

Creating Capacity

The Ohio Autism Diagnosis Education Pilot Project



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Project Manager

**Autism Diagnosis Education
Pilot Project.**

**Ohio Chapter, American
Academy of Pediatrics**

Disclosure

This presentation is funded through a grant from the Ohio Department of Health's Bureau of Early Intervention Services.

I'm a Pittsburgh Steelers fan.

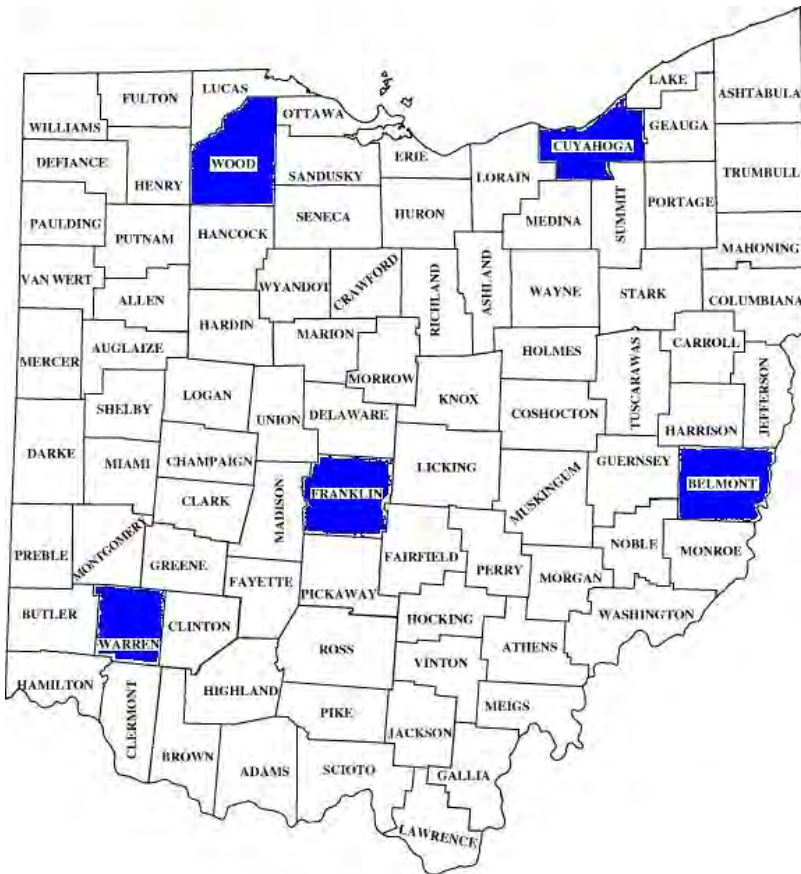


One other disclosure



How We Got Started

Autism Diagnosis Education Pilot Project



ADEPP Objectives

- Heighten public awareness of early signs of autism
- Improve access to developmental screening
- Improve coordination of medical diagnosis
- Enhance access to evidence-based services

ADEPP Structure

- Medical Director: Dr. John Duby
- Intervention Specialist: Marilyn Espe-Sherwindt
- Project Manager: Me
- Quality Improvement Consultants: Cincinnati Children's Hospital Medical Center
- Expert Panel
- Advisory Board

Focus Group Findings

- There are limited local public awareness efforts related to early identification of developmental disorders.
- There is agreement that developmental screening, including for autism, is important.
- Many medical practices do surveillance.

Focus Group Findings

- Very few medical practices do standardized screening.
- No one is doing routine screening for **all** children.
- Diagnosis of autism is currently being done at academic pediatric centers with long waits.

Focus Group Findings

- Resources for children and families affected by autism are available, but fragmented and not well known, even in the local community.
- Successful efforts for systems change have been marked by passionate leadership, broad-based community support that includes parents, and financial backing.

Step One:

Increase the supply of people who screen for delayed development through the use of evidence-based tools.

How?

The Concerned About Development Learning Collaborative



American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN™



Ohio Chapter



Concerned About
Development

LEARNING COLLABORATIVE

Better results for you and the children you serve

It's Best Practice

Ohio Chapter AAP Recommendations

AGE	Recommended Tool
9 months	PEDS or ASQ:3
12 months	ASQ : SE
18 months	PEDS or ASQ:3
24 months	M-Chat
30 months	PEDS or ASQ:3
36 months	ASQ: SE
48 months	PEDS or ASQ:3
Annually ages 6-18	Pediatric Symptom Checklist

CADLC Content

- How do you use screening tools?
- How do you refer children suspected of having delayed development?
- How do you refer children who fail an autism screen?
- How do you get billed fairly for your work?



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Better results for you and the children you serve

CADLC Process

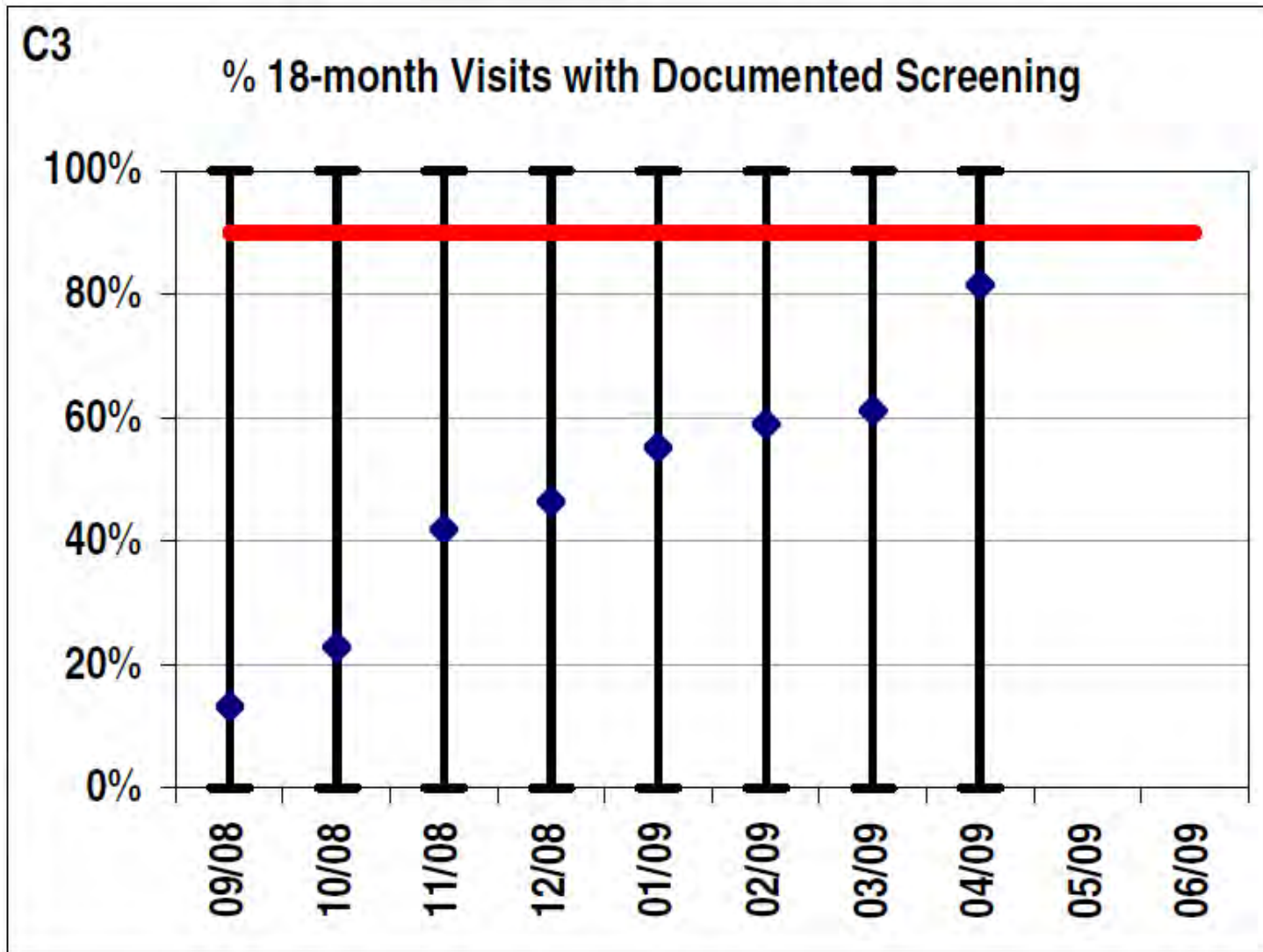
- How will you implement screening into your busy practice?
- How will you receive continuing support?
- How will you collaborate with other practices?
- How will you use quality improvement to make you better at your job?



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LEARNING COLLABORATIVE

Better results for you and the children you serve

CADLC Delivers Measured Results



Screening Collaborative Results

- 85 sites
- They employ more than 800 practitioners
- All Ohio pediatric residency programs agreed to participate
- 2 family medicine residency programs
- Continuing Education Credits
- Maintenance of Certification

Communicating Step One:
Find a local champion.



Communicating Step One: Pound the pavement.



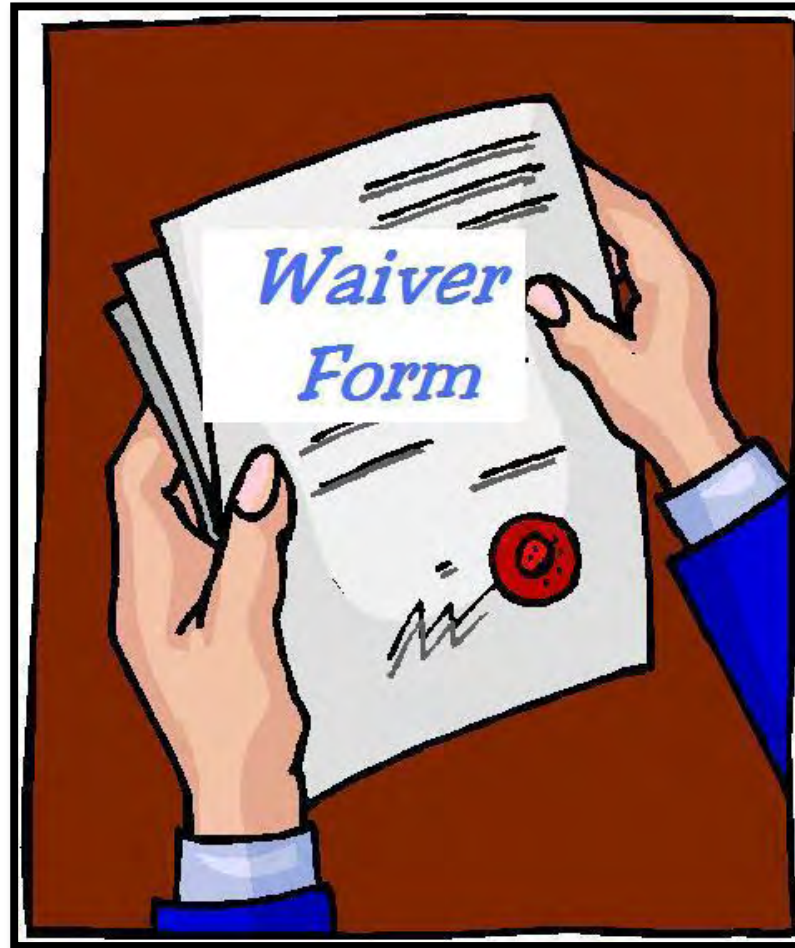
Communicating Step One:
Give yourself six months.



Communicating Step One: Get everyone in the same room.



Communicating Step One: Just do it.



Help Me Grow Referral Form

RELEASE OF INFORMATION CONSENT

I, _____ (print name of parent or guardian), give my permission for my child's health care provider, _____ (print provider's name), to share any and all pertinent information regarding my child, _____ (print child's name), with Help Me Grow, Special Education programs or other provider(s).

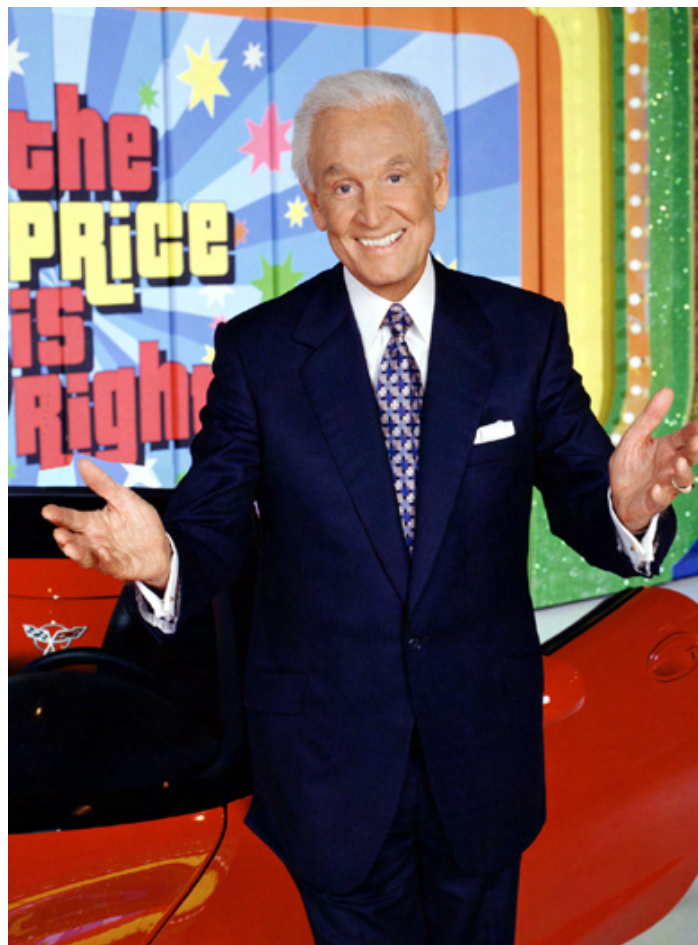
Parent/Legal Guardian Signature:

_____ Date: ____/____/____

Revised American Academy of Pediatrics referral form. EXCLUSIVELY FOR REFERRALS AMONG HEALTH CARE PROVIDERS. _____

Ohio Help Me Grow (Early Intervention), Ohio Local Education Agency (Special Education) or Other Provider(s) Referral Form

COME ON DOWN!!!!



Step Two:

Increase or Create Local Diagnostic Capacity

How?

Community Based Diagnostic Partnerships

- ▣ A strategy to increase timely access to a standardized, comprehensive diagnostic evaluation
 - Psychoeducational component
 - Medical component
- ▣ A strategy that builds on existing local, community-based resources
- ▣ A strategy that requires collaboration and communication among families, local physicians, HMG, and LEAs/ESCs
- ▣ A strategy that acknowledges the current and future practice of pediatrics (R3P)

How do the diagnostic teams work?

- Doctors from Step One screen the child.
- If a child fails a screen, they are referred.
 - Kids 0-3 go to Help Me Grow.
 - Kids 3 and up go to local schools (LEA).
- If the child isn't suspected of having autism, the normal protocol applies.

HMG/LEA: The “Enhanced Evaluation”

- Additional tools for the “enhanced” evaluation:

The Routines-Based Interview (RBI)

The Autism Diagnostic Observation Schedule (ADOS)

What will the Partnership MD do?

Evaluation team sends
“referral” and report to
Partnership MD

Partnership
MD completes
medical evaluation
& counsels family

Partnership MD sends
report to HMG/LEA
and referring MD

Partnership MD
refers to regional
diagnostic center

Are results such that
further consultation
is recommended?

Diagnostic Partnership Update

- Four of Five pilot counties still involved
- 24 counties trained in April
- Next round of training set for Fall 2010
- In all, 140 people trained on the ADOS

Findings from the Pilot Partnerships

Number of children evaluated		46	
Gender	(Missing: 2)	31 M	13 F
Chronological age			
Range		11-95 months	
> 12 months		1	
13-24 months		7	
25-36 months		8	
37-48 months		13	
49-60 months		11	
> 60 months		6	

Diagnoses (N = 45)	Number	%
Autism	14	31%
“ASD” (PDD-NOS)	5	11%
Aspergers	1	2%
TOTAL ASD	20	44%
Language Delay/ Disorder	13	28%
Language + Behavior	4	9%
Language + Motor	1	2%
Global Delay	5	11%
ADD	1	2%
No Clinical Dx	1	2%

Findings from the Pilot Partnerships

Diagnosis x Age (N=45)		
Age	ASD	Other
< 12 months	0	1
13-24 months	4	3
25-36 months	5	3
37-48 months	3	10
49-60 months	6	5
> 60 months	2	3

What have we learned about Step Two?

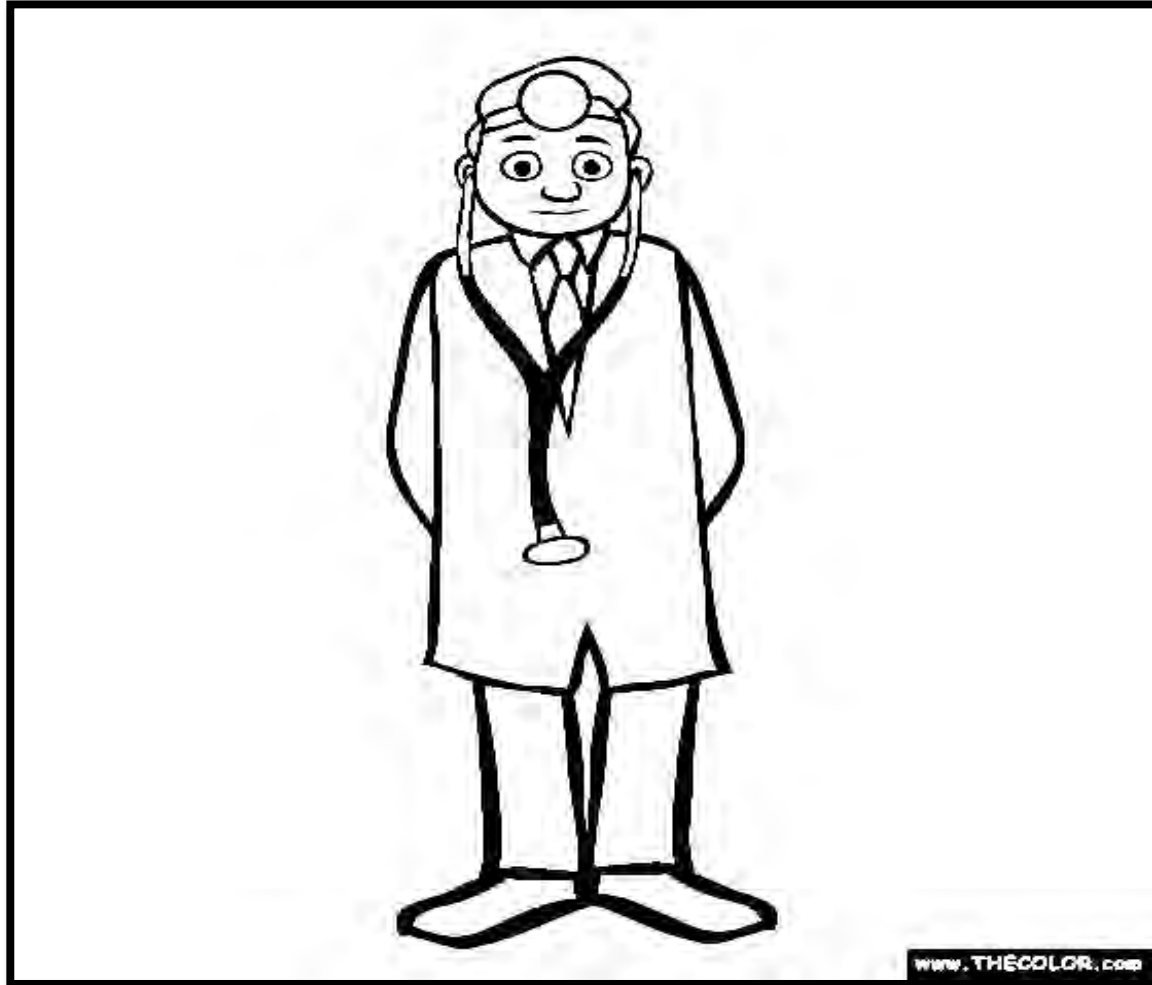
Step Two (Diagnostic Partnerships)

- People think this is the right thing to do.
- It's harder than we think it is.
- Every county is different.
- Screening and diagnosis go hand in hand.
- Counties aren't going to get slammed.

Communicating Step Two:
Talk. Talk often.



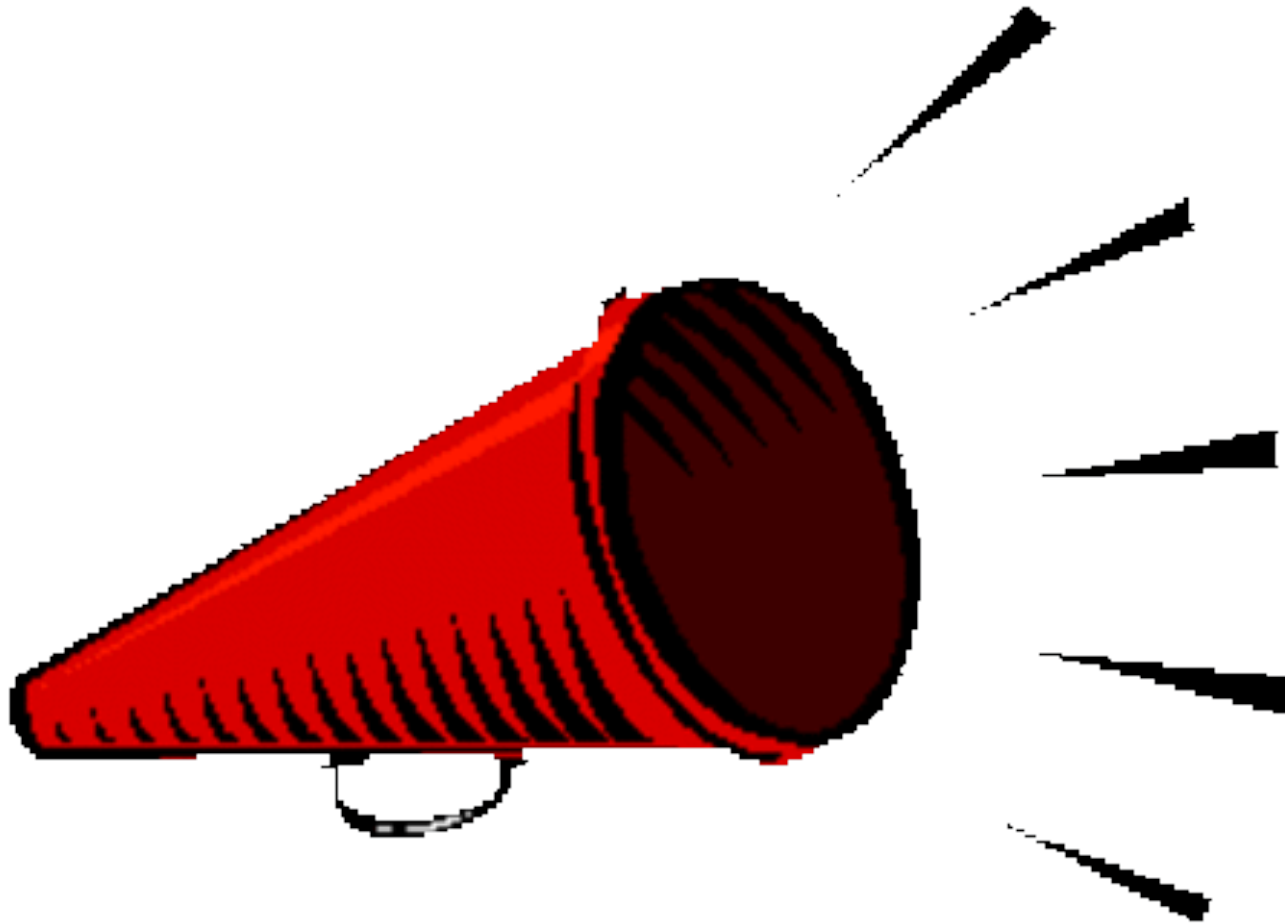
Communicating Step Two: Docs make the call.



Communicating Step Two:
Make the call at a round table.



Communicating Step Two: Families like being heard



Communicating Step Two: This can work anywhere.



WE'RE PLAYING THE FEUD!!!



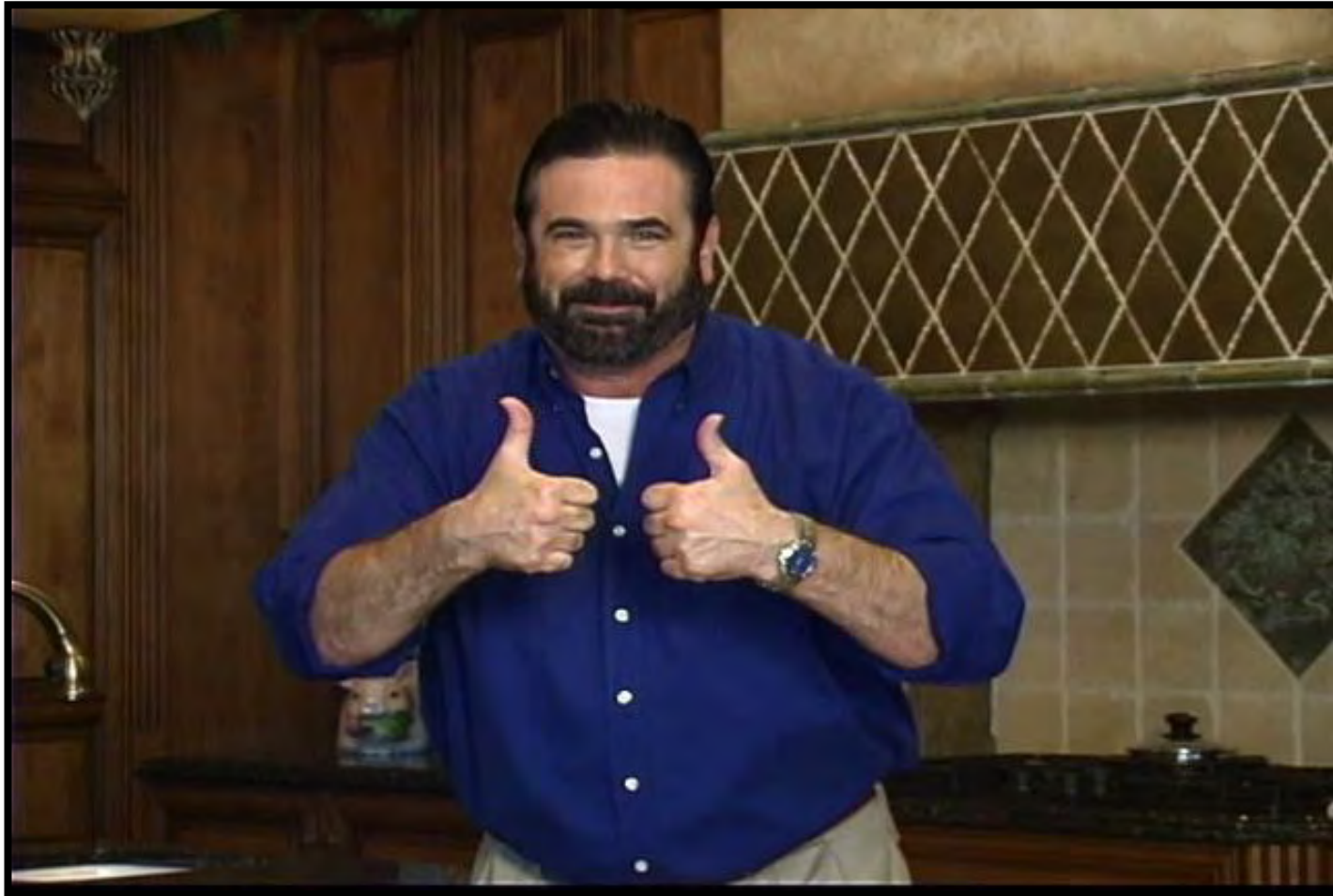
Step Three: B2B Outreach

- Grand Rounds:
 - Plan to reach all 8 pediatric and 23 family medicine programs
- Web Based Learning Modules:
 - Developmental Surveillance and Screening.
 - The Evidence for Early Intervention
 - The Referral Process
 - The Model for Improvement

Step Three: B2B Outreach

- Enhance communication between health care and early and education providers.
- Organize town hall forums to unite stakeholders.
- Create opportunities for people to learn more about autism and delayed development.

Communicating Step Three:
They serve as infomercials.



THE PASSWORD IS BLANK!!!



Step Four: Public Awareness

- Media Relations Campaign.
- Coordinated with CDC for Ohio content.
- Social Media
- Targeted commercials
 - TV
 - Print/Billboards
 - Buses
 - Radio

Media Relations Goals

- ADEPP Lives
- Expect Developmental Screening
- Trust Your Gut
- Visit www.concernedaboutdevelopment.org

Communicating Step Four: Social Media is where it's at.



Communicating Step Four:
Different strokes for different folks.



Communicating Step Four:
News coverage still works.



LIGHTNING ROUND!!!



In Conclusion

- Start small.
- Find a local champion.
- Meet with living breathing humans.
- Waiver forms rock.
- Stay social.
- Once you build it, they will come.

Ohio Autism Pilot Contact

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