Building Collaborative Bridges of Support for Individuals with Autism Spectrum Disorder

Michigan Association of Administrators of Special Education (MAASE)
October 9, 2012

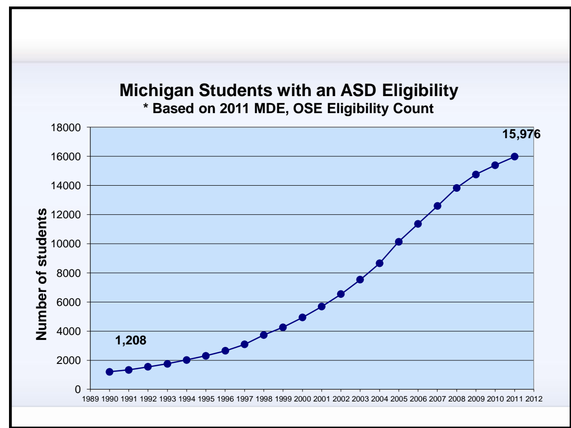
Agenda

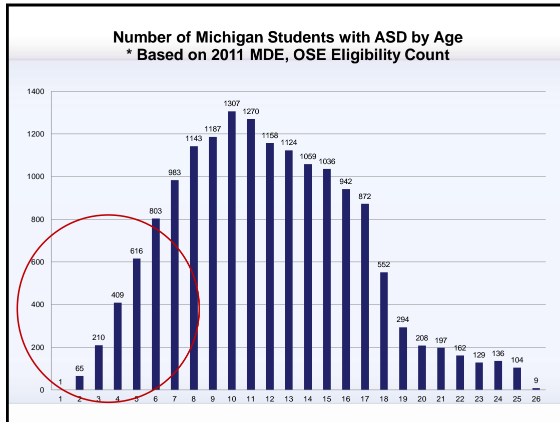
- Welcome and Introductions
- State Planning and Resources
- State Vision
- Evidence-Based Practice in Early Childhood
- Evidence-Based Practice in K-12
- College and Career Ready

Michigan Autism Spectrum Disorders State Plan

June 2012

*awaiting adoption by the Governor's Autism Council





History and Background of State Plan

- Impetus for the plan development
  - Early Intervention Workgroup
  - Eligibility for Combating Autism Act funding
  - National Professional Development Center on ASD collaborative award and state plan process
- Development committee and advisory committee (~50 members)
- Systematic development process with advisory committee and public input

Michigan ASD State Plan

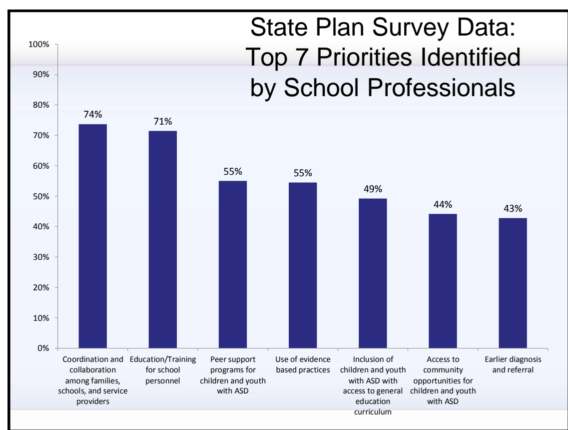
- The Michigan ASD State Plan will serve as a guide to expand the state's capacity to address the complex challenges of individuals with ASD and their families.
- One challenge identified in the plan is the degree to which education and treatment of people with ASD cuts across numerous service delivery systems, including physical, mental, and behavioral health care, early intervention, education, vocational rehabilitation, and community services.
- A rapidly growing ASD population does not mean the creation of a separate system of care specific to ASD, but rather increasing the knowledge, coordination, and capacity of current systems.
- To achieve the goals identified in the plan will require efforts at all levels of government and across public and private sectors

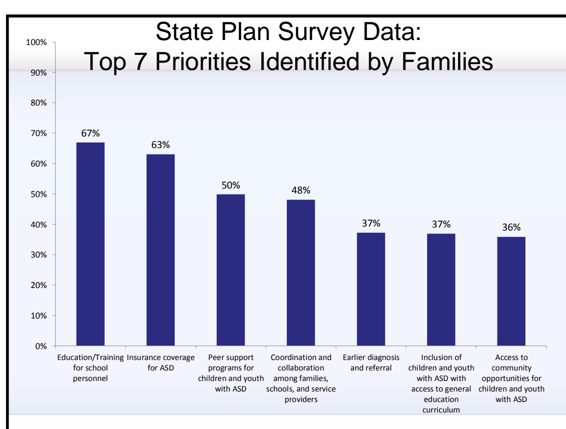
Michigan ASD State Plan

- Infrastructure: System and Service Coordination
- Family Engagement and Involvement
- Early Identification and Intervention Services
- Educational Supports and Services
- Adult Supports and Services
- Physical, Mental, and Behavioral Health Care
- Training and Professional Development

State Plan Survey Data

- Family members and school professionals were surveyed separately using Survey Monkey, an online survey tool.
- **School Professional Survey** (16 questions)
  - 612 respondents
- **Family Survey** (22 questions)
  - 318 respondents





Michigan ASD State Plan

Key Recommendations

- **Autism Council**
- **State Autism Center for Resources and Information**
- Service Coordination and Statewide Infrastructure
- Regional Collaborative Sites/Regional Partnerships
- Early Screening, Evaluation, and Intervention for Young Children With ASD
- Best Practice and Service Navigation Guidelines
- Crisis Intervention
- Training and Professional Development
- University Collaboration and Coordination
- Data system
- State Plan Review and Update

Implementation of Recommendations

- Executive Order from the Governor's Office for a State Autism Council (June 2012)
- Representatives:
  - 4 state agencies
  - Parents
  - Individual with ASD
  - Local Education Agency
  - Local Community Mental Health
  - State Initiative
  - Universities
  - Non-profits
  - Healthcare

Michigan Autism Council

- Adoption of the MI ASD State Plan
- Implementation of the MI ASD State Plan
  - Priority Recommendations
  - Focus Areas
    - Early Childhood
    - Transition

Implementation of Recommendations

- Autism Resource and Information Center (ARIC)
  - Clearinghouse of information
  - Navigation of service systems
  - Coordination with State Centers of Excellence and Regional Collaboratives

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Early Intervention for ASD Roadmap and Brochure

- Navigating Services for Young Children with Autism Spectrum Disorder (ASD): *A Michigan Guide for Families*
- Michigan Quick Guide for Families of Young Children with Autism Spectrum Disorder Resources

http://ddi.wayne.edu/publications.php

Supported by a grant from the Association of Maternal and Child Health Programs (AMCHP)

Michigan ASD State Plan

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Supporting Autism Initiatives in Michigan…

Michigan Autism Insurance Implementation

MI Association of Administrators of Special Education (MAASE)

Colleen M. Allen, Ph.D., President & CEO
Autism Alliance of Michigan
Chair, MI Autism Council

Agenda

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- Clinical Best Practice Management
- The Legislative Process: Getting a Bill Passed
- Autism Bills: Overview
- Autism Bills Specifics:
  - What Is and Is Not Covered
  - Who Can Provide Care
- Autism Bills Essentials: What Educators and Families Need to Know Now
- Implementation Obstacles and Solutions

Purpose of Presentation

- Understand the new autism insurance laws
- Understand what an educator of a child with ASD needs to know about the insurance
- Describe opportunities for bridging clinical and educational practice with the new autism insurance reform
- Understand what resources are available to educators and parents for understanding the new autism insurance

The Autism Alliance of Michigan

- Why We Started
- Who We Are
- Strategic Initiatives
  - Service Delivery Model for Insurance
  - Autism Safety Initiative
  - Autism Navigator

Clinical Best Practice Management

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- Screening, Identification, and Referral
- Evaluation and Diagnosis
- Evidence Based (EB) Intervention
  - What is EB treatments?
  - What is Applied Behavior Analysis?
  - Speech and Occupational Therapies

Understanding the New Autism Insurance Legislation

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The Legislative Process: Getting a Bill Passed

- The original bill and what was included
- Legislature negotiations
- The final bill
- Effective Date: October 15, 2012

***REMEMBER:** Law is effective mid-October but most insurance plans do not renew until January, 2013, some even later.*

Understanding the New Autism Insurance Legislation

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The Michigan Autism Insurance Bills

- Senate Bills (SB) 414/415
- Bills for BCBSM and all other HMO's/private insurers
- Includes all insurers covered under state regulated laws
- Does NOT include ERISA (self-insured, federally regulated) companies (larger companies): overrides state mandates
- Does NOT include Medicaid eligible children
- Is limited to services for children MEDICALLY diagnosed with an ASD (classic autism, PDD-NOS, Asperger's)
- Does not cover co-pays or deductibles

Understanding the New Autism Insurance Legislation

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Autism Bill Specifics: What's Covered

- Covers ABA, Speech and Occupational Therapies, Psychiatric and Psychological Care
- Dollar Limits/Caps
  - $50,000 (ages birth to 6)
  - $40,000 (ages 7-12)
  - $30,000 (ages 13-18)
- What the caps mean
  - All inclusive of therapies listed above

Understanding the New Autism Insurance Legislation

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Autism Bill Specifics: Who Can Provide Care

- Provider Qualifications: Evaluation and Diagnosis
  - Licensed Psychologist or Physician
  - *Insurers determine through networks and centers of excellence who can give the child a diagnosis*
  - Educational Eligibility of ASD DOES NOT COUNT! A medical diagnosis of ASD is needed, which will include documentation of a standardized test like the Autism Diagnostic Observation Schedule (ADOS)

Understanding the New Autism Insurance Legislation

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Autism Bill Specifics: Who Can Provide Care

- Provider Qualifications: Therapy
  - Speech Therapy: Certified and Licensed SLP
  - Occupational Therapy: Certified and credentialed OTR
  - Psychological Care: LLP working under LP
  - ABA Therapy: Board Certified Behavior Analyst or Licensed Psychologist meeting very specific qualifications as an ABA provider
- *Insurers determine through networks and centers of excellence who can provide treatment for the child*

Understanding the New Autism Insurance Legislation

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Autism Bill Essentials:
What Educators and Families Need to Know Now—Diagnosis

- *Insurers will confirm that all of these criteria are met and nothing more is needed*
- Does the child have a medical diagnosis of Autism Spectrum Disorder?
  - The diagnostic code for autism is 299.0
- Is there a report or some type of documentation of the diagnosis by a licensed physician or psychologist?
- How long ago and where was that evaluation conducted?
  - If less than 3 years ago and a standardized test was used, the child *may* be ready to start therapy in October

Understanding the New Autism Insurance Legislation

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Autism Bill Essentials:
What Educators and Families Need to Know Now

- What if the child has not had a medical evaluation in >3 years?
  - Insurers will likely require that the child be re-evaluated
  - Parents need to inquire of their doctor or psychologist if they use a standardized tool (example: ADOS)
  - Parents may want to consider an evaluation NOW, with a center or individual physician or psychologist that can administer the ADOS *and is approved by your insurance company*

Understanding the New Autism Insurance Legislation

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Autism Bill Essentials:
What Educators and Families Need to Know Now—Therapies

- MI does not have enough therapists to service all the children with autism who need therapy
- It will take time for our state to "ramp up"
- Other states have required 3-5 years for supply to meet demand
- This will be very frustrating for families and providers. AAoM is aggressively working with our partners to increase access as quickly as possible

Understanding the New Autism Insurance Legislation

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Autism Bill Essentials:
What Educators and Families Need to Know Now—Therapies

- Only evidence based therapies will be covered
- Evidence-Based Practice Defined:
  - Maintains strength in research
  - Based on sound theory and empirical data
  - Assures replication of research demonstrating effectiveness of treatments via peer reviews and consistencies across studies
  - Number of expert panels, task forces, and reports reviewing research agree on the following points (ASAT):
    - Behavioral and educational interventions currently main treatments
    - Applied Behavior Analysis (ABA) has received most extensive research, supporting its effectiveness
    - Medications also may be effective for challenging behaviors, when appropriate
    - Majority of research conducted focusing on young children; additional research is needed for older children and adults with ASD

Understanding the New Autism Insurance Legislation

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Autism Bill Essentials:
What Educators and Families Need to Know Now—Therapies

- How will insurers know what is evidence-based and what is not?
  - Provider qualifications will be first indication
  - Objective criteria will be used to evaluate what gets covered and what does not
  - Several organizations are considered at the forefront of evidence-based practice in treating autism

Understanding the New Autism Insurance Legislation

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Autism Bill Essentials:
What Educators and Families Need to Know Now—Therapies

- **Organizations currently leading EBP research in Autism Interventions** (ASAT, NPDC, NSP)
  - Association for Science in Autism Treatment (ASAT): Purpose is to share objective, accurate, and scientifically sound ASD treatment information.
    - Provides extensive information on treatments available, EBP definition and summaries, pseudoscience information, and being an informed consumer
  - ASD's: Missouri Best Practice Guidelines: for screening, diagnosis, and assessment
  - National Autism Center (NAC) National Standards Project (NSP), 2010: evaluated over 770 peer-reviewed studies in treatment efficacy for ASD
    - Behavioral-based interventions identified as primary EBP as concluded in this large initiative
  - National Professional Development Center (NPDC): Multi-university center promoting use of EBP's in treating ASD's including UC Davis Medical School MIND Institute, University of North Carolina at Chapel Hill, and the Waisman Center at University of Wisconsin at Madison
    - Alignment of EBP agreement between NSP and NPDC
    - Behavioral-based interventions identified as primary EBP

Note both NSP and NPDC overlap in findings significantly, representing greater reliability of data.

Understanding the New Autism Insurance Legislation

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Autism Bill Essentials:
What Educators and Families Need to Know Now—Therapies

- Alternative and non-conventional therapies WILL NOT be covered as they are not considered evidence based:
  - Special Diets
  - Supplements
  - Chelation
  - Hyperbaric Oxygen Chambers
  - Listening Therapies
  - Recreational Therapies

Understanding the New Medicaid Autism Benefit

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Autism Bill Essentials:
What Educators Families Need to Know Now

- Not covered by the autism bills, but approved in state budget at $21M for year 1, effective January 1, 2013
- Coverage closely mirrors the autism bills
- Broader provider qualifications
- Includes intensive (15-25 hours/week) and less intensive (5-15 hours/week)ABA
- Does not include Speech and Occupational Therapy
- Will require collaboration/consultation with schools
- Specifics not yet revealed

Understanding the New Autism Legislation

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Implementation Obstacles and Solutions

- Obstacle 1: "Diagnosis Crunch"
  - Solution 1A: Parents and educators understanding insurer requirements for diagnosis and making the evaluation appointment ASAP with approved provider/center

Understanding the New Autism Legislation

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Implementation Obstacles and Solutions

- Obstacle 2: Lack of qualified therapists
  - Solution 2A: Parents should call ABA centers now and put their name on a waitlist. This helps centers early on to justify need to hire new therapists
  - Solution 2B: AAoM working with universities to recruit alumni back to MI, job fairs, etc.
  - Solution 2C: Universities working with clinics to utilize student therapists
  - Solution 2D: Parent Training Models

Understanding the New Autism Legislation

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Implementation Obstacles and Solutions

- Obstacle 3: Getting Claims Paid
  - Solution 3A: AAoM working with insurers to facilitate ease of claims processing, communication with parents, providers and state departments

Understanding the New Autism Legislation

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Implementation Obstacles and Solutions

- Obstacle 4: Self-Funded/ERISA(Federally Regulated) Companies that Do NOT Adopt the Autism Benefit. ERISA overrides state mandates
  - Solution 4A: AAoM is working with the Lt. Governor to identify self funded companies in MI and encourage self adoption
  - Solution 4B: Parents need to check with their Human Resources department and/or their insurer to determine whether or not they work for a self funded company.
  - Solution
  - 4C: Families should inform AAoM if their employer is a self funded company. We can get information to the employer on self adoption

IMPORTANT! Self-funded companies will be reimbursed by the State of Michigan!

Understanding the New Autism Legislation

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Available Resources

- NEW! AAoM Insurance Collaborative Portal: has information for parents, insurers, providers, employers, universities, workshops, handouts from presentations: https://sites.google.com/site/aaominscollaborative/home
  - Today's Power Point (on Portal under Calendar and Events/Parents Informational Webinars)
- AAoM Website: www.autismallianceofmichigan.org
- AAoM Resources:
  - Colleen Allen: colleen@autismallinaceofmichigan.org
  - Stacie Rulison: stacie.rulison@autismallianceofmichigan.org

Resources for Educators and Parents

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American Academy of Pediatrics (AAP), http://aappolicy.aappublications.org/cgi/search

American Psychiatric Association, DSM-5 Development: www.dsm5.org/ProposedRevisions/Pages/proposedrevision.aspx?rid=94

Association for Science in Autism Treatment (ASAT): www.asatonline.org

Behavior Analyst Certification Board (BACB): www.bacb.com

Centers for Disease Control and Prevention, Autism Spectrum Disorders, DSM-IV Diagnostic Criteria: www.cdc.gov/ncbddd/autism/hcp-dsm.html

Cooper, Heron, & Heward (2007). Cooper, J., Heron, T., & Heward, W. (2007). *Applied behavior analysis* (2nd Ed.), Upper Saddle River, NJ:Pearson Education Inc.

Educating Children with Autism, National Research Council (2001). Online: http://www8.nationalacademies.org/onpinews/newsitem.aspx?RecordID=10017

Lovaas, O. I. (1987). Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology, 5*, 3-9.

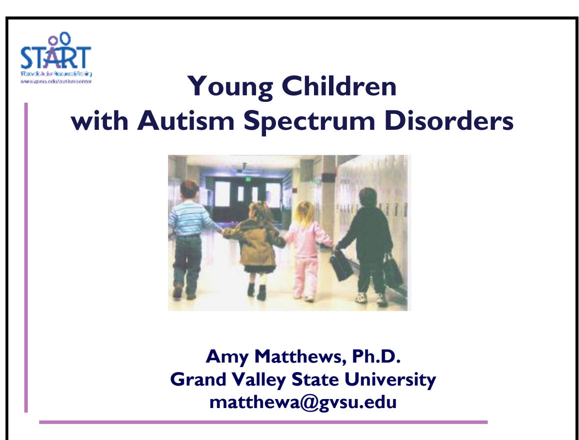
Missouri Autism Guidelines Initiative, http://www.autismguidelines.dmh.mo.gov/

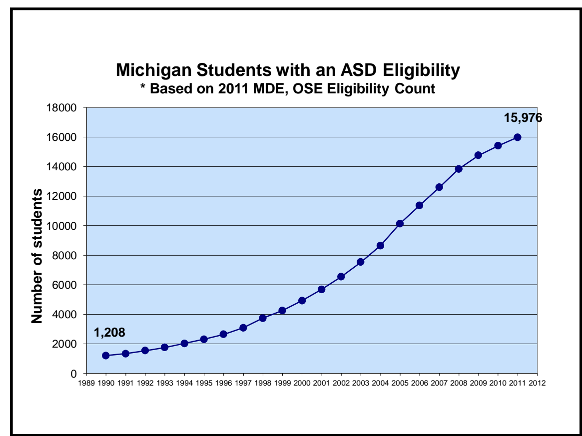
National Standards Project (2010). National Autism Center: www.nationalautismcenter.org/about/national.php

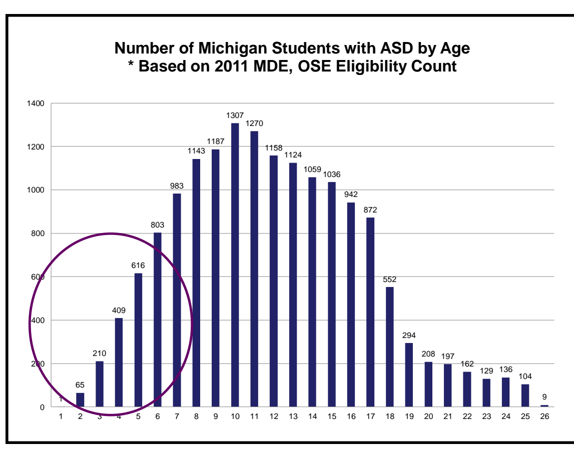
National Professional Development Center. on Autism Spectrum Disorders: http://autismpdc.fpg.unc.edu

Prelock, P.A. (2006). Working with families and teams to address the needs of children with MRDD. *Perspectives in Language, Learning, and Education 13*(3), 7-11.

Statewide Autism Resources and Training (START): http://www.gvsu.edu/autismcenter


START
Young Children
with Autism Spectrum Disorders
Amy Matthews, Ph.D.
Grand Valley State University
matthewa@gvsu.edu


Michigan Students with an ASD Eligibility
* Based on 2011 MDE, OSE Eligibility Count
Number of students
15,976
1,208
0
2000
4000
6000
8000
10000
12000
14000
16000
18000
1989 1990 1991 1992 1993 1994 1995 1996 1997 1998 1999 2000 2001 2002 2003 2004 2005 2006 2007 2008 2009 2010 2011 2012


Number of Michigan Students with ASD by Age
* Based on 2011 MDE, OSE Eligibility Count
0
200
400
600
800
1000
1200
1400
65
210
409
616
803
983
1143
1187
1307
1270
1158
1124
1059
1036
942
872
552
294
208
197
162
129
136
104
9
1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26

Centers for Disease Control (CDC)

Autism is no longer a low incidence disorder

Effective Practice

Wrightslaw

"All available research strongly suggests that intensive early intervention makes a critical difference to children with autistic spectrum disorders. Without early identification and diagnosis, children with autism are unlikely to learn the skills they need to benefit from education."

Critical Periods

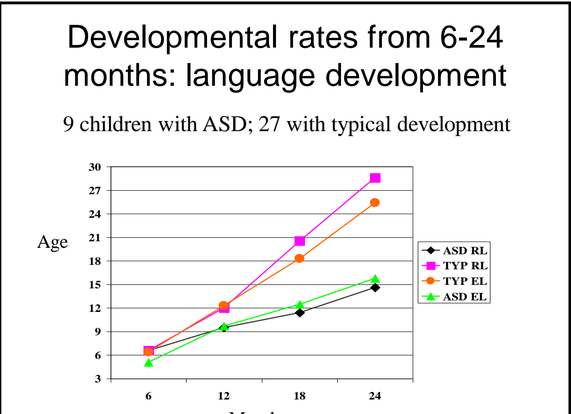
Intervening early and intensively is key to skill development and avoiding behaviors before they happen

Brain Development

- Dr. Eric Courchesne explains the underlying brain biology autism at the International Meeting for Autism Research (IMFAR)

Developmental rates from 6-24 months: language development

9 children with ASD; 27 with typical development



Rogers, et al, in progress

Effective Practices for Young Children with ASD

We Know What Works

- National Research Council Report
  - Educating Children with Autism (download for free at the National Academy Press)
- National Autism Center
  - National Standards Project (http://www.nationalautismcenter.org)
- NPDC (http://autismpdc.fpg.unc.edu/)
  - Michigan is one of 12 states that is a collaborative partner
- OCALI
  - AIM website (http://www.autisminternetmodules.org)

What are the Critical Components of Effective Programs?

- **Early is better** (by 3½)
  - Intervention at identification
  - Identification/intervention before age 3
- **Intensity matters** (at least 25 hours/wk, full year, with low ratio)
  - Model programs range from 15-40 hours a week with an average of 25 hours per week
- **Active engagement**/Structured teaching time
  - Minimal "free time"
  - Lots of learning opportunities
  - Each moment is a teachable moment
- **Family participation**
- **Individualized goals**, regularly monitored

National Research Council, 2001

We need to change our approach to educating young children with ASD

Why would public school programs have trouble adjusting to fit the recommendations and needs for young children with ASD?

Implementation challenges in public school settings

- Ratios (ECSE classrooms)
- Intensity/Time (0-3 and 3-6)
- Training of staff
- Philosophy
- Getting families involved

Changing Systems

Innovative practices do not fit well in old organizational structures

--Dean Fixsen

Intervening Early with Effective Programming

Big Ideas for Early Intervention

- Identify and intervene early
- Use evidence based practices
- Increase learning opportunities (i.e. opportunities to respond with feedback) and student engagement
- Focus on meaningful, functional goals and tasks (independence and socialization)
- Use effective instructional delivery (3 Rs- Request, Response, Reaction)

Big Ideas for Early Intervention

- Establish positive patterns of behavior early on
- Many problem behaviors are preventable with planned supports
- Provide lots of meaningful integration opportunities
- Use data to confirm that what you are doing is working
- Carefully plan for transition
- Work as a team with families

Early Childhood Assessment Tool

Statewide Autism Resources and Training (START)
Effective Practices Assessment Tool
for Young Children with Autism Spectrum Disorders

Team: ____________________ **District:** ________________ **Date:** ______________

AREA 1: Critical Program Components	Current Status/Progress — **Not in Place** 1	2	**Partially In Place** 3	4	**In Place** 5	**Priority Level 1 – 5 1=low, 5=high**
CRITICAL COMPONENTS 1. Students are actively engaged with many learning opportunities throughout the day	☐ 1 Students each receive less than 5 learning opportunities (including entire request, response, reaction sequence) per hour on average. Students are actively engaged in productive activities less than 50% of the time.	☐ 2	☐ 3 Students each receive approximately 10 learning opportunities (including entire request, response, reaction sequence) per hour on average. Students are actively engaged in productive activities more than 80% of the time.	☐ 4	☐ 5 Students each receive more than 20 learning opportunities (including entire request, response, reaction sequence) per hour on average. Students are actively engaged in productive activities more than 80% of the time.	**Priority** ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5
CRITICAL COMPONENTS 2. Programming is individualized to meet student needs	☐ 1 Students receive traditional preschool instruction with minimal adjustments for individual needs.	☐ 2	☐ 3 Programming is individualized for some students, some of the time, but not consistently enough to make rapid progress toward IEP goals.	☐ 4	☐ 5 Instructional goals, methods, prompts and response requirements are individualized to meet the student's abilities, needs, and developmental level.	**Priority** ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

Go to www.gvsu.edu/autismcenter -->training-->early childhood)

Optimal Approach

- Inclusive preschool classroom with core preschool curriculum and lots of learning opportunities

- Intensive instruction
  - Embedded in the school day, and/or
  - Following the school day
    - See Project DATA study (pilot in Michigan)
    - Parent Training (e.g. Project Impact)

START

The convergence of neuroscience and economics tells us that the clock is always ticking, and the costs of ignoring problems keep rising

Creating Partnerships for Evaluating Young Children with ASD

Vonnie VanderZwaag
Ottawa Area ISD

Issues Related to Collaborative Systems Care for Children with ASD

- Redundancy
- Inconsistency
- Miscommunication
- = POOR OUTCOMES

Redundancy, Inconsistency, Miscommunication

- Excessive and Replicated Testing
  - Educational Assessment
    - Interview
    - History
    - Informal Assessment
    - Formal Assessment/Standardized Testing

*Indicates overlap with educational and/or medical/clinical assessment

Redundancy, Inconsistency, Miscommunication

- Excessive and Replicated Testing
  - Community Mental Health Assessment
    - Interview*
    - History*
    - Informal Assessment*
    - Formal Assessment/Standardized Testing*

*Indicates overlap with educational and/or medical/clinical assessment

Redundancy, Inconsistency, Miscommunication

- Excessive and Replicated Testing
  - Medical/Clinical Assessment
    - Interview*
    - History*
    - Informal Assessment*
    - Formal Assessment/Standardized Testing*
    - Physical Exam/Medical Testing

*Indicates overlap with educational and/or CMH assessment

Redundancy, Inconsistency, Miscommunication

- Solutions
  - Identify redundant areas of assessment across systems; what can be eliminated?
  - Identify areas which differ and are unique to a particular diagnostic/assessment protocol
  - Keep in mind that assessments serve different functions in different systems

Redundancy, Inconsistency, Miscommunication

- Solutions (con't)
  - Authorization to Share Information
  - Communication
    - One representative from each system takes lead in communicating/collaborating assessment findings
    - Explore reasons for discrepant findings when they exist
    - Consensus diagnosis/shared understanding of discrepancies to facilitate better communication to caregivers

Redundancy, Inconsistency, Miscommunication

- Reasons for Uncoordinated Intervention Plans
  - Educational/IEP Objectives: Addressing function/skills in the academic environment
  - Clinical Objectives: Addressing function/skills in the home and community
    - Are these *always* different?
    - Should these be different?
    - Where is the overlap?

Redundancy, Inconsistency, Miscommunication

- Reasons for Uncoordinated Intervention Plans (con't)
  - Disagreement in Treatment Philosophies/Approaches
  - Parent Input may be more influential in clinical setting
  - Limited communication among educators and clinical specialists
  - Privacy Obstacles

Redundancy, Inconsistency, Miscommunication

- Solutions for Improved, Coordinated Intervention Planning
  - Identify discrepant objectives
  - Identify discrepant approaches
  - Identify where/under which circumstances child's performance is enhanced and the most progress is attained

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Redundancy, Inconsistency, Miscommunication

- Solutions for Improved, Coordinated Intervention Planning (con't)
  - Consensus building through:
    - Technology!
    - Standard, Shared Reporting Forms? Is this a possibility?
    - Monthly conference calls; family, school, clinical therapists
    - IEP participation (when possible)
    - Cross Setting Training

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Redundancy, Inconsistency, Miscommunication

- Lessons Learned from the Henry Ford Health System Center for Autism and Development Disabilities Diagnostic Center
  - The Medical Team
  - Multiple Sources of Input
  - How Educational Data was Incorporated into the Assessment
  - A Streamlined Process/Protocol

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Redundancy, Inconsistency, Miscommunication

- Lessons Learned from the HFHS CADD Diagnostic Center: Outcomes
  - More accurate, reliable diagnosis
  - Better profile of child's functioning in different settings
  - Eliminated testing redundancy
  - Lower costs/resource utilization
  - Less stress, better communication with caregivers

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Implementation of Recommendations

- Interdepartmental Team (IDT) issues RFP to participate as pilot site to Intermediate School Districts and Local Special Education contacts-March 2008
- IDT selects Ottawa Intermediate School District and Washtenaw Intermediate School District as pilots-May 2008

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Ottawa County

Autism System of Care Pilot

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Ottawa
Our Goals

- Connect with the medical community
- Connect with Community Mental Health
- Support families through earlier intervention
- Improve communication with families and partners

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Ottawa
Partners

- Holland Pediatrics—Dr. Kate Davis
- Helen DeVos Childrens' Hospital—Dr. Anthony Richtsmeier
- Department of Community Mental Health—Ottawa and Allegan Counties
- Early On of Ottawa County
- 11 local school districts which make up Ottawa Area Intermediate School District

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Ottawa
Role of Partners

- Holland Pediatrics gives the M-CHAT at 18 months and 2 years of age
- Dr. Richtsmeier available to consult with the team as needed
- Referrals come to Early On for children who do not pass the M-CHAT and are under 3
- Referrals go to the school system of residence for children 3 and over
- CMH has assisted Early On in implementing Project ImPact

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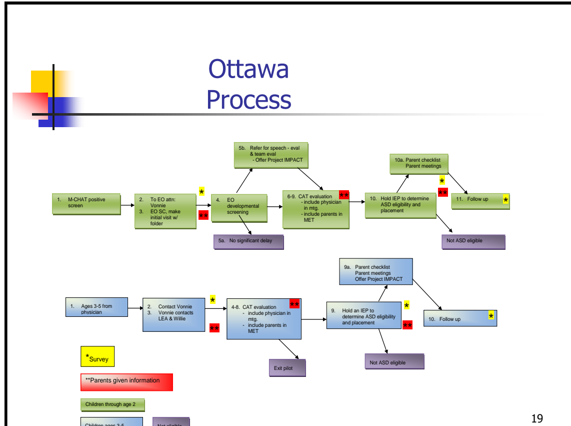

Ottawa
Use of M-CHAT

- Holland Pediatrics completes the M-CHAT with the parents at 18 and 24 months
- Follow-up is done for any children who "fail"
  - Pediatrician's office
  - Early On staff
- Referral to Early On or school system for further evaluation

20

Ottawa
Project ImPACT

- Description of the Project: Project ImPACT (Improving Parents as Communication Teachers) trains early intervention and early childhood special education providers to teach parents of children with autism spectrum disorders (ASD) evidence-based strategies for improving their child's social-communication skills during on-going family routines.
- Worked with Brooke Ingersol from MSU

21

Ottawa
Collaborative Implementation of Project Impact

- Staff training held for teachers and CMH staff
- School and CMH staff did coaching with families
- Program design—12 weeks, alternate training and coaching

22

Ottawa
Parent Supports

- Information given at 3 points: initial referral, at first home visit, and after IFSP/IEP determines ASD eligibility
- Project ImPACT training/coaching
- Parent information meetings, based on the First 100 Days document
- Additional supports based on need (examples: pediatric behavioral health, community mental health)

23

Ottawa
Benefits of a System of Care

- Families get one message
- Better utilization of resources
- Improved understanding and communication among agencies
- Regularly scheduled conference calls with partners

24

Ottawa Challenges

- Finding the time to do the job well
- Scaling up to include other medical practices
- Scoring the M-CHAT was initial challenge
- Closing the loop with physicians

25

Ottawa Successes

- Ability to tap into the knowledge of the medical home and pediatric behavioral specialist
- M-CHAT follow-up interview is a useful tool
- Improved understanding of other agencies and of parents' point of view

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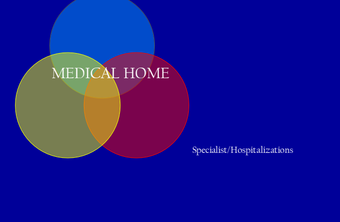
Building Collaborative Bridges of Support for Individuals with Autism spectrum Disorder (ASD)
Tisa M. Johnson MD, FAAP

Coordinating services between school and service providers

Education



Medical Home

- *A Medical Home is an* ***approach*** *to providing high quality and cost effective health care rather than a structure or health care complex.*

Medical Home Common Elements Care That is:

- *Family Centered*
- *Continuous.*
- *Comprehensive*
- *Accessible*
- Coordinated
- *Compassionate*
- *Culturally Competent*

Components of a comprehensive care plan

- Medical Summary
  - Health status
  - PMH
  - Medications
  - Allergies
- Emergency care plan
  - DNR status
  - Emergency contact
  - Neurologic status
  - Vital signs
  - Baseline laboratory levels
- Action Plan
  - List of problems
  - Plan for each problem outlining roles & responsibilities
  - Timeline

HFHS Electronic care plan

- Patient demographics
- Caregiver/Guardian
- Diagnosis
- Consent
- Mental Status
- Medical History
- Hospitalization
- Functional status
- Communication
- Behavior
- Social skills
- **School**
- Therapy and intervention both at home and school
- Transition plan (education, medical, and community)
- Equipment and supplies
- Community resources
- Providers
- Action plan.

Children with Special Health Care Needs (CYSHCN)

- *Those children who have or at risk for chronic physical, developmental, behavioral, or emotional conditions who require health related services of a type or amount beyond that required by children generally.*

The Federal Maternal and Child Health Bureau, 1997

Children with Special Health Care Needs

- Cerebral Palsy
- Intellectual Disability
- Autism
- ADHD
- Rett's Syndrome
- CHARGE Association
- Down's Syndrome
- Congenital Abnormalities
- Fetal Alcohol Syndrome
- Spin Bifida
- Neurofibromatosis

Utilization

- Primary care
- Emergency room
- Hospitalization
- Referral process to specialist
- Schools
- Family members
- Respite
- Transition to adult care

HOSPITALIZATION

Hospitalization

Henry Ford Health System hospitalizations	November 2004 HF Hospital asthma exacerbation with respiratory distress March 2004 Children's Hospital, Detroit - Status epilepticus
History of hospitalization	January 2006 Children's Hospital, Detroit - Dehydration
History of hospitalization	Aug 2008 Children's Hospital, Dallas - rash secondary to Zonegran October 2008 Children's Hospital, Detroit - for gastric tube replacement
History of hospitalization	January 2009 Children's Hospital, Detroit - Asthma exacerbation

FUNCTIONAL STATUS

Functional status

Functional status	Dependent
Functional limitations	Contractures, Speech

Diet

Method of eating	Gastro/Jejunostomy tube
Diet	Kid's Boost Essential 200ml/hour x 1.5 hour at 6am, 12 noon, 4pm, and 8 pm. 100cc water flush after each feeding. NPO
Assessment of diet	Tube feedings

COMMUNICATION

Communication

Primary language	English
Nonverbal communication	Gestures to Respond
Comprehension	Recognizes name, Responds with gestures, Understands different tones/voices

SOCIAL

Eye contact	Appropriate
Affect	Appropriate
Insight	Appropriate
Intent	Requests, Protests, Shares, Shows
Reciprocity	Play

SCHOOL

School

School name	The Charter School
Address	123 Mockingbird Lane Detroit, MI 2345
School FAX	(313) 666-3333
School phone	(313) 444-5555
Program contact	Jennifer Love
Education diagnosis	Cognitive impairment
Date of last educational plan	9/5/2009
Educational setting	Extended school year services

Benefit of an IHCP

- Provide concise, up to date snapshot of the patient
- **Enhance communication** during referral process, schools, emergency room visits, and hospitalizations
- Reduces family burden to continually repeat their child's situation to new providers
- Ensures that information is accurately conveyed (especially under stressful situations)
- Increases comfort level of care providers in managing complex cases.

Benefits of an IHCP

- Improve efficiency of care
- Reduce duplication of services
- Decrease fragmentation of care
- Improve the identification of and access to needed community resources
- Facilitates coordination of care

Actionable steps

- Advocate for the role of the primary care provider as a fundamental IEP team member.
  - phone
  - Fax
  - In person
- Expand on medical education include information on special education rules, regulations, eligibility, etc.
- Advocate for a medical home standard of care
- Advocate for IEP + IHCP = comprehensive plan

Resources

- [1] AAP 2002 Policy Statement. Medical Home Initiative for Children With Special Needs Project Advisory Committee. *Pediatrics* Vol. 110 No.1 July 2002, pp. 184-186
- [1] AAP 1999 Policy Statement. Emergency Preparedness for Children with Special Health Care Needs. . Committee on Pediatric Emergency Medicine. *Pediatrics* Vol. 104 No. 4 October 1999, p.e53
- [1] National Medical Home Learning Collaborative II, *Comprehensive Care Plan Packet*