

Wisconsin Team

Introduction & Presentation

2019 Peer-to-Peer Exchange



Welcome from WI Title V



Sharon Fleischfresser

Medical Director, WI CYSHCN Program

Learn the Signs.
Act Early.



Welcome from WI Title V





Wisconsin Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Program

WI Care Integration Initiative

– built on partnerships

Title V CYSHCN Network in WI



Other Key Partners

Parent and community support agencies

- Alianza Latina Aplicando Soluciones
- Autism Society of South Central WI
- Autism Society of Southeastern WI
- Autism Society of WI
- WI FACETS
- WI Family Ties

State disability partners

- WI Board for People with Developmental Disabilities

State Department of Health Services

- Bureau of Children's Services
- Supplemental Nutrition Program for Women, Infants and Children (WIC)

State and regional educational services

- WI CESAs (Cooperative Educational Service Agencies)
- Department of Public Instruction
- WI Statewide Parent Educator Initiatives
- Higher Education and Research

Professional/Interprofessional Groups

- WI Chapter of the American Academy of Pediatrics (AAP)
- Community and health care providers
- Community of Practice on Autism Spectrum and other Developmental Disorders
- Urban Autism Summit
- Waisman Center Clinics



No Wrong Door

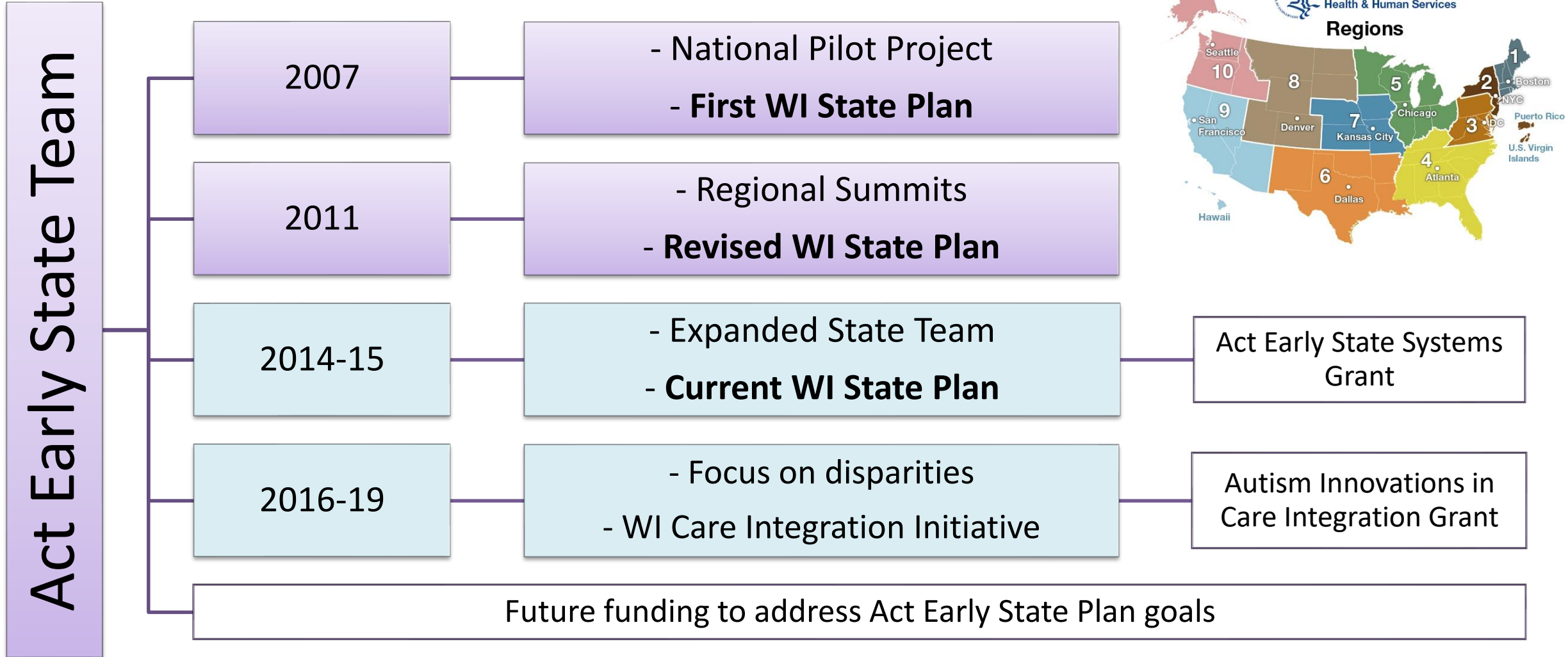
All groups have a common goal – to help families find their way through engaging with others

Family leadership and engagement is foundational

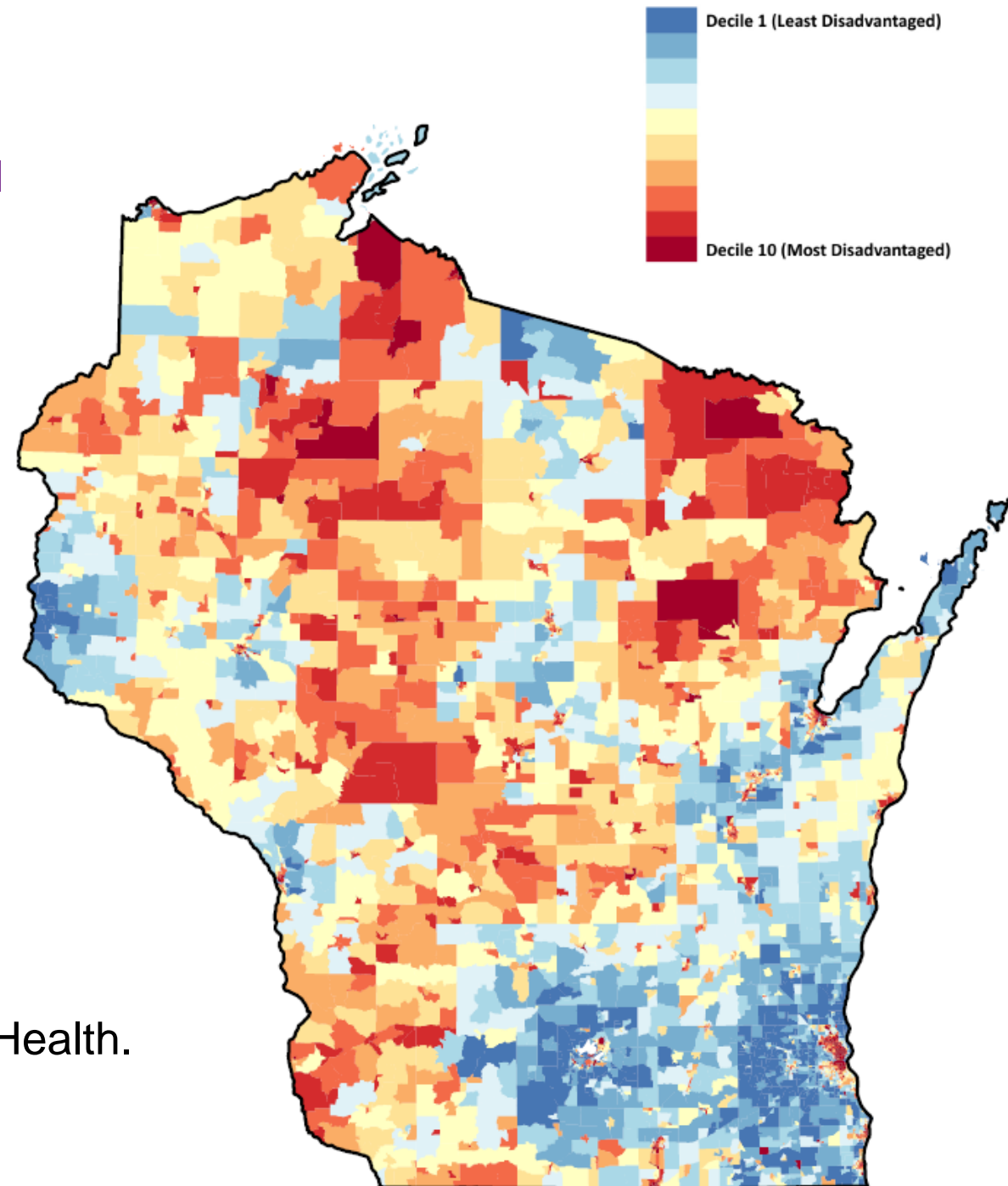


Act Early State Team

State Systems for Early Identification, Diagnosis, Intervention



Deprivation Index



University of Wisconsin School of Medicine and Public Health.
Area Deprivation Index. 5/1/2018. Available at:
<https://www.neighborhoodatlas.medicine.wisc.edu/>

Disparities in WI

Metro areas with highest black-white segregation

2000 and 2013-2017*

2000		2013-2017			
	Segregation Index**		Segregation Index**		
1	Detroit	85.7	1	Milwaukee	79.8
2	Milwaukee	83.3	2	New York	76.1
3	Chicago	81.2	3	Chicago	75.3
4	New York	79.7	4	Detroit	73.7
5	Cleveland	78.2	5	Cleveland	72.9
6	Buffalo	78.0	6	Buffalo	72.2
7	St. Louis	74.0	7	St. Louis	71.7
8	Cincinnati	73.6	8	Cincinnati	67.3
9	Indianapolis	71.7	9	Philadelphia	67.0
10	Philadelphia	71.0	10	Los Angeles	66.8
11	Kansas City	70.8	11	Pittsburgh	66.1
12	Los Angeles	70.0	12	Hartford	65.7

* Among 51 metro areas with populations exceeding one million and with black populations exceeding 3 percent of metro population (metro area names are abbreviated).

** Segregation Index is a dissimilarity index, which represents the percent of blacks that would need to relocate to be fully integrated with whites across metropolitan neighborhoods.

A value of 100 indicates complete segregation; a value of 0 equals complete integration (See values for all metro areas and further details in Table A).

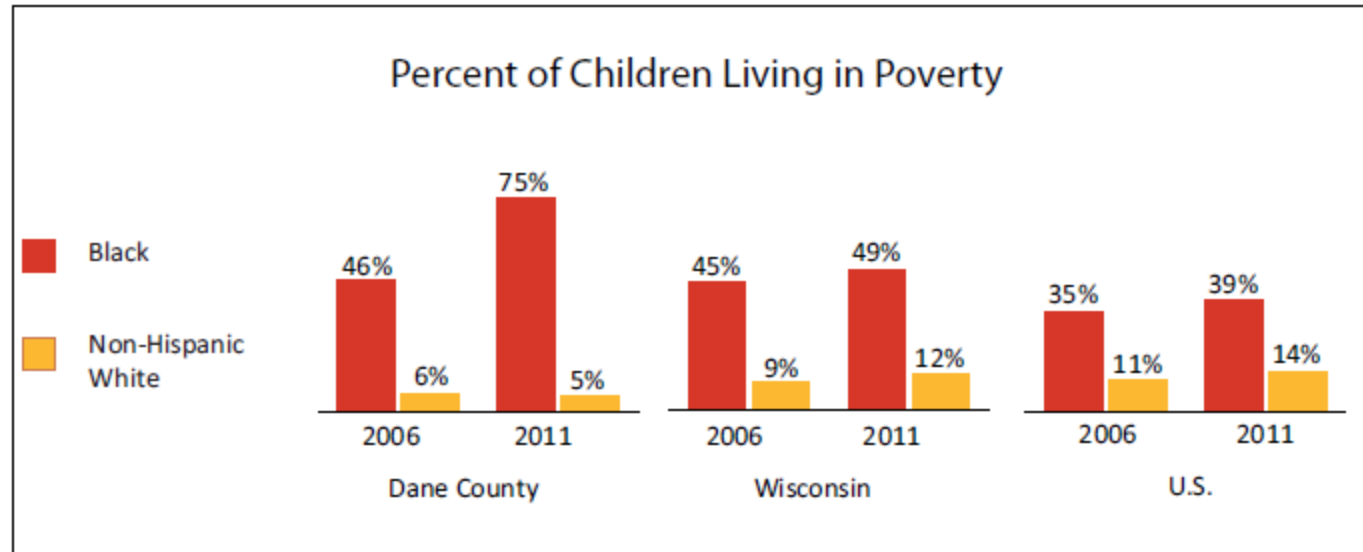
<https://www.brookings.edu/blog/the-avenue/2018/12/17/black-white-segregation-edges-downward-since-2000-census-shows/>

Source: William H Frey analysis of 2000 Census, and 2013-2017 multiyear American Community Survey (released December 6, 2018)

B | Metropolitan Policy Program
at BROOKINGS

Race to Equity:

A Baseline Report on the State of Racial Disparities in Dane County (2013)



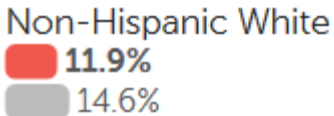
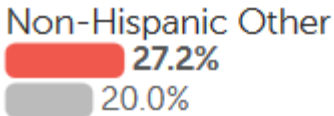
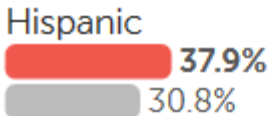
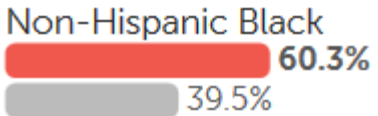
Wisconsin Council on Children & Families. 2013. Race to Equity: A Baseline Report on the State of Racial Disparities in Dane County. Available at



Disparities in WI

Wisconsin's Rankings

Infants and toddlers in poverty, by race



Race for Results Index Ranking Child Well-being in Wisconsin, by Race

Wisconsin's ranking for the indicators that make up the index, compared to children of the same race in other states

	Wisconsin's overall rank on index	High school graduation	Delayed childbearing	School or work	Low poverty areas	Normal birthweight	Two-parent families	Math proficiency	Assoc + degree	Above 200% of poverty	Family education	Preschool enrollment	Reading proficiency
WHITE Non-Hispanic	10 of 50 states	1 of 50	9 of 50	9 of 50	10 of 50	11 of 50	12 of 50	15 of 50	17 of 50	17 of 50	19 of 50	28 of 50	30 of 50
BLACK	46 of 48 states	30 of 50	49 of 48	50 of 50	44 of 50	33 of 44	50 of 50	35 of 38	45 of 45	48 of 50	44 of 50	16 of 50	39 of 42
LATINO	17 of 47 states	11 of 50	23 of 48	13 of 50	25 of 50	15 of 47	31 of 50	29 of 45	31 of 47	29 of 50	26 of 50	17 of 50	39 of 47
ASIAN	37 of 43 states	24 of 50	38 of 40	40 of 50	30 of 42	19 of 44	34 of 50	29 of 33	41 of 48	49 of 50	42 of 50	34 of 50	28 of 37
NATIVE AMERICAN	12 of 25 states	11 of 50	36 of 41	39 of 48	N/A	5 of 31	35 of 46	N/A	24 of 28	31 of 45	17 of 50	9 of 41	N/A

How Wisconsin ranks among the states

- Top quarter
- 2nd quarter
- 3rd quarter
- Lowest quarter

Indicator descriptions

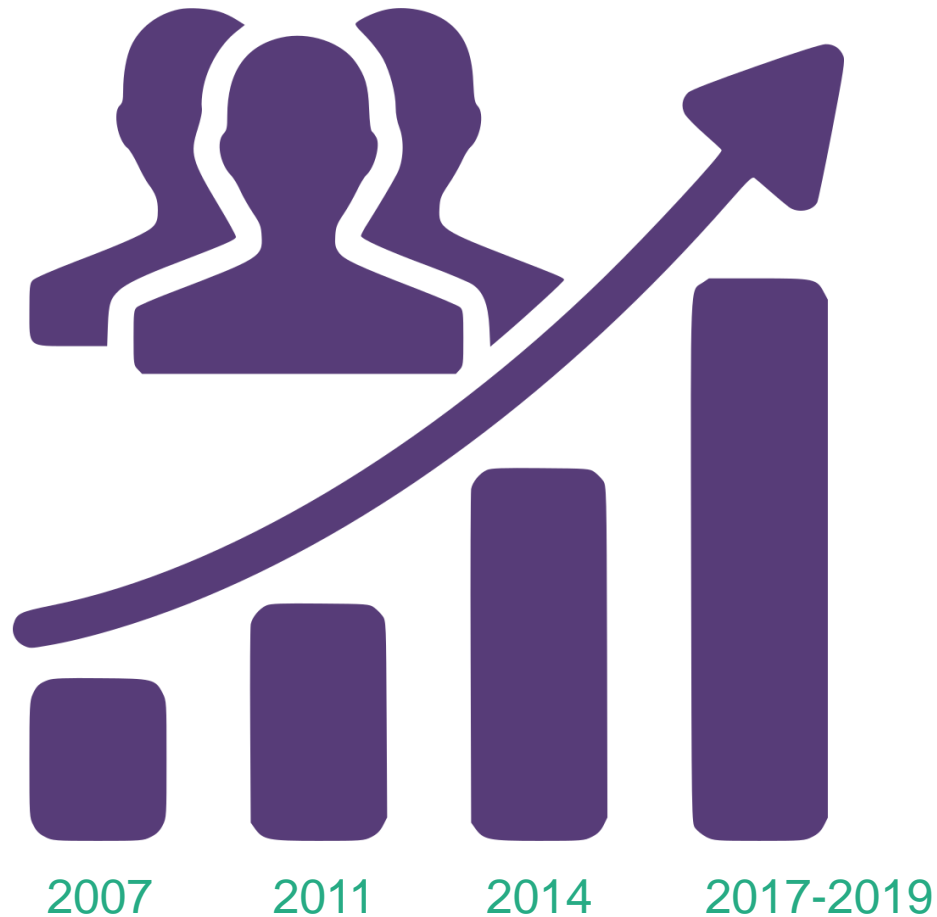
- Average freshman high school graduation rate, 2009-10
- Females age 15-19 who delay childbearing until adulthood, 2010
- Young adults ages 19 to 26 who are in school or working, 2010-12
- Children who live in low poverty areas (<20%), 2007-2011
- Babies born at normal birthweight, 2011
- Children who live in 2-parent families, 2010-12
- 8th graders scoring at least proficient in math, 2013
- Adults age 25 to 29 who have completed at least an associate's degree, 2010-12
- Children living above 200% of poverty, 2010-12
- Children who live with someone who has at least a high school degree, 2010-12
- 3 to 5 year olds enrolled in preschool or kindergarten, 2010-12
- 4th graders scoring at least proficient in reading, 2013

N/A means information is not available for Wisconsin due to small population size

State of Babies Yearbook 2019. Available at <https://stateofbabies.org/>

WisKids County Policy Brief. Fall 2014. WI Council on Children and Families. Available at <http://kidsforward.net/assets/RaceForResults.pdf>

Act Early State Team



Membership has grown dramatically since 2007.

Approximately 55 members representing 38 organizations



Act Early State Team

STATE AGENCIES
WI Dept of Health Services, Bureau of Children's Services, Andrea Jacobson, Section Chief
WI Dept of Health Services, CYSHCN Program (Title V), Sharon Fleischfresser, Medical Director; Becky Burns, Statewide Coordinator
WI Dept of Health Services, MCH Program (Title V), Leah Ludlum, Infant, Child, Youth Consultant; Karen Morris, MCH Nurse Consultant; Nafla Poff, MCH Equity Consultant
WI Dept of Health Services, Women, Infants, and Children (WIC), Kari Malone, State Nutrition Coordinator
WI Dept of Public Instruction, Jenny Giles, Education Consultant, Early Childhood; Sherry Kimball, Early Childhood Consultant; Jennie Mauer, WI Head Start State Collaboration Director; Jessica Nichols, Educational Consultant for Autism and EBD
UCEDD
Waisman Center UCEDD, UW-Madison, Anne Harris, WI LEND Director; Gail Chödrön, WI LEND Training Director; Lynn Hrabik, Evaluation Coordinator
PROGRAMS REPRESENTING & SUPPORTING PARENTS AND INDIVIDUALS WITH DISABILITIES
Alianza Latina Aplicando Soluciones, Monica Lopez, President and Founder, and Family and Community Engagement Associate with Milwaukee Public Schools
Autism Society of South Central WI, Kirsten Engel, Executive Director
Autism Society of Southeastern WI, Emily Levine, Executive Director; Daysi Jimenez, Information & Referral Coordinator, Spanish helpline
Autism Society of WI, Kirsten Cooper, Executive Director
Board for People with Developmental Disabilities, Molly Cooney, Employment and Diversity Outreach Specialist
Family Voices of WI, Barbara Katz, Co-Director; Lynn Renner, Communications and Information Coordinator
Parent to Parent of Wisconsin, Robin Mathea, Director
WI Family Assistance Center for Education, Training and Support (WI FACETS), Nelsinia Ramos, Parent Services & Multicultural Outreach Coordinator
WI Family Ties, Hugh Davis, Executive Director
WI Statewide Parent-Educator Initiative (WSPEI), Caroline Rossing, Statewide Grant Coordinator; Cheri Sylla, Family Engagement Coordinator
WI Women's Health Foundation/Well Badger, Kristine Alaniz, Maternal & Child Health Program Manager; Lisette Khalil, Operations Director

COMMUNITY & HEALTH SERVICES
Aiming for Acceptance, Rose Cutting, President and Executive Director (ASD Parent)
Catalpa Health, Jillian Schuh, Pediatric Neuropsychologist
Headwaters, Inc., Cory Dart, Children & Family Services Program Manager
Prevailing Pathway, LaKesha Pettigrew, Executive Director
Southwest Community Action Program, Tawny Hardyman, Dir, Head Start/Early Head Start
Southeast Regional Center for CYSHCN at Children's Hospital of WI, Brad Holman, Project Mgr
Southern Regional Center for CYSCHN at Waisman Center, Tim Markle, Director
Waisman Center UCEDD Autism Treatment Program, Molly Murphy, Treatment Services Lead
Waisman Center UCEDD Specialty Clinics, Maria Stanley, Medical Director; Lindsay McCary, DD Autism and Developmental Disabilities Clinic Director
PROFESSIONAL ASSOCIATIONS AND PROFESSIONAL SUPPORT ORGANIZATIONS
Children's Health Alliance of Wisconsin, Wisconsin Medical Home Initiative, Geeta Wadhvani, Program Leader; Naomi Kowald, Project Manager
Cooperative Educational Service Agencies (CESA), Katie Berg, ES3 Grant State Coordinator; Erin Lausten, Autism Consultant, CESA 6
Disproportionality Technical Assistance Network, Donald Rosin, Tribal Ambassador (ASD Grandparent)
Mental Health America of WI, Leah Jepson, Project Director
Supporting Families Together Association, Connie Dunlap, Family Engagement Specialist
Wisconsin Chapter of AAP, Mala Mathur, President
Wisconsin Early Childhood Association, Jeanette Paulson, Director of Workforce Initiatives
Wisconsin Head Start Association, Barb Tengedal, Executive Director
HIGHER EDUCATION AND RESEARCH
Marquette University, Amy Van Hecke, Associate Professor, Department of Psychology
Medical College of Wisconsin, Jennifer Koop, Associate Professor of Neurology and Neurosurgery; Lauren Haisley, Postdoctoral Fellow
UW-Madison, Maureen Durkin, Professor, Department of Population Health Sciences
UW-Milwaukee, Elizabeth Drame, Professor & Chair, Department of Exceptional Education, ASD Program Coord; Kris Barnekow, Associate Professor, College of Health Sciences

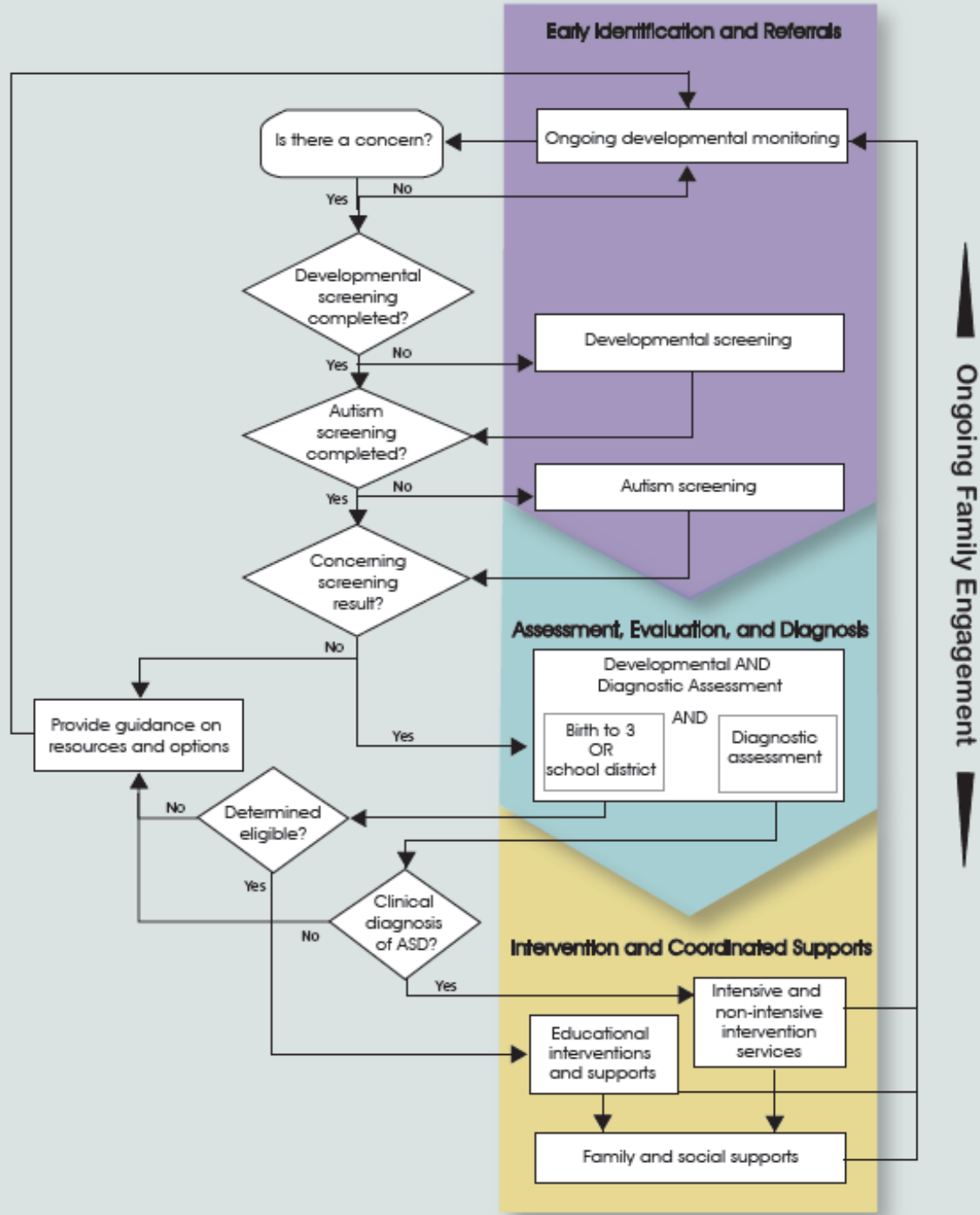


WI Act Early State Plan

Goal 1: Family Engagement	Goal 2: System of Early Identification and Referrals	Goal 5: Statewide Coordination			
<p>Long-term vision: Families who have children with ASD/DD have access to clear and useful information, accessible community supports, and coordinated systems of care that are family-centered.</p> <p>Intermediate Goals</p> <ol style="list-style-type: none"> All families are connected to support in the way they choose (e.g., telephone, chat, text, email). A consistent set of information, both on-line and in print, is shared with families upon diagnosis, assessment or eligibility determination. All families can access and advocate for services and supports. 	<p>Long-term vision: All children receive developmental screening and ongoing developmental monitoring, and are referred to services when a concern is identified, within a coordinated system of care including a Medical Home.</p> <p>Intermediate Goals</p> <ol style="list-style-type: none"> All families are informed and actively engaged partners in developmental screening and ongoing developmental monitoring. All primary care, public health and early care and education providers consistently implement ongoing developmental monitoring and screening for child development and autism utilizing evidence-based, culturally normed validated screening tools. All primary care, public health and early care and education providers are knowledgeable of available resources and utilize a system of coordinated referrals and follow-up services that align with best practices. All primary care, public health and early care and education providers utilize a system of coordinated data collection that evaluates Wisconsin’s system of developmental screening, ongoing developmental monitoring, referral and follow-up. 	Coordinated Communication Plan	Knowledgeable Referrals	Data Collection/Evaluation	Family Engagement
	<p>Goal 3: Assessment, Evaluation and Diagnosis</p>				
	<p>Long-term vision: All children receive an evaluation within three months after a concern is identified through screening or developmental monitoring.</p>				
	<p>Intermediate Goals</p> <ol style="list-style-type: none"> All providers, including primary care providers within a Medical Home, are knowledgeable of where to refer a child for assessment, evaluation and diagnostic services, and supportive services. Increase the capacity to assess, evaluate and diagnose children who have a concerning result from early developmental screening. Assessment, evaluation and diagnostic services are available, conveniently located and timely, for children who have a concerning result from developmental screening or as necessary. 				
	<p>Goal 4: Intervention and Coordinated Community Supports</p>				
<p>Long-term vision: All children who have been identified and/or diagnosed with ASD/DD receive timely and effective individualized interventions within a system of coordinated community-based care.</p>	<p>Intermediate Goals</p> <ol style="list-style-type: none"> Local communities have a coordinated system of evidence-based intervention, treatment and educational services. Families, Medical Home providers, service providers, and educators coordinate to support families in building individualized service and support plans that are family-centered. Children have their individual needs met after diagnosis in a timely manner by a network of providers in their local community. 				



Child and Family Pathway

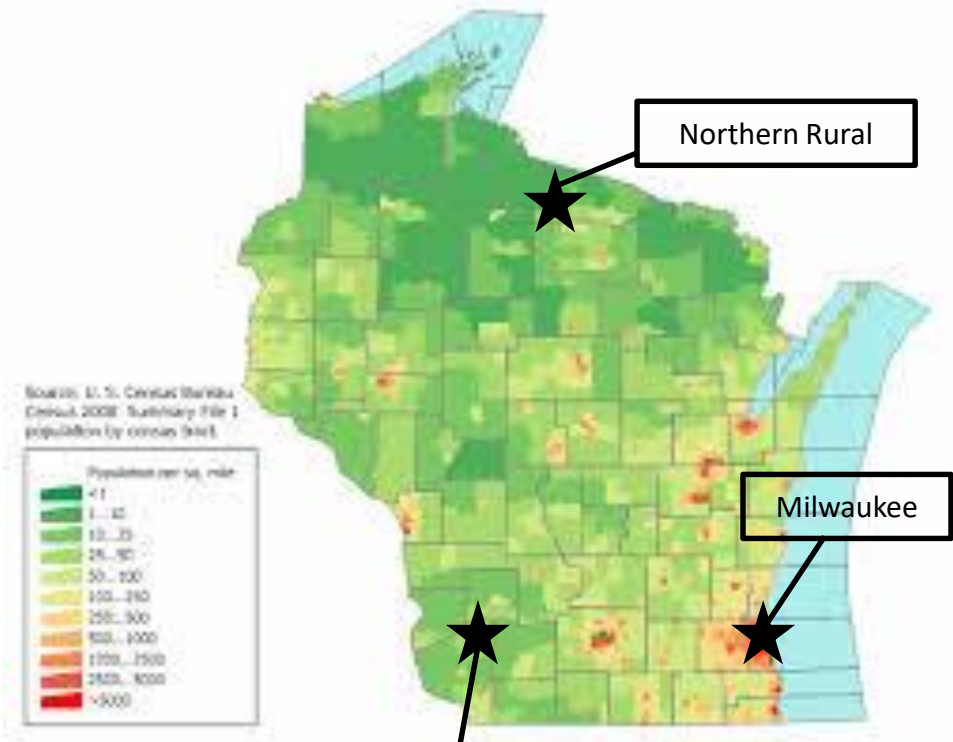
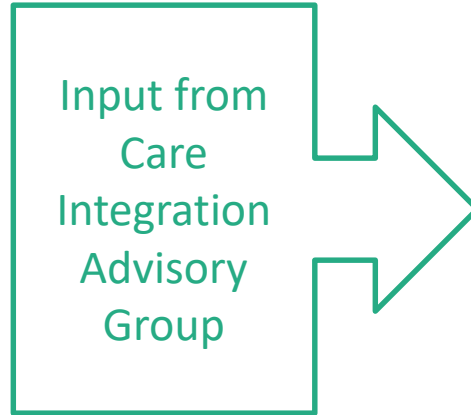


WiCII as Outcome of Act Early State Team

<p>Goal 1: Family Engagement</p> <p>Long-term vision: Families who have children with ASD/DD have access to clear and useful information, accessible community supports, and coordinated systems of care that are family-centered.</p> <p>Intermediate Goals</p> <ol style="list-style-type: none"> All families are connected to support in the way they choose (e.g., telephone, chat, text, email). A consistent set of information, both on-line and in print, is shared with families upon diagnosis, assessment or eligibility determination. All families can access and advocate for services and supports. 	<p>Goal 2: System of Early Identification and Referrals</p> <p>Long-term vision: All children receive developmental screening and ongoing developmental monitoring, and are referred to services when a concern is identified, within a coordinated system of care including a Medical Home.</p> <p>Intermediate Goals</p> <ol style="list-style-type: none"> All families are informed and actively engaged partners in developmental screening and ongoing developmental monitoring. All primary care, public health and early care and education providers consistently implement ongoing developmental monitoring and screening for child development and autism utilizing evidence-based, culturally normed validated screening tools. All primary care, public health and early care and education providers are knowledgeable of available resources and utilize a system of coordinated referrals and follow-up services that align with best practices. All primary care, public health and early care and education providers utilize a system of coordinated data collection that evaluates Wisconsin's system of developmental screening, ongoing developmental monitoring, referral and follow-up. <p>Goal 3: Assessment, Evaluation and Diagnosis</p> <p>Long-term vision: All children receive an evaluation within three months after a concern is identified through screening or developmental monitoring.</p> <p>Intermediate Goals</p> <ol style="list-style-type: none"> All providers, including primary care providers within a Medical Home, are knowledgeable of where to refer a child for assessment, evaluation and diagnostic services, and supportive services. Increase the capacity to assess, evaluate and diagnose children who have a concerning result from early developmental screening. Assessment, evaluation and diagnostic services are available, conveniently located and timely, for children who have a concerning result from developmental screening or as necessary. <p>Goal 4: Intervention and Coordinated Community Supports</p> <p>Long-term vision: All children who have been identified and/or diagnosed with ASD/DD receive timely and effective individualized interventions within a system of coordinated community-based care.</p> <p>Intermediate Goals</p> <ol style="list-style-type: none"> Local communities have a coordinated system of evidence-based intervention, treatment and educational services. Families, Medical Home providers, service providers, and educators coordinate to support families in building individualized service and support plans that are family-centered. Children have their individual needs met after diagnosis in a timely manner by a network of providers in their local community. 	<p>Goal 5: Statewide Coordination</p> <p>Coordinated Communication Plan</p> <p>Knowledgeable Referrals</p> <p>Data Collection/Evaluation</p> <p>Family Engagement</p>
---	--	--

Last Revised 4/11/2016

ASD/DD refers to Autism Spectrum Disorder (ASD) and other Developmental Disabilities (DD)



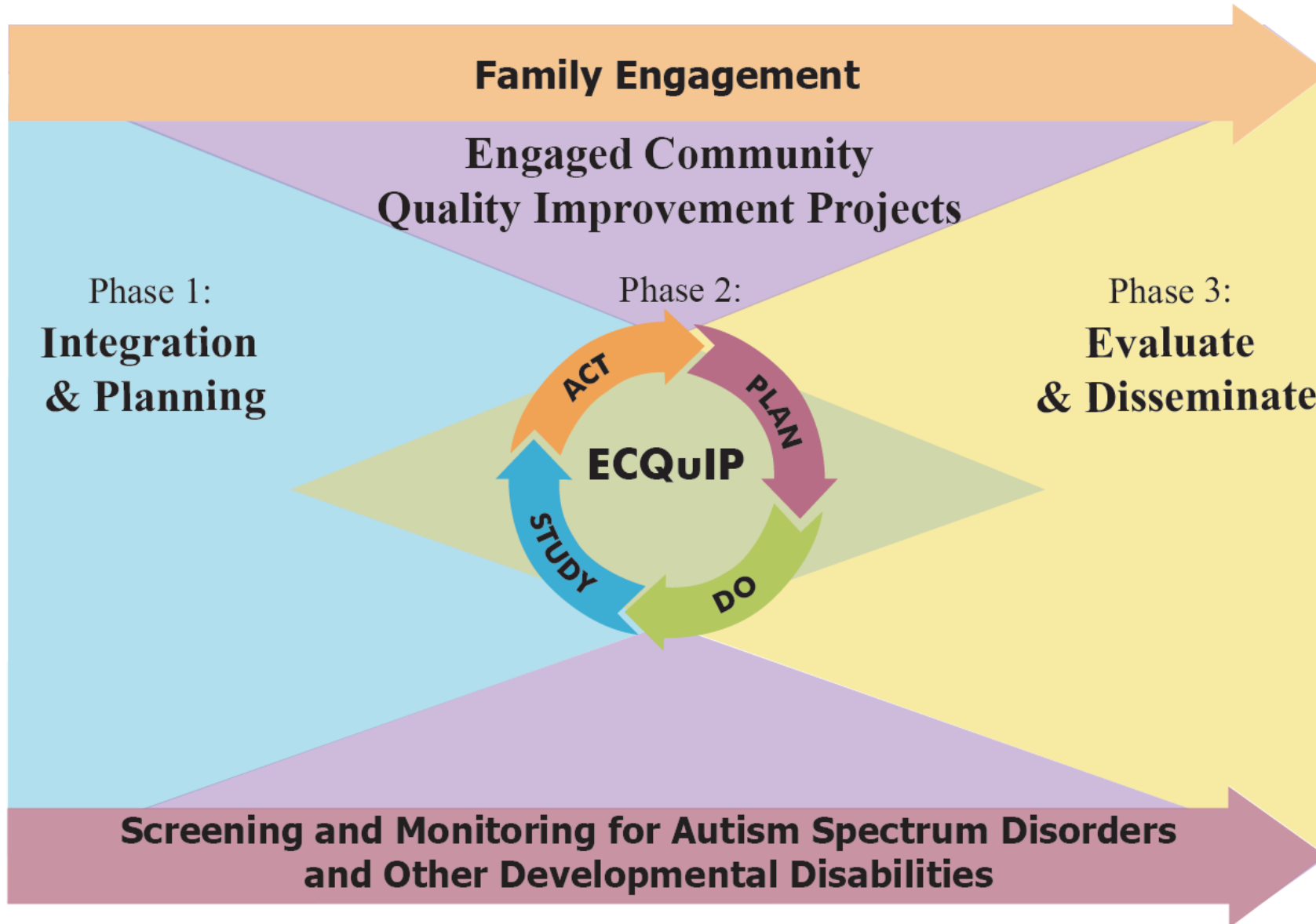
Quality Improvement & Data Collection Methods

QI & Data Collection Methods

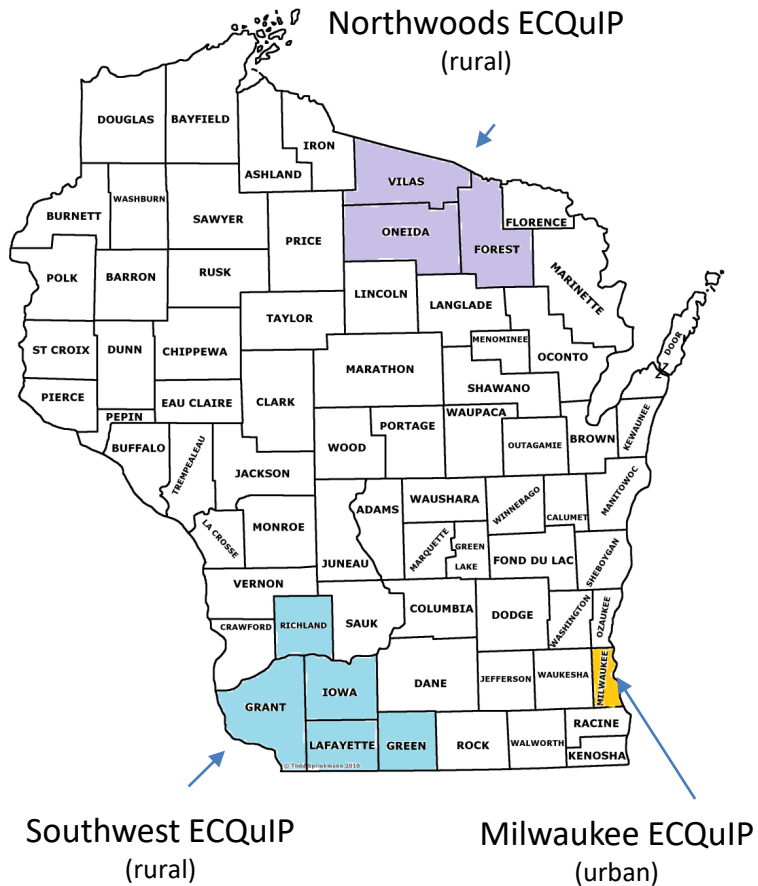
- Quality improvement cycles
- Discovery phase
- REDCap
- Parent listening sessions
- Family surveys
- Data use agreements / Early Childhood Integrated Data System



Wisconsin Care Integration Initiative



Engaged Community Quality Improvement (ECQuIP) Sites



Wisconsin Care Integration Initiative (WiCII) Leadership and Implementation Staff

WI Act Early State Team



38+ organizations represented

Includes parents of children with ASD/DD

Statewide and growing...



Information & Referral Services

- Open Monday – Friday, 7 AM – 6 PM
- After hours inquiries responded to within 24 hours
- Interpretive services available
- Individuals can reach out directly OR health/social service provider can call on their behalf



Call

1-800-642-7837



Text

608-360-9328



Email

help@wellbadger.org



Facebook Messenger

@wellbadger



Live Chat

wellbadger.org



Searchable Database

wellbadger.org



Survey Results (250 total responses):

- **84% Community Members**
- **16% Health/Social Service Professionals**
- **94% of respondents are parents**
 - **67% have children with special needs**
 - **41% have children < age 5**
- **Gender: 97% Female**
- **41% Eligible for BadgerCare Plus/Medicaid**
- **Race/Ethnicity:**
 - 77% Caucasian
 - 8% African American
 - 4% Hispanic or Latino(a)
 - 4% Asian/Pacific Islander
 - 2% Mixed Race
 - 2% Native American

Well Badger Resource Center

Please read both sides of this sheet and then answer the questions starting on page 3. Please make notes as you read below, marking anything that is confusing or that could be improved. Thank you!



Well Badger Resource Center
Support is out there. We'll help you find it.

Attention Wisconsin residents:

- Not sure how to pay for healthcare?
- Need assistance feeding your family?
- Want more resources for your special needs child?
- Would you like help buying new baby supplies?
- Worried your child has autism or delayed development?
- Wondering if you can get a free health screening?
- Looking for assistance caring for a loved one?

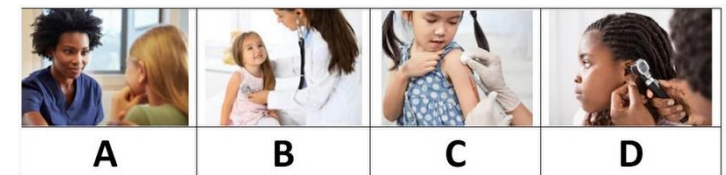
Your first step: call us today
1-800-642-7837

Well Badger information & referral specialists are ready to help you from **7:00 AM to 6:00 PM, Monday through Friday.**

We're also available via live chat, text message, and email!
www.wellbadger.org

Then you've come to the right place! Well Badger

Calling after hours? You can leave a



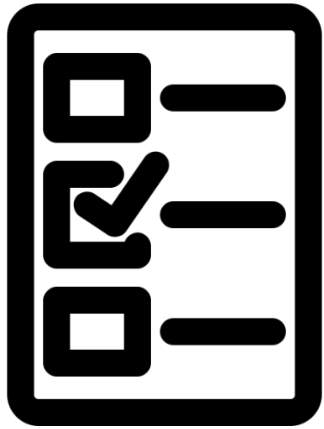
Survey Results

Top Taglines:

- Not sure where to turn? Start here.
- You have questions. We find answers.
- Connecting you to the resources you need.
- Support is out there. We'll help you find it.
- *Start Here.*



Discovery Phase



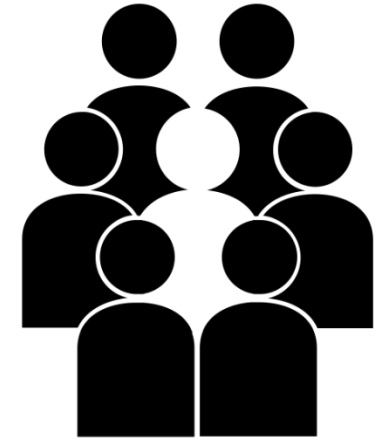
online
survey



stakeholder
interviews



discovery
meeting



listening
sessions



ECQuIP Debrief

- 1 → What new information did we learn during the event/activity?

- 2 → What worked well?
(i.e. If we did this again, what would we do the same?)

- 3 → What didn't work well?
(i.e. If we did this again, what would we do differently?)

- 4 → What will we do differently before/when we complete a similar event/activity?

Northwoods ECQuIP | BAR-AAR | DATE 1/3/19

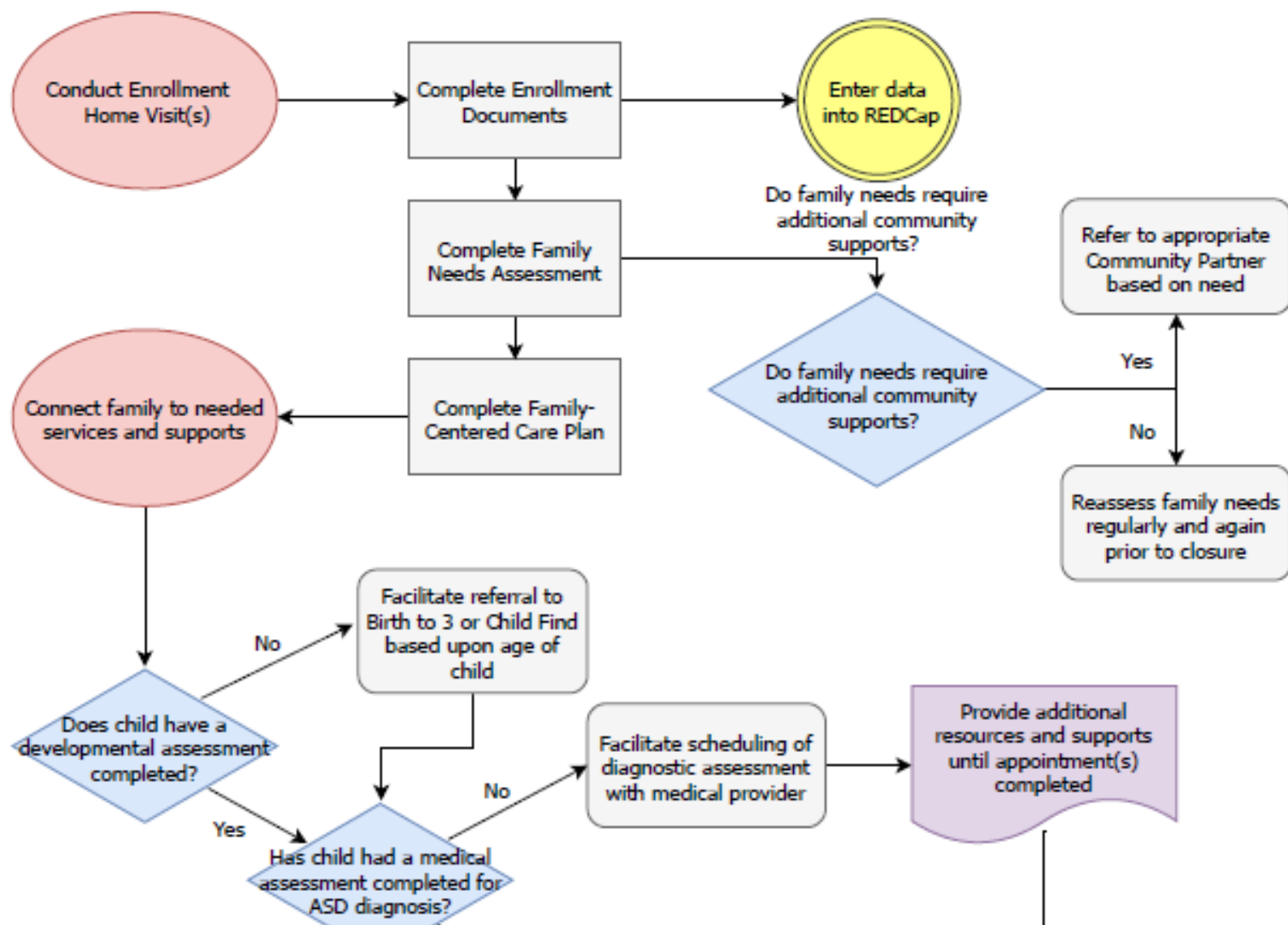
Brief description of event/action: Feb 1, 2019 Community Conversation

Framing question(s): How do we create community awareness of what families experience when trying to obtain a diagnosis and/or services for autism in the Northwoods? How do we garner commitment to action on improving the system?

BEFORE ACTION REVIEW	AFTER ACTION REVIEW
<p>Date of BAR: 1/3/19</p> <p>Participants: Jenny Felty, Cory Dart, Kari Mueller, Lynn Hrabik</p> <p>What are our intended results?</p> <ul style="list-style-type: none"> • Engage families from Parent Café into planning/hosting event • Garner participant commitment (advocacy, funds, time) to do one small thing to improve the system • Increased community awareness of what families experience (i.e. their struggles navigating the system) • Get connected to families that don't know about ECQuIP but need the support <p>What will that look like?</p> <ul style="list-style-type: none"> • Families in leadership roles (planning event, making personal invitations, table hosts, etc.) • Diverse participant attendee list (families impacted by autism, healthcare providers and/or clinic managers, public health, Birth to 3 Program Supervisor and/or line staff, school district Early Childhood Special Ed programs, childcare directors, CYSHCN regional center staff, Autism Society staff, United Way, large industry/business, faith-based leaders, family support providers, civic orgs such as Lions/Kiwanis/Rotary, elected officials and media) • A list of participants identified in each county/community (including partners that haven't been engaged before) with stated commitment to putting time and energy towards this effort; advocacy, funds and/or time • # of new family navigation referrals <p>What challenges might we encounter?</p> <ul style="list-style-type: none"> • Low attendance 	<p>Date of AAR: 2/?/19</p> <p>Participants:</p> <p>What were our actual results?</p> <ul style="list-style-type: none"> • <p>What caused/contributed to these results?</p> <ul style="list-style-type: none"> • <p>What will we sustain or improve? (If we could turn back the clock, what would we do differently?)</p> <ul style="list-style-type: none"> • <p>When is our next opportunity to test what we have learned?</p> <ul style="list-style-type: none"> •

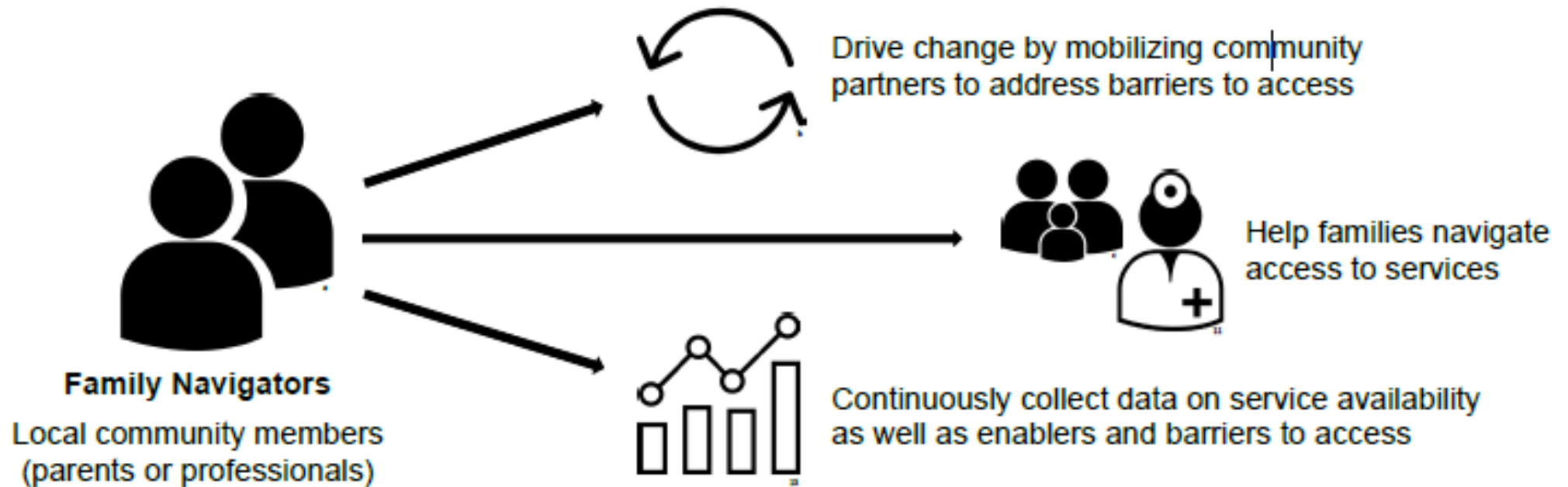
Family Navigation Services Protocol Flowchart v3.0

for families consenting for enrollment in FN services following concerning ASD screen result



ECQuIP Family Navigation Model

Draws on evidence for Family Navigations from “community health worker” and “patient navigation” models^{7,8,10}



- Feinberg, E., et al. (2016). “Disparities in Timely Autism Diagnosis Through Family Navigation: Results From a Randomized Pilot Trial.” *Psychiatry Services*, 67(8), 912-15.
- Roth, B., et al. (2016). “Impact of Autism Navigator on Access to Services.” *Journal of Developmental & Behavioral Pediatrics*, 37:188–95.
- Russa, M., et al. (2015). “Expanding Supports to Improve the Lives of Families of Children With Autism Spectrum Disorder.” *Journal of Positive Behavior Interventions*, 17(2) 95–104.





Client tracking forms
 Agency tracking forms
 Quality Improvement forms

Applications [-]

- Calendar
- Data Exports, Reports, and Stats
- Data Import Tool
- Data Comparison Tool
- Logging
- Field Comment Log
- File Repository
- User Rights and DAGs
- Data Quality
- REDCap Mobile App
- External Modules

Reports [Edit reports](#) [-]

- 1) # of FN-enrolled children
- 2) # of FN-enrolled children w/ an ASD educ. determination
- 3) # of FN-enrolled children with ASD clinical dx
- 4) Family Empowerment Scale for Enrolled Children
- 5) # of FN-enrolled children with concerning ASD screener
- 6) Number of FN conducted screens
- 7) Demographics of children
- 8) Barriers
- 9) Enablers
- 10) Comparing data and results

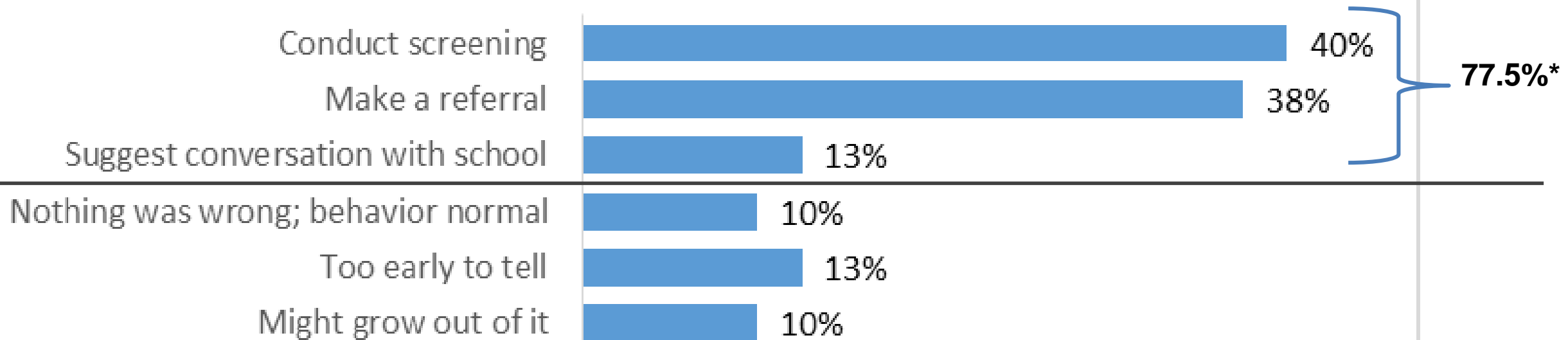
Data Collection Instrument	Status
Referral form (survey)	
Child And Family Identity	
Family Contact Information	
Family Empowerment Scale	
Demographics	
Family Concern	
Screening	
Educ Deter Medical Dx And Interv Services	
Additional Support Services	
Family Navigation Begin/End Dates	
Family Navigation Notes	

Repeating Instruments

Family Empowerment Scale	
1	
2	

REDCap Data Use Example

ECQuIP: MD Response to Concern of Ever Enrolled Children (n=40) Oct 2017 thru Feb 2019



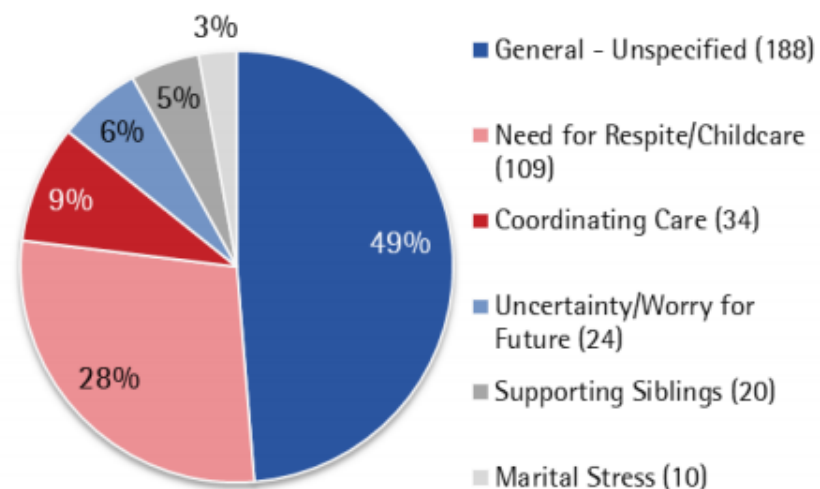
*Ranged from 43% in Northwoods (n=7) to 57% in Southwest (n=7) to 92% in Milwaukee (n=25)

Autism in Wisconsin 2017 Report



1 STRESS/NEED FOR SUPPORT

The most frequent answer to this question was in regards to individual, family, or caregiver stress and the need for more support. Fifty-two (52%) percent of all respondents listed this as a challenge and this answer accounted for 18% of all challenges reported. As the graph shows, 28% of the answers falling in this category were categorized as a need for more support in the form of better respite or childcare options, 9% discussed the difficulties in coordinating care/appointments, 6% mentioned a worry and uncertainty for the future, 5% discussed the need for supporting siblings of children with autism as a challenge, 3% cited marital stress, and the other 49% answered generally about stress and/or the need for better support.



“Feeling isolated and alone because former friends don’t understand what our family is going through.”

“Inability to support self due to complex paperwork.”

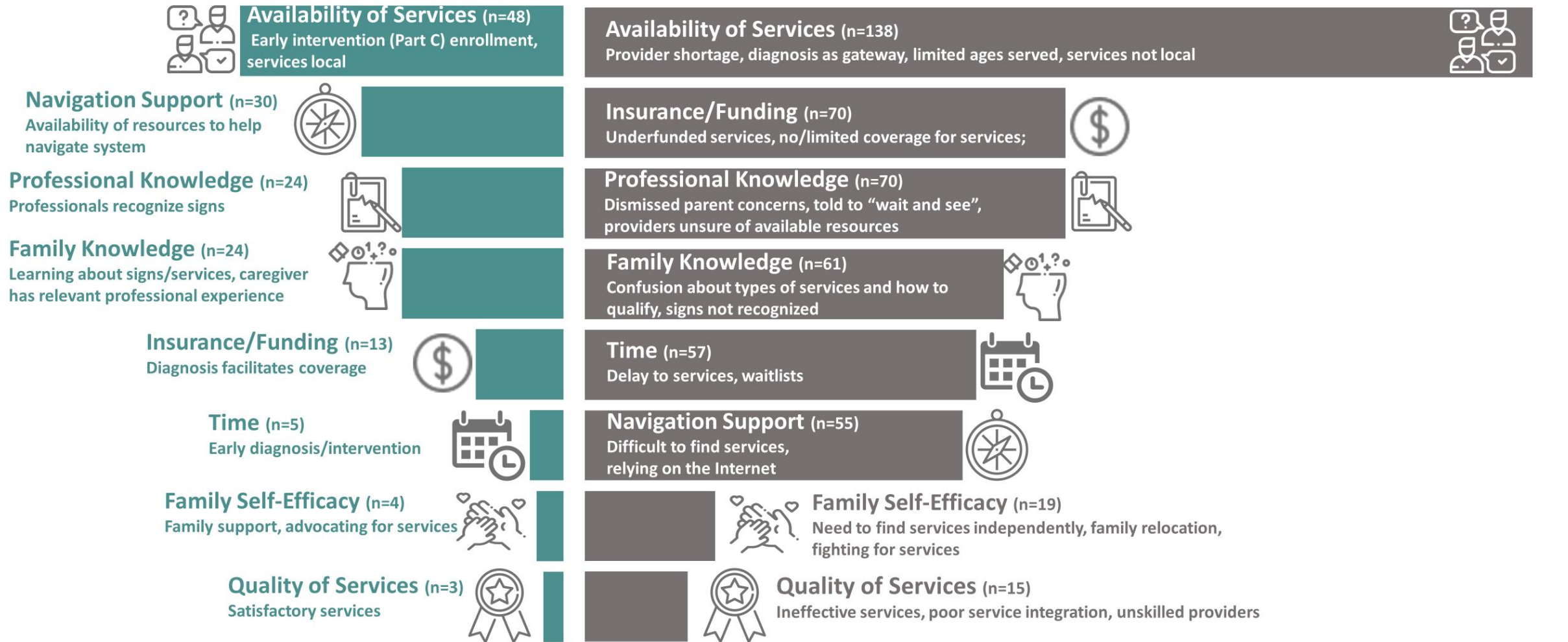
“Extreme parental fatigue and stress prior to receiving support services.”

Frequency and Type of Enablers and Barriers Mentioned by Focus Group and Survey Respondents **DRAFT**

Data about families' experiences gathered through 2 rural (December 2017) and 1 urban (March 2018) family focus group (n=20) and the Wisconsin Family Autism Survey administered March 2018 (n=363 respondents)

Enablers: Makes it easier to access services

Barriers: Makes it harder to access services



Number of Mentions

Wisconsin Family Enabler and Barrier Code Definitions



Availability of Services: Access to providers or services; availability of providers or services in area; ability to get to providers and services (e.g., transportation, insurance provider network)



Navigation Support: Getting help to navigate the system; searching the Internet to figure out what is available or what to do next; agencies that help families navigate the system; difficulty finding support in navigating the system; confusion about how to navigate the system; anything else related to trying to find one's way through the autism pathway



Insurance/Funding: Cost of services; having or not having insurance; co-payments, deductibles, and out-of-pocket expenses; applying for Medicaid; other Medicaid support (e.g., long-term support waiver, COP)



Professional Knowledge: Knowledge, skill, and attitudes of providers; provider training level; provider compliance with professional standards; degree of family-centeredness; degree of bias



Time: waiting lists; waiting for help; “wait and see”; time spent trying to get help; time demands of seeking or getting help; conflicting needs in terms of time



Family Knowledge: knowledge of autism symptoms; knowledge of providers and services; knowledge of where to go to get help; knowledge of “the system” and how to navigate it; attitudes and assumptions about autism; attitudes and assumptions about providers, services, agencies, or system



Quality of Services: perceptions of strength or weakness of services; satisfaction or dissatisfaction with services



Family Self-Efficacy: parents pushing for what they and their child need; fighting to protect rights; educating and empowering other families; feeling empowered or disempowered

WI's Early Childhood Integrated Data System

Wisconsin developed five Essential Policy Questions during the Feasibility Study.

1. Are children, birth to 5, on track to succeed when they enter school and beyond?
2. Which children and families are and are not being served by which programs/services?
3. Which children have access to high-quality early childhood programs and services?
4. What characteristics of programs are associated with positive child outcomes for which children?
5. What are the education and economic returns on early childhood investments?

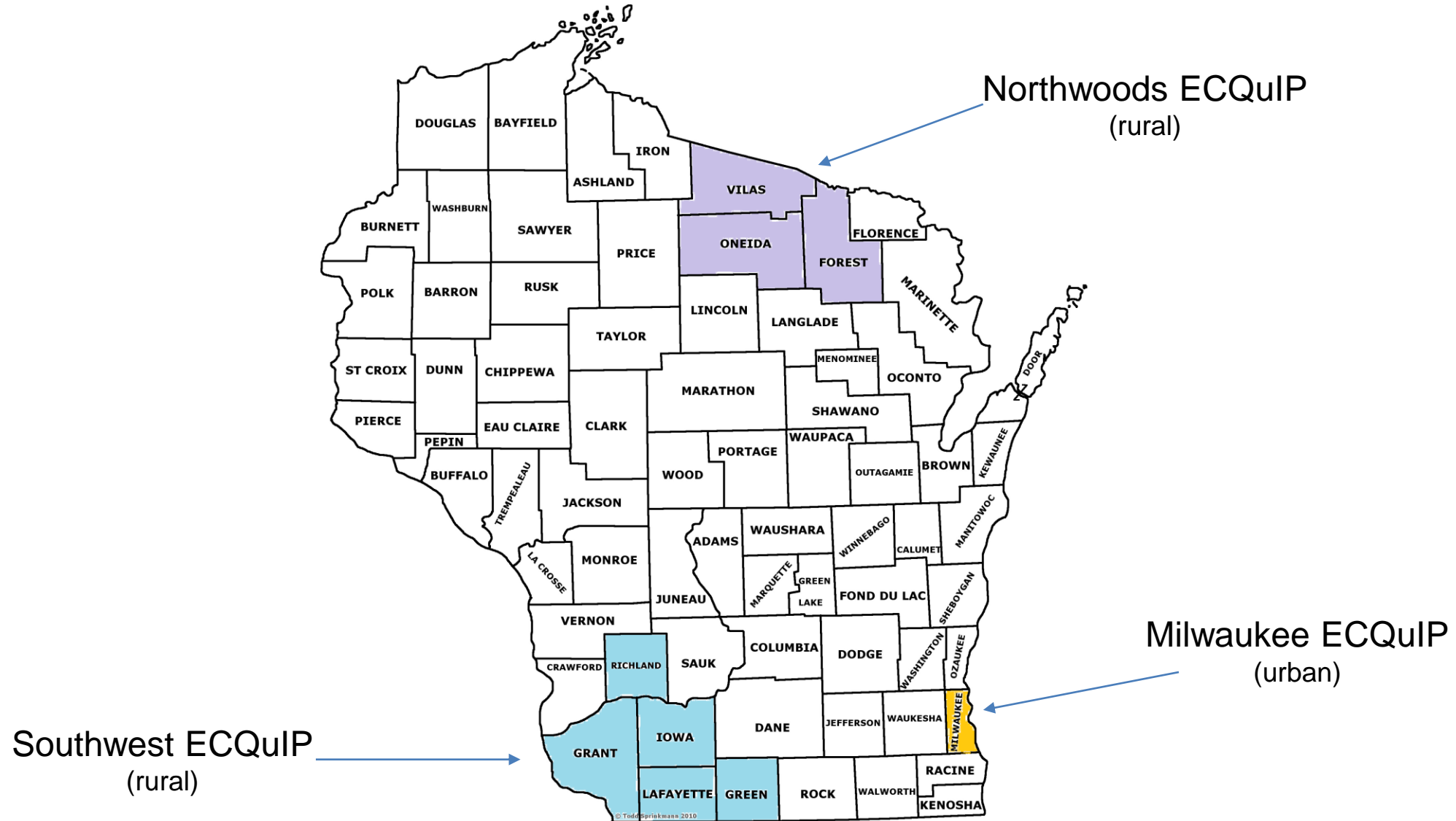
Key partners: Department of Children and Families (DCF), Department of Health Services (DHS) and Department of Public Instruction (DPI)]

<https://dpi.wi.gov/early-childhood/ecids>



ECQuIP Sites

Engaged Community Quality Improvement (ECQuIP) Sites



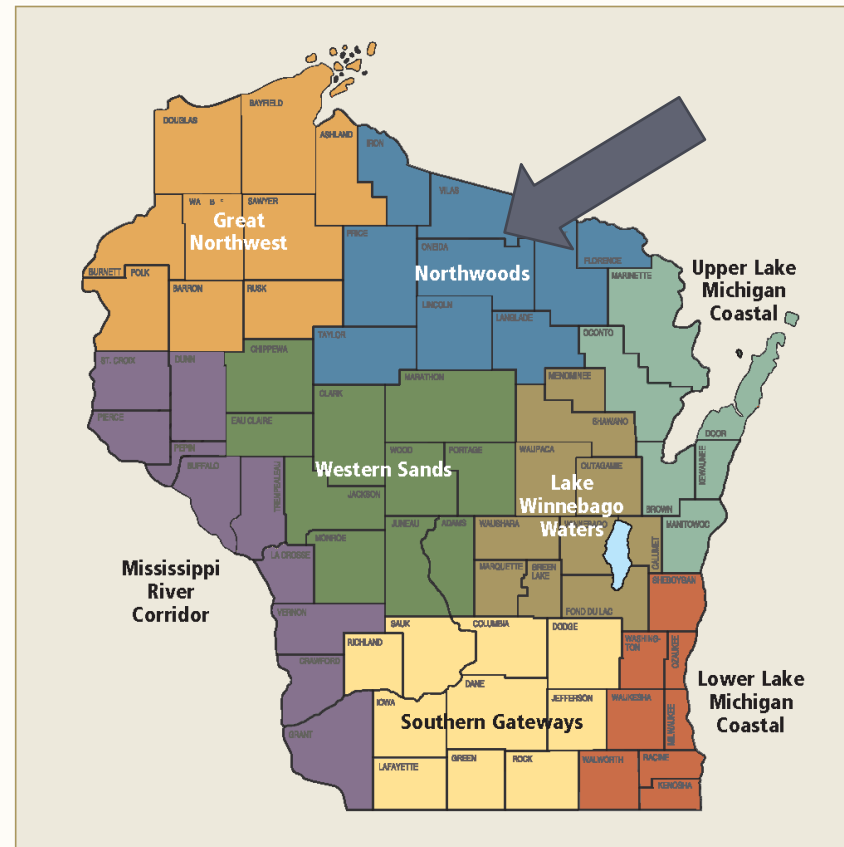
Northwoods ECQuIP



Cory Dart

Kris Barnekow

Tri-County area of the Northwoods of Wisconsin



The Journey



- Vilas County Family Resource Coalition
- Connecting the Waisman Center to the Coalition
- Identifying Headwaters, Inc., as the lead agency
- Discovery Phase – engaging community partners
- Screening trainings, family navigation services
- Sustainability – partnerships with Ascension



The Future



- Northwoods Autism Consortium – partnership with Ascension Healthcare
- Building Capacity for ASD diagnostic and intervention services
 - Presentation to the medical staff- Interprofessional practice and Autism
 - ADOS training – to develop a diagnostic team
 - Targeted hiring practices – ADOS -trained clinical psychologist, BCBA
 - Exploring the use of telemedicine for intake and family feedback sessions

Milwaukee ECQuIP

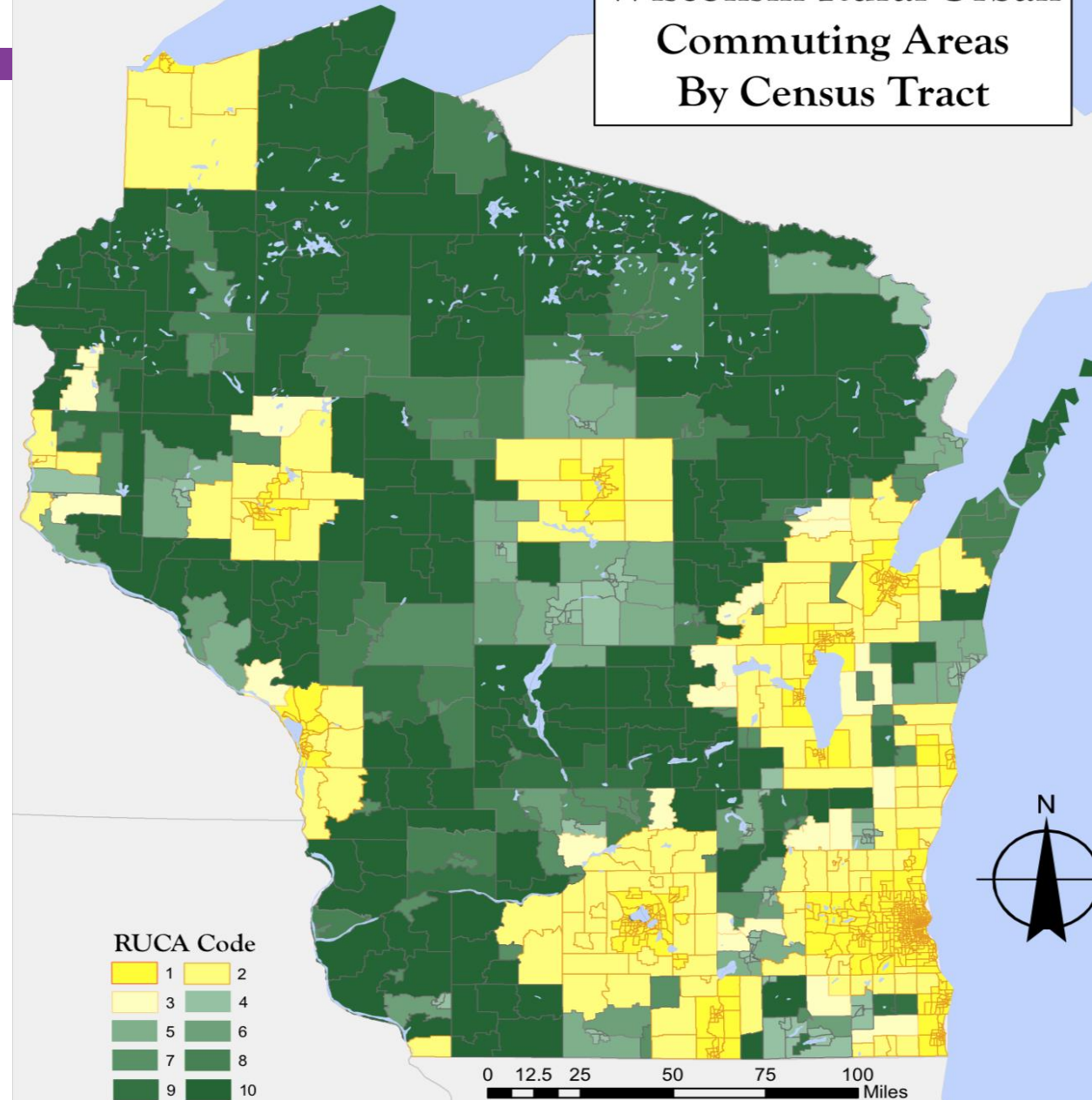


Learn the Signs.
Act Early.



Southwest ECQuIP

Wisconsin Rural-Urban Commuting Areas By Census Tract



QUESTIONS?

