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Implementing Services for Children with ASD and Their Families Within State Early Intervention Programs: A View from Two States – Opportunities, Challenges, and Future Directions

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Abstract

The US Centers for Disease Control and Prevention estimates about 1 in 59 children in the USA has an autism spectrum disorder (ASD). A compelling parallel can be drawn between states' implementation of the national Part C Early Intervention Program, established in 1986 under the Individuals with Disabilities Education Act (IDEA), and the increased prevalence of very young children affected by ASD. States participating in this national program for infants and toddlers and their families have been on the front line of service delivery to the growing population of very young children with ASD and their families. This chapter provides a broad overview of the Part C Early Intervention Program, state practices and challenges related to Part C implementation with import to young children with ASD and their families, and the experiences of two states, New York and Massachusetts, in addressing the needs of these toddlers and families.

Introduction

Scientific understanding of identification, diagnosis, and early intervention with toddlers with ASD has rapidly evolved in the past five decades. According to the Centers for Disease Control, epidemiologic studies conducted in the late 1960s and 1970s estimated 1 in 2500 children in the population had autism, with prevalence estimates from the 2000s indicating 1–2% of children with autism (Centers for Disease Control and Prevention, 2014). Based on 2014 data from the Autism and Developmental Disabilities Monitoring Network, CDC now estimates that about 1 in 59 children in the USA has an ASD (Baio et al., 2018). In addition, research has demonstrated ASD can be detected as early as 18 months and reliably diagnosed by experienced professionals by the age of 2 (Centers for Disease

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Control, 2016). The positive impact of early intervention services on young children's development is well-established, and science-based evidence in this area is rapidly expanding (Boyd et al., 2010; Lord & Bishop, 2010; Warren et al., 2011; Weitlauf, McPheeters, Peters, et al., 2014).

A compelling parallel can be drawn between states' implementation of the national Part C Early Intervention Program, established in 1986 under the Individuals with Disabilities Education Act (IDEA), and the increased prevalence of very young children affected by ASD. Arguably, states participating in the national program have been on the front line of service delivery to the growing population of young children under the age of 3 with ASD and their families (Noyes-Grosser et al., 2013).

The delivery of family-centered services is a central tenet of the IDEA Part C Early Intervention Program founded in the federal act, a primary purpose of which is to implement statewide, comprehensive, coordinated, multidisciplinary interagency service delivery systems to provide early intervention services for infants and toddlers with disabilities *and their families*. (Individuals with Disabilities Education Act, Purpose and Findings, §§631, 2004, 2016a). A substantial body of literature exists on family-centered services and parent involvement in early intervention programs (Dempsey & Keen, 2008). The Early Intervention Family Alliance has aptly articulated guiding principles of family-centered early intervention services (Early Intervention Family Alliance (2016) Guiding Principles, http:// http://eifamilyalliance.org):

- Families are essential partners in implementing family-centered practices in all levels of early intervention.
- Families are respected experts on the services their child should receive.
- Families have equal access to training and technical assistance to foster meaningful involvement.
- Family diversity and voices of the underrepresented are essential to quality services and implementation of policies and practices.
- Family-centered services that are community based and culturally competent ensure the highest quality programs.

This chapter provides a broad overview of the IDEA Part C Early Intervention Program (Part C) for infants and toddlers with disabilities and their families, state practices and challenges related to Part C implementation with particular import to young children with ASD and their families, and experiences of two states, New York (NY) and Massachusetts (MA), in addressing the needs of these toddlers and families.

Overview of Part C

The Part C program under IDEA is a national program for families and their infants and toddlers from birth to 3 years of age with disabilities and their families, including young children with ASD. In contrast to Part B of IDEA, which requires states[1] to provide a free, appropriate public education (FAPE) for children and youth aged 3–21 years with disabilities, participation in Part C is discretionary to states. All states currently participate in the program.

Required components of Part C for states are a state definition of developmental delay, which specifies the level of developmental delay and diagnosed conditions used for eligibility purposes; availability of early intervention services; evaluation, assessment, and nondiscriminatory procedures; Individualized Family Service Plans (IFSPs); comprehensive child find system; public awareness program; central directory of early intervention services, resources, and research and demonstration programs; comprehensive system of personnel development; personnel standards; a lead agency responsible for oversight of the program; a policy for contracting or otherwise arrange for services; reimbursement procedures; data collection system; state interagency coordinating council; and policies and procedures to ensure services are delivered to the maximum

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[1] For purposes of this article, the term "state" encompasses the 50 states and 6 US territories.

extent appropriate in natural environments (Individuals with Disabilities Education Act, §§635, State Requirements, 2004) (Individuals with Disabilities Education Act of 2004, 2016b).

States participating in the national program receive an annual appropriation through a formula grant for Part C implementation, driven by the proportion of children under 3 years of age residing in the state. These federal grants obligate participating states to adhere to a rigorous and comprehensive set of statutory and regulatory requirements applicable to all state Part C programs, including an entitlement to early intervention services included in children and families' Individualized Family Service Plans (IFSPs). While states are allowed to use their Part C formula grants to fund early intervention services (Individuals with Disabilities Education Act of 2004, §§638) (Individuals with Disabilities Education Act of 2004, 2016a), singularly the federal appropriations have been insufficient to meet the full need experienced by states in delivering services to eligible infants and toddlers and their families (IDEA Infant Toddler Coordinators Association, 2014). Importantly, in establishing and reauthorizing Part C, congress was clear in its intent that services were to be financed through a broad array of existing federal and state programs, most notably the Medicaid program under Title XIX of the Social Security Act (Individuals with Disabilities Education Act of 2004, §§635(a)(10), 2004) (Individuals with Disabilities Education Act of 2004, 2016b).

All states and territories currently participate in the Part C program. Collectively, in the 2014 program year, states delivered early intervention services to 350,581 or 3% of infants and toddlers in the USA and outlying territories based on the annual point in time count of children with an IFSP and in the Part C EIP on either October 1 or December 1 of that year (US Department of Education, Office of Special Education Programs, IDEA Data Products 2014–2015, 2016). Across 40 states optionally reporting the count of infants and toddlers receiving early intervention services at some point during the 2014–2015 reporting period (referred to as a "cumulative count" of children and families participating in state early intervention programs), 434,806 children and their families received early intervention services in this time frame. In our respective states, 4% of children under the age of 3 in NY and 8.89% in MA (which includes infants and toddlers at risk for disability in the state's eligibility criteria) participated in Part C, with 54,560[2] children in NY and 36,092 in MA receiving early intervention services at some point during the reporting period (US Department of Education, Office of Special Education Programs, IDEA Data Products 2014–15, 2016).

Both NY and MA have experienced significant growth in the number of children with ASD and their families enrolled in our respective Part C programs. In the 2014–2015 program year (July 1 through June 30), 7986 toddlers in NY's Part C program had a reported diagnosis of ASD, compared with 639 children reported with an autism diagnosis in 1999–2000 (the first year in ICD-9 diagnostic codes associated with children's eligibility for were collected). MA anticipates that 2066 children with ASD will participate in the MA Part C program 2016 state fiscal year.

The reauthorization of IDEA in 2004 added new requirements on states intended to shift the focus from compliance with federal law and regulations governing early intervention and special education systems to results-driven accountability. The state is required to develop state performance plans and report annually on federally established compliance and performance indicators (Individuals with Disabilities Education Act of 2004, §§616) (Individuals with Disabilities Education Act of 2004, 2016c). For Part C, performance indicators include metrics related to delivery of services in natural environments (defined as settings where typically developing peers are found, including home and community settings), percent of children under 3 years of age receiving Part C services, percent of children under 1 year of age receiving Part C services, child outcomes, and family outcomes. Notably, states are required to

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[2] For NY, the child counts reported to the US Department of Education exclude toddlers aged three and older who have been found eligible for Part B preschool special education services and, at parent option, can remain in the early intervention program for a period of time determined by their month of birth.

collect and report on the following child and family indicators: percent of infants and toddlers who demonstrate improved positive social-emotional skills, including social relationships; acquisition and use of knowledge and skills, including early language and communication; and use appropriate behaviors to meet their needs (Indicators 3a, b, and c) and percent of families who report early intervention services helped them know their rights, effectively communicate their child's needs, and help their child develop and learn (Indicators 4a, b, and c). Table 28.1 presents all compliance and performance indicators for Part C programs reported annually by states (US Department of Education, Office of Special Education Programs, 2014a, 2014b).

In 2014, the state performance plan/annual performance report requirements were augmented to include a new State Systemic Improvement Plan (SSIP) designed to focus state efforts on a State Identified Measurable Result (SIMR), either a child outcome, family outcome, or suite of outcomes, selected in conjunction with stakeholders (US Department of Education, Office of Special Education Programs, 2014b). In further alignment with the enhanced focused on accountability for results being achieved for children and families in state early intervention service delivery systems, the US Department of Education, Office of Special Education Programs, recently included child outcomes data for the first time in determining the extent to which states met federal requirements for the Part C EIP (US Department of Education, Office of Special Education Programs, 2014a).

Table 28.1 State performance plan and annual performance report indicators

1	Percent of infants and toddlers with IFSPs who receive the early intervention services on their IFSPs in a timely manner
2	Percent of infants and toddlers with IFSPs who primarily receive early intervention services in the home or programs for typically developing children
3	Percent of infants and toddlers with IFSPs who demonstrate improved A. Positive social-emotional skills (including social relationships) B. Acquisition and use of knowledge and skills (including early language/communication) C. Use of appropriate behaviors to meet their needs
4	Percent of families participating in Part C who report that early intervention services have helped the family A. Know their rights B. Effectively communicate their children's needs C. Help their children develop and learn
5	Percent of infants and toddlers birth to 1 with IFSPs compared to (A) other states with similar eligibility definitions and (B) national data
6	Percent of infants and toddlers birth to 3 with IFSPs compared to (A) other states with similar eligibility definitions and (B) national data
7	Percentage of eligible infants and toddlers with IFSP's for whom an evaluation and assessment and an initial IFSP meeting were conducted within Part C's 45-day timeline
8	Percent of all children exiting Part C who received timely transition planning to support the child's transition to preschool and other appropriate community services by their third birthday including A. IFSPs with transition steps and services B. Notification to LEA, if child potentially eligible for Part B C. Transition conference, if child potentially eligible for Part B
9	Percent of hearing requests that went to resolution sessions that were resolved through resolution session settlement agreements (applicable if Part B due process procedures are adopted by the lead agency under 34 CFR §303.420(a))
10	Percent of mediations held that resulted in mediation agreements
11	State Identified Measurable Result (from among indicators 3 and 4 or related to 3 and 4) and State Systemic Improvement Plan

Adapted from the US Department of Education, Office of Special Education Programs (2014b). FFY 2013–2018 Part C SPP/APR Part C SPP/APR Indicator/Measurement Table – Page 1 (OMB NO: 1820-0578/Expiration Date: 5/31/2017)

From Policy to Practice: Variations in State Implementation of the Part C EIP

The IDEA Infant Toddler Coordinators Association (ITCA) is a membership association for state Part C coordinators and staff organized as a not-for-profit corporation. The core work of ITCA is to promote mutual assistance, cooperation, and exchange of information and ideas in the administration of Part C and to provide support to state and territory Part C coordinators (IDEA Infant Toddler Coordinators Association, Association Information, 2016). MA and NY are long-standing members of ITCA, which in the ITCA fiscal year 2015 included 51 states. An important function of ITCA is to work strategically with the membership on identifying, assessing, and reporting on a wide range of policy and operational issues impacting state participation in Part C.

Annually, ITCA works with member states on issues related to eligibility criteria included in state definitions of developmental delay, a required Part C component. ITCA also conducts an annual state challenges survey (known as *Tipping Points*) of member states to assess current status of states' implementation of federal Part C requirements, including state challenges and responses (IDEA Infant Toddler Coordinators Association, Board Approved Surveys, 2015). On a biennial basis, a finance survey is conducted to examine the revenue sources used by states to support their early intervention systems (IDEA Infant Toddler Coordinators Association, Board Approved Surveys, 2014). Combined results from the Tipping Points and finance surveys provide comprehensive information available on state management and implementation of Part C requirements.

Among ITCA's initiatives with and on behalf of member states, these three areas of focus – eligibility, state challenges and responses, and finance – are especially informative in understanding the milieu in which infants and toddlers with ASD and their families are receiving Part C services and in which specific service delivery models to treat ASD are being delivered. Highlights of key findings from each of these three areas of focus follows.

Eligibility Issues

Under Part C, states must include infants and toddlers with disabilities (defined as inclusive of developmental delay) in state definitions of developmental delay and may include children at risk for disability in state-established eligibility criteria (Individuals with Disabilities Education Act of 2004, §§ 635) (Individuals with Disabilities Education Act of 2004, 2016b). State eligibility criteria establish the degree of delay required for eligibility in one or more areas of development (cognition, communication, physical, social, emotional, and adaptive) and specify the diagnosed physical and mental conditions with a high probability of resulting in developmental delays. ITCA works with member states to review and categorize states' definition of developmental delay as "broad" (15 states), "moderate" (18 states, including MA and NY), and "narrow" (19 states) (IDEA Infant Toddler Coordinators Association, Child Count Data Charts, 2013).[3] Only five states, including MA, include children at risk for developmental delay in their eligibility criteria. Children with ASD are frequently referred to and found eligible for state early intervention programs based on developmental delays rather than on a particular diagnosed condition.

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[3] Broad eligibility is defined as including state eligibility definitions which include children at risk or with any delay or atypical development: a delay of one standard deviation in one developmental domain, 20% delay in two or more domains, 22% delay in two or more domains, or 25% delay in one or more domains. Moderate eligibility is defined as state eligibility definitions which include children with a 25% delay in two or more domains, 30% delay in one or more domains, 1.3 standard deviations in two domains, 1.5 standard deviations in any domain, or 33% delay in one domain. Narrow eligibility is defined as state definitions of eligibility which include children with a 33% delay in two or more domains, 40% delay in one domain, 50% delay in one domain, 1.5 standard deviations in two or more domains, 1.75 standard deviations in one domain, 2 standard deviations in one domain, or 2 standard deviations in two or more domains.

ITCA has also developed an innovative "birth cohort" approach to collecting and analyzing data on child and family participation in state Part C EIPs (Noyes-Grosser & MacCleod, 2013). Using the common demographic characteristic of year of birth, ITCA queries states on the extent to which children born in a given calendar year participate in major benchmarks of program participation (referral, evaluation/eligibility determination, IFSP/early intervention services, and transition/exit). Data available from 30 states demonstrate that of children born in 2010, the most recent cohort for which data are available, across all states on average 10% of children were found eligible for the Part C EIP at some point between birth and age 3 (Barger et al., 2015). The birth cohort approach provides a clearer picture of the scope and reach of state Part C EIPs by examining the extent to which young children access early intervention services at any point in time while age-eligible for the program.

More recently, ITCA has collaborated with member states and federal partners, including the Centers for Disease Control and Prevention, National Center for Birth Defects and Developmental Disabilities, and the US Department of Education, Office of Special Education Programs, on a project to collect and analyze information on the diagnosed physical and mental conditions with a high probability of developmental delay used by states to establish eligibility for Part C. At least 20 states include autism spectrum disorder as diagnosed conditions with a high probability of resulting in developmental delay (Barger et al., 2015).

State Challenges and Responses and Financing of Early Intervention Services

Lead Agency and Organizational Structure

States are required under IDEA to identify a state lead agency responsible for the administration of their early intervention programs. Of 49 states responding to the Tipping Points survey in 2015, 21 (43%) reported the state health agency (including NY and MA), 12 (24%) reported the education agency (24%), and 16 (33%) reported others (e.g., developmental disabilities agencies, early childhood offices, human services) as responsible for administration of their early intervention programs. State-level organization of Part C varies across states which have been described and analyzed using data from Tipping Points in four broad categories:

- Private programs (57% of respondents, $n = 28$): programs/agencies in a direct relationship with states are responsible for all eligible children from referral through transition in an assigned regional or local catchment area, with services provided by program/agency employees or contractors.
- Regional public/private (18% of respondents, $n = 9$): regionally based programs responsible for initial intake (referral, service coordination, and initial IFSP development), with services provided by practitioners or agencies and reimbursed as contractors/vendors through a state fiscal administrator.
- State operated (14% of respondents, $n = 7$): state personnel from one ($n = 5$) or multiple lead agencies ($n = 2$), based in state-defined local areas, are responsible for all activities from referral through service delivery.
- Others (10%, $n = 5$): alternative structures uniquely identified by respondent states.

Funding and Sources for Early Intervention Services

States are responsible for maintaining systems of payments for financing of early intervention services, which may include use of public and private insurance and a system of parent fees that meet federal requirements (parents cannot be charged for functions related to child find, evaluation and assessment, service coordination services) (Individuals with Disabilities Education Act of 2004, §§636, Individualized Family Service Plan) (Individuals with Disabilities Education Act of 2004, 2016d). Results of the finance survey, based on 47 state member respondents, revealed reimbursement for early intervention services approaching $3.7 billion in the

2013–2014 federal fiscal year, across all identifiable sources of funding. Only 15 of the 47 states participating in the survey were able to account for all revenues for each fund source reported, suggesting that reimbursements were unreported with the exception of federal Part C formula fund grants (IDEA Infant Toddler Coordinators Association, 2014).

States participating in the finance survey reported a range from 2 to 15 different funding sources supporting early intervention services, with an average of seven fund sources. Across all funding sources for early intervention services reported by respondents, state funds (including state general funds) accounted for 55% of all reimbursements to providers for early intervention services delivered to infants and toddlers and their families participating in state Part C programs. Federal funding, largely Medicaid, accounted for 31%, local governments accounted for 15%, and private insurance accounted for only 3% of provider reimbursement for early intervention services delivered to children and families through state Part C programs. Twenty-one percent of finance survey respondents indicated that their states have statutory requirements related to use of private insurance for reimbursement of early intervention services (IDEA Infant Toddler Coordinators Association, 2014).

Forty-four states responding to the finance survey reported some form of family cost participation in use in the Part C EIPs. Eleven states reported use of private insurance (i.e., parents are required to use insurance coverage for early intervention services), three states reported use only of a parent fee schedule, and fourteen states implement both parent fee schedules and require parents to use private insurance coverage for early intervention services (IDEA Infant Toddler Coordinators Association, 2014).

In a recent program year, NY reimbursements to providers totaled $137 million in state and local funds for early intervention services delivered to children with an ASD diagnosis and their families. Total reimbursements for services to children with ASD and their families were over $200 million, with Medicaid reimbursement of more than $67 million. MA reimbursed providers $7 million in state funds for services to children with an ASD diagnosis, with a total of $22.8 million across all fund sources combined (Medicaid and commercial insurance) for ASD specialty services only (applied behavior analysis (ABA), ABA-informed), not inclusive of other early intervention services provided to toddlers and their families.

As noted above, Medicaid is a critical source of funding for early intervention services delivered through state Part C programs. With respect to children with ASD, important new guidance was recently issued by the US Department of Health and Human Services, Center for Medicare and Medicaid Services (CMS). On July 7, 2014, CMS published an Informational Bulletin indicating that federal approval for autism-related services for children, such as ABA, may be available under traditional Medicaid state plan authority (Centers for Medicare and Medicaid Services, Center for Medicaid and CHIP Services, 2014a). CMS indicated that federal requirements for early and periodic screening diagnosis and treatment (EPSDT) entitle Medicaid-eligible children under 21 years of age to all medically necessary services that can be approved under a traditional Medicaid State Plan, which would now include autism-related services. Subsequent information provided by CMS in September 2014 indicated that states do not have to provide ABA therapy per se but must provide services that produce similar outcomes. CMS encouraged states to develop state plan amendments and offered assistance in this process (Centers for Medicare and Medicaid Services, Center for Medicaid and CHIP Services, 2014b).

Planned and Delivered Hours of Service

The Tipping Points Survey asks states to respond to two questions related to the intensity of services delivered to children and families in their Part C programs. First, states are asked to report the number of planned hours of direct services (excluding service coordination and evaluation and assessment services) per child per month. Of 49 states participating in the 2015 survey, 24 responded to this question. The number of planned services across these states ranged from

1 to 12 h per month, with a median of 5 h per month. Second, states were asked to report the average number of direct service (excluding service coordination and evaluation and assessment services) per child per month. Across the 25 state respondents, delivered service hours per child per month ranged from less than an hour (54 min) to 12 h, with a median of 4.3 h per month (IDEA Infant Toddler Coordinators Association, 2015).

The Tipping Points survey does not ask states to provide data on planned and delivered services based on the type of developmental delay or diagnoses affecting children. In both NY and MA, children with ASD receive a more intensive level of services than toddlers with other disabilities or developmental delays and their families. In NY, on average, the median hours of service per month delivered to toddlers with ASD is 37 and ranges from 11 (tenth percentile) to 78 h (ninetieth percentile) per month. In MA, the median hours per month of service for toddlers with ASD is 40 h, with a range from 24 to 100 h per month.

Length of Child and Family Program Participation

Tipping Points also asks states to report the average length of time children participate in the state Part C program. Thirty-six states responded to this question. Among these states, the average length of time children and families participate in Part C programs ranged from 9 to 36 months, with a median of 15 months.

The *Tipping Points* survey does not ask states to provide these data based on the type of developmental delay or diagnoses affecting children. In NY, children with ASD experience a similar length of stay as other children with developmental delays and disabilities, with an average length of Part C program participation of 16 months. In MA, the average length of program participation for children with ASD and their families is 14 months.

State Identified Measurable Results (SIMR) for State Systemic Improvement Plans (SSIP)

Because State Systemic Improvement Plans will be a driving force in state Part C EIPs through 2020, the Tipping Points survey was expanded to request information from member states on the State-Identified Measurable Result included in those plans. Twenty-three (50%) of 49 states responding to this question identified child outcome indicator 3a, "social-emotional development, including positive social relationships," as the SIMR selected by the state in collaboration with stakeholders (State Interagency Coordinating Councils, parents, providers, state and local officials, etc.) (IDEA Infant Toddler Coordinators Association, 2015). MA is included among these states. Eleven states (24%) selected child outcome indicator 3b, "acquisition and use of knowledge and skills (including early language/communication)," and two states selected child outcome indicator 3c, "use of appropriate behavior to meet their needs," as the SIMR.

Three states selected family outcome indicator 4c, "help their child develop and learn," as the SIMR. NY is among states selecting family outcomes as the focus of the SIMR, collaborating with stakeholders to set a state standard on NY's modified version of the National Center for Special Education Accountability Monitoring "Impact on Family" scale which encompasses all three indicators for family outcomes (New York State Department of Health, Bureau of Early Intervention, 2015).

The New York Experience

New York has one of the nation's largest early intervention programs, delivering services to about 65,000 infants and toddlers with disabilities and their families with an Individualized Family Service Plan (IFSP) annually. The NYS Department of Health (NYSDOH) is the lead agency for NY's Early Intervention Program (NYEIP). The NYEIP local programs are administered by 57 counties and New York City, largely by public health agencies. Providers of early intervention services are approved by and have agreements with the NYSDOH to deliver services to eligible children and their families and include both agencies and independent practitioners. Statewide, close to 15,000 professionals participate in the NYEIP.

Like many states across the nation, in the initial years of statewide implementation of Part C, the NYSEIP experienced increasing referrals of children with ASD and their families. As noted above, participation of children with ASD and their families has grown dramatically during the past two decades, from 639 children reported as having an autism diagnosis in the 1999–2000 PY (1% of all children participating in the NYSEIP) to 7986 in the 2014–2015 program year.

Both nationally and within NY, wide variation existed in the types and amounts of early intervention services provided to young children with developmental disabilities during the first several years of the Part C EIP implementation in the 1990s (Noyes-Grosser et al., 2005). A key challenge experienced by NY and other states across the nation was the need for information and support for program administrators, parents, and early intervention service providers in making decisions about high-quality and cost-effective evaluation, assessment, and early intervention services for children and families referred for Part C EIP services. This need was particularly pressing for children with autism and their families, given emerging evidence from research indicating that early and intensive treatment could significantly improve children's developmental outcomes.

Evidence-based Autism Clinical Practice Guideline

In 1996, a multiyear effort was initiated by the NYSDOH to develop a series of evidence-based clinical practice guidelines focused on the identification, assessment, and intervention for young children with developmental problems likely to require early intervention services. The overall goal of this effort was to improve the quality and consistency of care for young children with developmental disabilities by providing families, service providers, and public officials with recommendations about best practices based on scientific evidence and expert clinical opinion.

To ensure that the guidelines would have maximum credibility and impact, the NYSDOH followed an established and well-accepted science-based methodology for guideline development used by the US Department of Health and Human Services Agency for Healthcare Policy and Research (later renamed the Agency for Healthcare Research and Quality (AHRQ)). The AHRQ clinical practice guideline methodology is considered to be the standard for developing evidence-based medical and healthcare clinical practice guidelines and has been described in numerous publications (Eddy and Hasselblad, 1995; Holland, 1995; Schriger, 1995; Shekelle et al., 2001; Wolf, 1991, 1995). The NYSDOH was the first to adapt the AHRQ methodology for use in development of clinical practice guidelines addressing assessment and intervention practices for children with disabilities (Noyes-Grosser et al., 2005).

Six Early Intervention Program clinical practice guidelines on assessment and interventions for young children (0–3 years of age) were completed by the NYSEIP. The first guideline, and arguably the guideline which has had the most impact, was *the New York State Early Intervention Program Clinical Practice Guideline: Assessment and Intervention with Young Children (0–3) with autism and pervasive developmental disorders (NY Autism Guideline)*. The guideline is posted on the NYSDOH website, http://www.health.ny.gov/community/infants_children/early_intervention/disorders/autism.

A defining feature of the AHRQ methodology is the use of a multidisciplinary consensus panel, including clinicians, researchers, and consumers, to review all available scientific evidence on the guideline topic and develop consensus recommendations based on the evidence. To develop the NY Autism Guideline, the NYSEIP engaged an expert project team and a panel comprised of consumers, researchers, clinical experts, and physicians (four parents of children with autism, two developmental pediatricians, four psychologists, two speech-language pathologists, a special educator, occupational therapist, social worker, and psychiatrist) to review 20 years of research and reach consensus on recommended practices for identifying, assessing, and treating autism in children from birth to 3 years.

The panel reached consensus on a total of 256 practice recommendations for delivering services to young children with autism/pervasive developmental disorders and their families, 122 of which addressed assessment (early identification and screening, diagnostic, developmental, and medical assessments) and 134 of which addressed intervention methods (general approach, behavioral and education approaches, other experiential approaches, and medical treatments). These recommendations include a combination of evidence-based (i.e., supported by scientific evidence from more studies published in peer-reviewed journals) and panel consensus opinion recommendations (i.e., opinion based on standards of practice in the field for which either a systematic literature search was conducted and no studies were found or no systematic literature search was completed). Each of these recommendations was rated by the panel for strength of evidence supporting the recommendation. Table 28.2 provides a broad overview of these recommendations and the distribution of evidence-based and consensus opinion recommendations.

The NY Autism Guideline underwent an extensive national peer review by 62 experts and parents, including clinicians, researchers, and early intervention program administrators. Reviewers were asked to comment on the final draft guidelines, rate them on usefulness and understandability, and identify any research that may have been missed by the panel that would lend support or provide evidence to modify or refute guideline recommendations. Comments received through the peer review process were reviewed by the panel at a final panel meeting. Final decisions regarding the recommendations were made by the panels on the basis of the strength of evidence provided by the reviewer and with the consensus of the full panel.

The NY Autism Guideline is intended to guide families, service providers, and local public officials with scientific evidence and expert clinical opinion on effective practices for early identification of children with ASD; conducting evaluations and assessments that establish a diagnosis of ASD or rule out this diagnosis, as well as information about children's developmental strengths and needs; and determining effective intervention strategies and reaching agreement on the frequency, intensity, and duration of early intervention services that will result in positive outcomes for children with ASD and their families.

The role of the parent and the family in early intervention services for children with ASD was an important area of focus of the 1999 NY Autism Guideline. Recommendations for family involvement include the early intervention process which includes the following:

Role of the Family in Assessment and Intervention Processes

> It is important that parents be involved as active participants in all aspects of the child's ongoing assessment and intervention process to the extent of their interests, resources, and abilities.
> Parental involvement is important to ensure that the family's desired outcomes for the intervention, as well as the family's values and priorities, are considered when developing the intervention plan.
> It is recommended that professionals share with parents the scientific evidence about effectiveness of intervention methods being proposed or used, as well as the advantages and disadvantages of the proposed methods.
> It is important for professionals working with the child to understand and respect the family's values, priorities, and parenting philosophies. New York State Department of Health, 1999, pg. 127).

Considering the Cultural Context of the Family

> A child's life is embedded within a cultural context. It is essential to consider and respect the family's culture when providing interventions for children with autism.
> If English is not the primary language of the family, it is important for professionals to look for ways to communicate effectively with the family and the child, including use of healthcare professionals, early intervention professionals, or translators who speak the family's language. (New York State Department of Health, 1999, pg. 127).

In addition, the guideline includes specific recommendations on parent involvement and training as an important component of early intervention service delivery to toddlers with ASD. These are:

Table 28.2 NYS Autism Guideline recommendations overview

Early identification and assessment	Number of evidence-based recommendations	Number of consensus opinion recommendations
Early identification	1	–
Establishing a diagnosis	3	3
Developmental assessment	–	9
Health evaluation	–	6
Consideration for professionals	–	9
Principles	–	7
Clinical clues	1	3
Screening	3	1
Autism assessment instruments	6	10
Developmental assessment	–	25
Assessing communication	–	3
Assessing social interaction	–	5
Child and family environment	–	2
General health evaluation	–	9
Associated conditions	–	8
Use of MRIs to diagnose autism	–	2
Use of SPECT to diagnose autism	–	–
Immune status	–	–
Food allergies	–	1
Yeast overgrowth	–	1
Intervention methods		
Linking assessment to intervention	3	11
General considerations	2	9
Role of the family	–	6
Common elements of effective interventions	9	–
Intensive behavioral and educational programs	1	1
Principles of behavioral techniques	13	1
Reducing maladaptive behaviors	8	3
Improving communications	9	5
Improving social interactions	3	3
Parent training	1	1
DIR model	–	5
Sensory integration	–	5
Auditory integration	1	–
Facilitated communication	–	1
Music therapy	1	–
Touch therapy	1	–
Diet and medication		
General approach	3	4
Psychoactive medications	5	6
Hormone therapies	–	1
Immunologic therapies	–	3
Anti-yeast	–	2
Vitamin therapies	1	2
Diet therapies	–	2

> It is important to include parents as active participants in the intervention team to the extent of their interests, resources, and abilities. Parent involvement is important to ensure that behavioral and educational outcomes, goals, and strategies most important to the family are incorporated in the intervention.
>
> It is recommended that parents be trained in behavioral techniques and encouraged to provide additional hours of instruction to the child.
>
> Parent training is important to help the family incorporate these techniques into the daily routines of the child and family and to ensure consistency in the intervention approach.
>
> It is recommended that training of parents in behavioral methods for interacting with their child be extensive and ongoing and include regular consultation with a qualified professional. (NYS Department of Health, 1999, pg. 140).
>
> It is recommended that parent training be included as an important component of comprehensive intervention programs for children with autism. Parent training programs may be useful because they help support the family in caring for the child; involve the parents in choosing intervention outcomes, goals, and strategies that are important to the family; help the family incorporate the intervention strategies into the daily routines of the child and family; help to ensure consistency in the intervention approach; improve the interaction between the parents and their child; and increase parent satisfaction and reducing parent stress (NYS Department of Health, 1999, pg. 150).

The guideline also included questions, based on recommendations on interventions that may be helpful to parents, caregivers, or other individuals when interviewing potential intervention providers to work with the child and family (New York State Department of Health, 1999, pg. 131). These questions are presented in Table 28.3.

More than 100,000 copies of the NY Autism Guideline are in circulation, and requests for the guideline have been received from around the world. Since its issuance, the guideline has been used as an educational tool and decision-making resource for families, primary referral sources, public officials, and providers on evidence-based practices for delivering early intervention services to young children with ASD. The NYSEIP implemented an intensive, initial statewide training effort on the guideline in 1999 and currently offers ongoing regional training sessions for program constituents.

To be effective and useful to clinicians, families, and public officials, clinical practice guidelines need to reflect current scientific evidence. The NYSDOH received a grant from the FAR Fund to update the NY Autism Guideline, work completed in 2017. A 20-member expert panel,

Table 28.3 NYS Autism Guideline: Questions to ask providers

Questions to ask providers The following are questions that may be helpful to parents, caregivers, or other individuals when interviewing potential intervention providers. These questions were developed from the guideline recommendations on interventions
1. What kinds of intervention, therapy, and services do you provide? Please describe a typical day or session
2. Do you have a particular philosophy on working with children with autism/PDD?
3. How many hours per week do these services require, and how much of this is one-on-one time with the child?
4. Please describe a typical day or session.
5. What experience do the teachers and/or therapists have in working with children with autism?
6. What experience does the person who supervises the program have? How closely does the program supervisor work with the therapists, teachers, and parents?
7. What kinds of ongoing training do your full- and part-time staffs participate in?
8. Are parents involved with planning as part of the intervention team?
9. Do you provide a parent training program?
10. How much and what kinds of involvement are expected of parents and family members?
11. Are parents welcome to participate in or observe therapy and/or group sessions?
12. What techniques do you use to manage difficult behaviors?
13. Do you ever use physical aversives or any physically intrusive procedures? If yes, please describe them.
14. Please describe your program for communication and language development. Do you use a picture communication system, sign language, other kinds of communication systems, or all of these?
15. Are there opportunities for integration with typical and/or higher functioning children?
16. How do you evaluate the child's progress, and how often?
17. How do you keep parents informed of the child's progress?

including several members of the original panel, was convened to use the AHRQ evidence-based methodology (Shekelle et al., 2001, Holland, 1995) to complete the guideline update. Research experts were commissioned to review new scientific evidence published in peer-reviewed journals since 2000 and prepare reports and presentations for the panel. Topic areas addressed by these expert reviewers were ASD screening and diagnosis, medical management (health evaluations and medical treatments), and early intervention approaches for young children with ASD and their families (New York State Department of Health, 2017b). The expert reports and presentations were used by the consensus panel in their deliberations to update the NY Autism Guideline (New York State Department of Health, 2017b).

As part of their initial work, panelists were asked to complete an extensive survey of all of the original recommendations in the 1999 guideline, to identify those recommendations which in the panelist's opinion were relevant and continued to be supported by the evidence; where new evidence had emerged such that the recommendation needed to be revised; and where new evidence was available to refute the recommendation. Three subsequent meetings and several webinars discussed the most recent scientific evidence with the expert reviewers and collaborated to update the original and develop new recommendations. Consistent with AHRQ methodology (Holland, 1995), a final draft of the guideline was reviewed by 21 peer reviewers, including parents of children with ASD, nominated by panel members. The final *Clinical Practice Guideline on Assessment and Intervention for Young Children with ASD, 2017 Update*, incorporating revisions based on the peer review process, consists of three documents: the *Report of the Research Evidence,* which details the expert literature reviews used by the panel (New York State Department of Health, 2017b); the *Report of the Recommendations*, which describes the work of the panel and includes all recommendations (New York State Department of Health, 2017a); and the *Quick Reference Guide for Parents and Professionals (New York State Department of Health, 2017c)*. All three documents are available on the NYSDOH website *(www.health.ny.gov/community/infants_children/early_intervention/memoranda.htm)*.

The important role of parents in all aspects the early intervention process for young children with ASD is reflected in panel recommendations included throughout the 2017 update. In addition, the 2017 update includes the following new recommendations on parent-mediated approaches to intervention and on family well-being and support:

Parent-Mediated Approaches

> It is recommended that parent-mediated interventions be offered to parents as part of a comprehensive plan of early intervention services for parents and young children with ASD.
> If a child spends significant amounts of time with other caregivers beside the parents (e.g., grandparents, nannies, daycare staff), these caregivers should be provided the opportunity to learn strategies for promoting learning objectives during familiar daily routines.
> It is recommended that parent-mediated interventions be implemented with sufficient duration and intensity to effectively increase children's learning opportunities during a broad range of familiar daily life routines.
> It is recommended that comprehensive parent-mediated interventions be implemented in the child's natural environment whenever possible. This includes the families' home, the child's daycare, and various community locations.
> It is recommended that the intensity, duration, and context of comprehensive parent-mediated interventions be adapted in ways that reflect the child's schedule, the parents' time constraints, and the families' physical and social home environment. (New York State Department of Health, 2017a, pages 71–72).

Family Support

> It is important to recognize that parents with children with ASD often experience high levels of stress.
> It is recommended that when professionals are interacting with families that they be aware of and be sensitive to family and caregiver well-being and increased stress levels of caregivers of young children with ASD.

> Families may benefit from referrals to other resources in their community and information and support that may be of assistance.
> It is important to recognize that many families can benefit from peer to peer support and should be provided information about parent support groups in their area.
> It is recommended that families who are experiencing stress in raising their children with ASD be referred to mental health support services. (New York State Department of Health, 2017a, 2017b, pages 71–72).

In addition to the NY Autism Guideline, the NYSDOH has completed two other major projects to improve early intervention services for young children with ASD and their families. In 2010, the NYSDOH was the recipient of a state implementation grant to improve services for children and youth with ASD and other developmental disabilities and their families from the Maternal and Child Health Bureau, Health Resources and Services Administration, US Department of Health and Human Services. A major area of focus for this grant was to implement training programs and resources for pediatricians to adhere to American Academy of Pediatrics (AAP) guidelines for the identification, evaluation, and management of children with ASD, including universal screening of toddlers at 18 and 24 months for possible autism (Johnson et al., 2007). The NYSDOH collaborated with the NYS Chapter of the AAP to develop a Best Practice Protocol for Universal Screening of Young Children for ASDs by Pediatric Primary Care Providers, available on the NYSDOH website at: *http://www.health.ny.gov/community/infants_children/early_intervention/autism/docs/best_practice_protocol.pdf*. A companion physician's desk reference on early identification, diagnosis, and referral for early intervention services was published and distributed to 4500 members of AAP across NY State.

More recently, the NYSDOH Bureau of Early Intervention completed a large study to evaluate the impact of participation in Part C services on toddlers with ASD and their families, funded by the US Department of Health and Human Services, Health Resources and Services Administration, Maternal Child Health Research Program.

In the first phase of this study, concept mapping methodology (Kane & Trochim, 2007) was used with stakeholders representing diverse perspectives to identify the ASD-specific child and family outcomes expected to be achieved through EIP participation. A detailed description of the concept mapping study is reported in Noyes-Grosser et al. (2013).

During the brainstorming phase, 724 child and family ASD outcome items were generated by study participants and reduced by the research team to a set of 105 items (54 child-related and 51 family-related outcomes) representing the breadth and depth of the initial brainstormed content for use in sorting and rating activities. The study found moderately strong agreement between parent and professional ratings of the importance of child and family outcomes to be achieved through early intervention program participation. Moderate agreement was also found between parent and professionals on ratings of the likelihood that EIP services will impact child and family outcomes (Noyes-Grosser et al., 2013).

Among the family outcome items, those with the highest ratings on importance and likelihood by parents and professionals were:

- Learn ways to help their child develop basic social interaction skills.
- Be supported and educated in understanding their child's diagnosis.
- Know and understand their rights with respect to early intervention services.
- Learn ways to promote positive behavior.
- Carry over techniques used by therapists and teachers and use these with their children (Noyes-Grosser et al., 2013, page 346, Table 28.3).

Among the child outcomes, those with the highest ratings on importance and likelihood by parents and professionals were:

- Learn how to communicate needs and wants using spoken language, sign language, or assistive device.
- Be able to seek assistance when distressed.
- Learn appropriate skills and behaviors to participate in social, educational, and recreational activities with other children.
- Develop trusting relationships with caregivers.
- Be able to handle every day transitions (Noyes-Grosser et al., 2013, page 3345, Table 28.2).

In a subsequent phase of this study, the child and family outcomes generated by stakeholders in concept mapping were integrated into existing NY Impact on Child (NYICS) and Impact on Family (NYIFS) scales included in the annual family survey conducted by the NYSEIP for program evaluation and federal reporting purposes (Elbaum et al., 2014). These scales measure the extent to which early intervention services are helpful to families in achieving child outcomes (NYICS) and family outcomes (NYIFS) expected from program participation (Noyes-Grosser and Elbaum, 2011). The NYIFS scale is a modified version of the national Impact on Family Scale developed by the National Center for Special Education Accountability Monitoring (Fisher et al., 2012), currently in use by 23 states for collection and reporting of family outcome data required by the US Department of Education, Office of Special Education Programs (Early Childhood Outcomes Center, 2015).

Families participating in the study were asked to complete a family survey with these modified NYSICS and NYSIFS, among other child and family outcome measures, as they exited the NYSEIP and the study. A total of 167 families in the ASD group and 95 families in the comparison group completed and returned the family survey.

Analyses completed on the results found no meaningful differences in how families in both groups responded to these scales, suggesting that a common set of items can be used for families receiving early intervention services, including children with ASD, for program evaluation purposes (Elbaum et al., 2014). Based on these results, the NYSEIP has revised the annual family survey completed by families of children exiting the program to include a subset of the ASD-specific items generated through this study in the NYICS and NYIFS scales. Both scales hold promise for state-level efforts to evaluate outcomes of early intervention services on children and families participating in state early intervention programs, including children with ASD and their families (Noyes-Grosser et al., in press).[4]

The Massachusetts Experience

By the late 1990s, the Massachusetts Department of Public Health (MA DPH), Part C lead agency, was concerned about meeting the needs of the increasing numbers of very young children identified with ASD. The MA DPH contracts with local Early Intervention Programs (MA EIPs) who are responsible for delivering evaluations, service coordination services, and therapeutic and support services when selected by families residing within the MA EIPs' designated catchment areas.

Existing MA EIPs did not have appropriately trained staff to deliver the clinical approaches most effective for this population. Resources to train staff with traditional early intervention disciplines (for example, special instruction, speech language pathology, occupational therapy, etc.) to meet this need in a reasonable time frame were insufficient, and changing the rate system for MA EIPs to accommodate intensive behavioral intervention would have been a time-consuming process. A request for response was issued to solicit providers able to offer intensive intervention to children with a diagnosis on the autism spectrum and work in conjunction with MA EIPs to address the needs of the family related to enhancing the child's development. Applicants responded to a competitive process that required demonstration of:

- Expertise in addressing the needs of very young children with ASD
- Ability to asses a child's functional skills across domains impacted by ASD
- Use of an evidence-based developmental approach designed to address the core components of ASD, with a focus on promot-

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[4] The NY State Family Survey, including the NYS Impact on Child and Impact on Family Scales, are available from the NYS Department of Health, Bureau of Early Intervention Program, upon request beipub@health.ny.gov, Room 208 Corning Tower Building, Albany, NY 12237-0660.

ing communication, social interaction, and play skills

- Ability to provide planned, systematic instruction based on the ongoing assessment of the child's strengths and needs
- Use of a functional behavioral assessment and support plan to decrease challenging behavior and increase appropriate behavior when indicated
- Commitment to work in collaboration with MA EIPs to address parent needs for technical assistance around promoting skill development, meeting behavioral challenges, and generalization of skills into the child's natural routines through individual and group networking opportunities
- Staffing patterns reflective of current credentialing and licensing requirements for performing child assessments, developing treatment plans, and training and supervision of direct care staff in the intervention approach used by the program
- Administrative capacity to meet MA DPH specifications regarding billing requirements and clinical record keeping and comply with MA EIP operational standards, health and safety standards, procedural safeguards and due process procedures, and other program requirements

The MA DPH contracted directly with the initial group of Specialty Service Providers (SSPs) selected through the competitive proposal process in 1998 and provided operational procedures to establish consistency in service provision across the state, a claims submission system, monitoring to assure fiscal and clinical accountability, and administrative support. SSPs have increased in number and approach since that time. Currently, 16 provider agencies use a range of intervention approaches to address the core characteristics of ASD (including applied behavioral analysis, Early Start Denver Model (Rogers & Dawson 2009a, 2009b) and Interventions Based on the Developmental, Individual Difference, Relationship (DIR or "Floortime") Model (Greenspan & Weider, 1997).

Services are selected in collaboration with families, using an Individualized Family Service Plan (IFSP). Services and staff reflect the cultural, linguistic, and ethnic composition of the state and of the families served. Programs must demonstrate a commitment to respond to the diversity of families in their communities. MA EIPs and Specialty Services Providers focus on the family unit, recognizing the crucial influence of the family on development. Children and families receive individualized services in accordance with the outcomes identified in the IFSP.

Intervention is designed to include the child, staff member(s), and parent or designated caregiver. Parents are strongly encouraged to participate in intensive services. Determinations of the number of hours per week of service are individualized, based on particular child and family circumstances. Factors such as the child's age, prevalence of the core characteristics of autism, behavioral characteristics, rate of progress, schedule of ancillary services, and family availability are taken into consideration. The service plan can be adjusted at any time as child and family needs change and are documented through the IFSP review process.

The growth in the SSP system has exceeded all expectations for a variety of reasons. There is near universal health insurance coverage for children in Massachusetts, which provides fiscal support for diagnostic services. There are a number of medical schools in Massachusetts that train developmental pediatricians and neurologists and several specialized diagnostic centers that focus on ASD and are committed to providing appointments for young children as quickly as possible. An active Massachusetts Act Early team has promoted the growing national focus on early screening and identification of developmental disabilities promulgated by the US Department of Health and Human Services, Centers for Disease Control and Prevention (Centers for Disease Control and Prevention, 2016). The average age of diagnosis of ASD for children in the Part C EIP in MA is under 26 months of age, and the number of young children identified with ASD from birth to age 3 cohort continues to increase, with 1 in 78 children in the 2010 MA birth cohort diagnosed with ASD by the time they reached 36 months of age (Manning & Kernan, 2015).

Dramatic growth typically equates with dramatic cost increases for the MA DPH Part C program. Autism-related services consumed ever increasing percentages of the MA DPH Part C budget annually. It was anticipated that legislation mandating insurance coverage for medically necessary services for individuals with ASD enacted in 2010 (Massachusetts GL 2010, H4935, An Act Relative to Insurance Coverage for Autism) would somewhat mitigate the fiscal demand on the MA DPH Part C program. However, the impact of this law, known as the ARICA Law, was minimal as most families whose health plans offered this benefit were reluctant to take on the burden of meeting private insurers co-payments and deductibles when they already had access to appropriate services for their young children with ASD through the MA Part C program.

Historically, the federal Centers for Medicare and Medicaid Services (CMS) deemed ABA and certain other autism-related services to be facilitative and therefore not coverable under traditional Medicaid state plan authority as a standard benefit. In 2011, the MassHealth, the State Medicaid, and the Child Health Insurance Program received approval under an existing 1115 demonstration waiver to provide ABA services through the MA DPH's intensive early intervention program, delivered by MA EIPs and SSPs to any eligible child under age 3. While navigating the waiver process, MassHealth and CMS were challenging; ultimately it was apparent that CMS was interested in working with MA to explore ways to support for behavioral interventions for young children with ASD.

The CMS application required specification of proposed treatment approaches for young children with ASD. Both ABA-based and DIR/Floortime-based treatment was proposed; however, only ABA-based treatment and the Early Start Denver Model (Rogers & Dawson, 2009a, 2009b) were approved as part of the delivery system by CMS. The MA EIP has continued to support the provision of DIR/Floortime (Greenspan & Weider, 1997)-based treatment as it is recommended by some diagnosticians and sought by families.

Implementation of the CMS waiver required systemic changes, most significantly in the methodology of contracting with SSPs. Prior to the waiver, all appropriate claims by SSP providers were processed and satisfied by the MA DPH. MA EIPs had no responsibility for assuring the appropriateness of claims, and SSPs were accustomed to the practice management system DPH had developed. When the CMS waiver was approved, SSPs were required to establish contracts with community MA EIPs, as only certified MA EIPs could submit claims to MassHealth. Implementation required significant guidance and training to the MA EIPs and SSPs communities to orchestrate a change not only in billing rules but in the relationships between MA EIPs and SSPs.

MA DPH prepared for the changes more than a year in advance of the implementation date, working with SSPs, MA EIPs, and MA DPH Part C practice management system developers to make the transition as smooth as possible. New billing procedures assured that there would be no interruption in MA EIP or SSP services, or in the panel of SSPs available to children with ASDs and their families, when the waiver was initiated in July 2012. Qualitative and quantitative analyses conducted by an independent evaluation entity determined that the transition was seamless from the family perspective but challenging for all MA EIP and SSP system administrators and billing staff. Despite this, service access, provision and utilization did not seem to be impacted, and transition activities were thought to be invisible to children, families, and direct service providers. The contracting shift has facilitated more communication between MA EIP and SSPs, promoted effective service coordination, and provided a more comprehensive approach for children and families.

The MA Part C program has had a long standing positive relationship with the private insurance community in the state. Private insurers were kept informed about the progress of the CMS waiver and expressed interest in replicating a similar model within their systems. A number of the major private insurance providers opted to roll out intensive behavioral services for children with ASD through their existing contracts with MA EIPs with the proviso that families would not be responsible for co-payments or deductibles.

This resulted in a significant shift in costs for intensive behavioral services from the MA DPH Part C program to private insurers. Private health plans typically applied the policies developed to implement the ARICA legislation to the MA DPH Part C program ASD benefit. Submission of a physician or licensed psychologist's diagnosis, an initial assessment of the child, and a detailed treatment plan developed by a board certified behavior analyst (BCBA) were typically required as part of the prior approval process. SSPs had to meet the private insurer's specifications for ABA-based service providers. DPH initiated a gradual rollout of this transition to coverage by private health plans to give MA EIPs the opportunity to accommodate the significant changes in practice management systems and prior authorization processes necessitated by this change.

From the initiation of autism specific service in the late 1990s, MA DPH reimbursed via a unit rate of service for a specific dollar amount. The initial rates were tied to a similar service type that had been implemented previously by MassHealth. For many years forward, these rates were exclusively paid by the MA DPH with either (or both) state appropriated funding or IDEA funds through the state Part C formula grant.

As efforts progressed seeking additional payment sources to support ASD services, including those for infants and toddlers, MA DPH staff and stakeholders worked in concert to identify and maximize to the extent possible these resources. As noted above, the MA DPH had been particularly successful in working cooperatively with public and private insurers to fund Part C services, and these sustainability efforts were pursued based upon that historic success. MA DPH staff were acutely aware that to be successful in working with insurance partners, autism services had to be defined within a unit of service context.

Coverage for treatment and diagnosis of ASD achieved through passage of ARICA in 2010 moved the question of broad-based coverage to the forefront of stakeholder's advocacy. This legislation was consistent with many efforts in many states led by Autism Speaks (Autism Speaks, 2016). While this legislation affected only certain types of healthcare policies, private insurers, the state insurance plan covering employees and retirees, hospital service plans, and HMOs are all required to comply with the autism coverage mandate. Although many employers have "self-funded" plans regulated under a federal law and were not subject to ARICA, a majority of "self-funded" plans in MA have covered autism treatments.

This action, while predating ongoing consideration of broad payment coverage by the federal Center for Medicaid and Child Health Insurance Programs, did lay critical groundwork for acceptance by public health coverage as well. MA DPH staff approached the state Medicaid program post passage of ARICA seeking a possible opening to cover infants and toddlers. These actions, coupled with MassHealth's desire to be assistive, took the form of a possible waiver from the Center for Medicaid and Medicare Services (CMS). This relationship focused on utilization of a federal 1915 Demonstration Waiver which was ultimately approved and implemented in MA state fiscal year 2013. The result of fiscal effort has led to a robust system of autism services within a shared public and private payment model.

Conclusions and Future Directions

The national Part C Early Intervention Program under the Individuals with Disabilities Education Act offers very young children with ASD and their families the opportunity to participate in statewide, comprehensive, multidisciplinary service delivery systems strongly grounded in principles of family-centered care. While the financing of early intervention services varies across states, including the extent to which family cost participation in early intervention services is required, *all* families of infants and toddlers from birth to 3 years must be provided, at no cost, with the opportunity to have their child identified (child find); receive case management (service coordination services); engage in a multidisciplinary evaluation to determine eligibility and assess the child's developmental needs and strengths and an optional family-directed assessment of the family's resources, priorities, and concerns; and participate in the development of an Individualized Family Service Plan (IFSP) and implementation of that plan with parent consent. State Part C programs are remarkable among early childhood delivery systems in their comprehensive approach and the entitlement to needed services for infants and toddlers who meet state eligibility criteria.

During the past two decades, the estimated prevalence of ASD among toddlers has changed dramatically, from a relatively rare condition to a disorder impacting 1 in 59 children (Baio et al., 2018). Children with ASD and their families are increasingly engaged in Part C EIPs, creating tremendous opportunities to improve their developmental outcomes and their families' abilities to help their children and the quality of life for their family. State administrators of Part C have been at the center of the changing landscape of services for young children with ASD and their families – uniquely challenged by the increasing demands on the service delivery system and uniquely positioned to offer help and support.

In considering how to work within state Part C programs to provide services to toddlers with ASD and their families, it is important for stakeholders to understand these programs by design and definition are very diverse. As discussed earlier in this chapter, data collected by the IDEA Infant Toddler Coordinators Association with member states demonstrate that states have different approaches to conceptualizing, financing, and delivering services to children with ASD and their families, within the framework IDEA Part C requirements.

Our colleagues in the IDEA Infant Toddler Coordinators Association identified some of these challenges and opportunities, and we close this chapter with our collective thoughts and compelling questions that remain to be addressed as we strive to deliver high-quality early intervention services for toddlers with ASD and their families.

Financing

States have had varied success in accessing third-party payers for reimbursement for early intervention services. Both NY and MA have been successful at accessing Medicaid reimbursement for early interventions, and MA has been the most successful state in the nation in accessing private insurance for early intervention services generally and now for specialty ASD services to children and families in the early intervention program. Increasingly, providers of early intervention services may need to meet potentially higher licensing and certification requirements for delivery of services to children with ASD and their families established by insurers or in state laws on insurance coverage for individuals impacted by ASD.

Service Delivery Approaches

In our experience, it is important to consider how the types of specialized and intensive services needed by children with ASD and their families can be coordinated and integrated within the Part C framework for early intervention services for all infants and toddlers with disabilities and developmental delays and their families. Some states, including MA, have developed specialty providers for toddlers with ASDs, and others, such as NY, have integrated ASD services across their provider systems. Regardless of the approach, states can expect an increase in growth of children with ASDs when specialized programs and services are developed to address the specific needs of these children and their families.

States are experiencing a high demand for highly qualified and experienced personnel with knowledge and expertise in delivering services to toddlers with ASD consistent with evidence-based practices, including service delivery in natural environments with typically developing peers. Personnel needs experienced by Part C programs include the need for teams of providers with training and certification in applied behavior analysis and other intensive behavioral intervention approaches to coordinate interventions and family supports. Strategies for supervision and monitoring to ensure high-quality service delivery are critical in states that rely on independent practitioners and contractors to deliver early intervention services.

Increasingly, state Part C programs will be competing with other service delivery systems for personnel with expertise in ASD services, as has been the experience in MA. A challenge for many states is balancing the fiscal demands associated with funding early intervention services and those needed to implement Part C federal requirements, including comprehensive systems of personnel development. Limited resources often mean a shift of funding from preservice and in-service training to support for direct services. Partnerships with other personnel development systems, especially institutes of higher education and resources such as training programs funded by the US Department of Health and Human Services, Maternal and Child Health Bureau (University Centers for Excellence in Disabilities, Leadership in Neurodevelopmental Disabilities, Developmental Behavioral Pediatrics, etc.), can be important resources for state Part C programs (US Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau (http://mchb.hrsa.gov/training/index.html)).

Measuring/Reporting Results

At the national level, the US Department of Educations Office of Special Education Programs is moving from compliance to results-driven accountability. For more than a decade, states have been required to collect and report child and family outcome data for children and families in Part C, including those with ASD. Because of these new requirements and state efforts to implement them, the use of state data systems for program evaluation purposes holds new promise. States will increasingly have the ability to analyze information on the ASD diagnosis/identify trends (e.g., age of child, diagnosis, by whom) and child and family outcomes. In this context, it is important to recognize that standardized developmental assessment tools may be inadequate to measure child and family outcomes being achieved through participation in state early intervention systems. There is a high need for child and family outcome measurement strategies that are appropriate to use pre- and post-intervention to provide helpful outcome information for children and families with ASD. NY's Impact on Child and Impact on Family Scales are potential promising approaches for measuring outcomes and engaging families in the program evaluation process (Noyes-Grosser et al., in press).

We view ongoing research specific to the very young child with ASD and their families as essential, particularly with respect to promising new approaches, such as parent-mediated intervention models and comprehensive programs such as the Early Start Denver Model (Rogers & Dawson 2009a, 2009b). Efforts to identify family characteristics that predict parent support of intervention approaches and link to treatment efficacy are essential. Some parent-mediated approaches (e.g., Hanen Centre "More Than Words"; http://www.hanen.org/Programs/For-Parents/More-Than-Words.aspx) that are routinely delivered by early intervention providers may be viewed as methods or approaches to service delivery that are available and may be appropriate for any child and family receiving early intervention services, and not necessarily as methods or approaches specific to toddlers with ASD and their families.

Given the insistence of public and private insurance payers that treatment approaches for children with ASD are based on scientific evidence, it is important that professionals committed to parent- implemented intervention continue to research and document positive outcomes from these approaches. As the field continues to evolve, strategies to informing policymakers, health plan decision-makers, early intervention providers, families, and public officials about scientific evidence validating intervention and treatment efforts will be important to ensure access to high-quality, effective intervention methods for children with ASD and their families. Evidence-based guidelines on recommended practices for assessment and intervention with young children with ASD and their families offer an approach to integrating scientific evidence with recommended practices for informing all stakeholders.

The following are specific considerations for states when deliberating expansion of services to young children with ASD and their families:

- *Financing*: Is there state legislation mandating autism-related coverage? Does the state Medicaid program have a mechanism for funding these services (e.g., incorporated in the state Medicaid plan or regulations or waiver program)? How does it impact the state's Part C program? Does such coverage mandate maximum benefits in dollar or hours of service amounts? Should the state's Part C program reflect similar limitations?
- *Eligibility*: Methods for establishing eligibility for ASD-specific services delivered through the state's Part C program have significant implications. Massachusetts elected to use a diagnosis of ASD conferred by a physician or licensed psychologist that reflected autism legislation and MassHealth eligibility criteria to confer eligibility for ASD-related intervention, which casts a rather wide net of eligible children. The MA DPH provides guidance indicating that a differential diagnosis by a licensed practitioner working within his/her scope of practice who is qualified and experienced in providing ASD evaluation services is preferred. Other states require substantiation of the diagnosis through administration of a recognized ASD diagnostic instrument. This narrows the eligibility net for ASD services as some diagnostic instruments are not sensitive in identifying very young children on the spectrum.
- *Work force*: Is there a cadre of appropriately trained personnel in the state's Part C program or is there a need to collaborate with other service delivery systems for a provider network? Can the staffing requirements of the state Medicaid program and private insurance providers be met within the state's Part C program? What credentialing and licensing requirement exist in the state? Do qualified personnel as defined in the state's Part C program meet ABA-based credentialing requirements? What additions to academic preparation, professional experience, or continuing education expectations need to be made to ensure availability of personnel to deliver the types of services and intervention methods needed by young children with ASD and their families?
- Practice management systems: What changes or enhancements may be necessary to Part C EIP billing and reimbursement systems to comply with public and private third-party payer requirements for claims submission and transmittal (e.g., diagnostic codes, procedure codes, policyholder information, compliance with federal Health Information Portability and Accountability Act (HIPAA) requirements, etc.)?
- Infrastructure: Is there sufficient capacity in the state's Part C EIP to design and oversee an expanded service system, either internally or through external contracting? Private and public health insurers expect Part C participation in the monitoring of medical necessity determinations for ABA-based treatment, ensure timeliness of service delivery, document improvement and sustainability of functional abilities of enrolled children, and measure the effectiveness of treatment type and staff training.

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