

# Using Data and Quality Improvement to Address Health Equity for Children Diagnosed with Autism Spectrum Disorder and other Developmental Disabilities



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# Presenters

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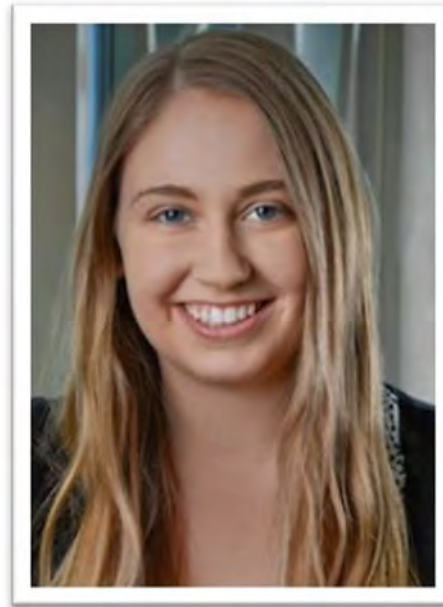
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# Who is AMCHP?

- **Vision:** A nation that values and invests in the health and wellbeing of all women, children, youth, families, and communities so that they may thrive.
- **Mission:** Protect and promote the optimal health of women, children, youth, families, and communities.
- **Members:** Leaders/staff from state/territory health agencies and their partners who implement programs to improve the health of women, children, and families.



**How does AMCHP provide support to states in developing and implementing systems of care?**

**SPHARC** 

**State Public Health Autism Resource Center**

[www.amchp.org/SPHARC](http://www.amchp.org/SPHARC)



**OUR AIM**



is to help increase state capacity to implement systems of care for children and youth with ASD/DD.

**AMCHP**

# How does AMCHP provide support to states in developing and implementing systems of care?



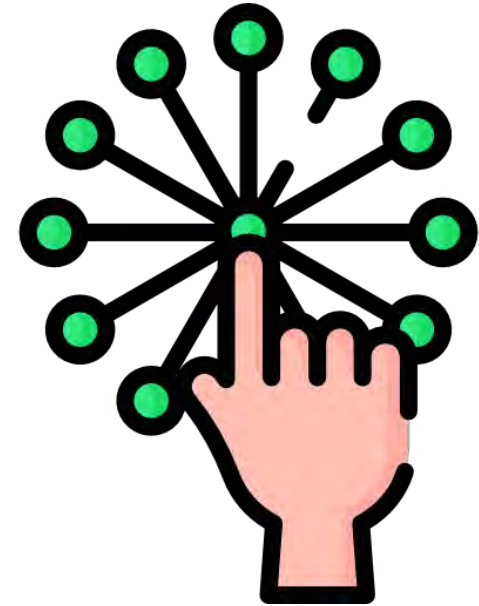
## 1. Resource Development

# Resource Development



**Publications  
& Tools**

**eLearning**



**Interactive  
Resources**

**AMCHP**

# Family Navigation Story Wall

## Family Navigation Story Wall

What are the challenges, benefits and rewards of being a family navigator? Click on each picture to read short, first-hand accounts from navigators and to access a report with case studies.

- Illuminates the experiences of family navigators across various states and settings
- Informs public health professionals, partners, and stakeholders of the roles that family navigators play within different contexts to better serve children and youth with special healthcare needs (CYSHCN) and their families.



<http://bit.ly/2Rx82R4>

# How does AMCHP provide support to states in developing and implementing systems of care?



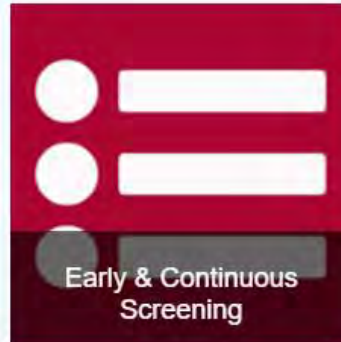
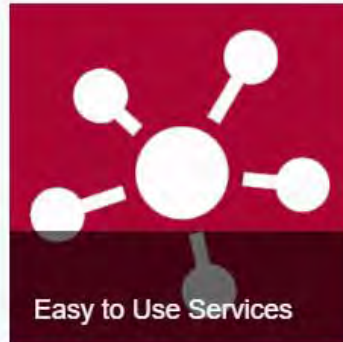
## 1. Resource Development

## 2. Technical Assistance





## Learning Modules



<http://bit.ly/2OEiabX>

## Early & Continuous Screening

**Core Outcome 3: All children will be screened early and continuously for special health care needs.**

Early identification allows communities to provide children with earlier treatment or interventions that are more effective in improving delays and disabilities and less costly than special education services in later childhood. It is also an integral function of the primary care medical home, and improving the developmental screening rate is a national performance measure for the Title V MCH Block Grant program.



Browse the resources below for tools, best practices and materials to support state efforts to improve systems and services for developmental screening and early identification, and collaborations across early childhood programs.

**NEW!** Check out the National Landscape of Developmental Screening presentation on the Archived Webinars and Meeting Materials page!

### Early & Continuous Screening Resources



# How does SPHARC provide support to states in developing and implementing systems of care?



## 1. Resource Development

## 2. Technical Assistance



## 3. Peer Learning

# SPHARC Peer-to-Peer Exchange

The SPHARC Peer-to-Peer Exchange was designed as a learning mechanism for State Autism Grantees to learn from one another about building systems of care for children and youth with autism spectrum disorders (ASD) and other Developmental Disabilities (DD).

## Meeting Preparation

Peer Leader develops focus topic and hands-on learning experiences

AMCHP supports meeting logistics and guidance

## In-person Meeting

Peer Leader

Community members

Exchange states

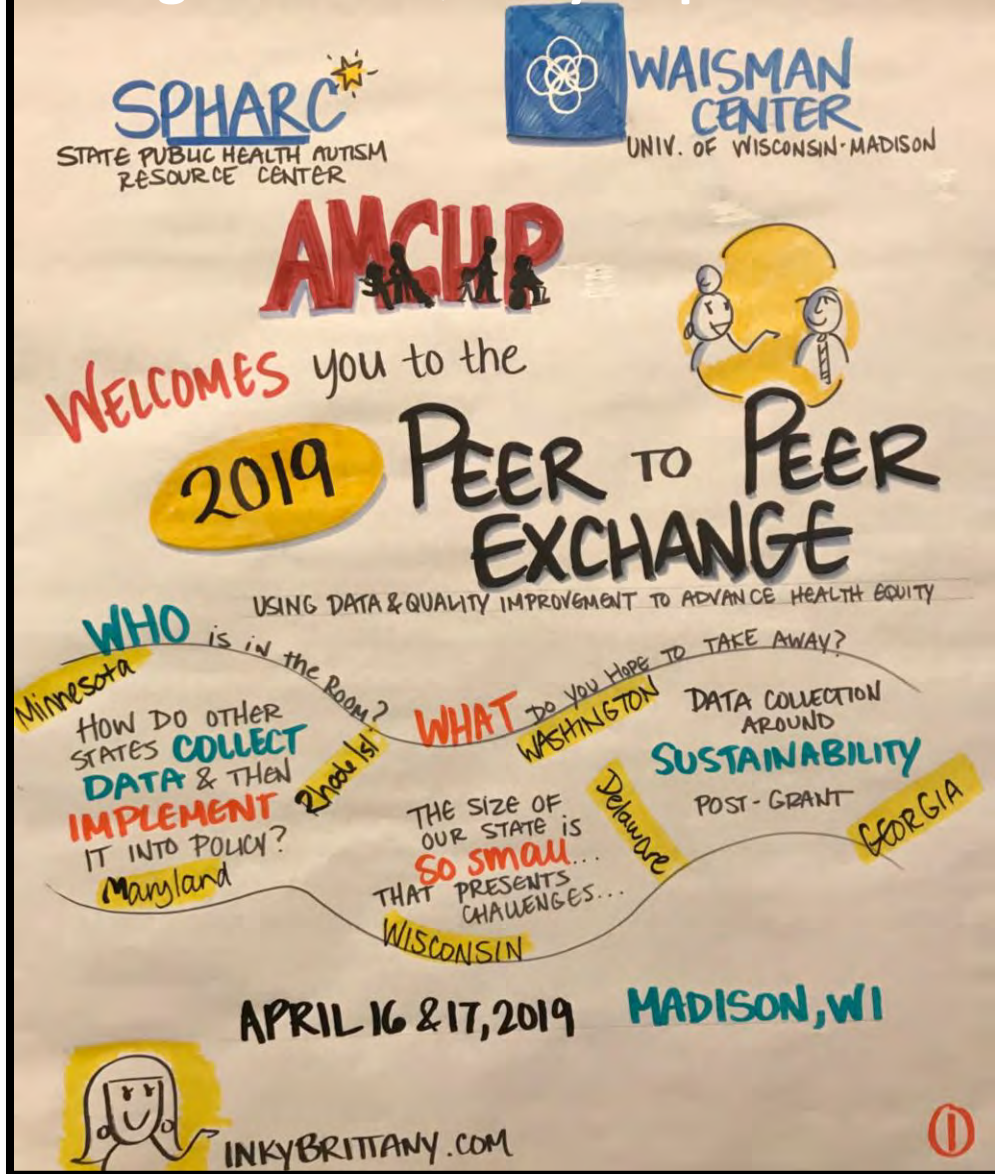
## Post-Meeting

Resource development

Peer site visits, Peer follow-up calls

# Using Data & Quality Improvement

# to Advance Health Equity

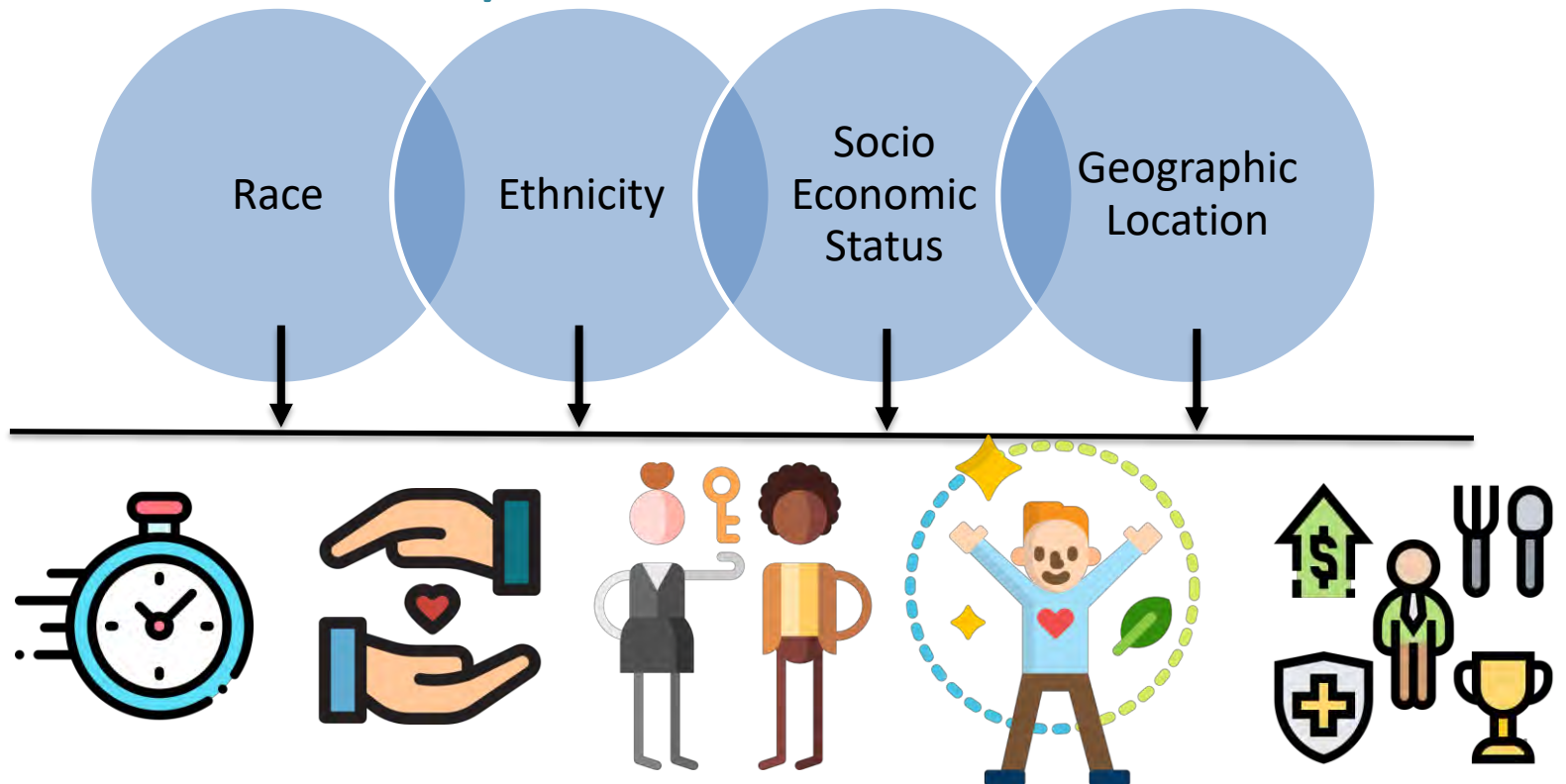


- Grantee state presentations
- State posters
- QI practical techniques
- State-led discussions on QI methodologies
- State action planning
- Panel and state-led discussions on exploring models for engaging people most impacted by inequity

# Health Equity Considerations

It is helpful to know a disparity exists, but to develop action plans that address the disparity, one needs to understand **how** and **why** this is impacting one individual/ group over another.

What disparities exist for children with ASD/DD and their families?



# Takeaway #1: Let's Talk Prevalence

- Prevalence data has been an essential tool for public health
- As our discipline continues to improve, we understand that an equity lens is required to ensure the health of ***all*** populations are being adequately monitored

*An example of why the equity lens is so important...*

*Brit. J. Psychiat.* (1980), 137, 410-417

# Childhood Autism and Social Class: A Question of Selection?

By LORNA WING



. But it remains true that a knowledgeable and determined parent of an autistic child is more likely to obtain an informed diagnosis.





# Equitable Evaluation Framework

<https://www.equitableeval.org/ee-framework>

## Equitable Evaluation Principles

1

**Evaluation and evaluative work should be in service of equity.**

→ *Production, consumption, and management of evaluation and evaluative work should hold at its core a responsibility to advance progress towards equity.*

2

**Evaluative work can and should answer critical questions about the:**

→ *Ways in which historical and structural decisions have contributed to the condition to be addressed*

→ *Effect of a strategy on different populations*

→ *Effect of a strategy on the underlying systemic drivers of inequity*

→ *Ways in which cultural context is tangled up in both the structural conditions and the change initiative itself.*

3

**Evaluative work should be designed and implemented commensurate with the values underlying equity work:**

→ *Multi-culturally valid*

→ *Oriented toward participant ownership.*

## Takeaway #2: Community-level data

- All communities are unique. Pay for the context expertise of impacted leaders!
- Community context expertise will shed light on the assets already available in the community, and how those assets can be scaled up

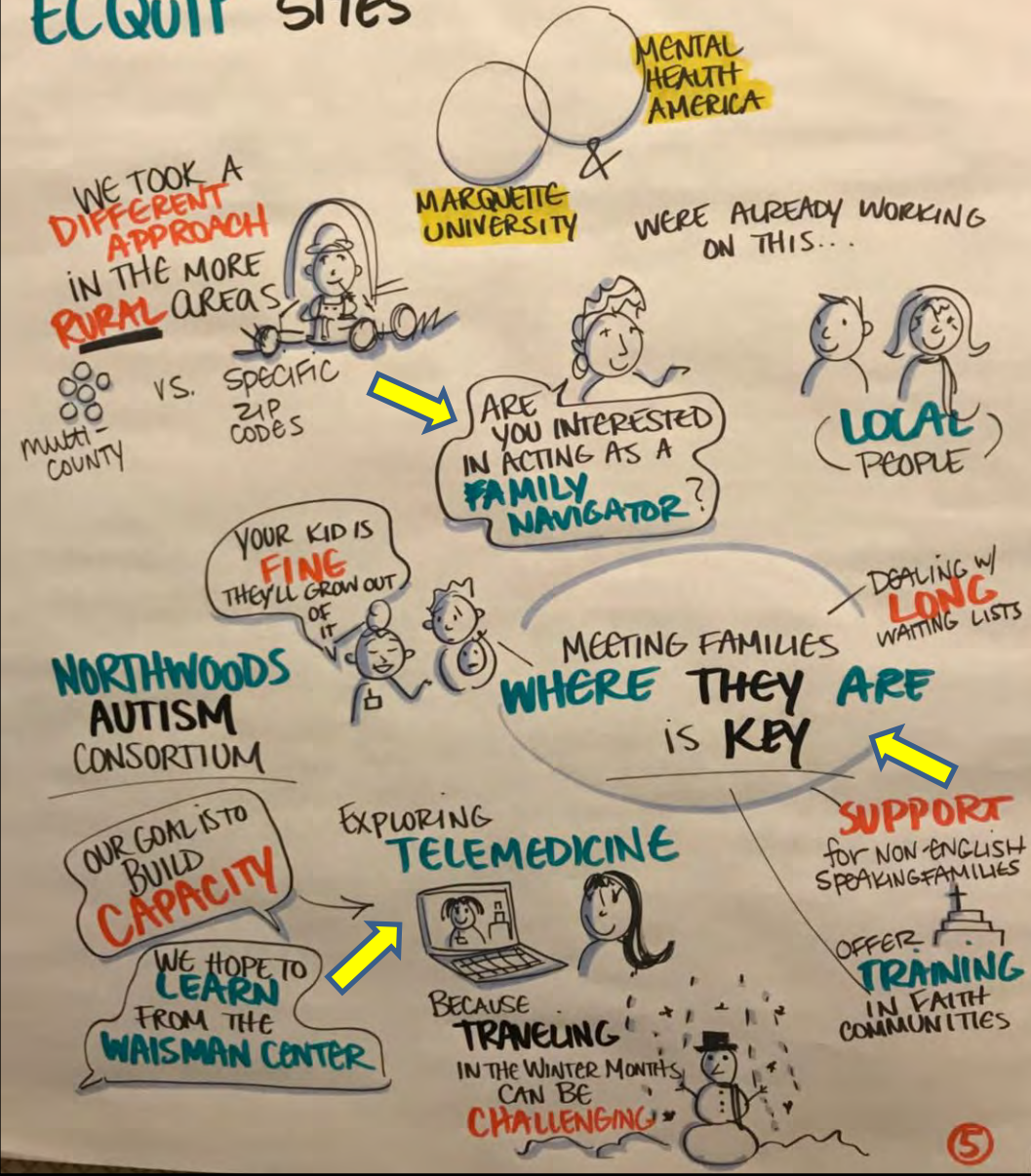
*For example...*

# Rose Cutting: *Impacted Leader & Context Expert*



**View video at:** <https://youtu.be/P1hV10DjDVs>

# ECQUIP SITES



Wisconsin's community-centered approach

# Two Takeaways

- ❑ **Prevalence data requires an equity lens** *Check out the equitable evaluation framework to think through how you can design your own data collection to be more equitable*
  
- ❑ **The solutions are already in the community** *Qualitative data from [compensated] local context experts will shed light on community assets*

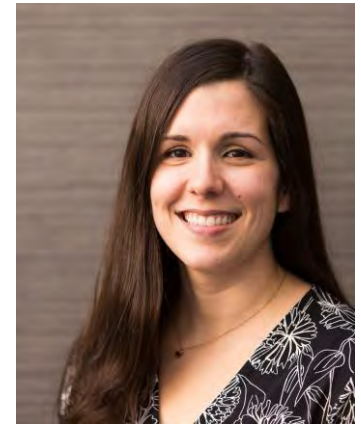
# Resources

- **SPHARC:** [www.amchp.org/SPHARC](http://www.amchp.org/SPHARC)
- **Creating more equitable evaluation frameworks:** [www.EquitableEval.org](http://www.EquitableEval.org)
- **AMCHP's Family Compensation Policy**
  - email Anna or Paige ([acorona@amchp.org](mailto:acorona@amchp.org) or [pbussanich@amchp.org](mailto:pbussanich@amchp.org))

**SPHARC**

State Public Health Autism Resource Center

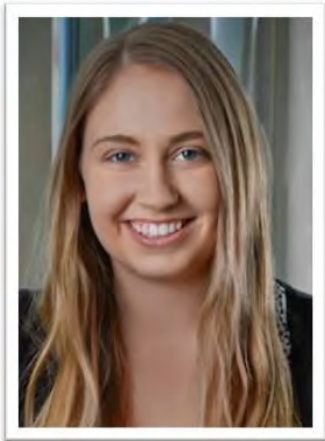
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