

# HPOE *Live!*

*2017 Webinar Series*

# The presentation will begin shortly.

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# Partnership to Improve Health for Children

## Zero to Three

**April 27, 2017**

**12:30 p.m. ET | 11:30 a.m. CT**

Nancy Swigonski, MD, MPH, FAAP

- Professor of Fairbanks School of Public Health and Department of Pediatrics, IU School of Medicine
- Co-chair of Indiana's Perinatal Quality Improvement Collaborative, Quality Improvement Committee
- Executive Director of Quality Innovation for the Riley Maternity and Newborn Health initiative
- Director of Child Health Improvement Partnership – Indiana (CHIP-IN)

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No financial disclosures

# Improving early identification and diagnosis of developmental delay and autism spectrum disorders

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SCHOOL OF MEDICINE

INDIANA UNIVERSITY



Indiana State  
Department of Health  
Children's Special Health  
Care Services



*Welcome to*

**Indiana**

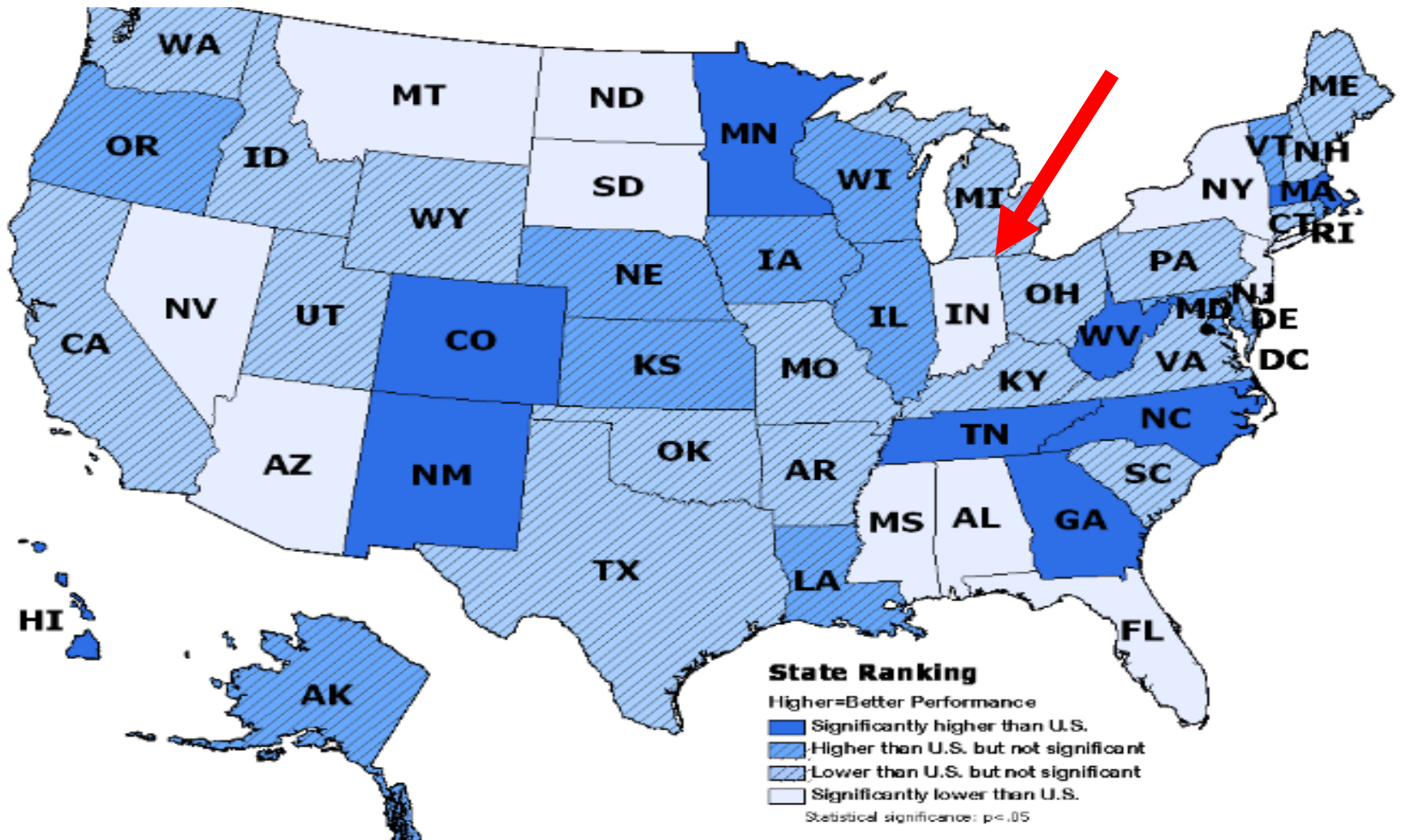
*Crossroads of America*

**THE PROBLEM**

# **Long waiting lists for diagnosis of autism spectrum disorders and developmental delay**

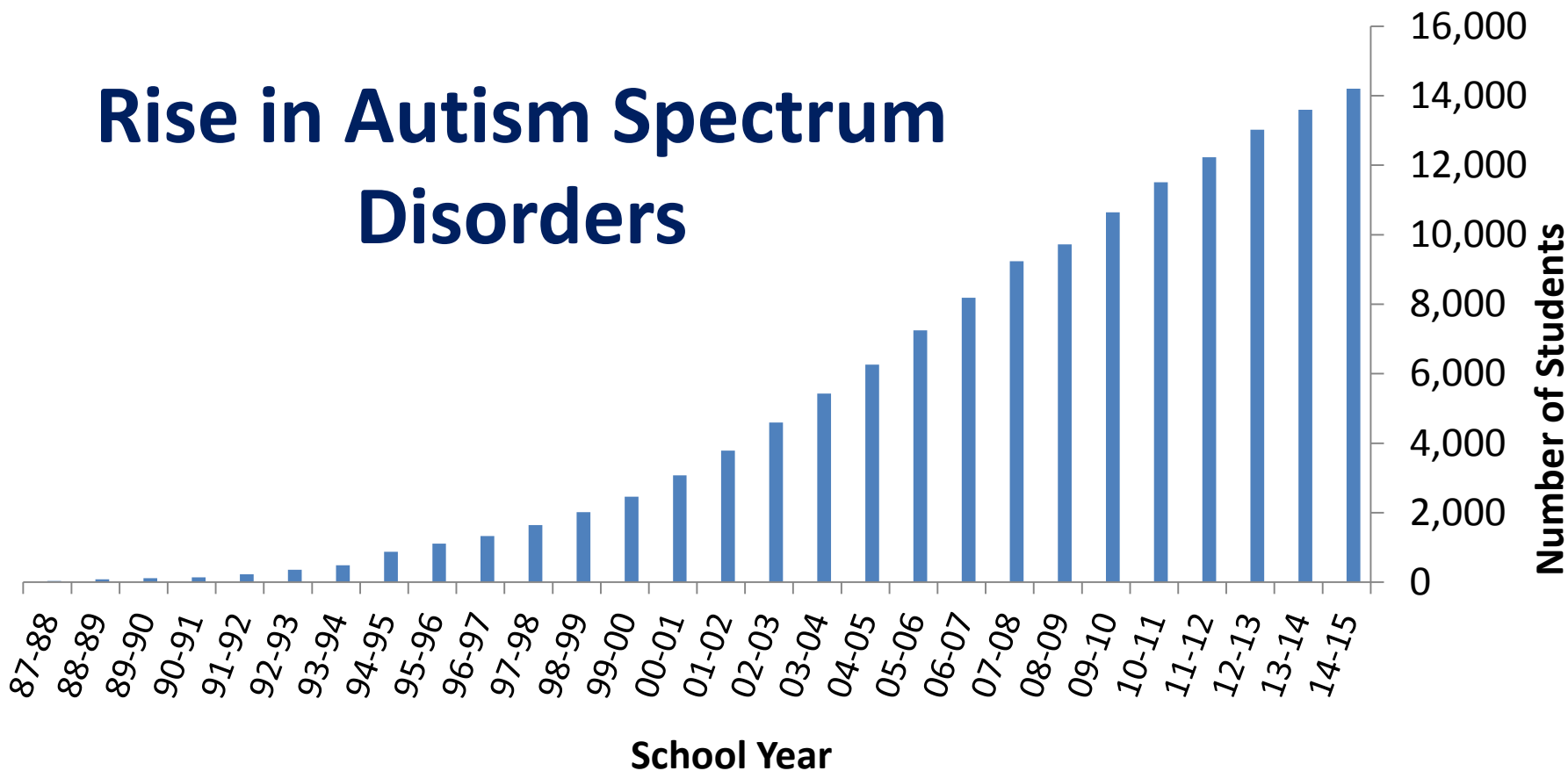
Nancy Swigonski, MD, MPH, FAAP  
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- More children in Indiana have developmental delay than nationally - IN 4.9% vs. US 3.6% vioral
- Fewer children ages 10 mos - 5 yrs receive developmental screening IN 24% vs. US 31%



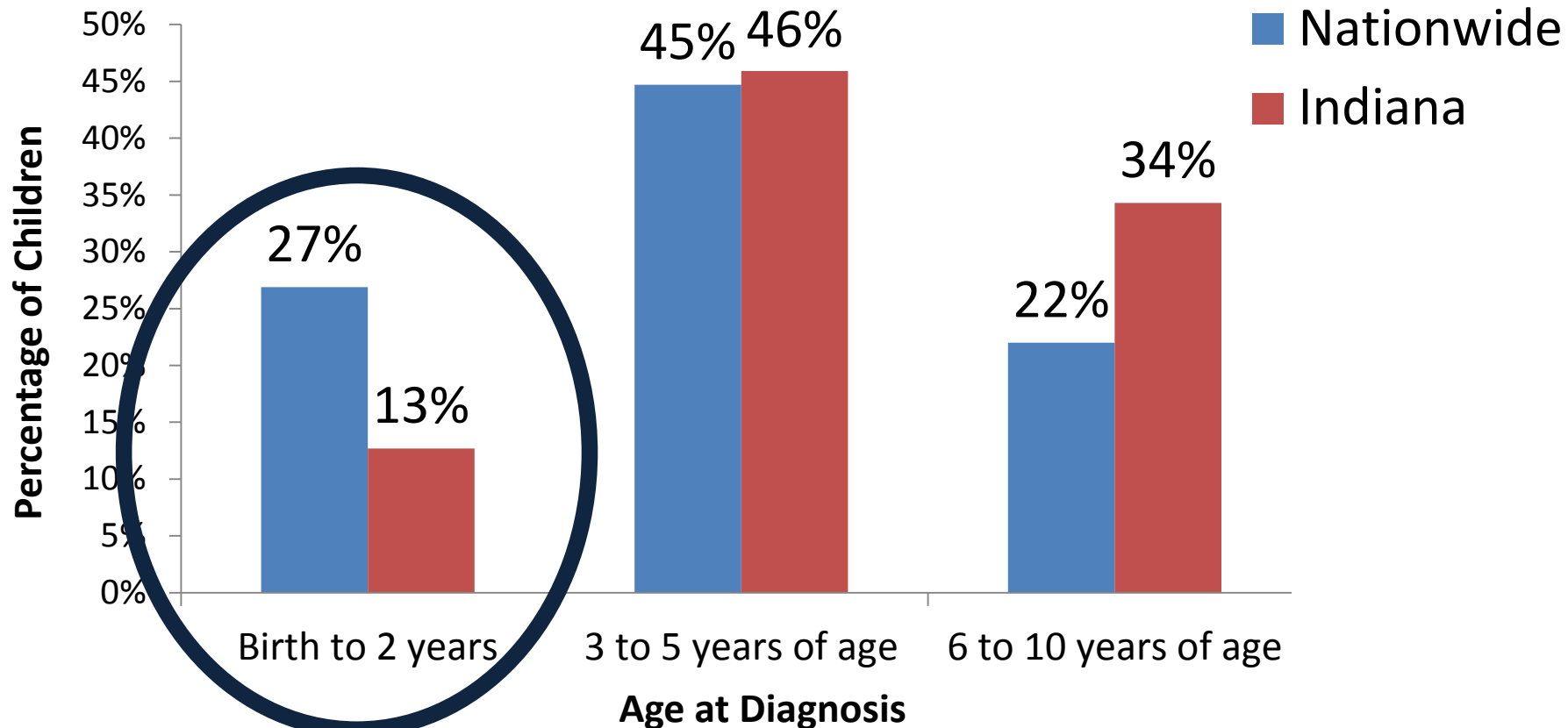
# # Students Identified with Autism Spectrum Disorder in Indiana's Public Schools

## Rise in Autism Spectrum Disorders



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nswigons@iupui.edu

# Average age of diagnosis in Indiana = 63 months



Source: NS-CSHCN 2009/10. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health [www.childhealthdata.org](http://www.childhealthdata.org).



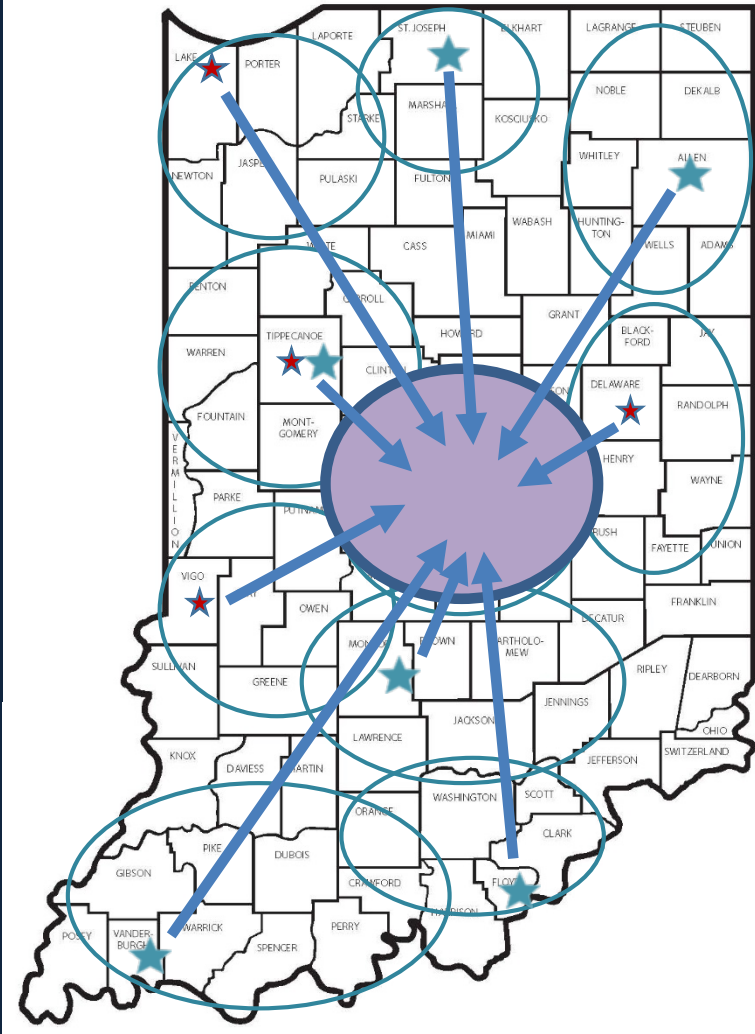
# Problems in Early Identification

- Fewer than 30% of children with developmental delays are identified before entering school
- While we may find children with high levels of impairment
  - miss many who have more subtle issues
  - children who may be great responders to intervention
- **Developmental and ASD Screening** **all** children, most of whom will not have identifiable risks or concerns at 9, 18, 24 or 30

Identifying Infants & Young Children with Developmental Disorders in the Medical Home: Algorithm for Developmental Surveillance & Screening  
*Pediatrics* 2006;118:405-420

- Lack of screening
- Long travel times
- Long waiting lists
- Late diagnosis
- Inconsistent diagnosis
- Difficulty coordinating with community resources

## State of Indiana



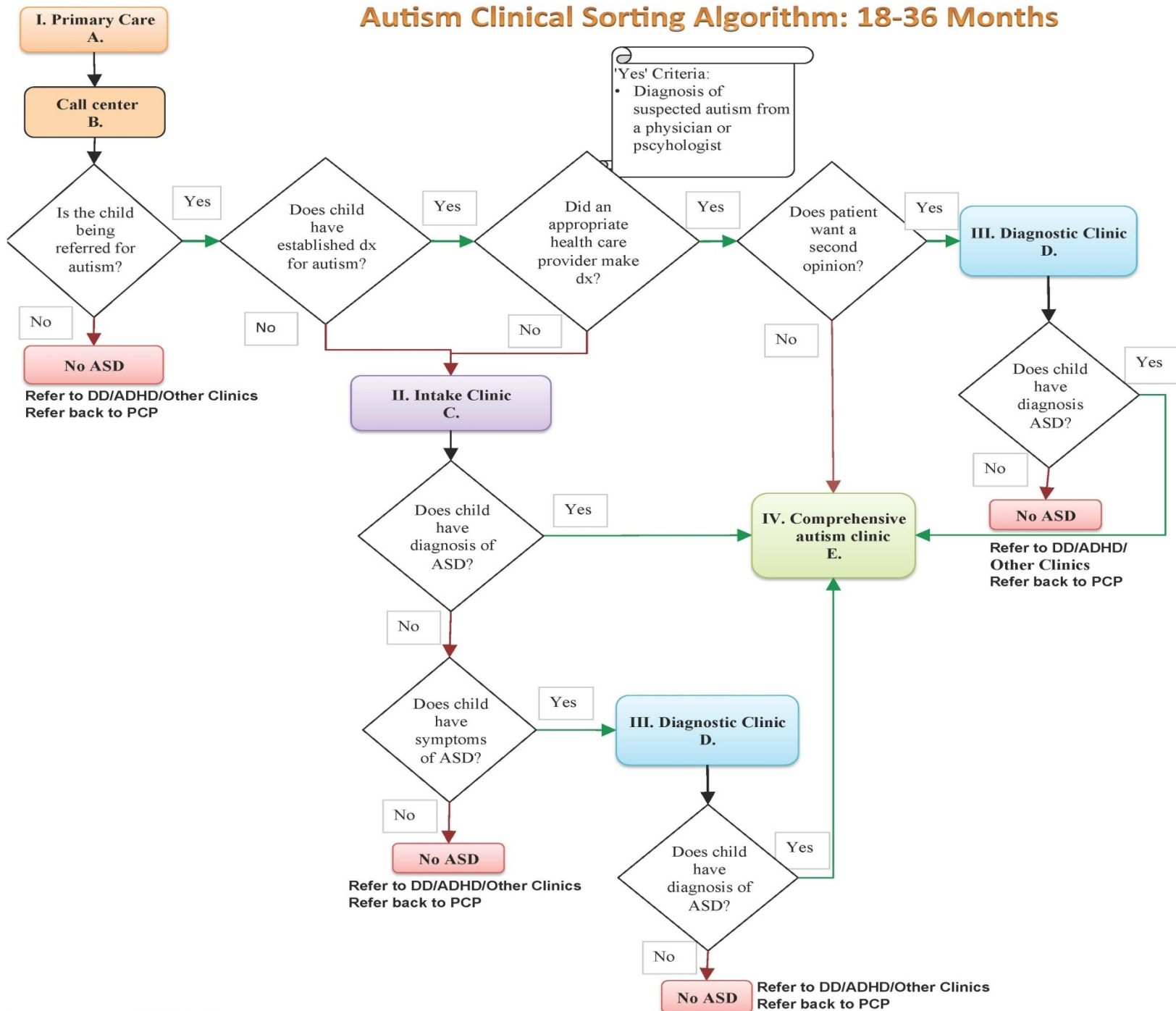
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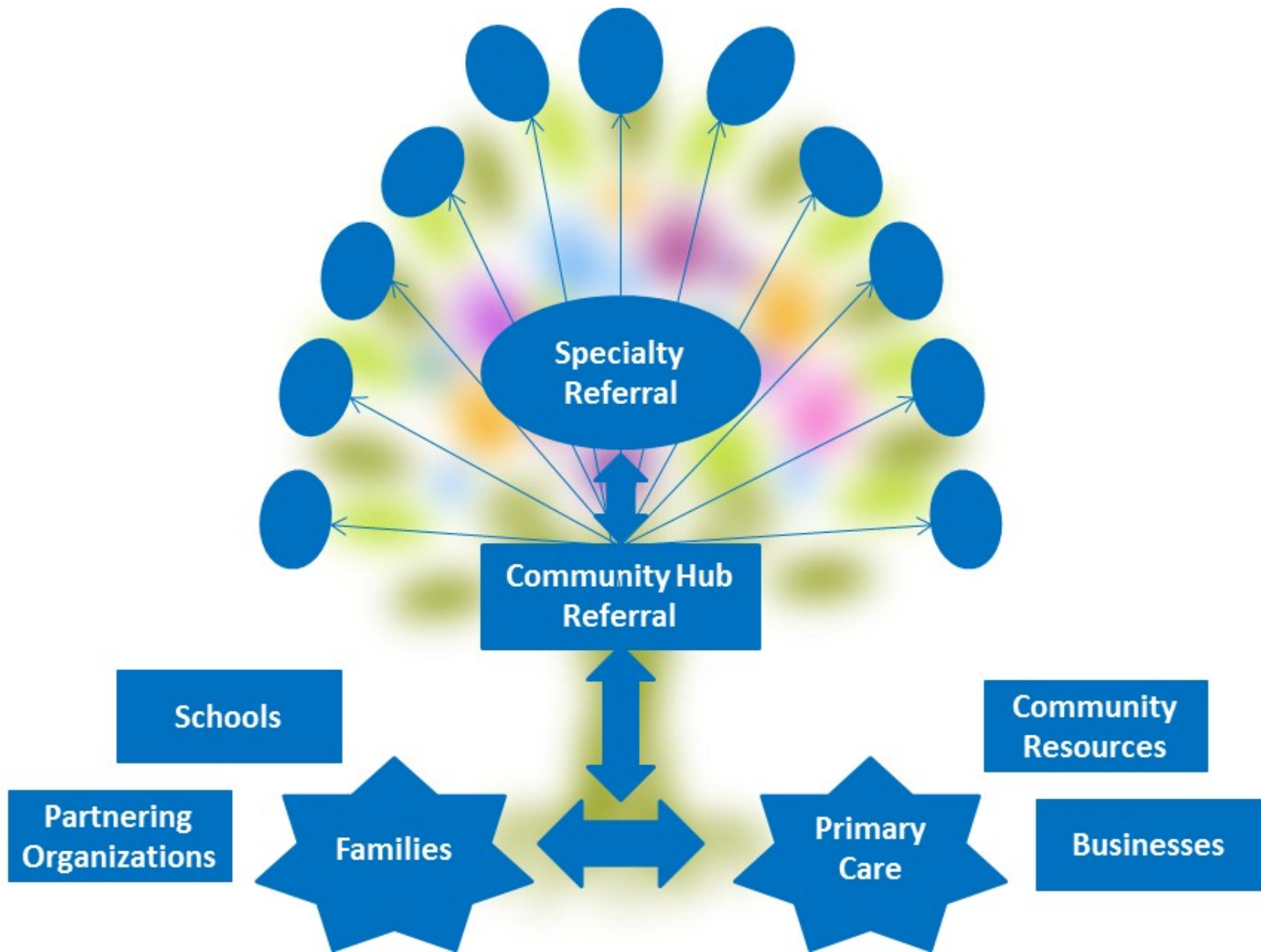
THE SOLUTION

# Autism Clinical Sorting Algorithm: 18-36 Months

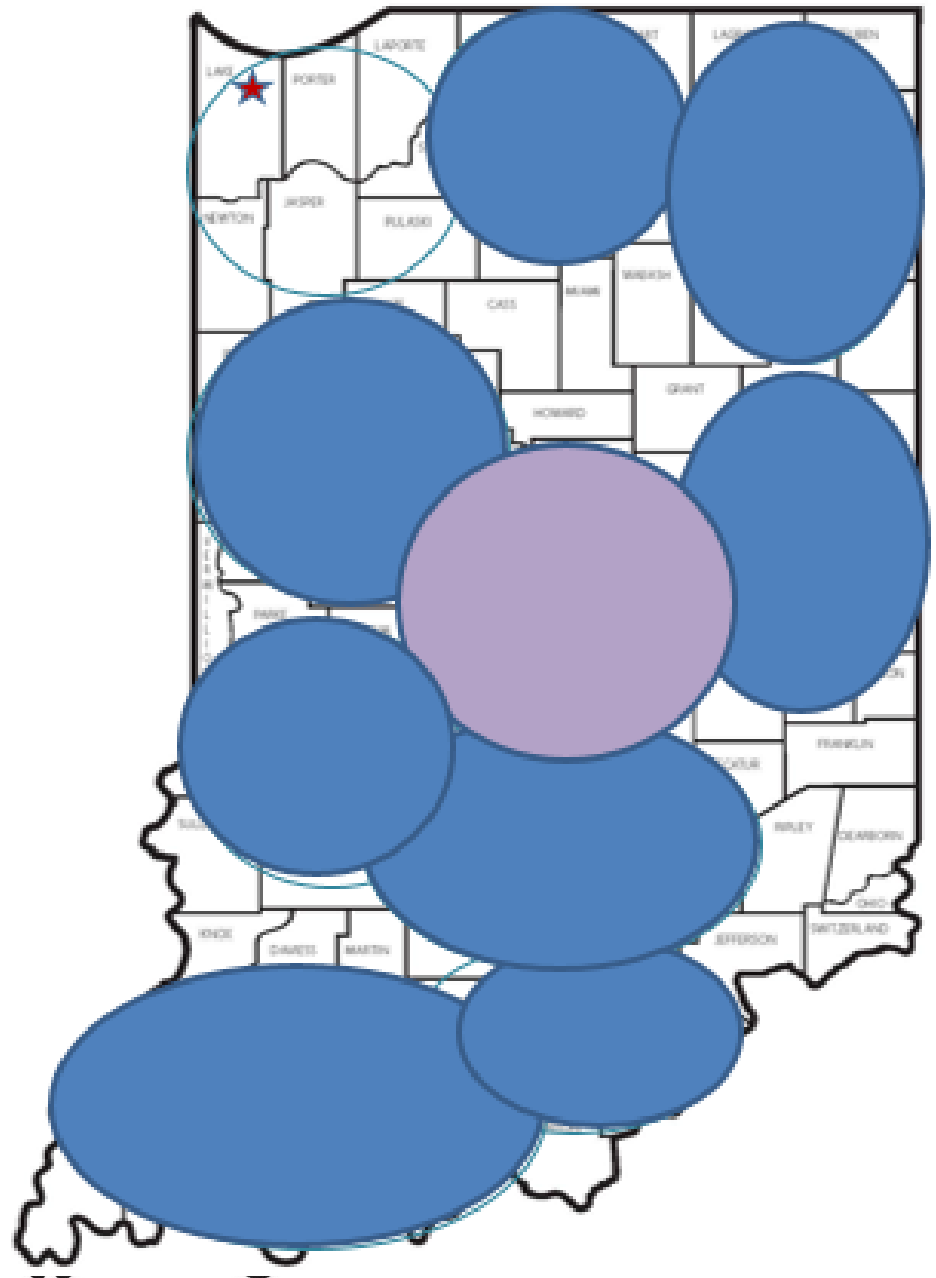


'Yes' Criteria:  
 • Diagnosis of suspected autism from a physician or psychologist





**92.7%**  
**of 0-4 year olds**  
**in the state**



## The Model for Improvement

### AIM

What are we trying to accomplish?

### MEASURES

How will we know that a change is an improvement?

### CHANGES

What changes can we make that will result in improvement?



© 2012 Associates in Process Improvement

What are we trying to accomplish?  
How will we know that a change is an improvement?

# Aim

**Decrease the age of diagnosis of DD/ASD from 5 years to under 3 years in Indiana over 3 years**

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# Drivers Diagram

## Statewide System for Early Evaluation of ASD / DD

### Global AIM

Decrease the age of diagnosis of DD/ASD from 5 years to under 3 years in Indiana over 36 months

Primary care evidence-based screening

Utilization of tiered system with evidence based, standardized assessments

Quality tracking of services and performance

Work with community including schools, other care providers, family organizations

*Welcome to*

**Indiana**

*Crossroads of America*

THE RESULTS

# Drivers or Core Elements

What changes can we make that will result in an improvement?

## Global AIM

Decrease the age of diagnosis of DD/ASD from 5 years to under 3 years in Indiana over 36 months

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# General Developmental Screening Tools

- Ages and Stages Questionnaire
- Parents' Evaluation of Developmental Status (PEDS)
- Battelle Developmental Inventory (BDI) Screening Test
- Bayley Infant Neurodevelopmental Screener (BINS)
- Brigance Screens-II
- Infant Development Inventory
- Child Development Review
- Child Development Inventory (CDI)
- Denver-II Developmental Screening

# Autism Screening Tools

- Modified Checklist for Autism in Toddlers (M-CHAT R/F)
- Autism Behavior Checklist (ABC)
- Checklist for Autism in Toddlers
- Modified Checklist for Autism in Toddlers-23 (CHAT-23)
- Pervasive Developmental Disorders Screening Test-II (PDDST-II) - Stage 1- Primary Care Screener
- Pervasive Developmental Disorders Screening Test-II (PDDST-II) - Stage 2- Developmental Clinic Screener
- Screening Tool for Autism in Two-Year-Olds (STAT)
- Social Communication Questionnaire



# Referrals by Hub from Primary Care Physicians

Hub Name	# PCPs who made	
	≤5 Referrals	>5 Referrals
A	26	17
B	12	0
C	55	2
D	4	1
E	23	1
F	19	1
G	22	1
H	49	5
I	257	2
<b>Total</b>	<b>467</b>	<b>30</b>

# Drivers or Core Elements

What changes can we make that will result in an improvement?

## Global AIM

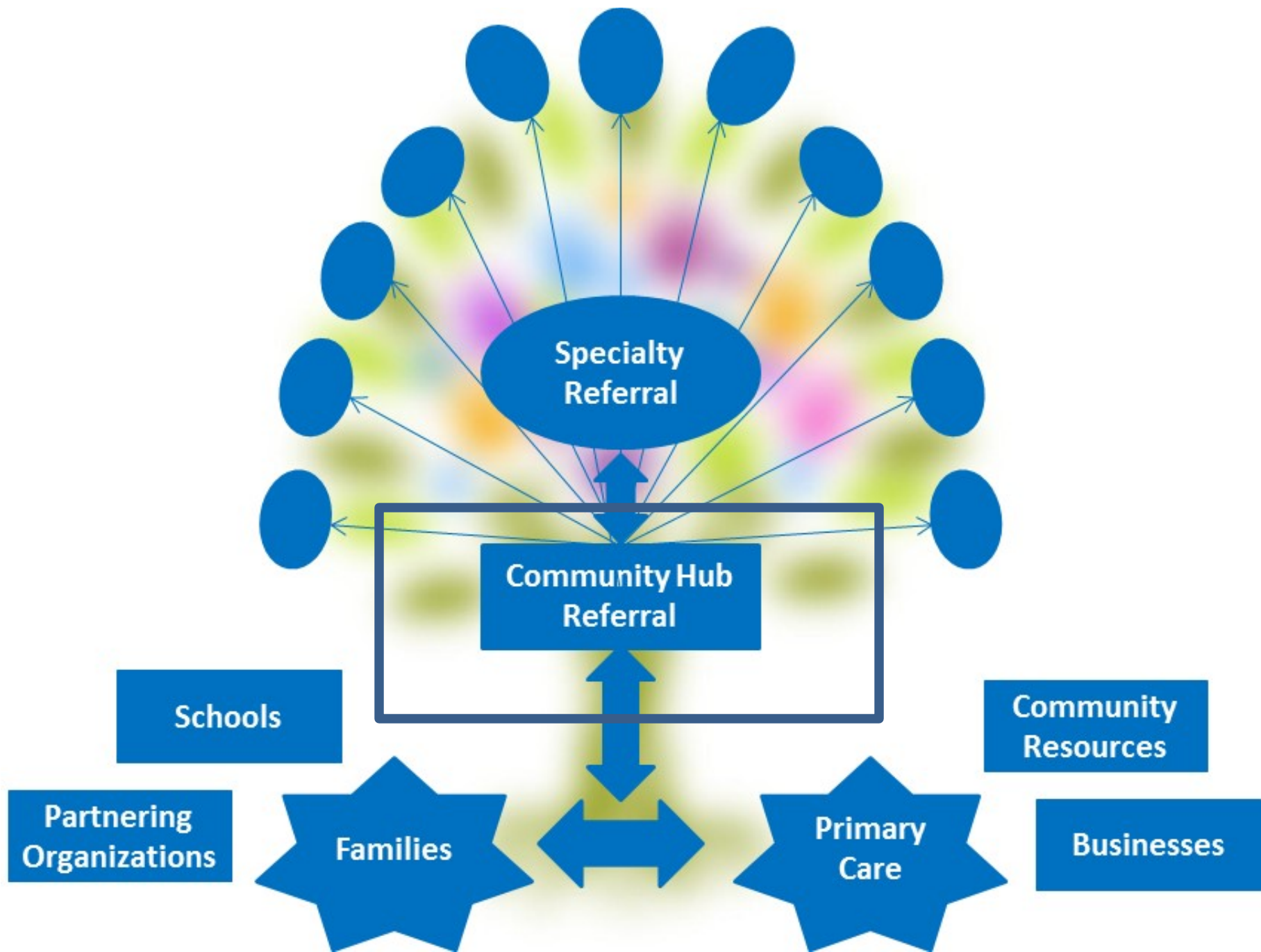
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# Memorandum Of Understanding

- Promote community screening with standardized tools
- Early Diagnosis Hub
  - Develop team (MD, nurse, care coordinator, staff)
  - Complete curriculum
  - Accept referrals of children with concerns based on screening [goal: across systems and insurers]
  - Provide medical work-up and evaluation
- Quality improvement
  - Collect and share de-identified data
  - Participate in a Learning Community
- Promote family-centered and community care

# Curriculum

## 6 day intensive with practicum

**Nancy Swigonski, MD, MPH**

**Mary Jo Paladino, MSA**

**Angela Paxton, BS**

**Mary Delaney, BA**

**Thomas Lock, MD**

**Angela Tomlin, PhD, HSPP**

**Cassie Karlsson, MD**

- Developmental Screening
- Common concerns
- Structured interview
- STAT and STAT practice
- Differential diagnosis
  - Medical / genetic conditions
  - Behavioral disorders
  - Autism DSM 5 criteria
- Delivering news / cultural issues
- Resources and referrals
- Billing
- QI basics and tests of change



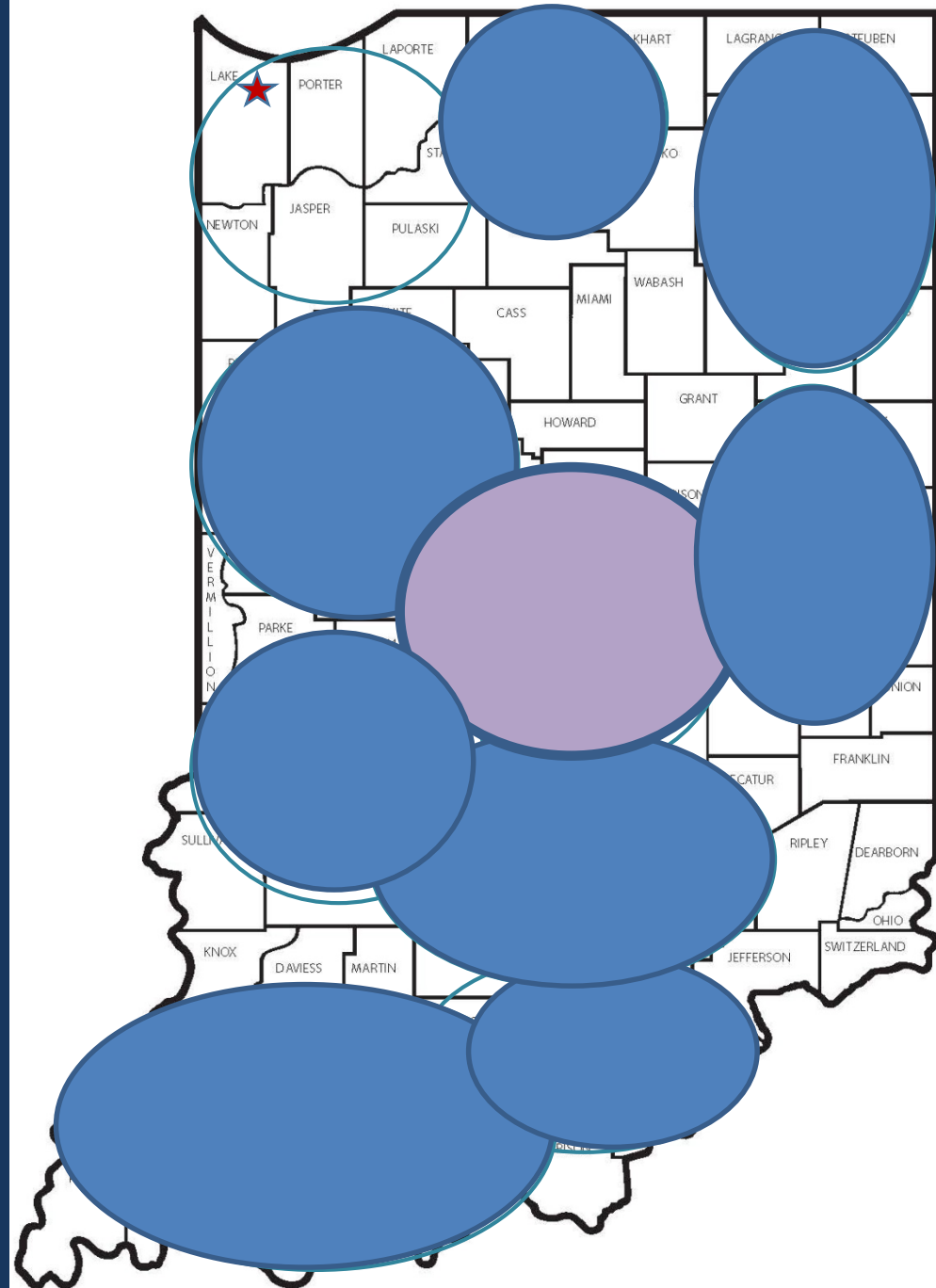
# Parkview Children's Clinic

11115 Parkview Plaza Dr.  
Fort Wayne, IN 46845  
T 260.266.5400

**Beacon Medical Group**  
**Centennial Health Center**  
621 Centennial Dr., # 402  
South Bend, IN 46601  
T 574.647.2500

**Suzanne Gresham Center**  
3620 W. White River Blvd  
Muncie, IN 47304  
T 765.741.0324

**Riley Outpatient Center (ROC)**  
575 Riley Hospital Dr., MSA 1  
Indianapolis, IN 46202  
T 317.944.4846



# Deaconess Riley Children's Specialty Center

4133 Gateway Blvd., Suite 220

Newburgh, IN 47630

T 812.858.3143

2305 Green Valley Rd.

New Albany, IN 47150

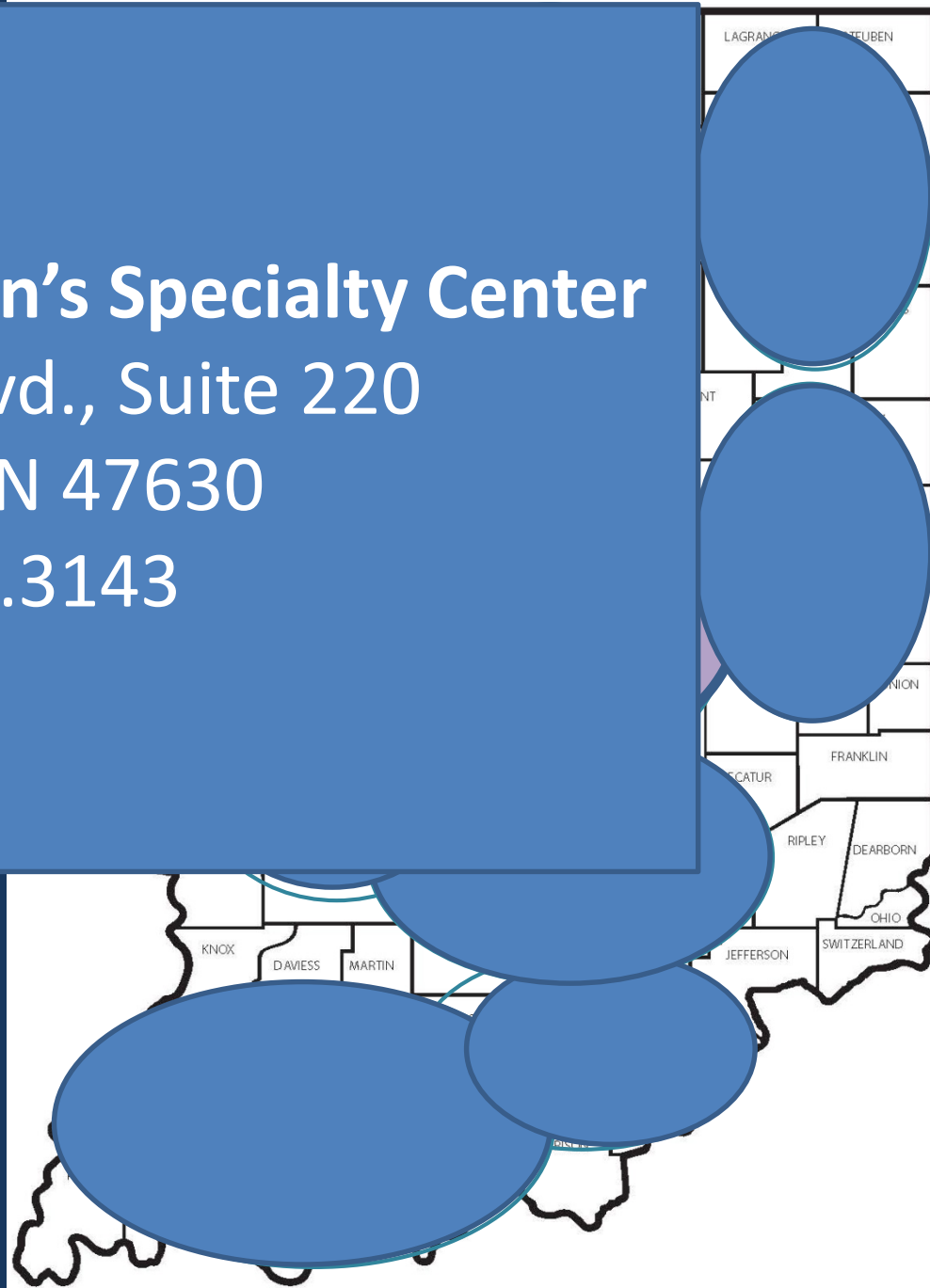
T 812.949.0405

## Union Associated Physicians (UAP Clinic)

221 S. Sixth St.,

Terre Haute, IN 47807

T 812.242.3105



# Drivers or Core Elements

What changes can we make that will result in an improvement?

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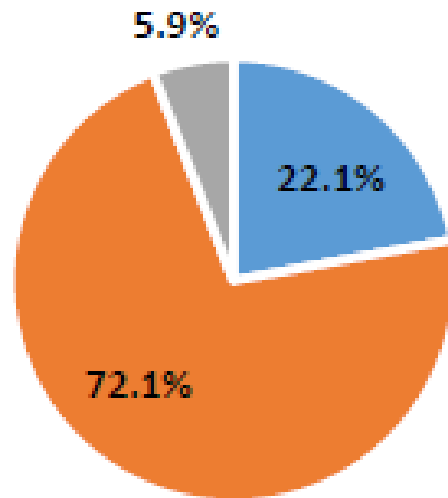
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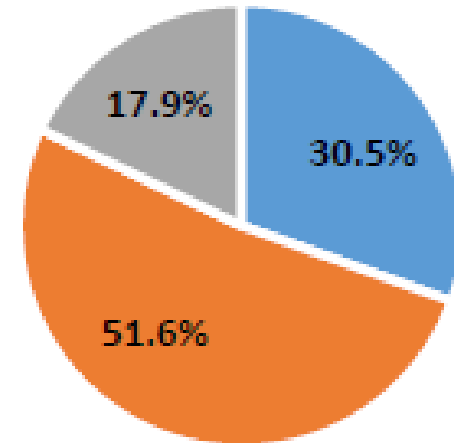
Work with community including schools, other care providers, family organizations

N=68  
Hub  
All Patients, Autism Spectrum  
Disorder Diagnosis



- ASD
- Developmental Delay, No ASD
- Needs Further Assessment

N=246  
Aggregate, Other Hubs  
All Patients, Autism Spectrum  
Disorder Diagnosis



- ASD
- Developmental Delay, No ASD
- Needs Further Assessment

# Drivers or Core Elements

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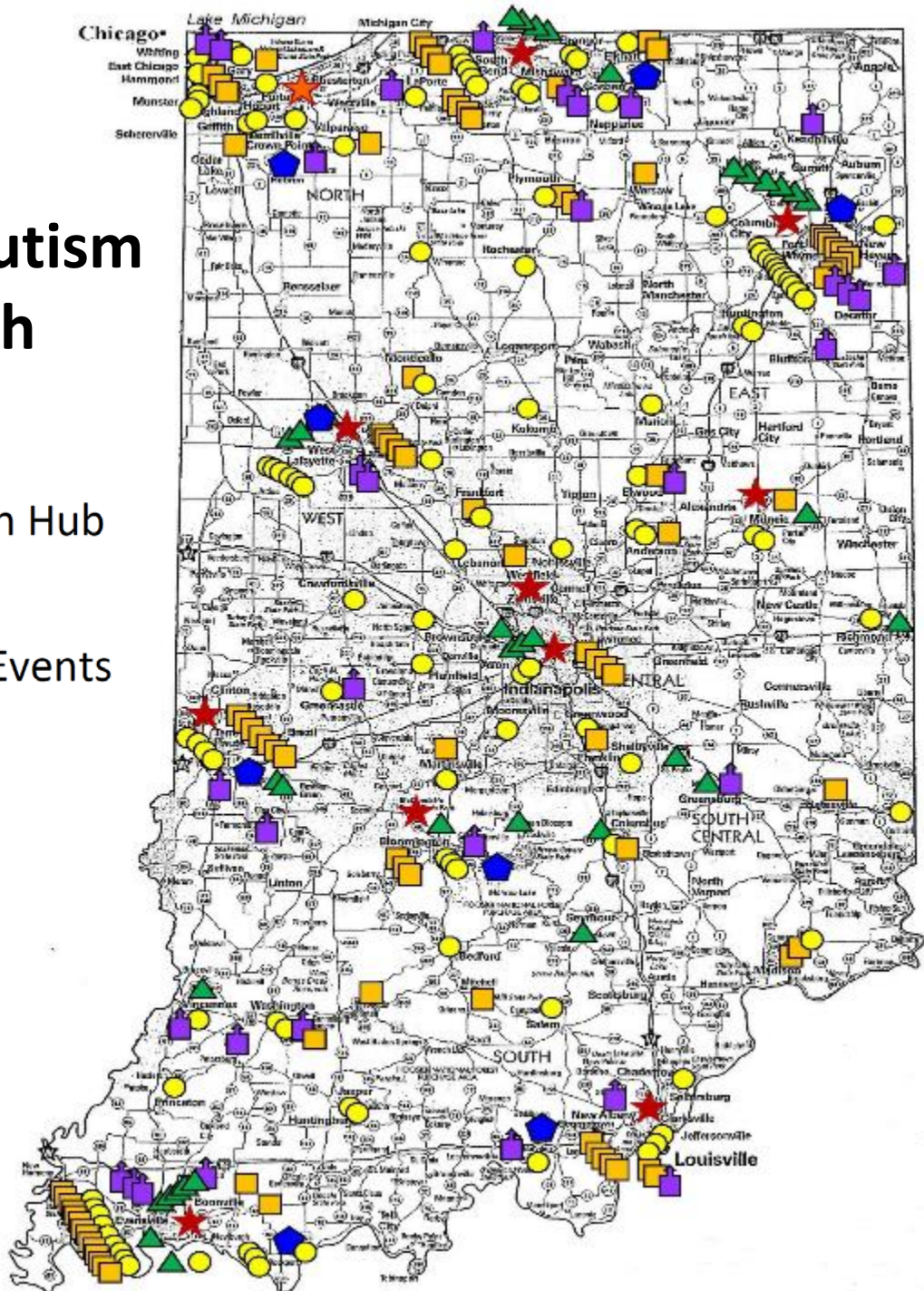
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# Developmental and Autism Screening Outreach

- ★ 9 Early Evaluation Hubs
- ★ 1 Future Early Evaluation Hub
- 108 Primary Care Visits
- ▲ 35 Grand Rounds/CME Events
- 87 Community Visits
- 32 School Visits



# Drivers or Core Elements

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N=1023

# All Indiana Early Evaluation Clinics

Average Age of ASD Diagnosis = 29 months

Average Age of DD Diagnosis = 29 months



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# Extra Slides for Questions

# What is Autism Spectrum Disorder?

- A group of complex disorders of brain development
- Characterized by difficulties in
  - Social communication (verbal and nonverbal)
  - Restricted interests / repetitive behaviors
- Associated with intellectual disability in 50-70%
- Most obvious signs and symptoms of autism emerge between 2 and 3 years of age

<http://www.cdc.gov/ncbddd/autism/index.html>

# How Common is Autism?

- 1 in 68\*
  - Girls 1/252
  - Boys 1/54 (4-5 X more common than girls)
- 10X increase in prevalence in 40 years

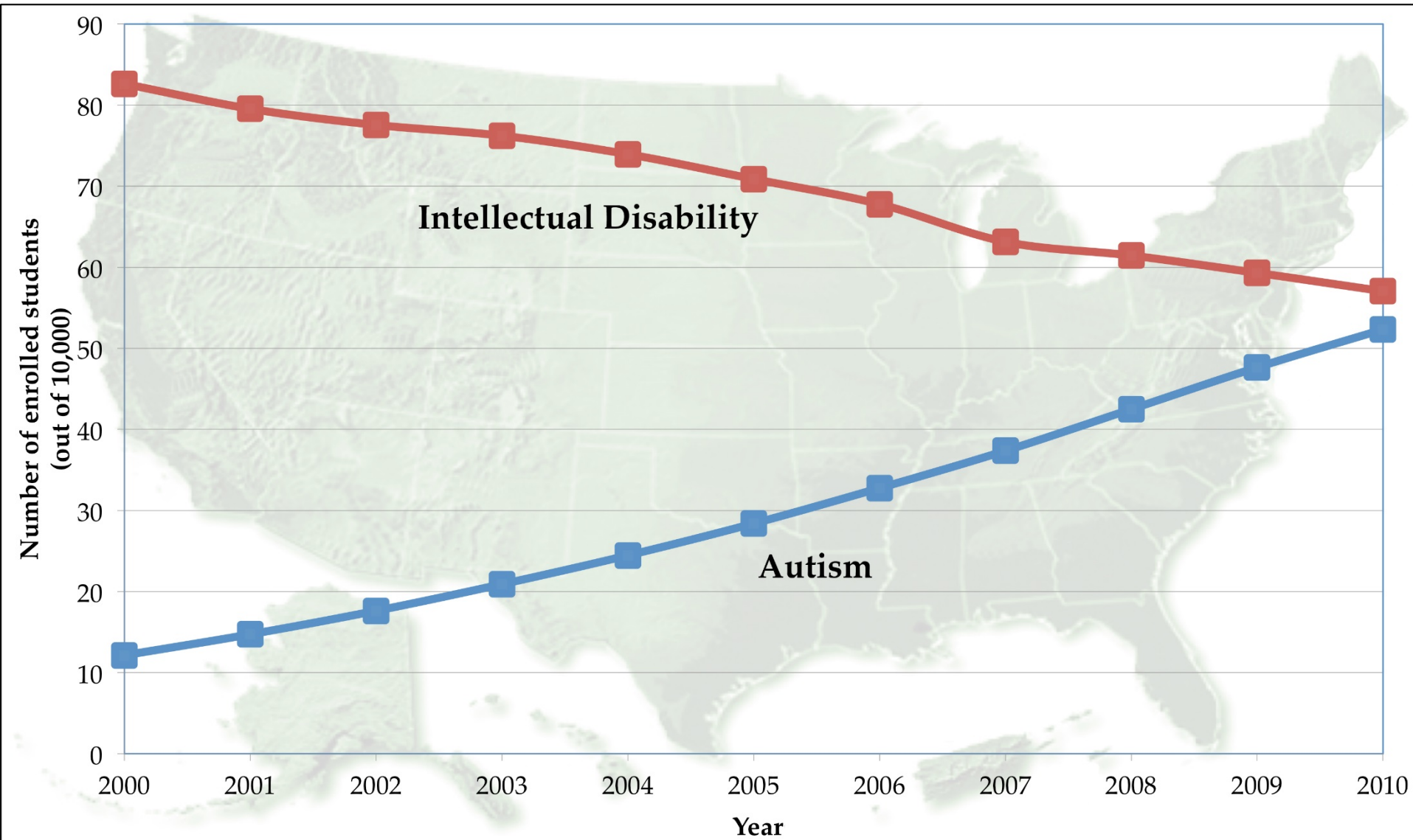
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# What Causes Autism?

- No one cause of autism and no one type of autism
- Gene changes or mutations associated with autism
- Combination of autism risk genes and environmental factors influencing early brain development
  - genetic predisposition to autism
  - nongenetic, or “environmental,” stresses -- advanced parental age at time of conception (both mom and dad), maternal illness during pregnancy and difficulties during birth

<http://www.cdc.gov/ncbddd/autism/index.html>





<http://science.psu.edu/news-and-events/2015-news/images/research/bmb/image-related-to-research-by-santhosh-girirajan> All Swigonski, MD, MPH, FAAP

# When Can ASD Be Identified?

- Sibling research (Mitchell et al, 2006)
  - 12 month - differences in gesture and receptive language
  - 15% siblings had ASD at 2 years of age
- Home movies looking back at children with ASD at 12-18 months of age (Palomo et al, 2006)
  - Less pointing to share an interest
  - Less eye contact as integrated communicative act
  - Less communicative babbling
  - No response to name
  - Confirms a regression in a third (33-39%)
- Screening 18 and 24 months of age with tool

<http://www.cdc.gov/ncbddd/autism/index.html>

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- May 9
  - [The AONE Care Innovation and Transformation Program: Improved Outcomes and Value-Based Care](#)

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