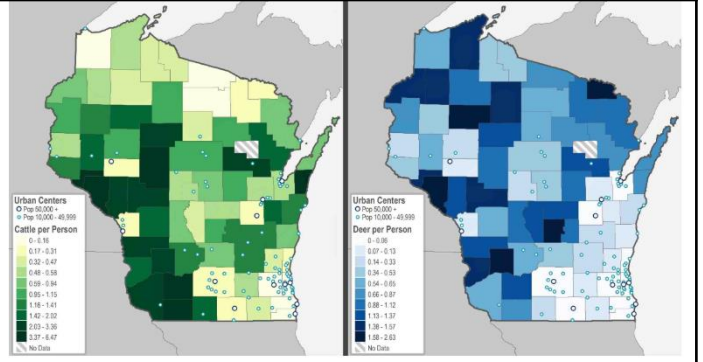
WISCONSIN – What is the definition of rural?

The UW Madison Applied Population Lab created 7 different maps to visualize urban versus rural areas in the state noting that there is no official definition across sectors: proximity to urban centers/urbanized areas/urbanized clusters, population density, metropolitan statistical area, rural-urban commuting area codes, frontier and remote areas classification, major land use, and even cows and deer per capita (*pictured here*).

COWS & DEER



Caitlin McKown/UW Applied Population Laboratory

Using Data to Identify Local Disparities:

ECQuIP site "discovery phase" provided data to determine barriers to getting services in 3 geographically diverse areas in Wisconsin (urban Milwaukee, Northwoods and Southwest).

survey responses (58) + stakeholder interviews (11) + community meetings (3) + parents in listening sessions (25)

+ Increased ability to target interventions to community needs
+ Heard directly from parents of children with ASD/DD
- Was time consuming to implement and analyze a variety of data gathering approaches within numerous communities
- Participation varied: Did we hear from most impacted?

QI Methods:

PDSAs/BAR-AARs/flowcharts

Drive change by mobilizing community partners to address barriers to access

Family Navigators
Local community members (parents and professionals)

Help families navigate access to services

Continuously collect data on service availability as well as enablers and barriers

Engaging Communities:

- Family Navigators (FNs) are identified as local family leaders
- FNs get training and experience
- FNs connect other families to what they need, and support the development of their self-efficacy
- FNs and some families receiving FN support take their leadership to new community efforts
- Other local family leaders identified, supported and connected to grant efforts

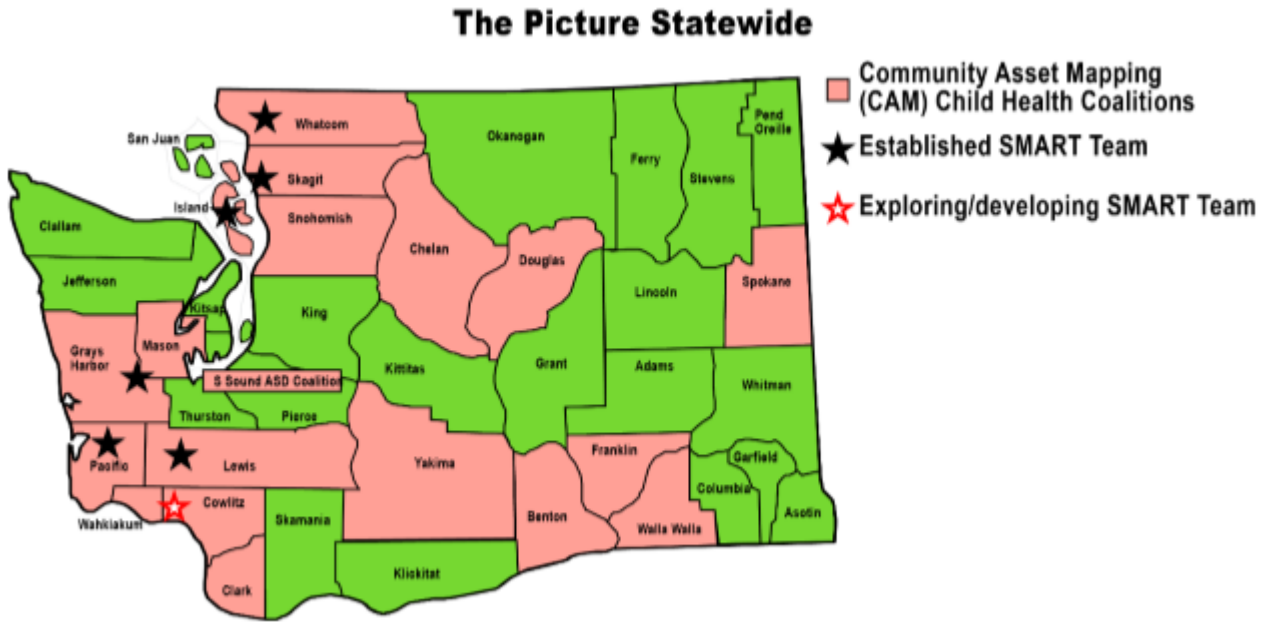
STATE NAME: WA Team

What is one interesting thing about your state? Yakima Valley produces over 77% of the country's hops, and Washington is the country's #2 premium wine-producing region (second to California) SOURCE: http://www.experiencewa.com/articles/wander-here-19-interesting-facts-about-washington

State Data

University of Washington Medical Home Partnerships Project

SMART Teams and CAM Communities: encouraging advocacy and leadership within the families being served



QI Method

Open Doors for Multicultural Families

Cultural Brokering strategy to address disparities in service delivery

Engaging Communities

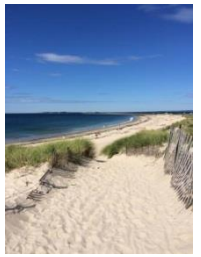
Washington Autism Alliance & Advocacy

Community Networking/Collaboration training
Family Support Network/ Supporting Parents of Autism
Coming soon! Insurance Navigation Portal

Rhode Island

What is one interesting thing about your state?

The oldest operating carousel in the United States is in Rhode Island, at Watch Hill Beach in Westerly.



Engaging Communities

Context:

- Our HRSA project is focused on:

1. Increasing access to information about ASD/DD , with emphasis on early signs (i.e. by providing training and webinars and engaging in community outreach).
2. Providing family navigation and support to families, especially in medically underserved communities

- Our HRSA family navigation model engages RI communities by:

1. Focusing on the state's core cities and the Narragansett Tribe (see State Data) in order to increase equitable access to resources.
2. Partnering with community organizations to reach target communities
3. Increasing our linguistic and cultural capability to provide accessible training, navigation, and support

Successful Strategies:

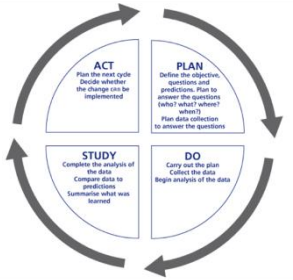
- Connections fostered by partnering with existing state efforts & committees focused on health equity and increasing access to information about screening/evaluation: e.g. Rhode Island's Health Equity Zones initiative, Rhode Island Department of Health Successful Start Screening Committee, EOHHS' Interagency Council.
- Investing in building relationships and partnerships with community leaders to increase linguistic and cultural capability, e.g. Center for Southeast Asians, Narragansett Tribe Pre-School and Health Center, Central Falls Parent Academy, Providence RTL, etc.
- Investing in a bilingual Community Engagement Specialist dedicated to the city of Providence.

Challenges:

- Relationships and partnerships with trusted community organizations require significant time investment to nurture and build, which often means it takes longer to assess the impact of activities.

QI Method

Method: PDSA Cycles *(initiated March 2019)*



Focus:

How might we engage more families in Rhode Island's core cities in The Autism Project's Creating the Connections training – a key strategy? Is tele-education a viable strategy for increasing access to information about early signs, screening, and evaluation?

Successful Strategies:

- Using PDSA cycles on a small team – the learn-by-doing nature of the methodology enables us to quickly implement plans, learn from them, and act accordingly.
- Partnering with community organizations enables our team to identify and mitigate barriers that prevent families from accessing information and significantly increase our reach.

State Data

- Rhode Island used/uses data from Kids Count to design its project model, focused on Rhode Island's Core Cities and the Narragansett Indian Reservation in Charlestown. 2/3 of the state's children living in poverty live in these cities; the concentration of Black and Hispanic children in these cities is the highest.

- The Autism Project keeps demographic data on each individual who receives training as well as records of family navigation and support engagements that enable us to assess our reach in the core cities.

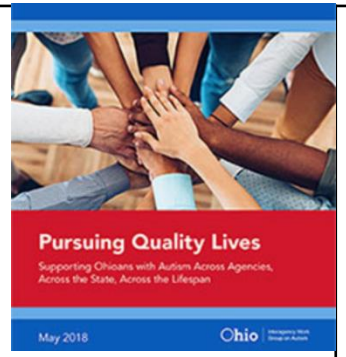
Challenges:

- Quantifying the impact of access to the information about early signs/screening/evaluation beyond the training, especially when training parents in the core cities - connecting the dots between the training and improved outcomes.

Ohio

Ohio is the birthplace of: the lightbulb, phonograph, motion picture camera, automobile, electric car motor, rubber, pop-top can, cash register, airplane, hot dog, Teflon, Life Savers, arced street lights, golf balls, Quaker oatmeal, gas mask, and… Superman!

QI Method: Collective Impact



Ohio's Interagency Workgroup on Autism: Pursuing Quality Lives

Choosing Metrics:

- State-level: Statewide data is available
- U.S.: U.S. data is available for comparison
- Reputable: Metric is nationally recognized (not home-grown)
- Trend: Trend data is available for at least two years
- Source integrity and data quality: Data are complete and accurate; response rates and sample sizes are adequate (if survey data)

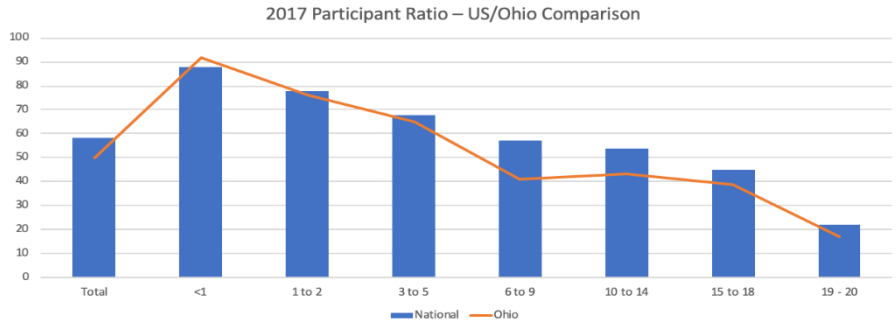
Preference to metrics which have:

- Sub-state geography: Data are available at the regional/county level
- Alignment: Metric aligns across two or more sources (Maternal and Child Health National Outcome Measures, National Autism Indicators Report, State agency metrics, etc.)
- Benchmarks: Benchmark values have been established for the metric by a reputable state or national organization or agency (e.g., Early Intervention Annual Performance Measures, Healthy People 2020)
- Face value: Metric is easily understood by the public and policymakers

Avoid metric duplication, remove similar metrics, keep metrics that best meet the above criteria.

State Data

EPSDT – Participant Ratio (Eligibles Who Should Have Received at Least One Initial or Periodic Screen/Those That Did)*



*National benchmark was 80% by 1995

Engaging Communities

- *Education: Family Engagement Network; Family Forums*
- *Health: State Health Assessment Forums*
- *Developmental Disabilities: Supporting Families Community of Practice; Family Advisory Council; Family Agency Coalition*

NEW HAMPSHIRE

Decision Making related to affairs of the state is jointly shared between our Governor and Executive Council (elected). The New Hampshire's Executive Council is responsible for overseeing the majority of state contracts and spending, acting as a check against the power of the state's governor. The Executive Council holds the distinction of being the first (1680) and the last of its kind in the nation. "It is a vestige of the Colonial era and a public reminder of the continuing indication of the basic distrust Granite State citizens have for dictatorial government."

Children with Special Health Care Needs - National Survey (2009-2010)		
Caregivers experienced difficulty or delays in getting services with degree of frustration		
Characteristics	Weighted Count	Proportion
State Overall	17912	33.0%
Race /Ethnicity		
Hispanic	1181	49.5%
Non Hispanic White	14526	31.1%
Non Hispanic Black	377	26.2%
Non Hispanic Other Race	1828	49.5%
Complexity of Needs		
CSHCN managed primarily by RX meds	3736	17.8%
CSHCN with more complex service needs	14177	42.7%
Emotional, Behavioral and Developmental (EBD)Problems		
CSHCN without Emotional/Behavioral Disorders (EBD)	9445	25.3%
CSHCN with EBD	8467	50.3%
Household Language		
English	17723	32.9%
Language Other than English	190	52.2%

State Data: As a part of the NH Autism Needs Assessment and State Plan activities this data which highlighted the discrepancies related to health care access for vulnerable populations was used to inform the design for stakeholder input and development of the State Plan. The State Plan workgroup decided to incorporate Access and Health Equity in all sections instead of pulling it out into a separate section.

NH programs for CSHCN (Title V, Part C Early Intervention and the Autism Registry - created 2009) have coordinated the use of CDC and NH Office Health Equity (OHE) recommended approaches for race, ethnicity and language access data collection for at least 10 years.

This data will facilitate evaluation of access to services and cross program data comparisons as recommended in the Autism State Action Plan and Workbook. Additional work is still needed in order to collect data from all NH contractors that demonstrates their adherence to CLAS standards and the impact on access/equity.

QI: Annual surveys are sent to caregivers that allow us to assess the differences in satisfaction across populations. Approaches include survey in family language of choice and having a neutral interviewer contact the caregiver with direct translation services.

Engaging Communities: NH emphasizes the use of focus/stakeholder groups that are moderated in other languages for populations served, including the use of bilingual Community Health Workers.

MINNESOTA

OUR STATE MUFFIN IS BLUEBERRY!

What was the average age at first clinical diagnosis of ASD in MN?

4 years **9** months

State Data: ADDM and the ASD Prevalence Study

The University of Minnesota (UMN) is an Autism Developmental Disabilities Monitoring (ADDM) Network site. The MN ADDM project tracks rates of ASD in MN. The specific goals of MN ADDM are to:

1) Estimate the prevalence of 8-year-olds with ASD with intellectual disabilities (ID) in Hennepin and Ramsey Counties, and identify other characteristics such as ethnicity and co-occurring conditions;
2) Identify disparities in prevalence, characteristics and age of diagnosis across demographic groups, including two large racial/ethnic groups unique to MN – Somali and Hmong children;
3) Use project data to improve services for children with ASD/ID in their community.

ADDM data provides a significant step forward in understanding ASD prevalence and characteristics in MN. Limitations are geographic scope and small sample size limiting analysis of subpopulations. Minnesotans outside the Twin Cities report delays in screening and diagnosis as well as unmet service needs. Future MN-ADDM goals include increased timeliness of ADDM data and the need for expansion to greater Minnesota. Other connections have been both MN Act Early and MN Help Me Grow to decrease the age of identification.

QI with EIDBI

In 2013, the Minnesota legislature authorized the Department of Human Services (DHS) to develop and implement the Early Intensive Developmental and Behavioral Intervention (EIDBI) benefit for children and youth under 21 years of age who are on Medical Assistance (MA), Minnesota's Medicaid benefit. The EIDBI service is intended to provide medically-necessary intensive intervention as early as possible for children with ASD and related conditions and their families.

EIDBI services include rigorous progress monitoring to ensure best outcomes for child and family. Involvement of a broad and diverse community of ASD stakeholders was key to the process of developing the EIDBI benefit, as well a critical component of QI. DHS implemented an extensive, intentional stakeholder input process that included parents, advocates, clinicians, professionals, state agencies and individual stakeholders, DHS ASD Advisory Council, and smaller focus groups to seek input on the EIDBI benefit. Over one third of EIDBI agencies serve culturally-specific groups such as Somali or American Indian communities. Additionally, DHS monitors demographics and outcomes of families enrolled in EIDBI benefit with a focus of identifying and addressing inequities.

Prevalence Estimate by Race and Ethnicity

Race and ethnicity	Children with ASD identified/ Total population	Prevalence estimate (prevalence per 1,000 children)
Overall	255 of 12,329	**1 in 48** (20.7 per 1,000)
Somali	31 of 1,007	**1 in 32** (30.8 per 1,000)
White	120 of 4,336	**1 in 36** (27.7 per 1,000)
Black (non-Somali)	53 of 3,312	**1 in 62** (16 per 1,000)
Hispanic	30 of 2,399	**1 in 80** (12.5 per 1,000)

ID/IQ by Race and Ethnicity

	Percentage of children with ID	Percentage of children missing IQ scores
Overall	33%	28%
Somali	100%	35%
White	20%	26%
Black (non-Somali)	30%	19%
Hispanic	22%	40%

ASD Prevalence by race and ethnicity

Engaging Communities through an Advisory Group

Minnesota has recently reestablished a legislative working group to focus on issues related to individuals with ASD and their families. To better understand the unique needs of specific cultural communities, there are a number of individuals representing their diverse backgrounds on the ASD Working Group. Representatives include those from Somali and South Asian cultural backgrounds as well as neurodiverse individuals that vary by gender, ages, and race.

MINNESOTA ADDM Minnesota Autism Developmental Disabilities Monitoring Network

Minnesota ACT EARLY

Maryland

What is one interesting thing about your state?
While small MD is incredibly diverse. PPMD covers both Health and Special Education topics and is a one-stop center for families with Children and Youth with Special Healthcare Needs and Disabilities.

Engaging Communities

PPMD has done intentional and targeted outreach to underserved populations, in both rural and urban areas of Maryland. We have started collaborative relationships with non profits such as the Lollipop Foundation, The Archdiocese of Washington's Special Needs Ministries, The Hispanic Community Resources, with a national refugee resettlement organization and Native Lives, the Native American Health Services Non Profit of MD that serve our targeted population in order to meet the families needs . We provide information and support to families via phone, in person, website, email and mail. We currently have 3 Native Spanish speaking staff and use the Language Line to interact with families that languages other than English and Spanish. PPMD staff meet families wherever they are at in their journey, provide a safe and confidential environment that supports the development of a relationship of mutual trust. We connect them to other agencies and organizations so they can access additional resources. We provide learning opportunities via workshops, webinars, translated materials, and soon a Face Book Page in Spanish. And starting September 2019 we have leadership and learning opportunities: "Padre, Tu Puedes" Conference ; LEADers Conference on the Eastern Shore in a significantly underserved portion of the state; and Serving on Groups Curriculum in Spanish. In addition, provide workshops and Special Education Clinics, year round, all across Maryland where we provide 1:1 assistance to families on issues related to the IEP and Healthcare.

State Data

The outreach position had been vacant for three years and there was no bilingual staff available to work with families. Therefore, we conducted a survey with our underserved families with children with disabilities and or Special Healthcare Needs. We used the data to guide the information and support provided to families; and our intentional and targeted outreach efforts. Results lead to collaboration with the American Academy of Pediatrics MD, John's Hopkins University, and the University of Maryland, the Lollipop Foundation, The Archdiocese of Washington's Special Needs Ministries, The Hispanic Community Resources, with a national refugee resettlement organization, and other agencies.

QI Method

We are currently on the *Do* phase of the first PDSA cycle. We are providing one on one assistance and workshops for families as per the results of data collection and the assessment, started a support group and increased outreach staff by 1.5 FTE. Mid year we will revise and adjust our PDSA and adjust accordingly.

GEORGIA

Georgia is bordered by five states including Florida, South Carolina, Alabama, North Carolina and Tennessee and is the 8th most populous state in the US.

State Data

MCHAT-R/F Training

- **300+** Service Coordinators trained via webinar

Georgia Autism Assessment Collaborative (GAAC)

- **105** Applicants; **67** Accepted; **54** Completed
- **4** Training Cohorts
- **5** GAAC Specialty Clinics

Autism Navigator

- **377** participating Early Interventionists; **28** Primary Care Providers

EI Coaching

- **46** providers

Professional Learning Community Groups

- **6** meetings scheduled; **17** out **18** districts participated

Pyramid Model Training – Tiers 1-3

- 235 providers completed Tier 1 webinar; 112 providers completed Tier II webinar; 44 completed Tier III in-person training

Timeline

July 1, 2015 – June 30, 2016

Cohorts 1 through 3 (42 Psychologists and other disciplines) trained on Autism Diagnostic Observation Schedule – Second Edition (ADOS-2) with 2-day clinical training at Emory and 2-day training and coaching in the regions

125 providers trained on the Autism Navigator with bi-weekly follow-up webinars

25 Providers participated in a 12-month Coach/EI Provider training model

August 1, 2016 – June 30, 2017

Cohort 4 (12 Psychologists) trained on ADOS-2 with a 2-Day Clinical Training at Emory and a 2-Day hands-on training with coaching

Follow up with Cohorts 1 through 3

127 Providers trained on the Autism Navigator with bi-weekly follow-up webinars

21 providers participated in a 12-month Coach/EI Provider training model

174 Providers participated in the *Parents Interacting with Infants* training

134 Providers participated in the Family-Coaching Pyramid model

148 providers participated in the Individualized Positive Behavior Supports training.

July 1, 2017 – April, 2019

MCHAT-R/F screening training provided for 300+ Service Coordinators

Two 1-day ADOS-2 Modules 3 and 4 trainings at Emory for all cohorts

125 providers trained on the Autism Navigator with bi-weekly follow-up webinars

18 EI-interactive case coaching webinars

72 Part C Evaluators and C1st staff trained on the Autism Navigator with bi-weekly follow-up webinars

18 Professional Learning Community/Case Coaching tele-meetings

15 providers participated intensive coaching model

Systems Improvement

The enactment by the Georgia legislature of House Bill 429, "Ava's Law", mandated insurance coverage for Autism services effective January 1, 2016. To respond to the mandate, the Department of Community Health (DCH) formed a state-level interagency collaborative team that included leadership from DCH, the Department of Public Health (DPH), and Department of Behavioral Health and Developmental Disabilities (DBHDD), to develop the policies to plan for and implement best practices for children diagnosed with ASD who are insured through Medicaid. Through these collaborative efforts, a state-wide Medicaid plan was implemented effective January 1, 2018, that provides for screening, diagnostic and treatment for children suspected of or confirmed to have a diagnosis of ASD.

DPH Leadership recognizes the importance of early identification and ensuring Autism services are available to young children in Georgia and has tasked Babies Can't Wait (Georgia's IDEA Part C program) with implementing behavioral support services to children birth to age 3 within the program. In order to address infrastructure needs, DPH partnered with academic institutions including Georgia State University' Center for Leadership in Disability, Emory University's Emory Autism Center, and Emory School of Medicine's Marcus Autism Center. This approach has proven to be a successful strategy to enhance statewide capacity to provide screening, diagnostic and behavioral intervention services.

In Georgia, we are working with all of the Health Districts to ensure all staff who receive and process referrals are adequately trained to administer the MCHAT-R/F screening and to understand the next steps to take when "red flags" for autism are identified. This ensures that all children receive the same service and that early identification and intervention happen as soon as possible. Georgia has conducted statewide and regional trainings on early identification & screening, diagnostic skill set, and addressing persistent and challenging behaviors for professionals with the ability to address ASD disparities, to include gaps between age at first diagnosis. Training has also focused on building diagnostic capacity through the training of psychologists on the ADOS-2, as well as extensive efforts to build awareness among primary care providers.

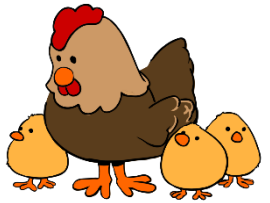
Challenges

Georgia is committed to developing an infrastructure that utilizes behavioral interventions in the natural environment when deemed appropriate to best meet a child's needs. Professionals in the applied behavior analysis field are found to have varying abilities to integrate their interventions into natural routines.

Due to the increasing identification of young children with red flags for Autism, the demand for diagnostic assessments from Licensed Psychologists has seen a corresponding increase. This has extended the wait time for evaluations and consequently delays in receiving intervention services once a diagnosis is confirmed.

DELAWARE

Fun Fact: Delaware is home to over **200 times** more chickens than people.

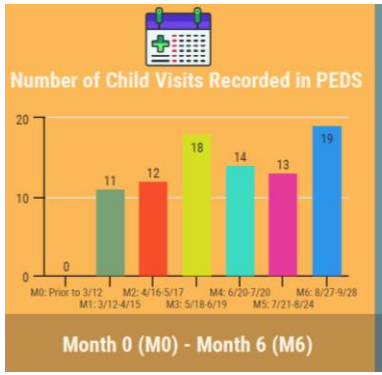


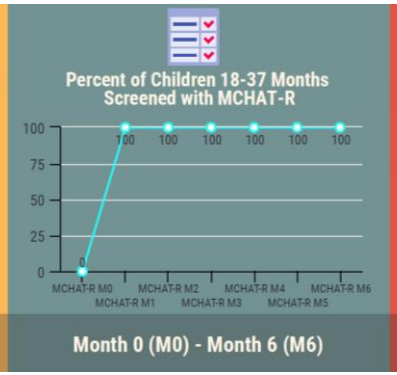
QI Method

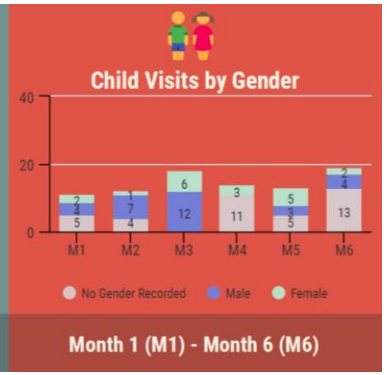
Plan Do Study Act (PDSA)

Implemented PDSA QI for the M-CHAT-R (Modified Checklist for Autism in Toddlers, Revised) Provider Training Pilot. *See below for data from one pilot practice.*

- ✓ **Plan:** Identified two primary care practices & provided training on autism screening
- ✓ **Do:** Practices implemented M-CHAT-R screening and data collection
- ✓ **Study:** Analyzed monthly data, share reports with practices, address barriers
- ✓ **Act:** Based on feedback, offered additional trainings and processes for implementation barriers (i.e. chart reminders and M-CHAT-R translations)







Successes

- Evaluation of training and technical assistance to inform additional training needs
- Monitor progress of M-CHAT-R integration and provide individualized support

Challenges

- Barriers integrating M-CHAT-R in EMR systems; not user-friendly; added time
- Language and literacy barriers; only English responses accepted in PEDS Online

State Data

Strategy: *Blueprint for Collective Action*

- Delaware's Strategic Plan for ASD, developed from statewide needs assessment conducted 2011-2013

Disparity: *Access to timely evaluations*

- Lack of trained providers
- 31.9% of families leaving DE for eval

Response: *Assessments through Part C*

- Nemours psychology fellow at Child Development Watch South clinics
- 100+ children <37 months assessed

Strategy: *PEDS Data*

- Division of Public Health funds PEDS Online for primary care practices

Disparity: *Autism screening rates*

- For all cases of PEDS screenings, only about 12% of children were also screened with the M-CHAT-R

Response: *M-CHAT-R Provider Pilot*

- Training, technical assistance for two practices on integration of M-CHAT-R
- M-CHAT-R added to Nemours EMR

Engaging Communities

Family Council

- Diverse group of parents of children with ASD of different ages

Engagement

- Empowered to share perspective
- Stakeholder meetings, program development, provider trainings

Bilingual Family Navigators

- Autism Delaware hired statewide bilingual family navigators

Engagement

- Family support, training, advocacy
- In 2017-2018, over 420 Spanish-speaking families served

Family Empowerment Scale & Needs Assessment Survey

- In 2019, new version of FES combined with community needs assessment developed and disseminated to identify areas of improvement in state services