

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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Dr Rotholz conceptualized the article, drafted the majority of the manuscript, and reviewed and revised the manuscript; as chair of the team that developed the process for presumptive eligibility in South Carolina, he contributed meaningfully to this process; Dr Kinsman contributed to conceptualization of the article, developed sections of the article, and reviewed and revised the article; as a member of the team that developed the process for presumptive eligibility in South Carolina, she contributed meaningfully to this process; Dr Lacy codeveloped the process for presumptive eligibility for young children at risk for autism spectrum disorder in South Carolina and led the process for its approval by the South Carolina Developmental Disabilities agency; she reviewed and edited the article; Dr Charles initiated the idea for training of physicians in advanced screening tools, initiated and organized the first Screening Tool for Autism in Toddlers

WHAT'S KNOWN ON THIS SUBJECT: Early intervention for children with autism spectrum disorder (ASD) has the potential to improve their developmental trajectory. Difficulty in timely identification and service provision results in missed opportunities for many children. Improvements are needed to help the growing number of children with ASD.

WHAT THIS STUDY ADDS: This article describes a statewide process that improved early identification of young children at risk for ASD and how they gained eligibility for early applied behavior analysis intervention. Results demonstrate improvements from a 2-tiered screening system with a low false-positive rate.

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Prevalence estimates for young children with autism spectrum disorder (ASD) have been steadily rising from 1 in 150 in 2000 to 1 in 68 in surveillance year 2010.¹ The importance of early identification and intervention for young children with ASD is well established.^{2,3}

It is estimated that approximately one-third of children and youth with special health care needs with ASD are covered by Medicaid or the state-based Children's Health Insurance Program.⁴ It has also been estimated that intensive behavioral intervention costs, in addition to medical costs, can range from \$40 000 to \$60 000 per year, with societal costs of caring for children with ASD estimated at over \$9 billion in 2011.⁵ Therefore, it is especially noteworthy that the Centers for Medicare and Medicaid Services (CMS) issued the bulletin "Clarification of Medicaid Coverage of Services to Children with Autism" in July 2014, providing information to states specifically noting the inclusion of "applied behavior analysis (ABA) therapy" as a benefit for those younger than age 21 under Medicaid's Early Periodic Screening, Diagnosis, and Treatment provision.⁶

Medicaid coverage for ABA therapy (sometimes described as early intensive behavioral intervention [EIBI]) has the potential to vastly broaden the population of children with ASD receiving this intervention, especially since CMS stated that the service may be covered under Medicaid waivers and Medicaid state plans. The latter option may provide intervention without waiting lists for services and eliminates the institutional level of care requirement existing in states providing the service under Medicaid waiver programs.

Significant challenges exist in appropriately identifying children at risk for ASD at an early age and providing them with effective early intervention (eg, EIBI).

Practitioners and state systems of care have struggled with these issues,⁶ including delays identifying suspected ASD and referral for evaluations. A strategy implemented in many states to address early identification comes from the Centers for Disease Control and Prevention (CDC) "Learn the Signs, Act Early" campaign.^{7,8} However, extended time often occurs between when concerns are first raised, referral, and the diagnostic evaluation. As noted by Marks et al,⁹ leadership is needed "across sectors to build capacity to increase and improve access to evidence-based practices and services that are tailored to child and family needs."

To address the small number of children under age 3 with or at risk for ASD who were receiving early intervention services in South Carolina, we (the South Carolina Act Early Team [SCAET]) developed a new policy of "presumptive eligibility." Implemented collaboratively by BabyNet and the South Carolina Agency for Developmental Disabilities (DD) services, this policy provides BabyNet EIBI for children under age 3 without a diagnosis of ASD on the basis of a 2-tiered screening process. Children are determined to be eligible under presumptive eligibility if found at risk on the Modified Checklist for Autism in Toddlers (M-CHAT^{10,11}) and the Screening Tool for Autism in Toddlers and Young Children (STAT¹²⁻¹⁴). The current investigation describes and examines the effectiveness of this policy implementation on access to EIBI services.

METHODS

In 2007, the CDC initiated a multiyear process to promote development of Learn the Signs, Act Early state teams. Teams were to create multidisciplinary statewide groups of key stakeholders to develop and

implement approaches to improve early identification and effective intervention for young children at risk for or diagnosed with ASD. In 2009, the South Carolina University Center for Excellence in Developmental Disabilities; known locally as the Center for Disability Resources at the University of South Carolina School of Medicine (USC), Department of Pediatrics formed the SCAET.

The SCAET comprises members with decision-making authority from the following: USC, Department of Pediatrics (University Center for Excellence in Developmental Disabilities director, board certified behavior analyst [BCBA]), South Carolina Autism Society (executive director), South Carolina Chapter of American Academy of Pediatrics (MD appointee), South Carolina Department of Disabilities and Special Needs (DDSN; Associate State Director for Policy), Medical University of South Carolina (MD, Developmental/Behavioral Pediatrics), BabyNet (Part C Coordinator), Winston's Wish (private autism-focused foundation, executive director), Greenville Health System (Director of Pediatric Psychology), Family Connection of South Carolina (executive director), South Carolina Department of Education (autism specialist), South Carolina Developmental Disabilities Council (executive director), and University of South Carolina, Special Education Program (professor). Since its inception, the SCAET has had membership changes, but the leadership, participation, and focus has remained to improve early identification and intervention for young children with and/or at risk for ASD. Subsequent to the CMS guidance that ASD services should be included in Medicaid State Plans the state Medicaid agency has joined the group (deputy director).

Measures

Modified Checklist for Autism in Toddlers

The M-CHAT¹⁰ is a parent-completed screening measure. Although the Positive Predictive Value using the established cutoff scores is low for the M-CHAT alone (eg, 0.36 +/- 0.05 for initial screening), it improves when follow-up questions are asked.¹¹ However, it has been suggested that use of an additional second level screening be used before implementing a comprehensive ASD evaluation, particularly in low risk samples.¹²

Screening Tool for Autism in Toddlers and Young Children

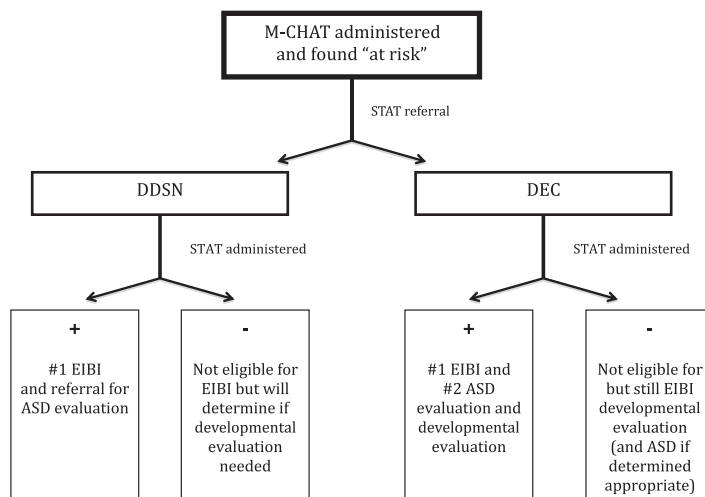
The STAT¹²⁻¹⁴ is a screening measure administered in a brief (15 to 20 minutes) interactive assessment with children. The STAT is normed on children ages 24 to 35 months, but extended scoring systems are available for children ages 3 years and as young as 14 months.¹³ The STAT assesses social communication skills and provides a total ASD risk cutoff score. Research has shown strong concurrent validity with the Autism Diagnostic Observation Schedule-G and clinical diagnosis¹⁴ and that specific training in the STAT had a positive impact on comfort in discussion and ASD diagnosis and diagnostic identification in pediatric practices.

Eligibility for and Receipt of Services

The South Carolina BabyNet program state office provided data on children age 0 to 3 related to presumptive eligibility, evaluations, diagnosis, and BabyNet service participation in EIBI.

Procedures

Procedures for developing and implementing presumptive eligibility included the following: (a) policy development for 2 state agencies focused on a new, 2-tiered screening system, (b) federal regulatory approval, (c) training for medical



In all instances, child will maintain BabyNet services other than EIBI if qualified for BabyNet

FIGURE 1

Implementation of presumptive eligibility, 2-tiered screening process and policy in South Carolina.

and other professionals, and (d) implementation across 2 state agencies with collaboration from developmental evaluation centers (DECs).

The presumptive eligibility policy requires that a child initially screens as “at risk” on the M-CHAT. Initial screening using the M-CHAT could be conducted through multiple channels, including the child’s early intervention provider or physician. In most instances, the M-CHAT was administered without follow-up questions.

For children already participating in BabyNet services, Early intervention providers are required to administer the M-CHAT at 18 and 24 months. If the child is identified as at risk, BabyNet policy requires early intervention providers to refer the child for a STAT administered by a STAT-trained professional either through the DDSN or 1 of 3 DECs (Fig 1). This policy was implemented, in part, because early intervention providers may not have the requisite training and experience to administer follow-up questions and determine the need for additional screening.

When physicians complete the M-CHAT as part of the child’s medical care, they typically make referrals to DECs for an ASD assessment and to BabyNet to determine overall eligibility for services. In this instance, a STAT-trained professional at the DEC administers the STAT.

Children who have an at-risk score on the STAT are eligible to begin EIBI services provided by BabyNet. If the STAT was performed at the DEC, the child is subsequently scheduled for a comprehensive evaluation. If not already referred to a DEC, these children are referred for a comprehensive diagnostic evaluation for ASD through DDSN and/or a DEC. In both instances, the child will continue EIBI services until they either age out of BabyNet services or are determined not to meet criteria for ASD based upon the comprehensive diagnostic evaluation.

Children who do not have an at risk score on the STAT but are receiving early intervention continue receiving their services. If the child has been referred to a DEC, a comprehensive evaluation will be conducted if

the specific professional deems it necessary.

Across both DDSN and the DECs, the comprehensive diagnostic evaluation for ASD includes the *Autism Diagnostic Observation Schedule, Second Edition*,¹⁵ as well as other ASD-specific measures as determined by the particular site (eg, *Childhood Autism Rating Scale, Second Edition*¹⁶), caregiver interview, child observation, and completion of *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* criteria. For those children evaluated through the DECs, the evaluation also typically includes a standardized assessment of developmental, behavioral, and adaptive skills. In all instances in which a child has been determined eligible for BabyNet services other than EIBI, determining that the child does not have ASD will not impact eligibility for these other services.

Policy requires that a STAT be completed by professionals who (a) successfully completed the SCAET-provided STAT training, (b) have training in standardized assessment, (c) have experience in conducting standardized diagnostic developmental assessments, and (d) be enrolled as a DDSN STAT "provider." These requirements were developed to insure that access to services via presumptive eligibility would be determined by professionals with the most appropriate training and experience according to the SCAET. Before this policy could be implemented, approval was required from the US Department of Education because they have authority over expenditure of BabyNet/Part C funds, including those to be used for their share of the EIBI costs.

Upon federal approval received in October of 2012, the presumptive eligibility process was published and disseminated jointly by the BabyNet and the SC DD agency in South Carolina. At that point STAT assessments for children age 18 to 36 months began for those who were found to be at risk on the basis of the M-CHAT.

Members of the SCAET organized and hosted training for professionals (medical and others) on the STAT^{13,14} on 3 separate occasions in different areas of South Carolina. All trainings were conducted by a certified trainer and faculty member from Vanderbilt University where the STAT was developed and where dissemination efforts are based. The training included 2 days of didactic instruction, practice, and follow-up quality review of initial assessment implementation. The SCAET maintains the list of the physicians, nurses, psychologists, social workers, and other professionals who successfully completed the training and provided it to the 2 state agencies directly involved in providing early interventions services for children with disabilities.

It is important to note that South Carolina has a Medicaid Waiver that provides EIBI for Medicaid eligible children ages 3 to 11 years. The state legislature also appropriated funds so that children meeting EIBI eligibility requirements but not Medicaid eligible could receive the EIBI paid for with state funds. With introduction of EIBI services for children under age 3 on the basis of presumptive eligibility, the 2 state agencies agreed that any child receiving EIBI from BabyNet would seamlessly transition to the DD agency funded (Medicaid Waiver) services upon reaching age 3 if they had a diagnosis of ASD. Because the children were referred for a full diagnostic assessment upon receiving presumptive eligibility, it was typically achievable to have the evaluation completed by the required age. Therefore, presumptively eligible children receiving EIBI were able to bypass the waiting list for EIBI from the DD agency.

RESULTS

Implementation of presumptive eligibility in South Carolina has been accompanied by large increases in

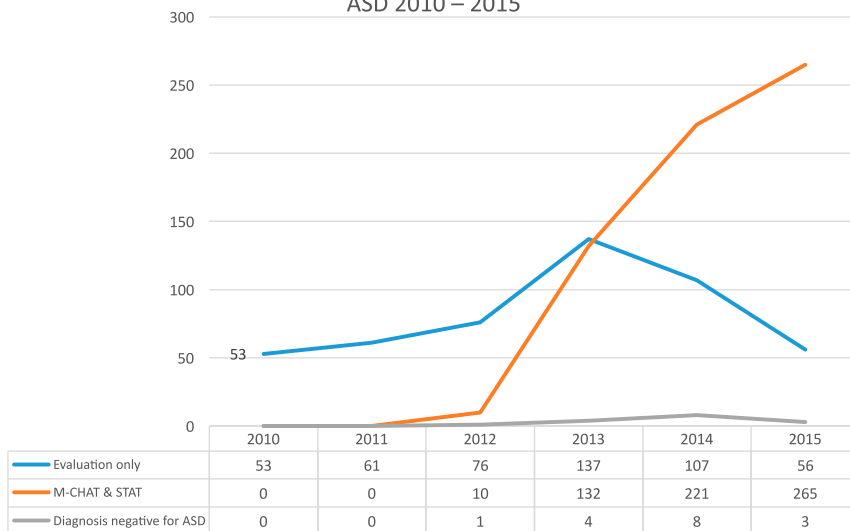
children age 18 to 36 months eligible for and receiving EIBI services. Children in this age range newly eligible to receive EIBI services increased from 53 children in 2010 to over 265 children in 2015 (Fig 2). It is important to note that the annual figures may underestimate the actual number of children eligible because children can stay presumptively eligible for EIBI services for consecutive years (eg, ages 2 and 3). This could increase those eligible in 2014 through 2015 to a number closer to the 628 children who received presumptive eligibility between 2012 and 2015. For this reason, a current point in time child count was obtained from the BabyNet database (Table 1). This count includes all children age 0 to 3 receiving EIBI in September 2015. Of the children receiving the service in August 2015, 267 received eligibility through the presumptive eligibility process, whereas 73 received a formal diagnosis of ASD.

DISCUSSION

Presumptive eligibility has had a measureable impact on the number of young children in South Carolina identified and determined eligible for and receiving EIBI services. Use of presumptive eligibility rather than a formal diagnosis allows for earlier access of services. For these children, this may mean months if not more than a year of intervention at a critical time in development. Further, given the seamless transition to the Medicaid Waiver at the age of 3, these children may be receiving services several years earlier by avoiding the waiting list. Although the longitudinal impact on functional and financial outcome for these children may not yet be known, these efforts align with research and policy identifying the importance of early intervention for young children with ASD.

Not all children who receive eligibility actually enroll in the service due to a combination of

South Carolina Presumptive Eligibility for Toddlers With ASD 2010 – 2015



Data through Aug 31, 2015

FIGURE 2

Number of children younger than age 3 determined eligible for ASD services in South Carolina.

TABLE 1 Point in Time Data on Children Younger Than Age 3 Receiving ASD Services in South Carolina

| 2015 Current Snapshot of Service Data for Children Under Age 3 (Aug 15, 2015) | |
|--|---|
| No. of Children Receiving EIBI Through Part C/BabyNet via Presumptive Eligibility Status | No. of Children Receiving EIBI Through Part C/BabyNet via ASD Diagnosis |
| 267 | 73 |

family factors and service sector challenges. Some families choose not to have the home-based intervention and others face the challenge of finding an available service provider.

The increase in children eligible for EIBI raises questions about whether other factors, such as socio-demographic changes, could contribute to this finding. Perhaps the most relevant data are those on ASD prevalence published by the CDC, which reported, in 2016¹⁷ that South Carolina had an ASD prevalence rate of 12.4 per 1000 children age 8 in 2012 compared with a national average of 14.6. The CDC also reported that in 2008¹⁸ South Carolina had an ASD prevalence rate of 11.1 per 1000 compared with a national rate of 11.3. With increases in ASD prevalence in South Carolina smaller than national increases, this does not provide an alternative explanation for the fivefold increase in children identified at risk for ASD reported.

Another issue is that while presumptive eligibility has been implemented there have been other concurrent efforts to improve pediatric practice in South Carolina. The South Carolina Quality Through Technology and Innovation in Pediatrics project includes emphasis on routine screening, including the M-CHAT, in the 18 practices involved. Although this might initially seem an alternate explanation for the improvements reported in this study, it is not. Instead it complemented the presumptive eligibility process. Recalling that the SCAET required a 2-tiered screening process to access EIBI without an ASD diagnosis, increased use of the M-CHAT alone would not have an impact on the results. Only through subsequent use of the STAT, by a professional who received SCAET-sponsored training and became an “approved STAT provider,” were children made presumptively eligible for EIBI.

Although some might be concerned about waiting time to receive a STAT and the services it enables, this has been addressed by the 26 qualified assessors and a waiting period that varies from 20 to 90 days across sites.

Use of an at risk status for eligibility raises concern that services could be removed if formal diagnostic evaluation determines the child does not meet criteria for ASD. This could also create distress and confusion for families who perceived their child as having ASD but then do not. Steps taken to reduce the likelihood of a false-positive for ASD (STAT training and qualified provider certification) have limited this outcome. Further, those administering the STAT inform families that presumptive eligibility is not a diagnosis but rather a determination of need for further assessment and a means to begin services while waiting for formal assessment.

Implementation of presumptive eligibility has met with some challenges. The implementation of a screening tool creates risk for identifying children as not at risk when they ultimately would be diagnosed with ASD. This could create instances where, after a determination of “not at risk,” a formal evaluation is not pursued and/or significant distress is experienced by families when at subsequent formal assessment a diagnosis is made. Families were counseled that the STAT is a screening tool and that formal assessment is still recommended, particularly as other diagnoses and intervention needs may be identified through formal evaluation. STAT assessors were highly trained and experienced and often able to clinically assess whether concerns remained and a formal evaluation was needed.

The determination of not at risk could also create the perception that assessment or intervention for

other developmental-behavioral conditions is not necessary. In some instances, other factors could account for the at risk determination. Steps were taken to ensure that children received appropriate services whether they were determined not at risk or at risk. For children already receiving Early Intervention services, results of the STAT did not alter eligibility or receipt of other services provided by BabyNet. For children not already receiving Early Intervention services or other therapies, a referral to BabyNet for a STAT included eligibility assessment for other BabyNet services. For children referred to the DECs, a comprehensive developmental-behavioral assessment was typically completed to assure determination of a comprehensive profile of the child.

We found during formal evaluation that some families opted not to pursue EIBI before the formal evaluation, in part because the child may later not be diagnosed with ASD. In some instances, this meant that families were not able to access services until after age 3, delaying services due to the Medicaid waiver waiting list. This suggests the need for more effective communication with families about pursuing EIBI before a formal diagnosis.

Some families encountered difficulties securing services due to limited availability of EIBI providers. This points to the need to increase availability of EIBI/ABA providers. Several efforts were implemented to address this issue. South Carolina was among the first states to implement a Medicaid Waiver for children with pervasive developmental disorders in early 2007. That same year the South Carolina legislature approved covering services for children with ASD under certain private health insurance plans which was associated with an increased demand for services. Additionally, the state DD agency implemented several initiatives to address the supply of

ABA providers (BCBAs) and the direct implementation staff they supervise (line therapists). The state DD agency contracts with USC for coursework required by the Behavior Analyst Certification Board with classes offered to participants free of charge in exchange for a 2-year commitment to provide services to state DD agency service recipients. To date, 5 cohorts of trainees have been implemented with an average enrollment of 15 to 20. To complement this effort, the state DD agency identified a group of BCBAs willing to provide the required supervision hours to course participants.

Challenges in recruiting, training, and retaining service provider staff who treat young children with ASD are noteworthy. Although the issue is not unique to South Carolina, we are fortunate that (a) the state legislature has increased funding, including the pay rate for early interventionists, (b) the DD agency has funded several initiatives to recruit and train interventionists, and (c) parent organizations are collaborating in the recruitment, training, and retention of ASD professionals.

The state DD agency also contracted for development of recruitment materials for use at relevant professional conferences nationally and with a recruitment company to create a pool of potential line therapists for behavioral services professionals and provider agencies. Additionally, the state DD agency collaborates with the USC psychology department to identify students interested in becoming line therapists. Finally, the state DD agency amended the EIBI/ABA service program to allow families to recruit and hire their own line therapists.

CONCLUSIONS

Although future research is needed to determine the impact of presumptive eligibility on

longitudinal outcomes for these children, the effectiveness of the South Carolina policy of presumptive eligibility demonstrates a method for early identification and implementation of services for young children with ASD. It also speaks to the impact that collaborative policy change by key stakeholders can have on the lives of children with ASD and their families. The use of readily available tools and training allows for implementation and suggests that this strategy would be feasible for other states.

ACKNOWLEDGMENTS

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ABBREVIATIONS

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| ABA: | applied behavior analysis |
| ASD: | autism spectrum disorder |
| BCBA: | board certified behavior analyst |
| CDC: | Centers for Disease Control and Prevention |
| CMS: | Centers for Medicare and Medicaid Services |
| DD: | developmental disabilities |
| DDSN: | Department of Disabilities and Special Needs |
| DEC: | Developmental Evaluation Center |
| EIBI: | early intensive behavioral intervention |
| M-CHAT: | Modified Checklist for Autism in Toddlers |
| SCAET: | South Carolina Act Early Team |
| STAT: | Screening Tool for Autism in Toddlers and Young Children |
| USC: | University of South Carolina School of Medicine |

and Young Children training, and contributed meaningfully to development of presumptive eligibility for young children at risk for autism spectrum disorder in South Carolina; and all authors approved the final manuscript as submitted.

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