Serving Children at Risk for ASD: Presumptive Eligibility in SC

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What it is:
A local effort initiated by the Association of University Centers on Disabilities with funding from the National Center for Birth Defects and Developmental Disabilities (CDC) and the Maternal and Child Health Bureau (HRSA).

Mission:
Focused collaboration among leaders representing professionals, state agencies, universities, healthcare systems, private organizations, and families to improve the quality of life for children, youth, and adults with Autism Spectrum Disorders and their families.
How Well Does the Eligibility Process for EIBI via Part C Work in Your State?

Are you able to get enough children into services early enough?

How well does this work to get young children into evidence-based early intervention?

- *How many children in your state are able to access EIBI?*
- *Are children able to access the service prior to turning age 3 years?*
Why was the Process For Accessing EIBI Changed in SC?

- Diagnosis of ASD (previous/typical route to services)
  - Was required for EIBI services in BabyNet (Part C)

- Resulted in very few children in South Carolina under age 3 receiving EIBI (7 in 2009)
Additional Reasons for Change

• Identification
  • Age

• Diagnostic Evaluation
  • Access has improved but history of long waiting lists has hampered many)
The Plan (circa 2010)

• Get kids identified earlier

• Use a screening process to gain access to EIIBI

• Link to the two state agencies involved
  • (BabyNet & SC DDSN)
Presumptive Eligibility in South Carolina

• Purpose is to improve early identification and intervention for young children at risk for ASD

• Grew from discussion among team members/decision makers from relevant state agencies

• Required collaboration across state agencies AND federal approval from US Dept. of Ed (re: Part C of IDEA)
Presumptive Eligibility

1) Use of MCHAT
2) If shows at risk, use the follow up questions
3) If at risk, refer to qualified STAT evaluator
4) If shown to be at risk for ASD on both screening tools, contact BabyNet to refer for EIBI. And, refer for comprehensive diagnostic evaluation
5) There is NO need to wait for a formal ASD diagnosis to receive EIBI
Faster Identification: Screening vs Diagnostic Assessment

• Screening is typically a more brief, less rigorous process that does not require implementation by a professional with training in standardized ASD assessment. It does not provide a diagnosis.

• Diagnostic assessment is performed by a trained professional, using assessment tools that require training in standardized assessment. It can provide a formal diagnosis depending on results.
Quality Control: Efforts to Minimize Over-Identification
How New Screening Process Differs

• Uses a two-tiered screening process (MCHAT with follow up questions and STAT).

Can be implemented, for purposes of presumptive eligibility, only by professional who has:
  a) training in standardized assessment;
  b) experience evaluating children with ASD;
  c) been trained in use of the STAT by Vanderbilt faculty in SC Act Early Team sponsored training; and
  d) enrolled as a “qualified STAT provider” through SC DDSN (in collaboration with BabyNet)
Key Steps

MCHAT = At Risk

MCHAT Follow Up Questions = At risk

STAT = At Risk

Presumptive Eligibility Criteria EIBI Met
Results of New SC Process

SOUTH CAROLINA PRESUMPTIVE ELIGIBILITY FOR TODDLERS WITH ASD 2010 - 2015*

*Data through 8/31/15
More Results

• New children made eligible for EIBI:
  • 2014 = 395
  • 2015 = 452
  • Combined 2014/2015 = 874
  • 2010/2011 = 114
Frequently Asked Questions

• If a child is receiving EIBI via the presumptive eligibility process should they still get a full diagnostic evaluation?

• YES! The evaluation is more comprehensive and is conducted by a professional who is qualified to diagnose ASD
• An ASD diagnosis is required to continue EIBI after age 3
• An ASD diagnosis is required if seeking reimbursement by private insurance
More FAQ

• Why not wait for an official diagnosis before starting EIBI?
  • The earlier intervention the better
  • Beginning EIBI before age 3 (and subsequent diagnosis) provides continuation of EIBI without interruption with transition from BabyNet to DDSN systems
  • If showing behaviors that would make the child come up as “at risk”, suggests that intervention would be of benefit even if eventually do not meet criteria for ASD
More FAQ

• What should I do if the child does not come up as at risk on the STAT?

  • Continue the evaluation process

    • Other developmental concerns

    • Some children are diagnosed via comprehensive evaluation
More FAQ

- Does presumptive eligibility apply to private insurance carriers?
  - No, an ASD diagnosis by a provider approved by the insurance carrier is required for coverage under SC’s insurance mandate (Ryan’s law)
  - But, the child could still receive EIBI under BabyNet
Why Did This Work????

- Organized Team Effort

- Built the Relationships/Collaborations

- Increasing level of buy-in and commitment to highest levels of quality and practicality

- Diverse Membership of Leaders/Decision Makers (policy, clinical, systems, family and related agencies)
Improving Early Identification and Intervention for Children at Risk for Autism Spectrum Disorder
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Abstract

OBJECTIVES: To provide an example of a successful, novel statewide effort to increase early identification of young children at risk for autism spectrum disorder (ASD) using a 2-tiered screening process with enhanced quality assessment, interagency policy collaboration and coordination.

METHODS: The South Carolina Act Early Team (SCAET) provided focused collaboration among leaders representing state agencies, universities, health care systems, private organizations, and families to improve quality of life for children with ASD. Specific focus was on implementing policy changes and training to result in earlier identification and home-based behavioral intervention for young children at risk for ASD.

RESULTS: Policy changes, training, and modified state agency practices were accomplished. Presumptive eligibility, on the basis of a 2-tiered screening process was implemented by BabyNet (South Carolina’s Early Intervention Program) in collaboration with the lead agency for developmental disability services. There was a fivefold increase in children eligible for early intensive behavioral intervention without waiting for a diagnosis of ASD, avoiding long waits for diagnostic evaluations. Only 16 children (2.5%) were later found not to have ASD from a comprehensive evaluation.

CONCLUSIONS: Improvements in early identification and intervention are feasible through collaborative policy change. The South Carolina Act Early Team and its key stakeholders committed to improving outcomes for this population used existing tools and methods in new ways to improve early identification of children with ASD and to make available evidence-based intervention services. This example should be replicable in other states with key stakeholders working collaboratively for the benefit of young children with ASD.

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Another Benefit

• An additional benefit was avoiding the waiting list for State DD Agency PDD Waiver

• As of January 2016 there are 1638 children on this waiting list . . .
Lessons Learned

- Provide more training for early interventionists and case managers on:
  - The eligibility process
  - Why it’s important to intervene as early as possible
  - How best to communicate with families about the difference between “at risk” screening and an ASD diagnosis
  - How best to encourage families to pursue the process
Major Challenges Facing the System

- Understanding of the presumptive eligibility process
- Number of EIBI providers
- Medicaid reimbursement rate in SC (new) is less than half that of other states
Medicaid State Plan

- The Centers for Medicare and Medicaid Services (CMS) have issued guidance to all state Medicaid agencies that ASD services should be included in the Medicaid State Plan.
  - Age birth to 21
  - Include but not be limited to Applied Behavior Analysis Therapy (EIBI)
  - State plan cannot have a waiting list – it is an entitlement
Non Sequitur by Wiley Miller

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