	<b>0</b>	N/A
<b>More than 1 race</b>	<b>71</b> (4.3%)	<b>21</b> (1.9%)	<b>4</b> (6.8%)	<b>2</b> (1.2%)
<b>White</b>	<b>1,106</b> (67.2%)	<b>875</b> (80.7%)	<b>34</b> (57.6%)	<b>113</b> (66.9%)
<b>Unrecorded race</b>	<b>90</b> (5.5%)	<b>52</b> (4.8%)	<b>5</b> (8.5%)	<b>25</b> (14.8%)

# Training Programs: Transition and Lifespan

**73.3%** of LEND programs included long-term trainees with lived experience. The lived experience was incorporated and improved trainee and faculty understanding of transition and lifespan in the following ways:

- Deeper and more authentic insights
- First-hand experience of transition
- Practical training on transition/lifespan
- Improved transition/lifespan curricula
- Provided mentorship and guidance

There were **998,076** total youth-to-adult transition activities for LEND and **19,386** total for DBP Training. Examples included:

- Addressing transition topics in their curricula
- Experience in transition clinics
- Engaging with community organizations and advocacy groups
- Develop statewide initiatives (e.g., virtual workshops, state-wide summits)



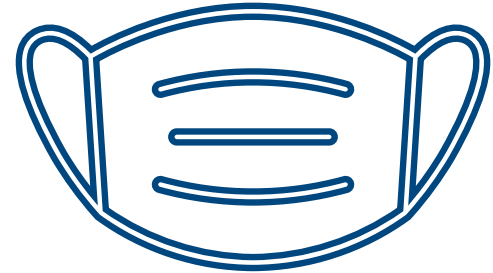
# Training Programs: Covid-19 Impacts

## **COVID-19 required changes in programming including:**

- Offering program curriculum in an online, interactive format
- Implementing telehealth initiatives to provide services to patients and continue clinical training

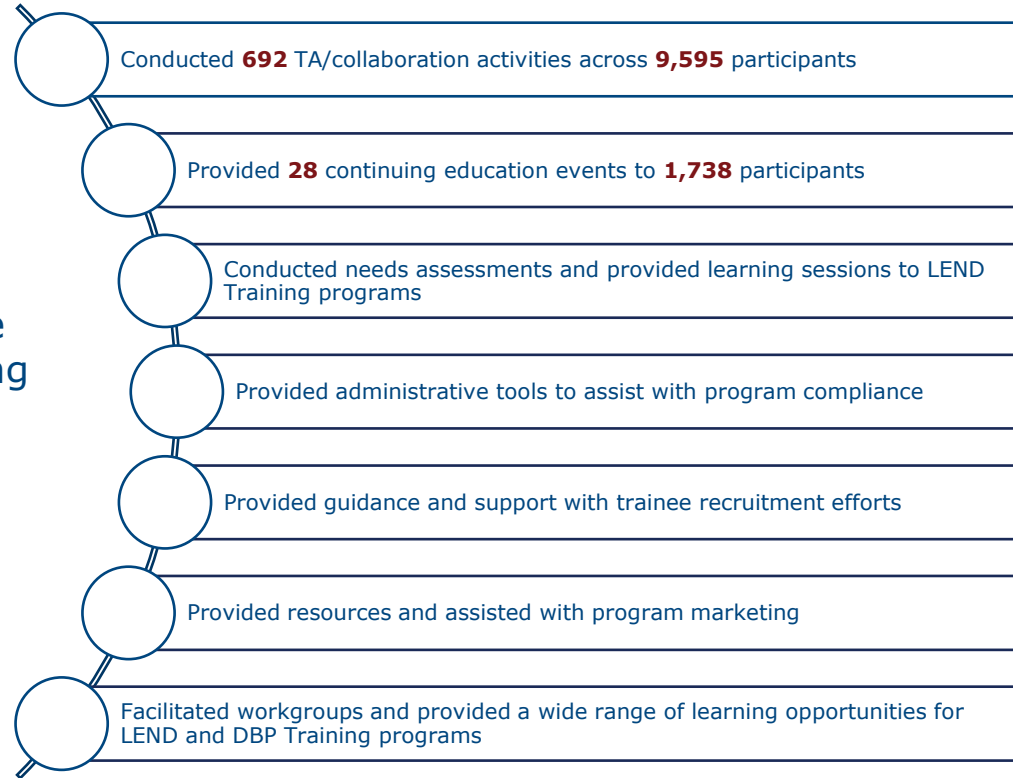
## **COVID-19 also resulted in both positive and negative effects:**

- Telehealth increased access to care and is more widely accepted
- Forced more meaningful collaborations across states
- Allowed for more trainees to participate due to virtual formats
- Lack of in-person training negatively impacted cohort camaraderie and ability to learn from each other
- Lack of access to services and loss of time in school for children



# Training Programs: ITAC Resource Center

ITAC's project scope is national, and they provide service to a wide range of geographic areas including urban, suburban, rural, frontier, and metro areas. ITAC provided support in the following ways.





# **Preliminary Findings from FY22 Data Collection:**

## State Systems

# State Systems Awardees

## Findings include data from the following 5 State Systems Awardees:

- University of Iowa
- University of North Carolina
- University of Virginia
- University of Wisconsin
- Vanderbilt University



# State Systems: Awareness

Awardees used the following methods to increase awareness of autism and DD:

## Partnerships

Engaged **458** community/local partners and **517** state and national partners

## Training

Engaged **3,064** providers and **10,633** families through training

## Dissemination

Disseminated *CDC's Learn the Signs. Act Early.* materials to their provider partners for developmental monitoring and tracking

# State Systems: Systems of Care

## Family Navigation



### The following data highlights advances in family navigation services from 2019 – 2023:

- There was more than a 100 percent increase in children enrolled in family navigation services
- The number of children receiving family navigator services increased from **1,277** children in 2019 to **4,207** children in 2023
- The number of families reporting self-efficacy in navigating the system of care for autism/DD increased from **1,159** families in 2019 to **2,302** families in 2023

# State Systems: Systems of Care

## Family Navigation

Providers increased their screening and referral rates and self-efficacy around the process by participating in training the awardees provided.

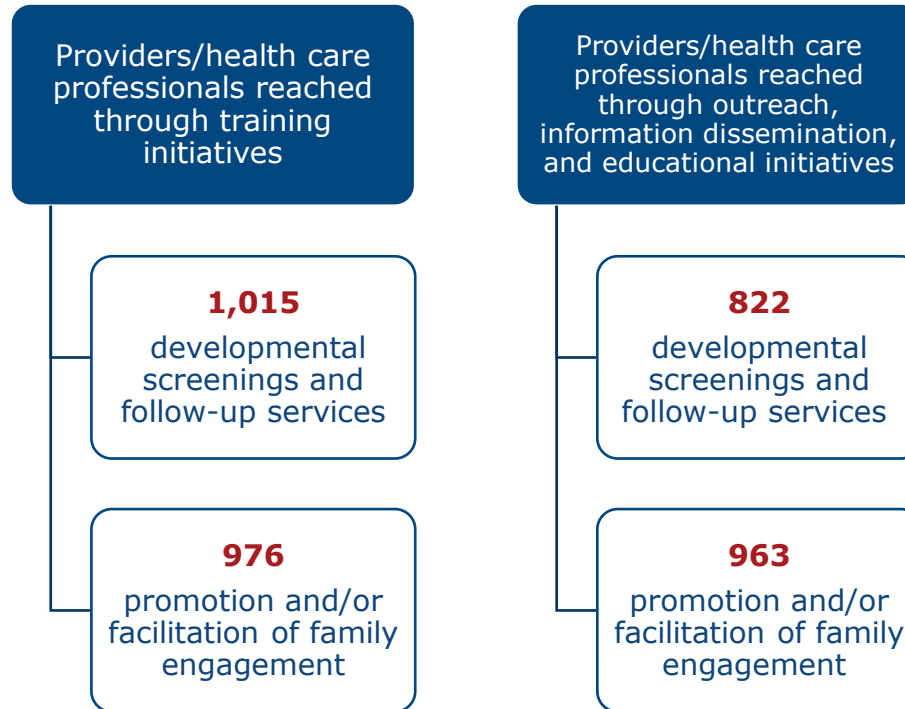
Number of children receiving simultaneous provider referrals, developmental screenings, and early intervention services increased from **489** children in 2019 to **1,164** children in 2023

Number of children enrolled in community-based services and supports before age 3 increased from **67** in 2019 to **1,002** in 2023

Number of primary care, specialty, and community-based providers implementing care coordination increased from **26** in 2019 to **331** in 2023

# State Systems: Systems of Care Provider Education

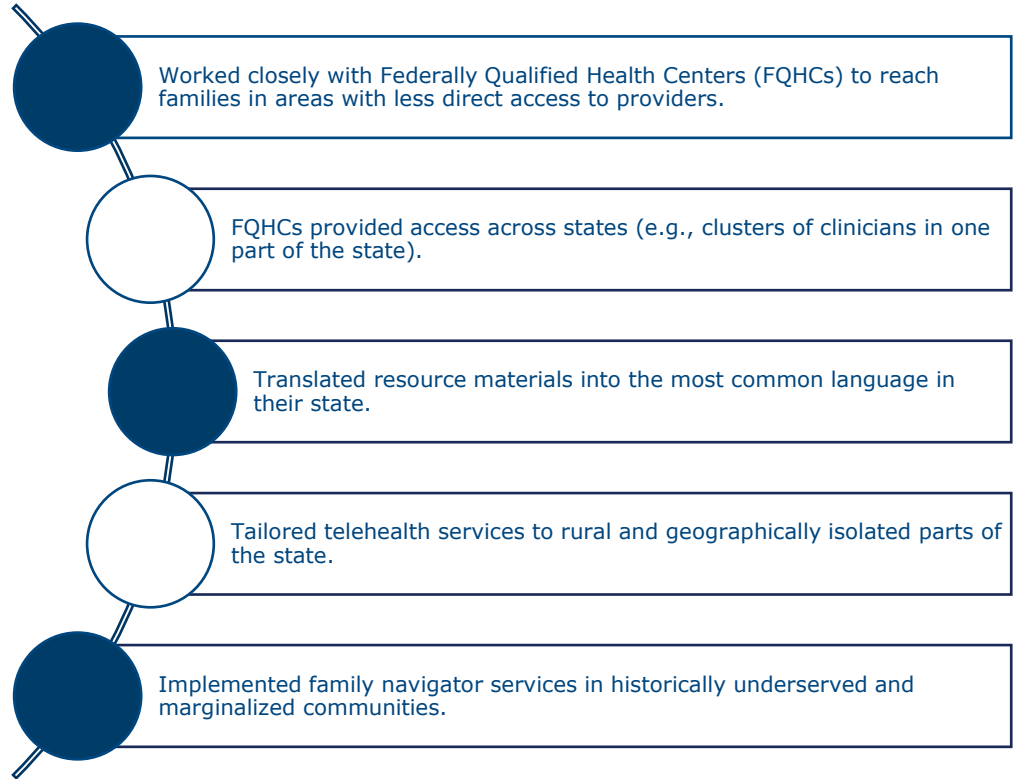
State Systems awardees continued with provider education by shifting to virtual training at the start of the COVID-19 pandemic





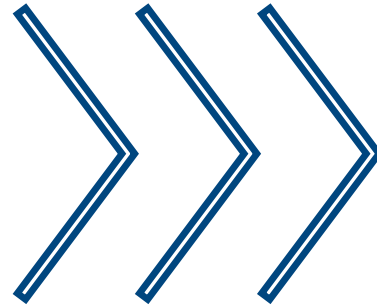
# State Systems: Health Equity

To address health equity and reach historically underserved and marginalized populations, State Systems awardees did the following—



# State Systems: Transition and Lifespan

- Many of the State Systems awardees focused on the early childhood period up to age 5 and thus did not engage in work related to transition.
- One State focused on transition, but through their Title V block grant rather than State Systems funding.



# State Systems: COVID-19



- COVID-19 affected almost all aspects of the State Systems programs. All awardee interventions had to immediately become remote and virtual.
- The emergence and acceptance of telemedicine is a positive result of COVID-19.



# **Preliminary Findings from FY22 Data Collection:**

Research Awardees

# Research Awardees

## 2 Single Investigator Innovation Program (SIIP)

- Autism Transitions Research Project (ATRP)
- Autism Longitudinal Data Project (ALDP)

## 2 Autism Field-Initiated Innovative Research Studies (FIRST)

15 research awards comprised—



76  
research sites



105  
studies

## 4 Research Networks

- Autism Intervention Research Network on Physical Health (AIR-P)
- Autism Intervention Research Network on Behavioral Health (AIR-B)
- Healthy Weight Research Network (HWRN)
- Developmental-Behavioral Pediatrics Research Network (DBPNet)

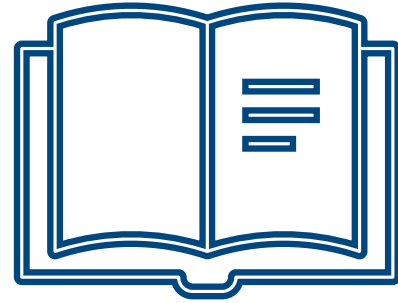
## 7 Secondary Data Analysis Research Program (SDAR)

# Research Awards: Research Activities

## Effective Interventions and Guidelines

**Research programs published 140 peer-reviewed articles on effective interventions and guidelines on topic areas such as:**

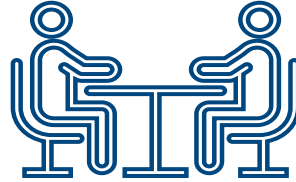
- Addressing needle anxiety
- Influence of national guidelines for managing childhood obesity
- Effectiveness of in-person versus remote autism interventions
- Using artificial intelligence to develop a risk assessment model for early autism prediction



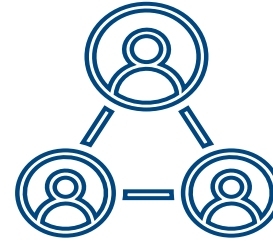
# Research Awards: Equity Including Underrepresented Populations in Research



Recruiting from Title I schools and providing adequate resources to participate in research (e.g., transit funds and meeting locally)



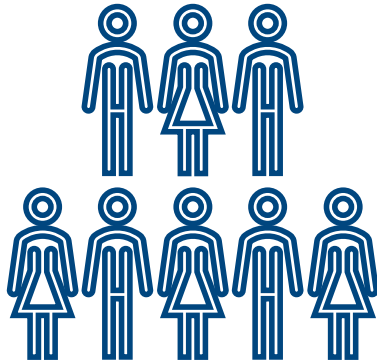
Community partnerships to advance services that support transition age youth in underrepresented populations



Engaging providers in rural areas and Tribal nations

# Research Awards: Research Activities Disparities and Co-Occurring Conditions

## Programs conducted research on disparities and co-occurring conditions across the autism/DD population in areas related to:

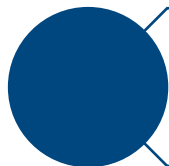


- Life expectancy for individuals with autism
- Obesity among children by race, ethnicity, gender, and sex
- Physical and mental healthcare
  - Among individuals with autism
  - Race and ethnicity within the foster system
- Females with autism
- Gender identity and gender assigned at birth
- Preventable co-occurring conditions among Black youth with autism

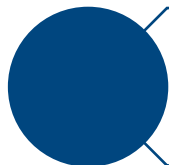


# Research Awards: Research Activities

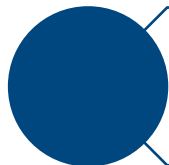
## Lived Experience



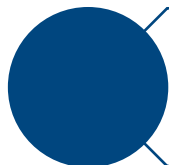
Using PhotoVoice to assess developmental-behavioral health care experiences of individuals with autism



Expanding engagement of researchers with autism

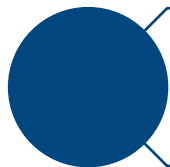


Providing services to families waiting for an autism evaluation or intervention – collecting feedback during the process

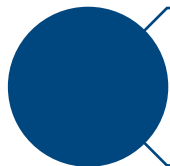


Conducting focus groups with individuals and their families to hear perspectives on peer support

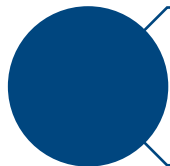
# Research Awards: Research Activities Addressing Data Gaps



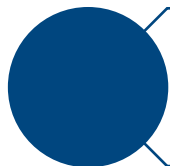
Developing infrastructure to decrease barriers to data access  
(Infrastructure for Collaborative Research)



Understanding youth-to-adult transition



Gender diversity and autism

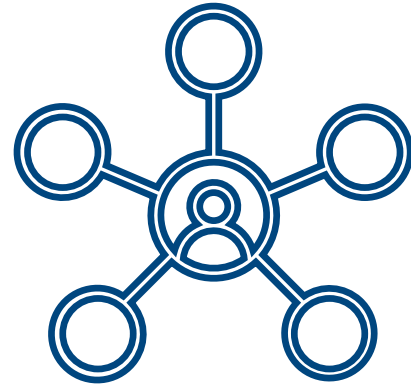


Health disparities among children with an existing autism  
diagnosis

# Research Awards: Awareness

**Awardees developed and disseminated 249 products in FY21 and FY22. In addition to peer reviewed publications, awardees disseminated research via other methods, examples include:**

- Conference presentations
- Web-based products
- Newsletters
- Audio/video products



# Research Awards: Equity Challenges Addressing Equity in Research

- Overcoming distrust in research institutions
- Slow progress diversifying a majority-white research field
- Limited categories for secondary data variables
- Engaging indigenous communities
- Engaging families who speak a language other than English
- Incorporating lived experience

# Research Awards: Transition and Lifespan

## Transition and lifespan issues were a focus of some CARES studies in the following ways:

- Behavioral health across educational transitions
- Big data studies on the transition to adulthood
- Expanding transition-related services in historically underserved and marginalized communities





# Summary and Next Steps

Summer 2024

# Next Steps

Year Two	Year Three
<p data-bbox="388 410 929 536">Synthesizing FY22 secondary data with surveys and interviews</p> <p data-bbox="388 590 765 628">FY22 Annual Report</p> <p data-bbox="388 683 871 809">Data Placemats for LEND, DBP, State Systems, and Research</p>	<p data-bbox="981 410 1460 492">Continue secondary data analyses using FY23 data</p> <p data-bbox="981 547 1460 628">Cumulative 3-year report (FY21-FY23)</p> <p data-bbox="981 683 1277 721">Data Placemats</p> <p data-bbox="981 770 1373 809">Bibliometric Analysis</p>

For questions contact:

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**Elizabeth Taylor**, Deputy Project Director –  
[ElizabethTaylor@westat.com](mailto:ElizabethTaylor@westat.com)





# Questions?





# Thank You!

- The recording, resources, and slides will be sent to grantees August 1, 2024.
- We will see you in-person next Summer! If interested in joining the 2025 Autism CARES planning committee, email [jczyzia@aucd.org](mailto:jczyzia@aucd.org).
- Please take 2 minutes to provide feedback on today's meeting: <https://www.surveymonkey.com/CARESeval24>

or scan the  
QR Code

