

FIVE STEPS FOR SUCCESS



Autism Diagnosis Education Pilot Project

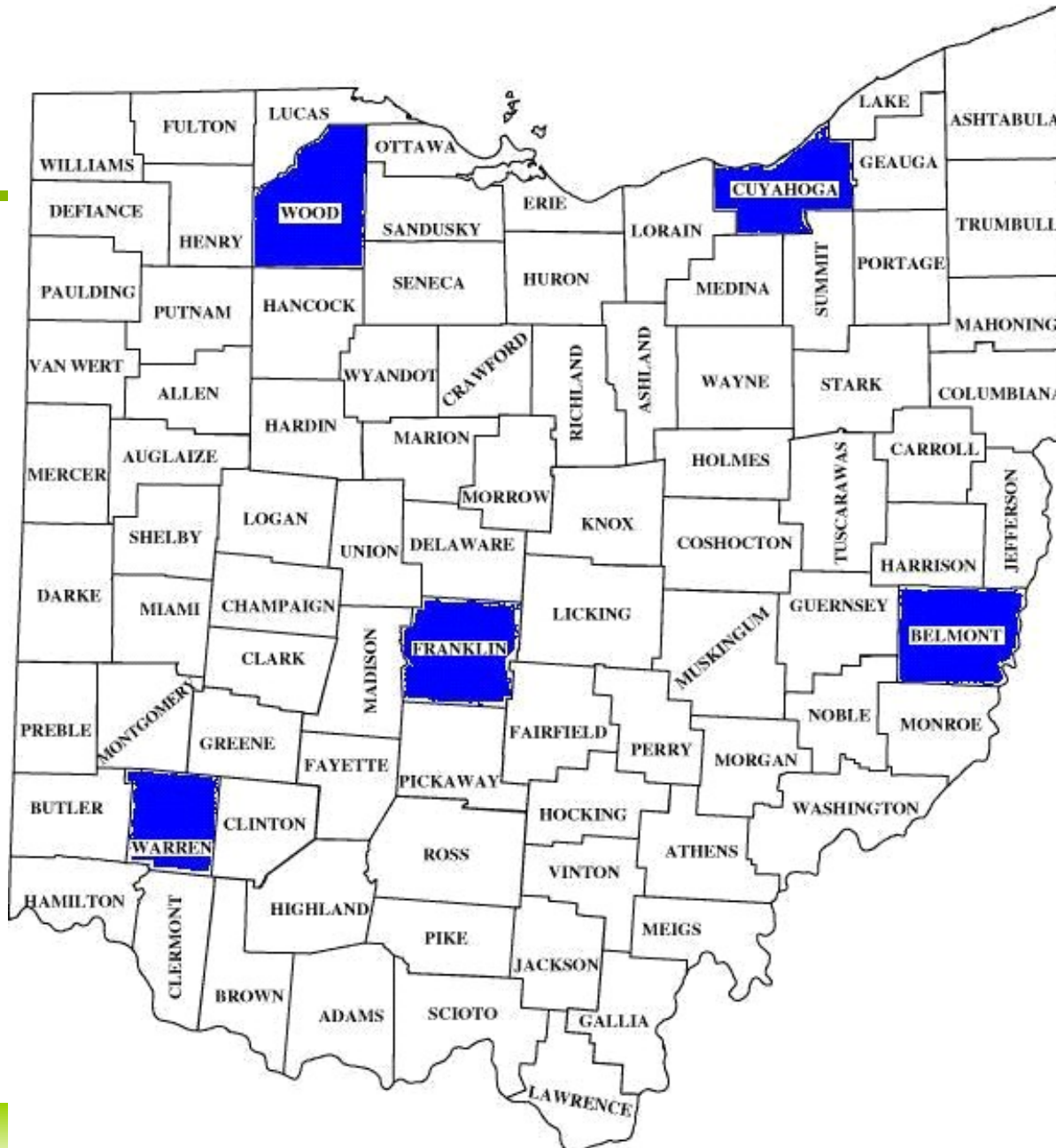


ADEPP Objectives

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



Autism Diagnosis Education Pilot Project





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 developmental delays like autism.



Autism &
Developmental
Screening

LEARNING COLLABORATIVE

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN™



Ohio Chapter



Why does Developmental Screening matter?

- **Developmental delays common in early childhood: estimated 10% of children**
- **Studies suggest ~15-18 month lag between family's first report of concerns and eventual assessment (with only small part of delay due to lack of access to specialist; more attributed to 'wait and see' attitude on part of clinician)**
- **Earlier identification leads to families being connected with appropriate services and the potential for intervention to lead to improved outcomes**
- **YET, studies suggest that <20% of children receive structured developmental screening**



Ohio Chapter AAP recommendations

- 9 month WCC
- ASQ or PEDS
- 18 month WCC
- ASQ or PEDS
- Autism screen (MCHAT)
- 30 (or 24) month WCC
- ASQ or PEDS
- Autism screen (MCHAT)



Learning Collaborative Aim

- 90% of children have a documented screening for autism at 18 and 24 month well child visits
- 90% of children have a documented developmental screening at 9, 18 and 24 or 30 month well child visits
- 90% of children identified as at risk or with delay are referred for diagnosis and treatment.
- 90% of families report practice receptive to developmental concerns



Autism and Developmental Screening Learning Collaborative

- 28 practices
- 488 practitioners
- 5 pediatric residency programs
- 2 family medicine residency programs
- Continuing Education Credits
- Maintenance of Certification



What we've learned about Step One

- Physicians want solutions.
- Physicians have different ways of learning.
- Families matter.
- Teamwork matters.
- There's strength in numbers.



Step Two: The 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)



What do we mean by a standardized, comprehensive diagnostic evaluation?

- Ideally, the definitive diagnosis should be made by a team: physician + specialists in child development
- A comprehensive evaluation addresses three major diagnostic areas:
 1. Determining the child's overall developmental/ functional levels
 2. Making the categorical diagnosis of an ASD
 3. Determining the extent of the search for a related etiology



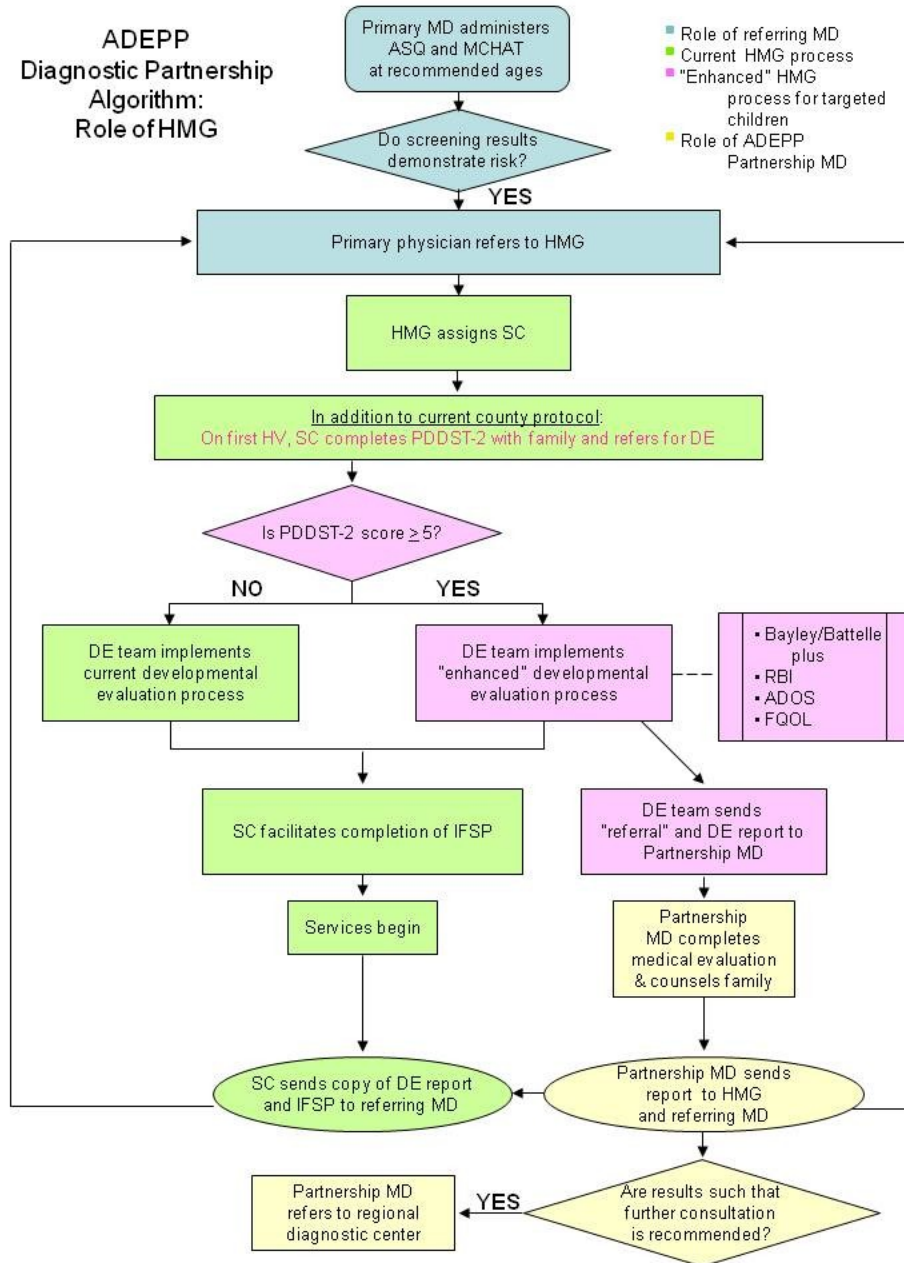
- A standardized, comprehensive diagnostic evaluation should include the following components:

 - Health, developmental and behavioral histories (including a 3-generation pedigree & review of systems)
 - Physical exam
 - Developmental, psychoeducational evaluation
 - Determination of the presence of a DSM-IV diagnosis (including a standardized tool)
 - Assessments of the family's knowledge of ASD, challenges, coping skills, and resources/supports
 - Lab work

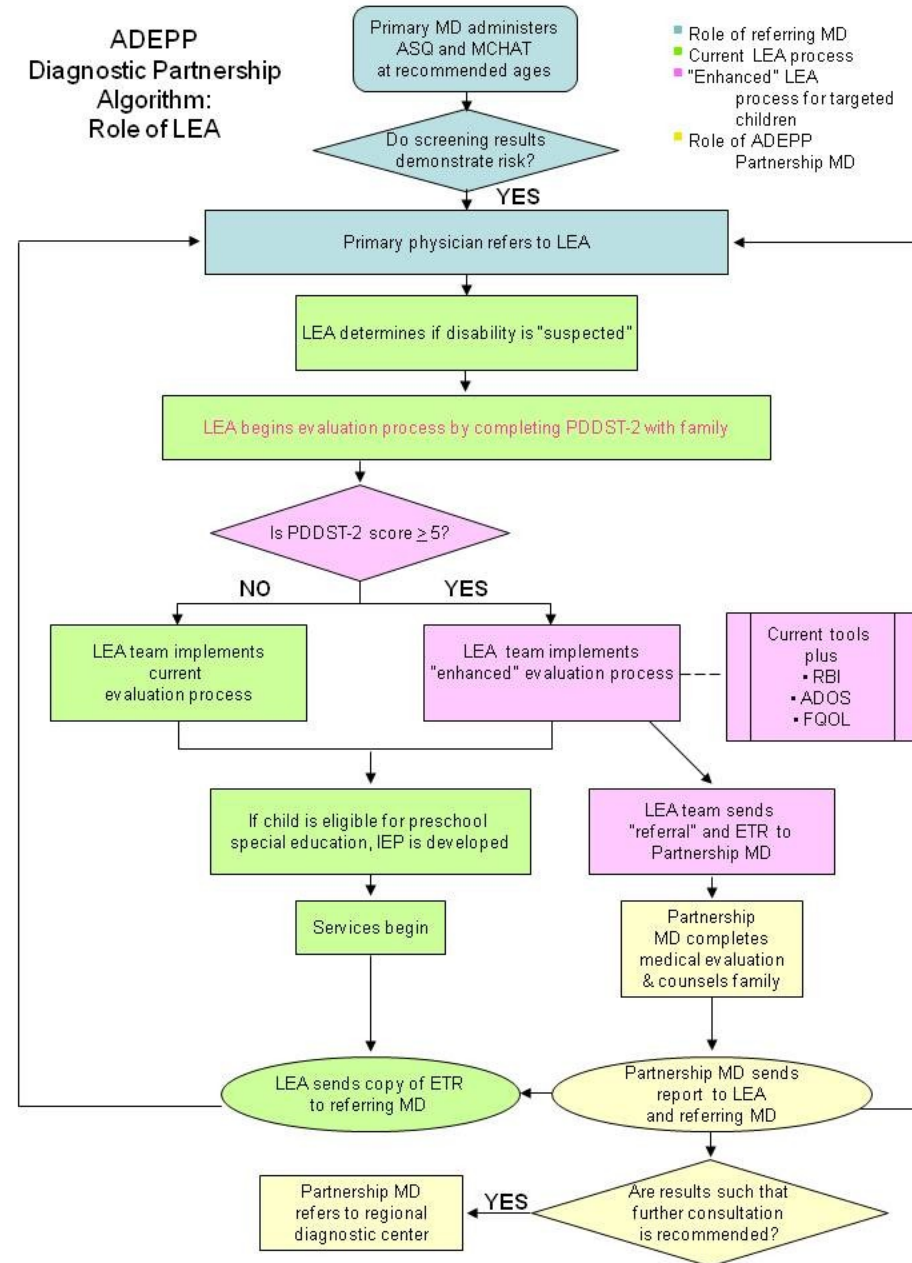


The Diagnostic Partnership Algorithm

ADEPP Diagnostic Partnership Algorithm: Role of HMG



ADEPP Diagnostic Partnership Algorithm: Role of LEA

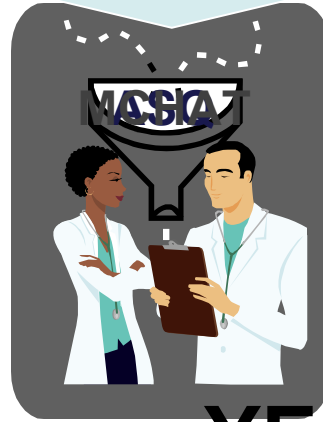




The Triage Process (Step One)

Primary MD administers
ASQ and MCHAT
at recommended ages

Do screening results
demonstrate risk?



YES

Primary physician refers to HMG or LEA



The Triage Process (Step Two)

Primary physician refers to HMG or LEA

PDDST-II, Stage 2, is completed

Is PDDST-II score ≥ 5 ?

Team implements
current developmental
evaluation process

Team implements
“enhanced” developmental
evaluation process and
refers child to Partnership MD



HMG/LEA: The “Enhanced Evaluation”

- Additional tools for the “enhanced” evaluation:
 - The Routines-Based Interview (RBI)
 - The Family Quality of Life Survey (FQOL)
 - 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?



What have we learned about Step Two?

- PCP's can make an autism diagnosis.
- It's not that much extra work.
- It is different region to region.
- People are nice when they meet each other.
- The wheels of change move slowly.
- Referrals are going to be huge.



Current Pains

- Autism Speaks suggests 1 in 150 are on the spectrum
- ODH data suggest 1 in 290 are on the spectrum.
- Kids aren't being diagnosed, or we're a statistical anomaly.



Current Pains

- Treatment can be expensive.
 - Some Ohio hospitals have programs that run \$80,000 a year
 - Certain therapies can run more than \$100 an hour
 - Other therapies ask for a 40-hour care commitment.
 - Time and efficiency costs for families.



Potential Gains through ADEPP

- ## Screening

- The earlier you identify a problem, the earlier you can work to solve the problem.
- Receiving care in a medical home starts the wheel.
- Screening doesn't take extra time.
- Screening has a billing template already in place with the 96110 code.
- Others can screen if they know where to refer.
- ADEPP can be that link.



Potential Gains through ADEPP

- **Diagnosis**
 - Average age of first concern: 2
 - Average age of diagnosis: 4 years, 7 months
 - Average wait time: 2 years, 7 months
 - Evidence suggest signs of autism appear in the **first** year of life.
 - ADEPP creates a model for earlier diagnosis.



Potential Gains through ADEPP

- Continuing care
 - The earlier intervention begins, the more efficient and effective intervention can be.
 - Intervention patterns are becoming more cost effective.



What is Early Intervention?

“Early intervention is the provision of support and resources to families of young children

from members of informal and formal social

support networks that both directly and indirectly influence child, parent and family

functioning.”



Public Law 105-17, Part C



*Supports family-centered
early intervention for
children birth to three
years of age with
or at risk
(biological/environmental)
for developmental delays.*



Paradigm Shift

Traditional

- Child-centered
- Deficit-based
- Segregated settings
- Single agency
- Direct service
- Single practitioner
- Therapeutic settings
- Therapeutic goals

Evidence-Based

- Family-Centered
- Strength-based
- Inclusive communities
- Interagency collaboration
- Consultation
- Team-based
- Typical settings
- Functional outcomes



How Children Learn

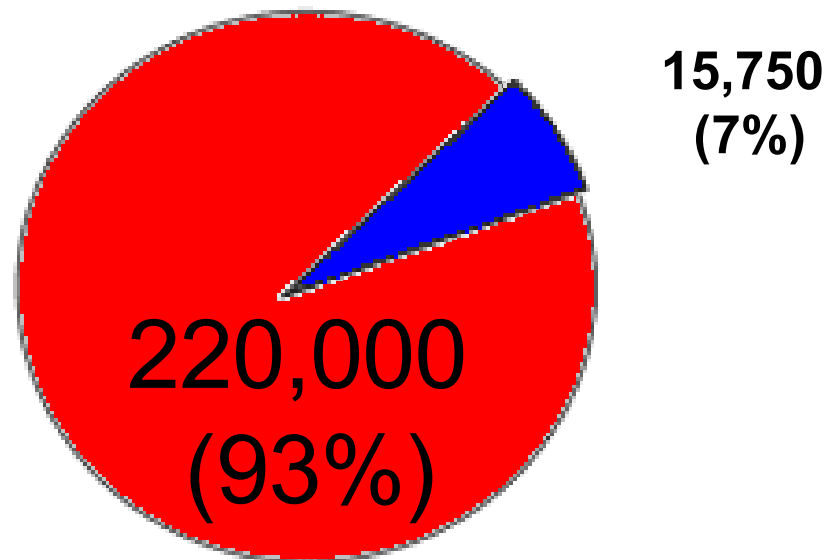
(Dunst, Hamby, Trivette, Raab, and Bruder, 2000; Early Childhood Connection, EI Guide)

- Learning is enhanced when children engage in meaningful activities
 - They do what they like!
- Participation in everyday activities increases when children have many opportunities to engage in interactions with people and objects that support and strengthen their abilities in naturally occurring ways
 - Practice!
- Children are more likely to develop when they have frequent opportunities to engage in interactions that support and strengthen existing and emerging abilities
 - Building on their skills!



Who Has the Greatest Impact?

(Mahoney et al, 2006)



 **Parent**

 **Therapist**

Courtesy: Dr. Gerald Mahoney



Who has the most opportunities to impact the child?

Courtesy: Dr. Gerald Mahoney

	Teacher/Classroom	Therapist/Specialist	Parent
Context for Interaction	2.5 hrs/day; 4 days/wk; 2 teachers; 12 children	30 minute session; 1 day/wk	1 hr per day (minimum); 7 days/wk (holding, playing, feeding, talking, etc)
One-on-One Time per Week	33 minutes	25 minutes	420 minutes
Weeks per Year	30	30	52
Minutes per Year	990	750	22,000
Interactions per Minute/Year	10/9,900	10/7,500	10/220,000
Comparative Opportunities to Influence Child	4.5%	3.4%	92.1%



Effects Of Family-Centered Practices

(Rosengaum et al, 1998; Law et al, 2003; Iverson et al, 2003; King et al, 2004; Chiarello & Jefferies, 2008)

CHILD

- u □ child's skills including motor and mental developmental gains
- o a psychological adjustment of child
 - FAMILY
 - F psychological well-being of mother
- l mperception of competency, self-efficacy, & sense of control
- s acquisition of developmental knowledge & ability to identify child's gains

- u □ participation with intervention program
- g i mother's perception of child's temperament
- e c developmental appropriateness of home environment
- o e family satisfaction with evaluation/assessment process
- s p family satisfaction with care

**NO NEGATIVE FINDINGS
NOTED!**



The end equation

Earlier Diagnosis +

Earlier access to intervention+

Family focused intervention

=

Better care.

Cost savings for family, employer, and providers.

Minimal increase in work time.



Step 3

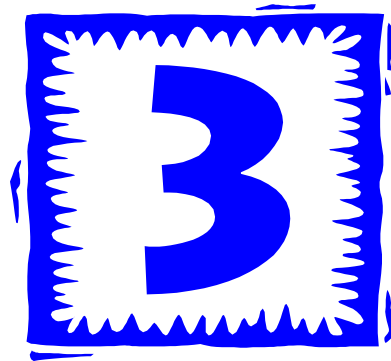


- Grand Rounds
 - Developmental Screening
 - 8 Hospitals August to March 2009
 - Plan to reach all 8 pediatric and 23 family medicine programs
- Web Based Learning Modules
 - Developmental Surveillance and Screening
 - The Evidence for Early Intervention
 - The Referral Process
 - The Model for Improvement



What are we learning about Step 3?

- Immediate access is key.
- Distinction between CME and MOC.
- Get them while they're young.





Healthy
Child Care
America



Step 4

- Enhance communication between health care and early and education providers
- Ohio's Step Up to Quality





What have we learned about Step 4?

- Tricky relationships.
- A willingness to find solutions.
- Help us help you.





Step 5: Public Awareness Campaign

- Raise Awareness
- Share your concerns with your doctor
- Expect developmental screening

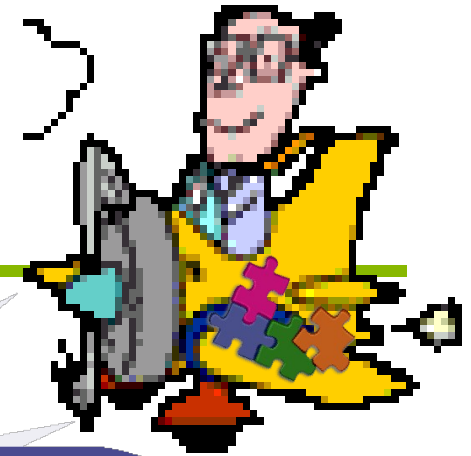




What have we learned about Step 5?

- Local, local, local.
- Parents have power.
- The autism community can unite.





THANK YOU

