New York State Department of Health Clinical Practice Guideline on Assessment and Intervention Services for Young Children (Age 0-3) with Autism Spectrum Disorders (ASD): 2017 Update

Report of the Recommendations

New York State Department of Health

Bureau of Early Intervention

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Preface

Why the Bureau of Early Intervention Issues Guidelines

As lead agency for the Early Intervention Program in New York State, the New York State Department of Health (NYSDOH) is committed to ensuring that the Early Intervention Program provides consistent, high-quality, cost-effective, and appropriate services that result in measurable outcomes for eligible children and their families.

This guideline is a tool to help assure that infants and young children with disabilities receive early intervention services consistent with their individual needs, resources, priorities, and the concerns of their families.

The guideline is intended to help families, service providers, and public officials by offering recommendations based on scientific evidence and expert clinical opinion on effective practices for the following:

- Early identification of children at risk or suspected of having a disability through routine developmental surveillance and screening targeted to identify specific disabilities.
- Provision of multidisciplinary evaluations and assessments that result in reliable information about a child's developmental strengths and needs and, when possible, a diagnosis.
- The determination of effective intervention strategies and reaching agreement on the frequency, intensity, and duration of early intervention services that will lead to positive outcomes for children and families.
- The measurement of outcomes achieved.

Overview of the Early Intervention Program

The New York State Early Intervention Program is part of the national Early Intervention Program for infants and toddlers with disabilities and their families, first created by Congress in 1986 under the *Individuals with Disabilities Education Act* (IDEA). IDEA is also the federal law that ensures all children and youth, ages 3 to 21 years, with disabilities the right to a free appropriate public education. In New York State, the Early Intervention Program is established in Article 25 of the Public Health Law and has been in effect since July 1, 1993.

To be eligible for services, children must be under 3 years of age and have a confirmed disability or established developmental delay, as defined by the state, in one or more of the following areas of development: physical, cognitive, communication, social-emotional, and adaptive development. Children with an autism spectrum disorder (ASD) are eligible for the Early Intervention Program.

The Early Intervention Program offers a variety of therapeutic and support services to infants and toddlers with disabilities and their families, including family education and counseling, home visits, parent support groups, special instruction, speech pathology and audiology, occupational therapy, physical therapy, psychological services, service coordination, nursing services, nutrition services, social work services, vision services, and assistive technology devices and services.

Major provisions of the New York State Public Health Law that govern the Early Intervention Program require the following:

- Local administration of the program by an Early Intervention Official (EIO) designated by the chief elected official of each of the 57 counties and New York City. The EIO is responsible for ensuring that eligible children and families receive the services included in the Individualized Family Service Plan (IFSP) that is developed for the child and family.
- Identification and referral of children at risk or suspected of disability by primary referral sources (including physicians and other health care providers).
- Periodic developmental screening and tracking of at-risk children.
- Provision of service coordination services to eligible children and their families.
- A multidisciplinary evaluation of children referred to the program, at no cost to families, to determine eligibility.
- Individualized Family Service Plans (IFSP) for eligible children and their families.
- Provision of early intervention services as specified in the IFSP at no cost to the family.
- Delivery of services in natural settings in the community where peers are typically found to the maximum extent appropriate.

The mission of the Early Intervention Program is to identify and evaluate, as early as possible, those infants and toddlers whose healthy development is compromised and provide for appropriate intervention to improve child and family development. The program goals are the following:

- Support parents in meeting their responsibilities to nurture and to enhance their children's development.
- Create opportunities for full participation of children with disabilities and their families in their communities by ensuring services are delivered in natural environments to the maximum extent appropriate.
- Ensure early intervention services are coordinated with the full array of early childhood health and mental health, educational, social, and other community-based services needed by and provided to children and their families.
- Enhance child development and functional outcomes and improve family life through delivery of effective, outcome-based high-quality early intervention services.
- Ensure early intervention services complement the child's medical home by involving primary and specialty health care providers in supporting family participation in early intervention services.
- Assure equity of access, quality, consistency, and accountability in the service system by ensuring clear lines of public supervision, responsibility, and authority for the provision of early intervention services to eligible children and their families.

New York State Public Health Law designates the New York State Department of Health (NYSDOH) as the lead agency for this

See Appendix C: The DEC Recommended Practices (Division for Early Childhood, 2014) provide guidance to practitioners and families about the most effective ways to improve the learning outcomes and promote the development of young children, birth through age 5, who have or are at-risk for developmental delays or disabilities.

The DEC Recommended Practices support children's access and participation in inclusive settings and natural environments and address cultural, linguistic, and ability diversity.

Division of Early Childhood (2014)

statewide program. As the lead agency, the NYSDOH is responsible for the overall supervision and administration of the Early Intervention Program. NYSDOH's responsibilities include the following:

- Implementing statewide policies, procedures, and programmatic and reimbursement regulations.
- Implementing a comprehensive public awareness and child-find system.
- Approving, compiling, and disseminating lists of approved service coordinators, evaluators, and service providers.
- Providing training and technical assistance to municipalities and service providers to enable them to identify, locate, and evaluate eligible children; developing individualized family service plans; ensuring the appropriate provision of early intervention services; and promoting the development of new services where there is a demonstrated need.
- Safeguarding parent and child rights under the Early Intervention Program.
- Establishing and maintaining an Early Intervention Coordinating Council to advise and assist the Department in program implementation.

REASONS FOR ISSUING THIS CLINICAL PRACTICE GUIDELINE UPDATE

The *New York State Department of Health, Clinical Practice Guideline on Autism/Pervasive Developmental Disorders: Assessment and Intervention with Young Children (Age 0-3)* was issued in 1999. The guideline was the first evidence-based guideline to be developed and issued for young children with autism spectrum disorders (ASD). Since the issuance of the guideline, there has been a proliferation of scientific research on the early identification, screening, assessment, intervention, and medical management of children with ASD. The purpose of this update was to ensure that recommendations on clinical practice for young children with ASD in the Early Intervention Program are based on the most current scientific evidence and best practices in the field.

This guideline is intended to:

- Help families learn about appropriate and effective services.
- Provide an education and information resource for professionals.
- Promote consistency in service delivery.
- Facilitate productive communication among professionals.
- Facilitate quality improvement in early intervention services.
- Indicate where more research is needed.

This guideline represents the consensus panel's concerted effort to use the evidence presented by expert reviewers systematic and unbiased way to inform their discussions and reach consensus on recommendations. Evidence ratings for recommendations were determined by expert reviewers. An evidence-based approach provides a set of recommendations that reflect current best practices and will lead to optimal outcomes for children and their families.

CHAPTER 1. INTRODUCTION

1.A Brief description of 1999 Guideline and Methodology Used

The *New York State Clinical Practice Guideline on Assessment and Intervention Services for Young Children with Autism/Pervasive Developmental Disorders* (Autism Spectrum Disorder (ASD)) (referred to as NYSDOH ASD Guideline throughout this report) was developed over a two-year period beginning in 1997 and was issued in 1999 (New York State Department of Health, 1999). The NYSDOH ASD Guideline is one of six evidence-based guidelines produced by the New York State Department of Health, Bureau of Early Intervention, on conditions impacting children's development (communication disorders, motor disorders, Down syndrome, hearing loss, and vision impairments). The intent of these guidelines is to provide parents, public officials, primary referral sources, Early Intervention Program providers, and other early childhood providers with practice recommendations based on the best scientific evidence available about assessment and intervention for young children with disabilities and their families. The New York State Department of Health sponsored the guideline development initiative with the broad goal of improving quality services provided to children within the Early Intervention system in New York State.

All six guidelines were developed using the methodology developed by the U.S. Agency for Healthcare Research and Quality (AHRQ - formerly the Agency for Health Care Policy and Research) (Noyes-Grosser et al., 2005; Bigos et al.,1994; Holland, 1995). An independent, multidisciplinary panel of topic experts, providers (both clinicians and educators), and parents was convened by the New York Department of Health (DOH) under the direction of the Early Intervention Program. The panel methodologist and project staff facilitated the guideline development. The panel employed a systematic process to review the scientific evidence, where evidence was available, and combined this with expert clinical judgment to develop evidence-based guideline recommendations on assessment and intervention of young children with autism. Standard principles of clinical epidemiology (Chalmers, Smith, & Blackburn,1981; Sackett, Haynes, Guyatt, & Tugwell,1991) and of social science research (Shaughnessy & Zechmeister,1997) were employed in evaluating the quality of the scientific evidence relevant to guideline topics.

To develop the 1999 NYSDOH ASD Guideline, a sixteen-member panel was convened and participated in seven meetings to develop the guideline. At initial meetings, the panel defined the scope of the guideline to provide guidance to the research staff who then gathered and summarized the relevant scientific literature on this topic. At later meetings, the panel reviewed and weighed the scientific evidence, along with information about harms and costs, as the basis for making guideline recommendations. For studies that met criteria for in-depth review, relevant information about study design, subject characteristics, and results was systematically abstracted onto evidence tables. The findings from these studies provided the evidence regarding efficacy of the clinical methods for assessing or treating autism. The panel critically evaluated each of the articles that met the criteria for review. Based on the information in each article, the panel developed conclusions about the strengths and limitations of the evidence for efficacy of the method being considered and the degree of applicability of the evidence to the guideline topic. Although the focus of the guideline is children under three years of age, the panel chose not to use age as an absolute cut-off for evaluating scientific evidence and considered that the guideline recommendations might also be useful for somewhat older children.

The panel used standard decision-making rules to develop guideline recommendations. The panel decided that when adequate scientific evidence was available on the efficacy or potential harms of a method, it should be given most weight in determining guideline recommendations. When adequate scientific evidence was not found about important clinical issues, the panel agreed it would make recommendations based on consensus panel opinion. In such cases, the panel agreed it was important to state explicitly in the guideline document that the recommendation was based on panel opinion rather than evidence from the literature.

Therefore, the panel's recommendations in the guideline were based on evidence in the published scientific literature to the extent possible, and reflected the current state of knowledge at the time of publication. When the scientific evidence was lacking or inconsistent for a topic, or when the topic was outside the primary focus of the guideline, the recommendations reflect the professional judgment and consensus opinion of the panel members. When adequate scientific evidence was available, the panel used it as the basis for guideline recommendations. Recommendations supported by the evidence were given a strength of evidence rating depending upon the amount and quality of the evidence and its applicability to the guideline topic. When adequate scientific evidence was not found, the guideline recommendations were based primarily on consensus opinion of the panel. All recommendations on topics based on a systematic literature review were considered "evidence-based" recommendations. Even if the literature review for a topic found no studies that met criteria for adequate evidence, recommendations about that topic were still considered evidence-based.

1.B Approach Used for Current Update

The demand for evidence-based recommendations on assessment and intervention for young children with autism spectrum disorders (ASD) continues to be high, and the scientific evidence has increased substantially during the past two decades. Given that the NYSDOH ASD Guideline was developed and published fifteen years ago, a review and update of the guideline was undertaken to determine the extent to which the recommendations on assessment and intervention issued in 1999 for young children with ASD are supported by current scientific evidence, needed review, or if evidence has emerged to support new practices. The intent of the current effort was to review the scientific research accumulated in the past two decades on early identification, assessment, and intervention for young children with ASD; identify meaningful advancements in the evidence with implications for practice recommendations; and issue an update to the 1999 NYSDOH ASD Guideline which summarizes the current state of the evidence and as applicable, revises or adds new recommendations. Therefore, this update is intended to supplement and enhance, rather than replace, the 1999 practice guideline.

In general, the AHRQ methodology for updating clinical practice guidelines consists of three components: (1) the identification of new evidence; (2) the assessment of the need to update; and (3) working with experts and consumers to review the evidence and where indicated, formulate new or modified recommendations (Shekelle, Woolf, Grimshaw, Schuenemann, & Eccles, 2001). The Bureau of Early Intervention determined such an approach to be appropriate, and worked with Concept Systems, Inc. to develop a process for updating the guidelines. Following the more specific guidance outlined in Vernooij et al. (2014), we designed a multi-step process described below to facilitate the updating of the 1999 NYSDOH ASD Guideline.

1.C Convening the Consensus Panel

A 20-member multidisciplinary consensus panel comprised of experts and consumers of Early Intervention Program services was convened to assist in updating the NYSDOH ASD Guideline. We assembled a group responsible for updating the NYSDOH ASD Guideline with attention toward the inclusion of multiple perspectives. Consistent with the recommendation that the consensus panel should consist of individuals with a background in methodology as well as experts in the field of interest, the consensus panel membership mirrored the original guideline group. Appendix E includes a table with each panel member, their discipline, and a brief biography of their experience.

All members of the original consensus panel convened to develop the 1999 guideline were contacted to ascertain their interest and availability in participating in the update process. Seven original panel members agreed to participate. Multiple perspectives were sought, and the panel membership included ASD service providers, researchers, advocates, and parents of children with ASD. Overall, the panel had extensive experience and familiarity with the 1999 guidelines, by way of the development of the recommendations or the use of guidelines in meeting expectations for care. The list of panel members and their affiliations can be found in the appendix. In convening the panel, it was expected the members would participate in the update process, including attendance and engagement at in-person meetings, review of all materials provided, completion of all review questionnaires, and engagement in virtual meetings.

1.D Literature Reviews

Prior to convening the panel to initiate their work, literature reviews were undertaken by clinical/research experts in ASD to review peer-reviewed, published scientific studies applicable to young children ages birth to three years of age in the areas of screening and diagnostic assessments for young children with possible ASD, and birth through five years of age for intervention methods, health assessments, and medical interventions and treatments. These exhaustive reviews were intended to provide members of the consensus panel with a current view of the status of the evidence to assist the panel in their work to update the CPG. In addition, the systematic review of therapies for children with ASD, ages birth to 12 years of age, prepared by the Vanderbilt Evidence-based Practice Center for the Agency for Healthcare Quality Review (AHRQ) (Weitlauf et al. 2014), was made available to the panel.

In total, six topic-focused literature reviews were conducted by expert reviewers for use by the panel, encompassing the following areas: (1) ASD screening instruments; (2) ASD diagnostic instruments; (3) health/medical assessments and interventions; (4) behavioral and educational interventions, through 2011; (5) parent-mediated interventions; and (6) interventions for children published in peer-reviewed studies after the AHRQ review (Weitlauf et al, 2014).

Evidence-based review procedures have evolved significantly and developed into more formal procedures (e.g., numerical ratings for research quality, inter-rater reliability checks) since the 1999 NYSDOH ASD Guideline was developed. For the current update, a mixed-methods review strategy was used by the expert reviewers, with a more formal evidence-based approach to literature review and study abstraction, and a systematic review approach (Grant & Booth, 2009) for research quality assessment, synthesis, and conclusions. The literature reviews across the clinical recommendation areas (screening, assessment, and intervention) were

rendered consistent by specifying search terms, data bases searched, clear inclusion criteria, abstract review, and article selection by a senior autism researcher, and detailed chart abstraction based on parameters detailed by a methodologist. The Report of the Research presents the work completed by expert reviewers to support the panel's deliberations. It is important to note that four members of the panel also served as expert literature reviewers (Drs. Towle, Siller, Romancyzk, and Hyman), and that other panel members did not participate in the literature review. Instead, the panel used the work of expert reviewers to inform its recommendations.

1.E Survey of Panel Members on 1999 NYSDOH ASD Guideline Recommendations

One of the early steps in the updating process was the development and administration of multiple web-based surveys completed by panel members to assess the currency of the guideline recommendations. Panelists were convened for a webinar in March 2015, to introduce them to the evidence-based methodology for the guideline update process, and to request their participation in these surveys. All 20 members of the panel were asked to review each individual recommendation, and make a judgment about the current body of evidence relative to that statement. Panel members were instructed to assess the current validity of the guidelines based on whether there were changes in available assessments and interventions for young children, or changes in the evidence since completion of the original guideline in 1999. Surveying panelists using the review questionnaires and the subsequent analysis of panelist input aided the assessment. The facilitators of the review process developed the review questionnaires, tested them for clarity and usability, and invited panelists through an online survey interface. Once there, panelists completed the semi-structured review questionnaire, providing information to the team that helped to determine which areas require focus of the panel meetings.

Four questionnaires were designed to facilitate collection of opinions of panel members. Two of the questionnaires focused on *Screening, Assessment, and Medical Evaluation* recommendations and the other two on *Intervention* recommendations. Within each area, one questionnaire asked panel members to consider new or emerging evidence in relation to the evidence-based recommendations (A, B, C, and D1 levels from the 1999 guidelines) and the other the consensus-based (D2 level from the 1999 guidelines) recommendations. Specifically, for the evidence-based recommendations, the review questionnaires directed panel members to use their knowledge, expertise, and experience to evaluate whether they believed there is evidence or new developments to: (1) support or (2) refute or invalidate the current recommendation. Additionally, panelists could provide written comments for each recommendation explaining their response. For the consensus-based recommendations, the review questionnaires directed panel members to use their knowledge, expertise, and experience to evaluate whether they believed the recommendation should still be considered a standard practice or whether new developments or evidence suggest the recommendation is now supported by evidence.

1.E.1 Survey Questionnaire on 1999 NYSDOH ASD Guideline Evidence-based Recommendations

Panelists responded to two separate questionnaires focused on the 36 evidence-based recommendations for *Screening, Assessment, and Medical Evaluation* and the 119 "evidence-based" recommendations for *Intervention* from the 1999 NYSDOH ASD Guideline. Both questionnaires had an 81% response rate (17 out of the 21 panelists provided feedback). For each questionnaire, panelists responded by indicating (a) Yes, there is new evidence to consider, (b) No, the recommendation should stand, or (c) Unsure. As expected, the proportion of responses on the three choices varied across the two sets of evidence-based recommendations. None of the 36 evidence-based recommendations for screening, assessment, and medical evaluation, and only one evidence-based recommendation for intervention, received unanimous responses on any one of the three choices.

To refine and organize the results, we sought to group recommendations by the tendency of the responses by panelists. For those recommendations where a clearly higher proportion ($\geq$ 65%) of panelists indicated a "Yes" or "No" response, the recommendation was assigned to the respective category. For those recommendations where there was not a clearly higher proportion of responses for either "Yes" or "No," recommendations were assigned to a "Mixed" category. For example, if 35% of the panelists responding to a specific recommendation indicated "yes, there are implications for the guideline" and 65% responded "no, the guideline should stand", the recommendation was grouped as a "No, guideline should stand." If, however, the panel was split between 40%-60% between answers, then the recommendation was categorized as having a "mixed" review.

The summary table below (**Figure 1.1**) indicates the number (and percent) of evidence-based recommendations where there is new evidence that has implications for review, the number (and percent) that should stand because there is no new evidence, and the number (and percent) of recommendations that received a mixed response.

Figure 1.1
Summary Table of Panelists Feedback on 1999 NYSDOH ASD Guidelines - - Evidence-Based Recommendations

	Is there new evidence or developments?			
	Yes, with implications for the guideline	No, guideline should stand	Mixed (split between "yes" and "no")	Total
	n (% of total)	*n* (% of total)	*n* (% of total)	
Screening, Assessment, Medical Evaluation	5 (13.9%)	17 (47.2%)	14 (38.9%)	36
Intervention	2 (1.7%)	42 (35.3%)	75 (63.0%)	119

1.E.2 Questionnaire on 1999 NYSDOH ASD Guideline Consensus-based Recommendations

Panelists responded to two separate questionnaires focused on the 91 "best-practices" recommendations for *Screening, Assessment, and Medical Evaluation* and the 26 "best-practices" recommendations for *Intervention* from the 1999NYSDOH ASD Guideline. The former questionnaire had an 81% response rate (17 out of the 21 panelists provided feedback) and the latter had a 76% response rate (16 out of the 21 panelists provided feedback). Panelists could respond by indicating (a) Yes, enough new developments or evidence to suggest a need to assess the strength of evidence of the recommendation, (b) Yes, there are some new developments or evidence to suggest a need to revise or eliminate the recommendation as a "best practice," (c) No, the recommendation should stand as a "best practice", or (d) Uncertain. Of the 91 recommendations for *Screening, Assessment, and Medical Evaluation* to consider, all 17 panelists agreed 7 of the recommendations should "stand as a best practice." Of the 26 recommendations for *Intervention* to consider, all 16 panelists agreed one of the recommendations should stand as a best practice.

To refine and organize the results, we sought to group recommendations by the tendency of the panelists' responses. For those recommendations where consensus varied, we would consider in greater detail recommendations ≤ 70% in the category of keeping the recommendation as best practice (consensus-based) (option C on the questionnaire). Based on this threshold, the result was 24 recommendations for *Screening, Assessment, and Medical Evaluation* and 6 recommendations for *Intervention* where the panel did not have consensus that the recommendation should stand as a best practice, suggesting new evidence or developments should prompt a careful review of these recommendations.

The summary table below (**Figure 1.2**) indicates the level of agreement amongst panelists for both sets of best-practice recommendations.

Figure 1.2
Summary Table of Panelists Feedback for Best Practice on 1999 NYSDOH ASD Guideline Recommendations

	Level of Panelist Agreement					
	≤ 70 % *n* (% of total)	71% - 79% *n* (% of total)	80% - 89% *n* (% of total)	90% - 99% *n* (% of total)	100% *n* (% of total)	Total
Screening, Assessment, Medical Evaluation	24 (26.4%)	12 (13.2%)	36 (39.6%)	12 (13.2%)	7 (7.7%)	91
Intervention	6 (23.1%)	9 (34.6%)	9 (34.6%)	1 (3.8%)	1 (3.8%)	26

1.F Panel Meetings to Update NYSDOH ASD Guideline Recommendations

The work of the panel was process-oriented in that it was a multi-step engagement leading to the final updated recommendations. It required an extended commitment on the part of panel

members to multiple activities carried out over time. Panel members were expected to be collaborative and contribute to a shared proposal and shape it to meet the concerns of all members as much as possible. The process was designed to be cooperative and facilitators worked to reach the best possible decision for the panel and all panel members, rather than competing for personal preferences. An emphasis on an egalitarian approach was maintained so that all members were afforded, as much as possible, equal input into the process. At all times, the facilitators worked to be inclusive and to involve as many stakeholders as possible throughout the multiple steps of the process. Finally, the process actively solicited the input and participation of all decision-makers.

Panel members represented the diversity of perspectives and areas of expertise with respect to identification, diagnosis, intervention, and medical management of young children with ASD. The evidence-based methodology used for the guideline update relied on the balance of the base of scientific evidence, as reported by expert reviewers and expertise and experiences of the panelists. The panel followed standard practices regarding potential conflict of interest with respect to specific guideline recommendations, including recusal from the deliberations where appropriate. Appendix E includes a table displaying the panel members, their disciplines, and a brief biography of their affiliations and areas of expertise.

In general, the work of the panel centered around six specific process elements:

1. Engage in panel deliberations using formal decision-making rules to reach consensus.
2. Review and discuss survey (i.e., Review Questionnaires) results to focus deliberations.
3. Weigh evidence available in reviewing and updating guideline recommendations.
4. Review and discuss new evidence related to assessment and evaluation.
5. Recommend new and/or modified guidelines.
6. Agree on the final update to the recommendations.

Several different modalities were used in working with the panel. A combination of in person and virtual meetings were facilitated. The process for panel engagement was designed to ensure that panel members were appropriately prepared and resourced to meet the objectives outlined for the meetings. In seeking agreement, the process attempted to help panel members ensure a level of comfort in updating the recommendation, particularly in those situations that were more controversial or required nuanced judgment. In general, the process intended to seek agreement by (1) collaboratively generating a recommendation, (2) identifying concerns on the part of panel members, and (3) modifying the recommendation to generate as much agreement as possible. In framing agreement, panel members were asked if the proposed recommendation was something they could live with, and, if not, what needed to change. Simple voting procedures were used to indicate the level of agreement of members.

Three in-person panel meetings were held over the course of 2015. Below, in Table 1.1, are the meeting topic, dates, and locations of the in-person meetings. Overall the meetings were well-attended and panel members were actively engaged in the deliberations. Each of the meetings generally followed the same process. In anticipation of the meeting, panel members were provided the meeting materials in advance. These materials included the agenda, the results of the review questionnaire for the relevant topic, the literature review and associated evidence tables, and lists of the recommendations to be considered. At each meeting, those that

conducted the literature reviews presented on the current state of evidence in the relevant topic area. The panel discussed the presentations, deliberated on the quality of the evidence, and sought clarification from topic experts on the implications of the evidence for the current recommendations. Panel members reviewed the relevant recommendations in the areas covered by the evidence review and worked to update the recommendations based on the panel deliberations. When non-controversial updates to recommendations were suggested, the panel would vote to accept the update. For those updates that required further review or discussion, the facilitators worked offline to organize the materials to be considered in a virtual format (i.e., webinar).

Table 1.1. In-person meetings

Meeting Topic	Date	Location
ASD Screening and Assessment	July 7-8, 2015	Rensselaer, NY
ASD Assessment and medical evaluation	October 14-15, 2015	Albany, NY
ASD Intervention	November 18-20, 2015	Latham, NY

1.G Webinars

Several webinars were held with panel members as a follow up to the in-person meetings. The webinars were held to review the suggested updates to the specific recommendations discussed during the panel meetings. Below are the topic focus and dates of the webinars.

Topic	*Date*
Review of the Medication and Diet Recommendations	*December 28, 2015*
Review of ASD Diagnostic Instruments Recommendations	*January 8, 2016*
Review of the Interventions Recommendations with the Subcommittee	*March 25, 2016*
Review of the Assessment Recommendations with the Subcommittee	*March 29, 2016*
Review of the Intervention Recommendations with the Subcommittee	*April 6, 2016*
Review of the Assessment Recommendations	*April 8, 2016*
Review of the Intervention Recommendations with the Subcommittee	*April 15, 2016*
Review of the Intervention Recommendations with Subcommittee	*April 19, 2016*
Review of the Intervention Recommendations with Subcommittee	*April 22, 2016*
Review of the Intervention Recommendations	*June 20, 2016*
Review of the Intervention Recommendations	*June 22, 2016*

1.H Level of Panel Agreement on Recommendations

The goal of the panel deliberations was to reach panel consensus (i.e., unanimity) on all recommendations included in the *2017 Update to the NYSDOH Autism Guideline*. In general, recommendations included in the Screening and Diagnostic Assessment and Medical Management sections of the guideline represent panel consensus.

However, full consensus could not be reached on all recommendations included in the Intervention section of the 2017 Update. Therefore, the recommendations in the Intervention section are based on the agreement of a majority (i.e., 11 or more members of the panelists). Most of the recommendations included in the Intervention section were agreed on by an overwhelming majority of panel members.

A small minority of panel members had different opinions with respect to the recommendations on early intensive behavioral and developmental interventions. Specifically, a small number of panelists did not fully support the recommendation that early behavioral and developmental interventions based on principals of applied behavior analysis (ABA) should be incorporated as an important element of any intervention approach for young children with ASD. However, a majority of panel members found that the scientific evidence reviewed supported this recommendation.

These same panelists thought there should be a stronger recommendation in support of parent-mediated intervention approaches, and expressed the opinion that such approaches also be incorporated as an important element of any intervention approach for young children with ASD. However, a majority of panel members found that although there is emerging evidence for parent-mediated approaches, more research is needed on the effectiveness of these approaches.

1.I Evidence-based Ratings

During their deliberations, the panel reached general agreement on content areas which were supported by the scientific evidence reviewed and presented by experts to the panel; or, the panel reached consensus agreement on content areas which are consistent with current best practices and standards of care. The panel did not reach conclusions or make judgments concerning the evidence for each recommendation. Final recommendations agreed upon by the panel were reviewed by the content area experts who conducted the literature reviews to determine whether a recommendation was evidence-based.

Recommendations with an “[E]” designation were determined to be supported by the scientific literature reviewed by expert reviewers.

Recommendations with a “[PO]” are based on the opinion of the panel on current best practices (literature was not systematically reviewed or information did not meet criteria for evidence in reviewed completed by expert reviewers).

The companion “*Report of the Research*” summarizes the reviews completed by the expert reviewers, and includes presentations delivered to the panel and a complete bibliography of studies reviewed for this update.

1.J Overview of Guideline Update Structure

This guideline update should be considered a supplement to the original guideline on assessment and intervention with young children with autism/pervasive developmental disorders. The guideline is organized in the following structure:

- Background: Understanding Autism
- Early Identification and Screening of Young Children with Possible Autism Spectrum Disorders
- Early Intervention for Young Children with Autism Spectrum Disorders and Their Families
- Medical Management of Young Children with Possible or Establish Autism Spectrum Disorders.

CHAPTER 2. BACKGROUND: UNDERSTANDING AUTISM SPECTRUM DISORDERS (ASD)

2.A. What Is ASD?

ASD is a complex neurodevelopment disorder characterized by difficulties with social communication and interaction and repetitive patterns of behaviors and interests. The symptoms are present from early childhood and impact social, communication, learning, and adaptive development and functioning. The term "spectrum" refers to the wide range of symptoms, skills, and levels of impairment or disability that children with ASD can have.
In 2013, the DSM-5 redefined autism from the umbrella term of Pervasive Developmental Disorders, with five subtypes, to autism spectrum disorder. Therefore, the terms Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) and Asperger syndrome are no longer applied. In addition, this iteration of the diagnostic definition allows for levels of severity in the two major symptom domains and specification along dimensions that improve characterization of different presentations of the disorder.

2.A.1. What Are the Symptoms of ASD?

ASD is characterized by social interaction and relationship difficulties, verbal and nonverbal communication challenges, and a tendency to engage in repetitive behaviors. However, symptoms and their severity vary widely across these core areas. In fact, two children with the same diagnosis may look very different when it comes to their behaviors and abilities.

Revised diagnostic criteria have been recently published in the *Diagnostic and Statistical Manual of Mental Disorders*, Fifth Edition (DSM-5) (American Psychiatric Association, 2013). The DSM-5 divides seven symptom domains of ASD into two main groups: deficits in social communication and social interaction; and restricted, repetitive behaviors and interests. Under the DSM-5, a diagnosis of ASD will require a person to exhibit, or have exhibited, all three symptom domains in social communication and at least two of the four symptoms domains in the category of restricted range of interests/repetitive behaviors. Table 2.1 is a short adaptation of the DSM-5 diagnostic criteria for ASD.

Table 2.1
DSM-5 Diagnostic Criteria for ASD (5 Symptoms Overall from A and B, as well as C, D, and E)

A. Deficits in all three areas of the Social Communication/Social Interaction Domain	B. Deficits in two of four areas in Repetitive Behaviors and Restricted Interests Domains
1. Deficits in social – emotional reciprocity and interaction	1. Stereotyped or repetitive motor movements or speech
2. Difficulties with communication involving gestures, eye contact, and other non-verbal communication	2. Need for, or insistence on, sameness in daily routines
3. Significant problems in developing and maintaining relationships and adjusting to social contexts	3. Restricted or obsessive interests
	4. Unusual responses to sensory input or sensations
C – Symptoms are present in early childhood but may not be fully evident until demands for social skills increase later in childhood	

Table 2.1 **DSM-5 Diagnostic Criteria for ASD (5 Symptoms Overall from A and B, as well as C, D, and E)**
D – Daily functioning must be clinically impaired.
E – Symptoms are not better explained by general delays /cognitive disabilities. Social and communication functioning should be below the person's general developmental level.

There are two more steps to the diagnostic process as detailed in the DSM-5. The first is an assignment of "severity level" in each of the social-communication and repetitive behaviors domains, described in one sentence. There are three levels that range from requiring support, requiring substantial support, and requiring very substantial support. In the DSM-5 manual, there is a table that provides behavioral descriptions related to these three levels (American Psychiatric Association, 2013). The last step is making characterizations for five "specifiers." They are: (1) whether the person also has an intellectual disability; (2) if a language delay or disorder is present; (3) if a known genetic condition or medical diagnosis is present; (4) and, if the person also has any other neurodevelopmental (e.g., ADHD, tic disorder) or psychiatric (e.g., anxiety disorder) condition; (5) if catatonia is present.

It should also be noted that individuals with a well-established DSM-IV diagnosis of Autistic Disorder, Asperger syndrome, or Pervasive Developmental Disorder-Not Otherwise Specified should be given the diagnosis of autism spectrum disorder and do not require an additional diagnostic evaluation. Individuals who have marked deficits in social communication, but whose symptoms do not otherwise meet criteria for autism spectrum disorder, should be evaluated for the new category of Social Communication Disorder (SCD), which is considered a communication disorder. This allows for a diagnosis of disability in social communication without the presence of repetitive behavior.

2.A.2. Are There Any Symptoms Not Covered by the DSM-5 Criteria?

There are some features that are associated with ASD that are not part of the diagnostic criteria. These may include language delays, motor delays, and certain cognitive/neuropsychological patterns. Children with ASD of all intellectual levels may have uneven levels of cognitive skills that can be observed even when they are under three years old. Many, but not all, of children's strengths tend to be in visual-spatial table-top skills (shape puzzles, recognizing patterns, stacking toys, visual discrimination and memorization), with lower skills in language-based tasks. Parents may report that their children have remarkable memories, music skills, or recognition of letters, numbers, and shapes. Children who will eventually have measurable intelligence in the average and above range may show a scattered level of skills increasingly as they become preschoolers and enter grade school (although verbal-performance IQ differences may lessen into adulthood). Children may also have difficulty with executive functioning.

It is common for even very young children with ASD to show challenges in attention span and distractibility. For many, attention span is quite long for their special interests and very short for most other things, with a greater contrast than is typical for other young children. Other toddlers with ASD may display over-activity or have short attention spans for many things and may be at risk for ADHD in the future.

Eating challenges. It is not unusual for very young children with ASD to be very picky eaters in comparison to other children their age, and thus have restricted diets (Olsson, Carlsson,

Westerlund, Gillbert, & Fernell, 2013). Sometimes this appears to be related to difficulties with textures (Field, Garland, & Williams, 2003). Sensory sensitivities may result in a hyper-reflexive gag or aversions to different textures in the sensitive oral region. Other sources of sensitivity can be related to smell, visual appearance, and texture of food. In addition to this, children with ASD can have difficulty with novelty in general or taking on new things such as different foods compared to those they are familiar and feel comfortable with.

Sleep challenges. Problems falling asleep, staying asleep, and in general establishing a predictable sleep-wake cycle are more common in children with ASD than in typically developing children (Richdale & Schreck, 2009). These difficulties can be very disruptive to parental and family daily life.

Behavioral challenges. Characteristics that are part of ASD can lead to difficulties with cooperation and behavior management in many different situations. The very common delay in language often leads to frustration from not being able to communicate needs, which may lead to crying, tantrums, and sometimes aggression. It is not unusual for the child to have problems with transitions, and these are times when behavioral difficulties can occur. The transition problems may stem from the child not wanting to leave his favorite activity, and sometimes transitions are difficult because the child does not understand what is supposed to happen next. Young children who do not understand language, are not “tuned in” to what other people want them to do, and are not attending to what peers are doing, will often not participate in the routine of programs such as “Mommy and Me” groups or early nursery school activities. When this is the case, their behaviors can be seen as “out of sync,” unsociable, or even uncooperative and disruptive. Finally, children who are overstimulated by sights, sounds, and people can also have “meltdowns” when they are in situations that challenge them in this way.

Another behavior challenge that can present itself in a young child with ASD is a tendency to wander or run off by him/herself. The child may bolt as soon as he gets out of doors, not aware of the danger of leaving the adult behind, running in the street, or through the parking lot. Such a child may also look for ways to get out of the classroom or schoolyard.

Self-aggression in the form of head-banging, or hitting, biting, or scratching one’s self may be seen in toddlers, typically in the context of tantrums.

2.B. How Common Is ASD?

Currently, prevalence statistics from the U.S. Centers for Disease Control and Prevention (CDC) identify around 1 in 68 American children as on the autism spectrum–a 10-fold increase in prevalence in 40 years (Christensen, Baio, Braun, et al., 2016). The apparent increase is largely explained by improved diagnosis, increased public awareness, and broadened diagnostic criteria, but an actual increase in prevalence cannot be ruled out. Studies also show that autism is four to five times more common among boys than girls. An estimated 1 out of 42 boys and 1 in 189 girls are diagnosed with autism in the United States.

2.C. What Causes ASD?

There is no known single cause for autism spectrum disorder. It is generally accepted that ASD is associated with differences in how the brain develops and/or functions. Brain imaging using a variety of technologies shows differences in the shape, structure, and in some cases activation and connectivity patterns of the brain in children with autism compared to children without ASD

(Di Martino et al., 2014; Maximo, Cadena, & Kana, 2014; Lainhart, 2015). However, no brain structure or functional finding has been consistent enough that it can be used to explain or diagnose ASD.

Although there are known links between certain genetic links and ASD, there is no single known genetic cause (Miles, 2011). In some cases, a risk for ASD is inherited. For example, if a family has one child with autism, the likelihood of a future child having the condition is as high as 20%, further documenting the genetic basis for the disorder (Constantino, Zhang, Frazier, Abbachi, & Law, 2010; Ozonoff, et al., 2011). The genetic patterns involved with ASD are very complex, however. Hundreds of genes may be involved and have some relationship to ASD; many of these genes may also be related to other conditions (e.g., ADHD, schizophrenia, depression (Cross-Disorder Group of the Psychiatric Genomics, 2013)). Family studies have shown that sometimes relatives of a child with ASD have related symptoms, such as language delay or social skill challenges, but do not share the full syndrome of ASD. Sometimes ASD is also associated with a genetic mutation that occurs anew and was not passed down from the family. There may also be an association with older parental age (Frans, E.M., et al., 2013). Thus, the genetics of ASD is neither specific nor consistent.

ASD tends to occur more frequently than expected among individuals who have certain known genetic conditions, the most common of which is Fragile X syndrome. Other identifiable ASD-associated genetic syndromes include Down, Williams, Mobius, Angelman, Prader-Willi, Smith-Lemli-Optiz, and CHARGE syndromes, and15q and 22q duplications; tuberous sclerosis and Duchenne muscular dystrophy (Jeste & Geschwind, 2014).

ASD has been associated with in-utero exposures to teratogens. It has long been known that certain viruses (e.g., cytomegalovirus, rubella), metabolic imbalances (Krakowiak, 2012), and some medications will increase the chance that a child has a developmental disability, including autism. Some problems that occur during pregnancy (such as maternal obesity and diabetes (Xiang et al., 2015)) and premature birth have also been associated with slightly increased risks of autism (Guy et al., 2015).

2.D. Is ASD Associated with Any Other Medical Conditions or Genetic Syndromes?

In some cases, children with ASD have other associated medical conditions or genetic syndromes. One such medical condition is epilepsy or seizures. A significant minority of children with ASD will develop seizures, sometimes after early childhood. Other medical conditions, such as sleep disorders and gastrointestinal disorders are now being investigated by researchers for possible increased associations with ASD. Recommendations about assessment of associated medical conditions and genetic syndromes are presented in Section F of Chapter III.

2.E. How Is ASD Diagnosed?

Arriving at the diagnosis typically involves experienced professionals gathering information about the child's behavior from the parents and from direct observation of the child. In the United States, the current criteria for diagnosing ASD are those given in the American Psychiatric Association's Diagnostic and Statistical Manual, Fifth Edition (DSM-5) (American Psychiatric Association, 2013).

Establishing a diagnosis is usually only one part of a comprehensive assessment process for a child with possible ASD. A typical comprehensive diagnostic evaluation involves a

multidisciplinary team of professionals, which may include some combination of a developmental-behavioral pediatrician, general pediatrician, psychologist, child psychiatrist, audiologist, special educator, speech and language pathologist, and occupational therapist. There may be other specialists involved in the diagnostic evaluation, depending on the needs of the child (e.g., pediatric neurologist, nutritionist, physical therapist, etc.). Genetic testing should be recommended, as well as screening for related medical issues such as sleep difficulties. This type of comprehensive evaluation helps parents understand as much as possible about their child's strengths and needs.

Specific recommendations for the appropriate assessment and diagnosis of young children with possible ASD are given in Chapter III. That chapter includes specific recommendations for: (1) identification of children with possible ASD, (2) establishing a diagnosis, (3) looking for associated developmental and health problems, (4) assessing the child's overall function in all developmental domains, and (5) assessing the child's family and environment.

Assessing children with ASD can be complex. Some manifestations of ASD are also seen in children who do not have ASD but have other conditions such as cognitive delays, language disorders, attention deficit and hyperactivity disorders, and various types of emotional/behavioral problems. Part of the diagnostic process is to identify if a child has ASD or one of these other conditions. In addition, disorders such as cognitive delays and language problems often co-exist with ASD.

2.E.1. When or How Early Can ASD Be Diagnosed?

One of the recent developments in the field of autism is an increasing ability to recognize this disorder at a very early age. ASD can often be detected at 18 months or even younger. In most cases, a young child (under the age of three) with autism can now, but not always, be recognized by observing very undeveloped social skills, including diminished social eye gaze, shared attention, and imitation, as well as emerging repetitive behaviors. Significant language delays are usually present as well. However, diagnosing ASD can be challenging since there is no medical test (like a blood test or a brain scan) to diagnose the disorder. Professionals examine the child’s behavior and development to make a diagnosis. In a minority of cases, multiple observations may be required, sometimes over a period of time, to confirm the diagnosis of ASD. By age two, a diagnosis by an experienced professional can be considered reliable. However, many children do not receive a diagnosis until they are four years of age or older. Factors contributing to the delay in diagnosis may include access to diagnostic teams with expertise in ASD; parent concerns, knowledge of symptoms, and readiness to pursue a diagnosis; and, whether parents have the support of primary health care providers and others who guide and encourage parents to pursue their concerns. Children with typical cognitive abilities and more sophisticated language might not be diagnosed until school age when the social demands of the environment become challenging for them. Delays in diagnosis may mean that children with ASD do not get the help and developmental supports they need in a timely fashion. Because diagnoses of children under about thirty months of age can also be difficult to make for some children, and because autism symptoms may be identified later in some children, re-evaluations during the preschool years are critical.

2.E.2. Who Can Make the Diagnosis?

Although the diagnosis of ASD may be fairly apparent in many cases, optimal clinical practice and specific practice regulations suggest that assessments be conducted by professionals

skilled in assessing autism and experienced in working with young children to assess communication, behavior, and developmental abilities. Practice regulations in each state generally provide more specific credential and licensure requirements for defining persons qualified to make a formal diagnosis of autism. In New York State, licensed physicians (including psychiatrists and developmental/behavioral pediatricians) and licensed psychologists can diagnose ASD.

2.E.3. Is There a Prenatal Test for ASD?

There is no genetic test diagnostic for ASD. If there is a family history of ASD, families should consider consultation with a geneticist or genetic counselor to determine if prenatal testing for other disorders associated with ASD might be indicated.

2.F. What Are the Important Elements of Effective Intervention Approaches?

The selection of intervention approaches is the most difficult question for families to answer, and one that may change over time, both as the child develops and as we learn more. Treatments for ASD should focus on improving core difficulties in social communication, paying attention to others to increase conventional learning and social relationships, addressing challenging behaviors and commonly associated difficulties (e.g., anxiety, attention difficulties, sensory difficulties), promoting functional independence, and improving quality of life. Goals for treatment should be individualized to the strengths and needs of the child and family. Parents are advised to engage in ongoing discussions of intervention options and approaches, including the progress and effectiveness of the current intervention(s), with their providers. Treatment choices may be influenced by availability, time commitment required for the family, child characteristics (such as cognitive skills and age) and costs.

2.G. What Is the Prognosis for Children with ASD?

ASD is a spectrum disorder with a wide range of presentations and no known etiology. An individual's eventual functioning level will vary with his or her specific profile of ASD, cognitive, language, and behavioral characteristics. Early intervention, as well as continued educational and therapeutic supports, are intended to help the individual reach his or her potential and to have the best quality of life possible. The eventual "picture" for people with autism ranges from functioning that is difficult to distinguish from those without disabilities to functioning that requires intensive supports, and most will be somewhere in the middle of these two endpoints. Every person should have the opportunity to fully participate in community life with acceptance for who they are, and to have as much self-determination as possible.

2.H. What Are Some Common Misconceptions About ASD?

Although much has been learned about autism in recent years, there are still some commonly held misconceptions. These may include:

- *Misconception:* All children with ASD are mentally challenged (have an intellectual disability).
  - ✓ *Fact*: Although intellectual disability frequently coexists with ASD, this is not true for all children with ASD. Intelligence ranges from very low to very high.
- *Misconception:* Children with ASD are undisciplined and unruly.
  - ✓ *Fact*: There are many reasons why certain children with ASD sometimes demonstrate disruptive or aggressive behaviors (such as communication difficulties, sensory

sensitivities, high anxiety, low tolerance for change, to name a few); however, these behaviors are generally not intended to cause harm by the child.

- *Misconception:* Bad parenting causes ASD.
  - ✓ *Fact:* There is no evidence that ASD is caused by deficient or improper parenting, contrary to what was falsely believed in the past.
- *Misconception:* The appearance of ASD is relatively new.
  - ✓ *Fact*: The diagnostic category of autism was first described by scientist Leo Kanner in 1943. There are, however, descriptions of individuals suspected of having ASD prior to 1799.
- *Misconception*: People who are not diagnosed with ASD will never exhibit characteristics like those with the diagnosis.
  - ✓ *Fact*: Characteristics associated with ASD exist on a continuum that includes those considered "normal" and can be exhibited to a lesser degree by those not diagnosed with ASD.
- *Misconception*: ASD is caused by vaccines.
  - ✓ *Fact*: There is no evidence that childhood vaccination causes autism. A 1998 study linking autism with vaccines has since been retracted. Multiple studies have demonstrated there is no association between vaccines and ASD.
- *Misconception*: Individuals with ASD are unable or unwilling to form meaningful social relationships.
  - ✓ *Fact*: Children with ASD can form close relationships with their parents and siblings and show a clear preference for familiar people over strangers. Although individuals with ASD have difficulty with social interaction, some can have close social relationships, fall in love, and have children.
- *Misconception*: All individuals with ASD have savant abilities.
  - ✓ Fact: Only a small percentage of individuals with ASD exhibit savant abilities. Many have what are called "splinter skills," meaning they have skills in one or two areas that are above their overall performance abilities.
- *Misconception*: Therapies and programs for individuals with ASD work across the board.
  - ✓ *Fact*: There are a wide range of symptoms and behaviors associated with ASD, as well as opinions on when treatment is required. Since all individuals are different, treatments and therapies that may be beneficial and effective for one person may not be for another.

The DEC Recommended Practices (Division for Early Childhood, 2014) provide guidance to practitioners and families about the most effective ways to improve the learning outcomes and promote the development of young children, birth through age 5, who have or are at-risk for developmental delays or disabilities.

The DEC Recommended Practices support children's access and participation in inclusive settings and natural environments and address cultural, linguistic, and ability diversity.

Division of Early Childhood (2014)

Chapter 3. EARLY IDENTIFICATION, SCREENING AND DIAGNOSIS OF YOUNG CHILDREN WITH POSSIBLE ASD

3.A Early Identification of ASD

Recent epidemiological studies suggest that approximately one out of 68 children in the general population is identified with ASD (Christensen, D.L., et al 2016; United States Center for Disease Control and Prevention, 2016). It is important to identify children with ASD and begin appropriate interventions as soon as possible since early intervention may help advance the child's overall development, reduce challenging or interfering behaviors, and lead to better long-term functional outcomes. In recent years, “early” has been redefined through advances in knowledge about the timing of symptom emergence of ASD, and about reliability of early diagnoses. For some children, observable symptoms may be detected as early as 9-12 months of age, and it is often possible to recognize ASD between 18 – 24 months of age. Diagnoses made at 24 months of age have been shown to be quite reliable (Woolfenden, Sarkozy, Ridley, & Williams, 2012). However, there is a small percentage of children whose diagnostic status will change at or after age three (some children will no longer meet the diagnostic criteria and some will only be first diagnosed at age three).

Early detection relies on converging efforts to monitor the development of infants and toddlers by parents, childcare and nursery school staff, pediatricians and family physicians, and the “Child Find” efforts of the public early intervention program. Specific ways that children with ASD are first identified include the following:

- A concern identified by a parent, grandparent, or other caregiver that some aspect of the child's development is delayed or something is atypical about the child's behavior.
- A healthcare provider's or other professional's concern about possible ASD either at the time of a periodic health exam, or when the child is being evaluated for some other health problem (for example, possible hearing loss) or developmental delay (for example, a delay in talking or does not talk, does not make eye contact).
- A healthcare provider’s or other professional’s concern raised during screening and confirmed through evaluation.

Primary health care providers play a central role in identifying ASDs as early as possible through developmental surveillance and screening, in accordance with recommendations issued by the American Academy of Pediatrics (AAP) (Johnson, Myers, et. al, 2007). Developmental surveillance is a flexible, continuous process in which knowledgeable professionals monitor a child's developmental status during the provision of health care services. Screening entails the periodic use of a standardized instrument (either parent report or structured interactions between the clinician and child) that yields a score indicating if the child is at risk for either developmental delays (“broad-band screening”) or for ASD (ASD-specific screening). The AAP recommends that a general developmental screen with a standardized tool occur at 9, 18, and 30 months, and at any point when concerns about development are raised by a parent. Screening, including the use of a standardized autism-specific screening tool, is appropriate any time a caregiver brings up a concern about ASD or because of clinician observations about social, communicative, and play behaviors. Most importantly, the AAP recommends that a standardized, ASD-specific screening tool be administered to ALL children at the 18-month preventive care visit and repeated at the 24- or 30-month visits (Johnson, Myers, et. al, 2007).

An essential component of effective surveillance for ASD is the primary health care provider or other professional's knowledge about the progression of development across developmental domains. This is aided by evidence-based, broad-band developmental screening instruments. However, use of these instruments does not preclude the need for a professional's knowledge of both general developmental milestones as well as "Clinical Clues" to the possible presence of ASD.

"Clinical clues," sometimes referred to as "red flags," are those historical facts and current observations that, if present, heighten concern about possible ASD in a young child. Clinical clues can include information about the child obtained from the parents or current observations made by the professional at the time of evaluation (for example, lack of gaze monitoring or unusual repetitive hand mannerisms). Clinical clues may be noticed by the parents, others familiar with the child, or by a professional as part of routine development surveillance or during health care visits for some other reason.

Children with ASD show signs and symptoms in two ways. One way is by not displaying expected developmental milestones and behaviors in the areas of language, social interaction, and play. The other is by showing unusual behaviors that are known to be associated with ASD. Examples of not reaching expected milestones would include not babbling in a complex way or not showing some awareness of the meaning of familiar words by the age of 12 months. Examples of unusual/atypical behaviors at any age would be flapping hands excitedly often, staring at a spinning fan for minutes at a time, or walking on tip-toes frequently. These motor symptoms may be present in other developmental disorders or as isolated symptoms but when present merit further evaluation. Table 3.1, Clinical Clues for ASD, presents both types of signs in an age progression.

While developmental surveillance and screening procedures are important for all young children, there are certain children considered at higher risk for ASD than others. Younger biologic siblings of children diagnosed with ASD have a higher probability than average of also having ASD (Constantino, Zhang, Frazier, Abbachi, and Law, 2010). Other higher-risk groups are children born preterm, or with genetic or other health conditions.

3.A.1. Recommendations on Early Identification of ASD

Recommendations with an "[E]" designation were determined to be supported by the scientific literature reviewed by expert reviewers.

Recommendations with a "[PO]" represent panel opinion based on current best practices.

1. It is important that periodic screening and ongoing developmental surveillance be accomplished routinely by primary care providers or other professionals at specific age points, starting from birth, to ensure ASD and other developmental disabilities are identified as early as possible. [PO]

2. The periodic preventive health care visits at 9, 18, and 30 months should include a general developmental screening to identify possible problems and concerns. A standardized, ASD-

specific screening tool should be administered to all children at the 18-month preventive care visit and repeated at the 24- to 30-month visit. [PO]

3. It is important for parents to be aware of typical milestones in development and monitor their child's progress. If parents become concerned that their child may have a developmental problem, including possible ASD, it is recommended that they discuss these concerns with a health care provider or other professional experienced in evaluating young children with developmental problems. [PO]

4. As part of periodic screening and developmental surveillance of young children, it is important to detect when developmental milestones have been missed or are delayed. It is also important to observe clinical clues and behaviors that may indicate ASD (see Table 3-1). [PO]

5. It is recommended that the pediatric health care provider administer a standardized screening tool appropriate for the child's age at any point when concerns about ASD are raised by a parent or because of clinician observations or surveillance questions about social, communicative, and play behaviors. [PO]

6. When a primary care provider or other professional suspects that a child may have a developmental delay or ASD, referral to the Early Intervention Program and further evaluation is strongly recommended. This should be done in a timely manner with continued follow-up. [PO]

7. Since younger siblings of children already diagnosed with ASD are at higher risk for the condition, a diagnostic evaluation should be recommended to the parent as soon as parental concerns are identified. Other children with higher risk are those with genetic disorders and children born preterm. [PO]

8. For children who are already receiving early intervention services who are not diagnosed with ASD, it is recommended that surveillance and screening for possible ASD should occur per American Academy of Pediatrics recommendations in the primary care setting. This is because some children are identified with language and cognitive delays and start receiving services before it has been recognized that the child has ASD. [PO]

EI Policy Note: In NYS, children with diagnosed conditions that are highly likely to affect development are eligible for early intervention services. Children with ASD are eligible for the Early Intervention Program on this basis.

Primary care providers and early childhood professionals are "primary referral sources" under the Early Intervention Program. When a primary referral source suspects possible ASD, or developmental delay or other disability, they must refer the child to the Early Intervention Official in the child's county of residence, unless the parent objects.

Communicating with parents

9. It is important that healthcare providers or other professionals communicate their concerns regarding the child's development and ASD symptoms to the child's parents. [PO]

10. In addition to the healthcare provider conducting routine developmental surveillance, it is recommended that providers be very responsive any time parents bring up concerns about development or ASD by listening to concerns and conducting any additional inquiry, screening, or referral. [PO]

11. After making a referral of a child to the Early Intervention Program or other needed services, it is important that health care providers follow up with parents on the outcome of the referrals and/or of evaluations and possible arrangement for services. [PO]

EI Policy: Primary referral sources are required to inform parents about the Early Intervention Program, the services available under the program, and the potential benefits of early intervention services for children and families.

Clinical Clues of ASD

12. It is recommended that observation of certain ASD-related behaviors, or the lack of certain age-appropriate behaviors in the social, language, and play realms, be considered as clinical clues for possible ASD. [PO]

13. The clinical clues in Table 3-1 signal a need for further evaluation for possible ASD. It is important to recognize that no single clinical clue stands alone as an indicator of risk for ASD. [PO]

The clinical clues in Table 3.1 were developed by expert reviewer and panel member Dr. Patricia Towle, and were reviewed by panel members. The clinical clues are derived from clinical research on the indicators of ASD in young children. The clinical clues are organized by age levels and include both speech and language delays (that may indicate non-ASD communication delay) as well as behaviors that are more specific to possible ASD.

Table 3.1
Clinical Clues for Autism Spectrum Disorder*

**No single behavior is indicative of ASD on its own. Children with more general developmental delays may have a few of these symptoms, but the more clues a child shows, the more alerted the provider or parent should be to seeking an ASD-specific evaluation.*

Age range	Language Delay	Social Communication	Repetitive Behaviors/Atypical Object Interactions
9-12 months	Does not play with sounds or babble	Does not respond to his/her name	May seem much more interested in toys or watching objects than interacting with others

Table 3.1 Clinical Clues for Autism Spectrum Disorder*			
**No single behavior is indicative of ASD on its own. Children with more general developmental delays may have a few of these symptoms, but the more clues a child shows, the more alerted the provider or parent should be to seeking an ASD-specific evaluation.*			
Age range	Language Delay	Social Communication	Repetitive Behaviors/Atypical Object Interactions
	Does not localize sounds from further away	Does not vocalize and smile when adult talks to and smiles at child	Is slow to pick up what to do with toys given to him/her; does not imitate simple use of toys
	Does not squeal, shout, laugh, make raspberries	Does not look at parents or others very much	Is overly distressed by loud sounds
	Does not vocalize pleasure and displeasure	Does not shift gaze between people and objects	Seems overly interested in the lights and sounds coming from toys or objects, such as phones
	Does not use sounds to get attention	Does not share positive and negative emotions much *unless* responding to sensory-motor actions or tickles	
	Does not imitate sounds or gestures spontaneously	Entertains self for a long time and does not try to get attention	
		Does not respond to peek-a-boo or simple back-and-forth games	
		Is not able to coordinate attention with another person for periods of time while working on activities, enjoying play and exchanging ideas	
By 12-15 months	Produces neither repetitive babbling (mamama, bababa) nor more complex babbling	SAME AS ABOVE, plus the following:	Only does a few babyish things with toys—shakes, bangs, throws
	Does not seem to understand most common names used in household or routines (bottle, sibling or pet's name, mama, daddy)	Does not point with index finger to get another person to pay attention	May love chasing, wrestling, tickling games, young versions of hide and seek, but not other activities that require more social interaction.
		Does not start to combine eye contact, gestures, and vocalizations	
		Does not monitor or look at the adult's face to see his/her reaction to things	

Table 3.1 Clinical Clues for Autism Spectrum Disorder*			
**No single behavior is indicative of ASD on its own. Children with more general developmental delays may have a few of these symptoms, but the more clues a child shows, the more alerted the provider or parent should be to seeking an ASD-specific evaluation.*			
Age range	Language Delay	Social Communication	Repetitive Behaviors/Atypical Object Interactions
By 15 – 18 months onward	Is not producing a few single words or imitating familiar and new actions, sounds and words (mama, dada, more, all gone, bye, cookie, up, go, etc.)	Does not look at adults face to see what to do next or when to take a turn. Does not request desired things with looks, vocalizations or gestures, or shake head "no" to protest	Does not pick up simple pretend actions such as "talking" into a phone or putting a spoon to a toy animal or doll to "feed" it
	Can't make his/her needs known through communication using words, tone of voice, word approximations	Does not hand objects or toys to parents to get interaction going	Does unusual actions with toys (such as spinning the wheels of toy vehicles); prefers to line objects up or stack them rather than use them in a variety of ways
	Does not understand simple commands or statement or recognize caregiver's voice	Does not imitate e.g., clap hands	Does repetitive motor movements such as spinning around, pacing back and forth in a pattern
By 24 months	Does not have at least 50 words, is not putting two words together	Does not wave bye-bye or respond to "come give me a hug" or look at object mom is holding, or draw attention to himself or herself	May favor just a few types of toys and does the same actions with them over and over again
At any time	Loses words or communication skills he/she had (language regression)	Suddenly, or over the period of a few weeks or months, stops being socially interactive, smiling, giving eye contact	
2- 3 years	Is not expanding number of words and sentences (expect several hundreds); not comprehending multiple directions, locations, questions	Does not join in play with others, prefers self-directed play When playing with objects in presence of caregiver, doesn't give eye contact, vocalizations, smiles – lacks reciprocity	Is particularly interested in certain topics, like naming letters and numbers, although he is not doing other things at age level, or can do complex puzzles past age level
	Not using language for pretend play	Does not try to engage socially with family or others – does not share attention or reciprocate	Carries an unusual object around much of the day

Table 3.1 Clinical Clues for Autism Spectrum Disorder*			
**No single behavior is indicative of ASD on its own. Children with more general developmental delays may have a few of these symptoms, but the more clues a child shows, the more alerted the provider or parent should be to seeking an ASD-specific evaluation.*			
Age range	Language Delay	Social Communication	Repetitive Behaviors/Atypical Object Interactions
	Likes books but needs to control them and does not show understanding	Does not engage in back and forth social interaction with parent, caregivers, relatives, or siblings – cannot sustain a continuous flow of interactions (e.g.,5-10 back and forth exchanges)	Gets distressed when something happens out of order; does much better when everything is predictable
		When others try to engage the child in an activity, he/she turns away, rejects it, or just ignores	Gets obsessed with videos and requests to watch the same one over and over
		Is “hard to read” in terms of emotions shown on face	Seeks unusual visual stimulation, such as by making things wave, flap, or spin in front of eyes, including wiggling own fingers or flapping own hand close to eyes
		Cannot regulate emotions, easily frustrated, tantrums, shuts down	
		Instead of vocalizations or pointing, combined with eye contact, pulls the adult’s hand to get what is desired	Finds spinning or waving things in the environment (for example, a fan) and watches for an unusually long time
		If speech is coming in, child begins to repeat what is heard rather than use his own words (echoes)	Flaps hands when excited, may combine with jumping up and down
		Child repeats word-for-word what characters say on favorite video, although he/she is not using language easily for every day needs (scripts)	Toe-walks
		Puts hands on adult’s hand to have them do something for the child, such as put a puzzle piece in.	Has unusual responses to sensory experiences: Touch—can’t tolerate certain fabrics in clothing, can’t stand certain textures on hands or feet Is overly interested in certain textures, like people’s hair

Table 3.1 Clinical Clues for Autism Spectrum Disorder*			
**No single behavior is indicative of ASD on its own. Children with more general developmental delays may have a few of these symptoms, but the more clues a child shows, the more alerted the provider or parent should be to seeking an ASD-specific evaluation.*			
Age range	Language Delay	Social Communication	Repetitive Behaviors/Atypical Object Interactions
		May be socially indiscriminate, that is, will leave parents without any concern, will go with anyone	Noise – is oversensitive to noise in general or to specific noises like the vacuum, food processor, garage door opening or closing Seeks out certain noises to hear over and over again
		May constantly try to run out the door, or away from an adult.	Vision- Does not like overly bright lights Seeks out certain visual experiences like things spinning, a light pattern on the wall, certain sounds or voices or music on the TV or video, loves repetitive or colorful patterns and is overly interested in watching them
			Becomes or has been extremely picky about food, may avoid textures, or only eat certain textures

3.B. Formal Screening Instruments for ASD

Screening instruments for ASD should be used as part of general monitoring of a child's development or if there is a heightened concern about possible ASD. A screening test for ASD is intended to lead to a yes/no decision that ASD either is unlikely or is possible and therefore requires further evaluation. Most screening tests are designed to be brief and easy to administer.

As described in the previous section, researchers and clinicians can now detect ASD symptoms in children ranging from 9 -18 months, but it is important to remember that not all children with ASD can be identified early. Recommendations about timing of screening are presented below.

Although all screening tools recommended in this document have acceptable and/or emerging evidence for sensitivity and specificity, that is, good rates of both detecting ASD and discriminating it from other conditions, none of them has perfect prediction. In addition, because the time of recognition and severity of symptoms vary, the younger the child is (e.g. 9, 12, 15 months), the less reliable the screener (Wetherby, Brosnan-Maddox, Peace, & Newton, 2008; Feldman, Ward, & Savona et al., 2012). A feature of all the screeners is that they yield many

false positives, meaning that the instrument suggests risk for ASD when it does not exist. This can be tolerated, however, since the screeners detect other disabilities that warrant evaluation for approximately 50% or more of their false positives. False negatives are also an important concern because in this case, a child that DOES have ASD is missed. Understanding these features of screening instruments is important for their proper use.

ASD screening instruments can be divided into **Level 1** and **Level 2**, which are defined as follows for the purposes of this document.

Level 1 are autism-specific screeners intended to screen all children rather than those who are already suspected to have ASD. They have fewer items and take less time to give.

Level 2 screeners are usually intended to be administered to children already flagged by a Level 1 screening procedure or to children who show enough symptoms to bypass the first level of screening. Level 2 screeners have more detailed items and procedures and take more time to administer than do Level 1 screeners. Some settings may benefit from using an instrument that is lengthier, more detailed, and focused on discriminating ASD from other developmental disabilities. Clinician-administered Level 2 instruments can be used by medical providers who want to enhance their ability to detect ASD at the primary care level, or in early intervention settings to determine if a child first entering the EI system will benefit from direct referral to a center or provider who has the expertise and credentials to diagnose ASD. Those employing the clinician-administered Level 2 tools need to be aware that a commitment of time and training may be required to utilize the screener.

All of the Level 1 and Level 2 screeners for which recommendations are made will benefit from further research to verify promising findings.

3.B.1 Recommendations on Screening for ASD

Recommendations with an "[E]" designation were determined to be supported by the scientific literature reviewed by expert reviewers.

Recommendations with a "[PO]" represent panel opinion based on current best practices.

14. The use of Level 1 screeners in primary pediatric health care settings is strongly recommended as part of ASD-specific early identification efforts. The screening instrument should have published research supporting its reliability and validity in detecting possible ASD. [PO]

15. For children with no additional risk factors, universal screening with an ASD-specific instrument at 18 and 24 to 30 months is recommended. [PO]

16. If a screening instrument suggests ASD is unlikely, it is still important to:
    - Assess the child for other developmental or medical delays that may have caused the initial concern.
    - Continue regular periodic surveillance for developmental delays that may be related to the cause of the initial concern.

- Repeat screenings at various age levels, including periodic exams, when concerns for ASD persist. [PO]

17. It is recommended that children with higher risk (have an older biologic sibling or twin diagnosed with ASD, were born preterm, or have certain genetic conditions) be screened earlier and more frequently, even starting at 12 months with valid and reliable screeners for their age. [PO]

Communicating with Parents

EI Policy: If a screening is conducted by a primary care provider and ASD is suspected, the primary care provider must inform the parent about the Early Intervention Program, the potential benefit of early intervention services for the child and family, and refer the child and family to the Early Intervention Official in the child's county of residence, unless the parent objects. Parents can also refer their children directly to the Early Intervention Official if they suspect ASD or have other concerns about their child's development.

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18. When screening young children for possible ASD, it is important for professionals to discuss with parents the purpose and importance of periodic screening, as well as limitations of screening instruments. Many primary pediatric health care providers and other qualified professionals are concerned about parents having needless worry and stress about what may be a false positive screening result. Therefore, it is important to communicate the prediction uncertainty about screening instruments to parents at the same as the screening is done, i.e., that these instruments can yield false positives and negatives but also the importance of additional evaluation if recommended. [PO]

Screening for ASD by Other Professionals

19. When any qualified professional suspects that a child may have ASD, including Early Intervention Program evaluators and providers, it may be useful to screen the child for ASD using a reliable and valid standardized autism-specific screening instrument. [PO]

EI Policy: If a screening is conducted by the multidisciplinary evaluation team for a child referred to the Early Intervention Program, and possible ASD is suspected, the multidisciplinary evaluation should include an assessment for ASD by professionals qualified to make a diagnosis.

3.B.2. Recommendations on Level 1 Screening Instruments

Recommendations with an "[E]" designation were determined to be supported by the scientific literature reviewed by expert reviewers.

Recommendations with a "[PO]" represent panel opinion based on current best practices.

MODIFIED CHECKLIST FOR ASD IN TODDLERS-REVISED WITH FOLLOW-UP (M-CHAT-R/F): The M-CHAT-R/F is the most recent iteration of the most well-known ASD screener, the M-CHAT (Robins, Fein, Barton, & Green, 2001). It is a two-stage screener for children 18-30 months old. The first part is a 20-item parent checklist, which takes about 5 minutes to fill out and score. If the child scores "at-risk," the second part is administered: a clinician-administered follow up interview, which takes another 5 to 15 minutes to administer.

20. The M-CHAT-R/F is a useful Level 1 screening instrument. This is the most recent revision. It is recommended that it be used instead of the M-CHAT because research shows it has improved ability for detection of ASD and other developmental disabilities. [E]

21. The M-CHAT-R/F is a two-stage screening instrument, and it is very important to use both parts. The first part is a 20-item parent checklist. If the child scores positive (for possible ASD) then the Follow-up Interview with the parent is to be given. By continuing to score positive on the Follow-up Interview, a referral for diagnostic evaluation for ASD is indicated. [E]

22. The M-CHAT-R/F also has risk ranges. If the child scores positive for ASD by having a score of 3 or greater with the M-CHAT-R/F, then it is recommended that the second part--the Follow-up Parent Interview be administered. However, if the child scores in the high-risk range of 8 or more, then it is recommended to bypass the Follow-up Interview with the parent and to refer the child immediately for a diagnostic evaluation for ASD. [E]

INFANT – TODDLER CHECKLIST (ITC): The ITC, which is a brief, parent-rated checklist for children 6 to 24 months of age, is part of the Communication and Symbolic Behavior Scales – Developmental Profile (Wetherby & Prizant, 2003). There are three parts to both the original and the Developmental Profile version: A short, parent-rated ITC; a longer parent-rated Caregiver Questionnaire (CQ), which is an elaborated version of the ITC and includes most of the same questions; and the Behavior Sample (BS). The ITC contains 24 individual items, which form seven cluster scores. The seven cluster scores sum to yield three composite scores, from which composite standard scores can be computed (mean of 10 and SD of 3).

23. The ITC is a useful Level 1 screening instrument for screening children from 12-24 months of age. [E]

24. The ITC is a "broadband" screening instrument, meaning that while it has been shown to detect with acceptable accuracy children with developmental disability, including ASD, it is not accurate in distinguishing possible ASD from other developmental delays. [E]

25. In the presence of increased risk of ASD or very early signs of ASD, screening every three months beginning at 12 months with the ITC may be useful. [E]

PARENT OBSERVATION OF SOCIAL INTERACTION (POSI): The POSI is a seven-item, parent-report, paper questionnaire. It takes 5 minutes or less to complete and is targeted at children ages 16-35 months (Smith, Sheldrick, & Perrin, 2013). Three or more positive answers indicate that a child is "at risk" and needs further evaluation. If confirmed in larger low risk samples, the POSI may prove to be a useful level 1 screener.

26. The POSI is a promising Level 1 screening instrument for potential use in a variety of clinical settings to screen children from 16-35 months of age for possible ASD. However, further research validation is necessary to recommend its use. [E]

3.B.3 Recommendations on Level 2 Screening Instruments

Recommendations with an "[E]" designation were determined to be supported by the scientific literature reviewed by expert reviewers.

Recommendations with a "[PO]" represent panel opinion based on current best practices.

SCREENING TEST FOR ASD IN TODDLERS (STAT): The Screening Tool for Autism in Two-Year-Olds (STAT) is a semi-structured, play-based, interactive tool designed for use with children from 24 to 36 months of age (Stone & Ousley,1997). It takes about 20 minutes to complete but can be given in less time if the child fails sufficient items to reach the at-risk cut-off score before all items are given. The STAT consists of 12 activities for observing children's early social-communicative behaviors. Although it was originally designed for children 24 to 36 months, one study showed validity for children under 24 months as well.

27. The STAT is a useful Level 2 screening instrument for use with children from 24 to 36 months of age when conducting screening for ASD by a variety of qualified professionals in across a range of settings. [E]

28. It is important to be aware that the STAT is intended to detect Autistic Disorder (as defined by the DSM-IV) and therefore will likely identify primarily the more severe presentations in young children. [E]

29. The STAT can be used with children 12-24 months, but within this age range has best prediction between 14 and 24 months. [E]

ASD DETECTION IN EARLY CHILDHOOD (ADEC): The Autism Detection in Early Childhood (ADEC) is a brief, interactive clinician-administered screening instrument designed to detect Autistic Disorder (AD) in 12- to 36-month-old children (Young, 2007). It takes about 10 minutes to administer and is comprised of 16 discrete behaviors such as response to name, initiation of joint attention and use of gestures, thought to reflect the core deficits of AD that can be identified in very young children.

30. The ADEC may be a useful tool for children 12 to 36 months of age by a variety of qualified professionals across a range of settings. [E]

31. It is important to be aware that the ADEC is intended to detect Autistic Disorder (as defined by DSM-IV) and therefore will likely identify primarily the more severe presentations in young children. [E]

PARENT OBSERVATION OF EARLY MILESTONES (POEMS): The POEMS is a 61-item checklist that qualified professionals can use with parents to prospectively monitor specific behaviors that may be early symptoms and associated behaviors of an ASD in their birth to 36-month-old infants. Parents can fill it out online, on paper and then send to the professional through the mail, or over the telephone. The authors developed POEMS as a screening instrument for high risk, younger siblings of children diagnosed with ASD.

32. The POEMS is a useful second-level screening instrument for children from 12 to 24 months of age. [E]

33. The POEMS is a screening instrument intended for high-risk, younger siblings of children diagnosed with ASD. It is recommended that parents fill it out every few months to catch emerging symptoms as early as possible. [E]

3.C ASD Diagnostic Assessment of Young Children with Possible ASD

Comprehensive diagnostic assessment for ASD is a resource-intensive process that requires highly skilled professionals and sufficient time. However, the process is important to ensure that ASD is diagnosed early and accurately to provide effective intervention and treatment for the child and family.

See Appendix C - The DEC Recommended Practices (Division for Early Childhood, 2014) provide guidance to practitioners and families about the most effective ways to improve the learning outcomes and promote the development of young children, birth through age 5, who have or are at-risk for developmental delays or disabilities.

The DEC Recommended Practices support children's access and participation in inclusive settings and natural environments and address cultural, linguistic, and ability diversity.

Division of Early Childhood (2014)

The diagnosis of ASD is complex and requires experience and expertise. No single source of information determines diagnosis. Instead, an ASD diagnosis is arrived at after careful consideration of key components of information-gathering. Currently, there are many different settings and strategies for the assessment, evaluation, and diagnostic process for children with or at risk for ASD. The options range from several days of appointments with different individual evaluators, to one session with a single professional (e.g., pediatric neurologist, developmental-behavioral pediatrician, psychologist, child psychiatrist) who may have his/her own protocol for diagnostic procedures that serve to inform application of the DSM-5 criteria for diagnosis. Parents may have differential access to these options based on where they live and, thus, what professionals and agencies they can access.

Some evaluation sessions are very focused on diagnostic assessment of ASD, and others examine an array of developmental domains that are related to ASD but also many other disability patterns (such as language, oral-motor functioning, cognition, social and play skills,

sensory issues, motor, and adaptive skills). The order in which the diagnostic evaluation and general developmental assessment are done may vary for children with ASD. These assessment processes may occur in several phases and may involve multiple professionals.

A primary consideration for the appropriateness and accuracy of diagnosis through assessment and evaluation is the experience and credentials of the professional(s) conducting the evaluation. Professionals conducting the diagnostic examination must be qualified to diagnose ASD in accordance with the practice acts of New York State. The next consideration is the extent of the information gathering from different sources including parents, direct observation of the child, application of standardized, normed instruments, and input from different professionals relevant to the developmental domains implicated in ASD symptoms (e.g., speech pathology, occupational and physical therapy, psychology).

The evaluation is serving two separate goals. One is to establish whether the child has ASD. The second is to map out the child's functioning across several important and interrelated developmental domains for the purposes of establishing a baseline and directing interventions. An evaluation primarily to establish the diagnosis from a single session in the community can be an expedient way to start the intervention process. However, it is important to pursue a more thorough evaluation as well for the purposes mentioned.

It is important to carry out developmental assessments for children with possible disabilities, including ASD. These assessments can identify possible developmental problems and assist in making an accurate diagnosis, determine eligibility for various programs and provide an objective description of the child's abilities and challenges. In addition, this will assist in planning for appropriate interventions, and provide a baseline for measuring progress and effects of interventions.

A final key consideration regards the professional-parent partnership. This relates to the extent to which the evaluators and families work together to make the diagnostic process understandable and meaningful to parents, so that the experience works equally to establish: (1) the diagnostic status and treatment pathways for the child; (2) the knowledge and guidance to parents so that they can be optimal advocates for their child and family; and, (3) resources and community supports that may be helpful and available in the community.

3.C.1. Recommendations on ASD Diagnosis and Assessment

Recommendations with an "[E]" designation were determined to be supported by the scientific literature reviewed by expert reviewers.

Recommendations with a "[PO]" represent panel opinion based on current best practices.

34. It is important to use multiple sources of information in assessing children suspected of having ASD. [PO]

35. Since making an accurate diagnosis of ASD is complex, particularly in children under 3 years of age, it is important that professionals who make the diagnosis have experience and expertise in assessing young children with ASD. [PO]

36. It is recommended that the diagnosis of ASD be based upon the criteria in the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), or the most current edition of this manual. [PO]

Professionals Conducting the Diagnostic Assessment and Evaluation

37. It is important that professionals participating in the developmental and diagnostic assessments have experience and expertise in assessing such young children with ASD and other childhood disabilities. [PO]

38. Feedback to parents about their child's diagnosis should be part of the assessment done by an experienced professional(s) with clinical training in discussing sensitive information. [PO]

39. It is important for all professionals involved in the assessment of a child with possible ASD to use a team approach when communicating and discussing their findings and recommendations with each other and with the child's family. [PO]

EI Policy: In New York State, the term used for professionals who are qualified to deliver early intervention services is "qualified personnel." "Qualified personnel" is defined in program regulations and includes those individuals who are approved to evaluate children and deliver early intervention services to the extent authorized by their licensure, certification, or registration in the area where they are providing services. To diagnose ASD, the multidisciplinary evaluation team must include a professional qualified to do so under his or her professional scope of practice.

General Process and Content of the Diagnostic Assessment and Evaluation

40. The components that should be included in the diagnostic assessment are from multiple sources and include:
    - A review of records (if available)
    - Interview with the parent(s)/parent regarding child history and current functioning,
    - Direct observation of/interaction with the child; and
    - Use of a standardized, evidence-based, ASD-specific instrument (see section 3.C.2., *Evidence-based Diagnostic Assessment Instruments for ASD*). [PO]

41. It is important to have concurrent assessments of the child's hearing, cognitive, language, motor, adaptive, and social/emotional skills. It is important for the assessment to generate functional skill information as well as test scores and age levels, and describe strengths and challenges. [PO]

42. The parent interview component of an ASD diagnostic evaluation may be accomplished using a standardized, evidenced-based instrument or through a clinical interview. The interview should be conducted in a manner so as not to distract the parent from engagement in and observation of their child's evaluation. Information to be gathered includes, but is not limited to, the information in Table 3.2. [PO]

Table 3.2 **Information to be Gathered During the Parent Interview Component**
<u>History and current domestic setting</u> • Pregnancy and birth history; child's medical history and current health status • History of developmental milestones, including early communication and social skill development • Family configuration and the caregiving setting and routines • Areas of parental concern including age of child when concerns emerged <u>Child's current skills and functioning, including core ASD symptoms</u> • Child's current language and communication skills • Child's current social relationships, social interest and skills, and ability to interact with a variety of people • Child's current play interests and capabilities • Probes into atypical communication, play and object interests, and behaviors <u>Child's current adjustment apart from developmental and ASD symptoms</u> • Current difficulties or concerns around eating, sleeping, and behavior management • Reports from or adjustment to community settings such as daycare or nursery school <u>Parents' current strengths, supports, concerns, and challenges</u> • Supports that parents have from family and community as well as current stressors and concerns

43. The direct observation/interaction component of an ASD diagnostic evaluation may be accomplished using a standardized, evidenced-based instrument or through direct observation of the components listed in Table 3.3. [PO]

44. Since the area of assessment of ASD is a rapidly developing field, it is incumbent on the evaluating professional to keep up with literature that examines the evidence base of instruments and strategies. [PO]

EI Policy Note: The child's multidisciplinary evaluation for the Early Intervention Program must include a parent interview about the child's development, developmental progress, and any concerns the parent has about the child's development. The interview can be a formal interview schedule or informal discussion. Families must also be offered the opportunity to participate in a voluntary family-directed assessment to identify their resources, priorities, and concerns related to enhancement of the child's development.

Table 3.3 **Components of Young Child Behavior to Observe for Assessment of Autism Spectrum Disorder – Referencing DSM-5 Diagnostic Criteria**
Social-Communication Behaviors
1. Deficits in Social-emotional Reciprocity
The child's interest and willingness to engage with adult(s), including joining in invitations to play, responding to other social overtures, making social overtures with and without objects, looking at the evaluator or other adults present, and engaging in back and forth interaction.
The child's ability to share emotion (looking and smiling at the adult when pleased or happy) and express a variety of emotions appropriate to the setting through facial expressions.
Whether the child looks to the parent to see their reaction to something novel or interesting.
The extent to which the child uses eye gaze to monitor the faces of the adults for social information, can follow the direction of another's gaze and point, looks at the eyes and face of others during communication and play, and alternates his/her gaze between objects and the play partner's face during an interaction.
2. Deficits in nonverbal communicative behaviors used for social interaction
The extent to which the child smoothly coordinates vocalization/verbalizations, gestures, eye gaze, and facial expressions during communication. Lack of use of canonical gestures (shoulder shrug, thumbs up, etc.) and the extent to which the child coordinates gestures with intentions directed to others using gestures.
The variety of types of messages (intentions) that the child directs to others, including requesting, commenting, negating, answering, greeting, and seeking attention.
How a child responds to a "communication challenge," such as a bag of toys or a bubble jar lid he/she can't open.
How a child repairs a "failed communication," such as when the examiner or parent deliberately does not respond or does not give the child what he/she wants.
The child's ability to use eye contact, communication (including vocalizations and gestures), and facial expression during *sustained* back-and-forth or engaged interaction (more than 1 or 2 exchanges).
3. Deficits in developing, maintaining, and understanding relationships*
*In young children, this may be seen in lack of interest in other children their age, and in lack of interest in siblings, including a new baby, and cousins or neighbors that the child has exposure to. Often the child does show interest in a sibling or someone that he has constant exposure to, but does not extend that interest to unfamiliar peers. In the same way, many children show attachment to and engagement with their parents, but are aloof to less familiar adults or the parent who is less involved in caregiving. ****
4. Developmental Features
The child's developmental history to explore possible delays across developmental domains (e.g., motor milestones).
The child's language and communication skills vis-à-vis their chronological age.
Restricted and Repetitive Behaviors
1. Stereotyped or repetitive motor movements, use of objects, or speech

Table 3.3 **Components of Young Child Behavior to Observe for Assessment of Autism Spectrum Disorder – Referencing DSM-5 Diagnostic Criteria**
Any atypical or stereotyped movements, vocalizations, or behavior. Whole body: spinning, rocking, running and pacing; part of body: hand flapping, arm tensing; self-injurious: head-banging, hitting, or biting self. Vocalizations: unusually repetitive babbling, echolalia immediate or delayed, scripting or repeating lines from videos or TV; overgeneralized use of phrases or words; unusual phrasing or pitch to voice.
Atypical use of vision: looking at objects very closely, looking out of side (peripheral) vision, rolling or moving eyes or shaking head seemingly to get a visual effect, specific unusual interest in lines (floorboards, window sills, blinds), fascination with visual movements in the environment such as fans, flashing lights, computer screens.
The degree to which the child uses objects and toys in typical, differentiated, and age-appropriate ways versus delayed, repetitive, or nonfunctional ways, including: lining things up, spinning objects, arranging them non-functionally, doing the same motion or function with an object many times without variation, waving or flapping objects or strings repeatedly. Contrast with: The child's play patterns with a variety of objects and toys, including those visual-spatial in nature (puzzles, stacking and nesting toys), functional (cars, crayons, balls), and those used in pretend play.
2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior.
The extent to which the child can move from one place, event, play situation or toy/object to the other as facilitated by the evaluator.
Rigid adherence to routines, such as route taken to places in the community; the order in which things are done in the household or at nursery school; greeting and conversational rituals; insistence on sameness where objects are placed, where the individual sits; rigid rules the child may impose on clothing worn, cups or utensils used, food eaten. *
3. Highly restricted, fixated interests that are abnormal in intensity or focus
Unusual focus on letters, numbers, puzzles, or music.
Over-focus on a particular character in videos or toys (Thomas the Tank Engine, Elmo), or on types of toys (e.g., will only play with cars and trucks).
4. Hyper- or hypo-reactivity to sensory input or unusual interests in sensory aspects of the environment
Atypical use of touch: tactile interest shown by rubbing hands on surfaces, seeking certain tactile experiences repeatedly; whole body: seeks whole body squeezing, rolls around floor, pushes head into carpet or corner of furniture, often seeks hard hugs, squeezes self into small spaces, puts face against vibrating toy, licks objects. OR: Atypical aversions to touch, to textures such as in clothing or in food.
Atypical responses to visual stimuli such as staring at lights, patterns, shiny objects, or many visual stimulation behaviors described above.
Atypical use of smell, such as repetitively smelling objects.
Atypical or unusual responses to noise, either by avoiding it (afraid of vacuum, blender, garage door closing), or by seeking out certain noises from toys or videos.
5.Developmental Features
The extent to which the child has age-appropriate gross and fine motor skills and has typical postures and movement patterns.

Table 3.3 **Components of Young Child Behavior to Observe for Assessment of Autism Spectrum Disorder – Referencing DSM-5 Diagnostic Criteria**
The child's activity level and attention span in relation to his/her age.
**These behaviors may not be easily assessed during a time-limited observation and often are best evaluated through the parent interview – See Table 3.2*

EI Policy Note: Children referred to the Early Intervention Program must receive a multidisciplinary evaluation and assessment. A child's eligibility for the program may be established without conducting an evaluation, based on medical or other records which document a diagnosed condition with a high probability of developmental delay, such as ASD. The child must still receive an assessment of all five areas of development (physical, cognitive, communication, social-emotional, adaptive) to inform the development of the Individualized Family Service Plan (IFSP).

Variable and Dynamic Nature of Diagnostic Assessment and Evaluation

45. A diagnostic and developmental assessment should be individualized for each child. [PO]

46. It is important that the developmental assessment not be viewed as a single event, but as an ongoing process that follows the child over time. [PO]

47. It is important to recognize that standardized tests may need to be adapted somewhat when assessing cognition and skill level in very young children with ASD and other developmental disabilities. Differences in learning styles and information processing abilities may need to be accommodated or else the tests may not elicit or accurately represent skills. It is important that evaluators be aware of curriculum-based instruments and play-based approaches that may complement standardized instruments. [PO]

48. It is important to follow up on significant findings in the assessment by adding elements to the assessment and/or referring the child to other professionals for more detailed evaluation and specific diagnosis. [PO]

49. If a young child with suspected ASD is found not to fulfill the diagnostic criteria (i.e., a specific diagnosis of ASD cannot be confirmed or ruled out), it is advisable to take the following actions:
    - Consider adding observation and assessment in different settings, (for example, clinical, home, or preschool).
    - Consider whether another expert opinion is appropriate.
    - Re-examine the child at least every three months or when there is a renewed concern. This is imperative as the child approaches 3 years of age—a time at which children may have a more definitive profile.
    - If the child qualifies for the Early Intervention Program because of developmental delays, it will be very important to continue to monitor for emerging symptoms that make an ASD diagnosis likely. Service providers, parents, and service coordinators all have a role in making sure a child

changes to more ASD-specific services if the need arises even though the child already has a set of services.

- Understand that some young children have features of ASD but neither meet a full diagnosis nor qualify for the Early Intervention Program due to developmental delays (e.g., language is not sufficiently delayed), and their developmental progress should continue to be monitored by their primary care providers.
- Recognize that some young children may not meet the diagnostic criteria or qualify for the Early Intervention Program if they have typical cognitive abilities and the social demands of the environment have not yet exceeded their ability to function; these children should continue to be monitored.
- If ASD is suspected, and the child does not meet the diagnostic criteria or qualify for the Early Intervention Program, it is recommended that professionals discuss with parents how to monitor the child's developmental progress and parent-child interaction strategies to promote and enhance social and communication development. [PO]

Setting of the Diagnostic Assessment and Evaluation

50. It is recommended that evaluators take into consideration environmental settings when planning, completing, and interpreting the results of the diagnostic assessment and evaluation. [PO]

51. Factors such as family preference, the presence of the parent or other individuals, the child's familiarity and comfort with the environment and examiner, aspects of the test environment that are distracting, adequate space, and control of the environment need to be considered in the choice between home and clinic settings. [PO]

52. If there is a practical need to evaluate children in a clinical setting, it is important to integrate information about the child's behavior in the home, which may be obtained through parent surveys, parent interviews, or video/audio recordings of the child's typical behavior. [PO]

Engaging Families as Partners in Diagnostic Assessment and Evaluation

53. The ASD diagnostic assessment and evaluation is an opportunity to engage the child's parents as full partners in the process. This is important to achieve optimal outcomes from the evaluation, including accurate results and a shared understanding of the findings with the family. This is helpful in establishing a partnership with families and ensuring full family involvement in decision-making around interventions and resource management going forward. [PO]

54. It is important to inform and involve parents in decisions about the setting for the assessment and evaluation(s), the referral questions being addressed, and the methods to be used to answer the referral questions, and the timeline for the process. [PO]

55. It is important to help parents understand that the assessment and evaluation is a process of gathering information and behavior samples from a variety of perspectives. There is not a single "test" that will give the final answer. [PO]

56. The parent interview, and proximity to and involvement in the observational strategy, can be useful opportunities to acknowledge parents' expertise regarding their child and their families' strength and concerns. [PO]

57. It is important to use the parent interview and the direct observation as opportunities to educate parents about ASD, the strengths and needs of their child, and to preview how intervention can address them. [PO]

58. In explaining results and giving feedback to parents from the evaluation and diagnostic decision-making process, it is important to:
    - Review and explain test scores, key behaviors and symptoms, and how information shared by parents helped inform the diagnosis.
    - Use terms that are easily understood and provide a thorough explanation about the assessment and evaluation procedures and findings.
    - Fully explain important terms and concepts used in assessment and evaluation reports.
    - Review the assessment and evaluation results and implications, and discuss how the child's performance compares with developmental norms and typically developing peers.
    - Actively engage parents in the discussion and use reflective listening techniques to ascertain their understanding of the process and the results, and identify any questions that need to be addressed.
    - Identify and discuss the strengths of the child and how intervention can capitalize on those strengths and address learning, communication, and social challenges.
    - Review how the assessment and evaluation process and results have informed the parents about next steps for intervention. [PO]

59. It may be useful to provide parents with recommendations about credible sources where they can obtain further information about ASD. [PO]

EI Policy Note: Under the Early Intervention Program, the multidisciplinary evaluation team is responsible for informing the parent about the results of the child's evaluation. The parent must have the opportunity to discuss the evaluation results with the multidisciplinary evaluation team, including any concerns a parent may have about the evaluation process. The multidisciplinary evaluation team is responsible for ensuring that any concerns the parent has about their child are addressed by the evaluation, and, that the parent understands the evaluation results.

Family-Centered and Culturally Competent Assessment and Evaluation

60. A child's life is embedded within a cultural and family context. When assessing children with possible developmental disorders, including ASD, it is essential to consider the family's culture, parent priorities, parenting styles, and family support systems. [PO]

61. In evaluating a child with possible ASD, it is important to recognize that there may be cultural and familial differences in expectations about such things as eye contact, play and social interaction, and pragmatic use of language. [PO]

EI Policy: Non-discriminatory procedures must be used to conduct the child's multidisciplinary evaluation and assessment. Responsiveness to the child's and family's culture must be a primary consideration in all aspects of evaluation and assessment. Tests and other evaluations must be administered in a child's dominant or native language unless clearly not feasible to do so. For purposes of the evaluation and assessment, native language means the language normally used by the child, if determined developmentally appropriate by the qualified personnel conducting the evaluation.

Communicating Diagnostic Assessment and Evaluation Results to Other Professionals

62. It is recommended that the professional(s) who conduct the diagnostic assessment and evaluation:
    - Communicate with other professionals who may be delivering services to a child and family in an effective and expedient manner, with parent consent.
    - Continue to be available to address follow-up questions and concerns that parents may have in the immediate period following the diagnostic assessment and evaluation.
    - Provide parents with information and referrals to services, resources, and community supports for children with ASD and their families, including information about the Early Intervention Program. [PO]

EI Policy: The child's multidisciplinary evaluation report for the Early Intervention Program may be shared with the child's primary care provider and other professionals with parent consent.

3.C.2 Recommendations on Evidence-based Diagnostic Assessment Instruments for ASD

Recommendations with an "[E]" designation were determined to be supported by the scientific literature reviewed by expert reviewers.

Recommendations with a "[PO]" represent panel opinion based on current best practices.

See Appendix C - The DEC Recommended Practices (Division for Early Childhood, 2014) provide guidance to practitioners and families about the most effective ways to improve the learning outcomes and promote the development of young children, birth through age 5, who have or are at-risk for developmental delays or disabilities.

The DEC Recommended Practices support children's access and participation in inclusive settings and natural environments and address cultural, linguistic, and ability diversity.

Division of Early Childhood (2014)

An evidence base for any given instrument is built incrementally. The essential components involve

demonstration of reliability and validity of the several accepted sorts (e.g. reliability – internal consistency, inter-rater, test-retest; validity – face, content, and different types of construct validity). However, demonstration of predictive validity specifically in the form of Receiver Operator Characteristics (sensitivity and specificity) is required if the instrument is to be used with confidence. Sensitivity and specificity analyses allow a judgment of what proportion of children are accurately identified vs. missed, and therefore have more direct application to the clinical experience. In addition, there are several methodological features that can contribute to sensitivity and specificity being higher or lower, and good quality studies adhere to them. When some standards are not used, the sensitivity and specificity can become artificially high.

There is interest in creating clinical observation instruments that are much shorter than those in current use. One example is the Autism Mental Status Exam (Grodberg et al., 2015), which has one paper with ROC analyses. Further studies will be needed to demonstrate its utility. Clinicians need to be aware that there are instruments that begin at age two and cover a relatively large age range. Instruments which can be reviewed for their potential utility for very young children but require more research include the Autism Spectrum Rating Scales (ASRS), the PDD Behavior Inventory (PDDBI), and the Behavior Assessment of Social Interactions in Young Children (BASYC).

Some authors have suggested using observational second-level screening instruments for diagnostic purposes, again because they are shorter. Examples are the Screening Test for Two-Year-Olds (STAT) and the Autism Detection in Early Childhood (ADEC). This trend would need to be supported by further research.

The following section contains recommendations for ASD-specific instruments that are considered evidenced-based for young children with ASD. As emphasized in the above section about general approaches to diagnostic assessment and evaluation, the results of such instruments should be considered in the context of a broader set of information that has been gathered about the child.

EI Policy: In conducting the multidisciplinary evaluation and assessment, the team can use a combination of standardized instruments and procedures, and can also use informed clinical opinion, to determine a child's eligibility for the program. The multidisciplinary evaluation and assessment must be provided at no cost to parents.

<u>ASD DIAGNOSTIC OBSERVATION SCHEDULE, SECOND EDITION (ADOS-2)</u>*:* The ADOS-2 is a semi-structured, standardized observational assessment of the child's communication, social interaction, and play (Lord, Rutter, et al. 2012). There are several modules that can be administered and are chosen in accordance with the child's language and developmental level. The Toddler Module and Module 1 are most often used for young children at risk for ASD. Administration time is about 45 minutes to 1 hour. Training is required to gain competence to administer the ADOS-2.

63. The ADOS-2 is a useful clinician interaction/observation instrument that can be used with young children 15 months of age and above, and with a mental age of 12 months and above as part of a diagnostic assessment for ASD. As with all other ASD measurement tools, it is to be used in conjunction with other information-gathering strategies and clinical judgment for a thorough assessment.

- The Toddler Module and Module 1 are appropriate for assessment of children under 36 months. Very occasionally Module 2 may be used.
- The use of Calibrated Severity Scores (CSS) will aide in comparing a child's current ASD symptoms to others who also have ASD, and in tracking the child's progress over time. [E]

64. It is important to recognize that the ADOS-2 requires an investment of training time to use the instrument appropriately (attending sponsored workshops and when used for research, administering the instrument until coding reliability has been attained). [PO]

CHILDHOOD AUTISM RATING SCALE, SECOND EDITION (CARS-2): The CARS-2 is a clinician-judgment instrument that is rated based on observations that the professional accumulates after spending time with the individual, for example, during an evaluation session. It consists of 15 items rated on a 7-point scale from normal to severely abnormal (Schopler, Van Bourgondien, Wellman, & Love, 2010). The possible range of scores on the CARS-2 is 15 to 60, and scores of 25.5 or higher are in the ASD range for young children. The CARS-2 yields standardized T scores as well as categorization in ranges of Mild, Moderate, and Severe Symptoms of autism spectrum disorder. The CARS-2 is strongly correlated with cognitive level. The CARS is not based on contemporary diagnostic criteria and available psychometric training is less extensive than for the ADOS-2.

65. The CARS-2 is a clinician-judgment/clinician-rated instrument that can be useful for evaluation of young children. The research applicable to its utility and predictive validity has yielded the following guidelines:
    - It is recommended that a cutoff score of 25.5 be used rather than 30, as designated in the manual, especially to include children with a milder presentation.
    - The CARS-2 has been shown to better detect children with ASD who have more cognitive delay compared to those with ASD and higher intellectual functioning.
    - Additional research will be important for use of the CARS-2 with children under 3 years old. [E]

AUTISM DIAGNOSTIC INTERVIEW-REVISED (ADI-R): The ADI-R is a standardized, semi-structured 93-item diagnostic parent-interview instrument. The diagnostic scoring algorithms in the domains of Reciprocal Social Interaction, Verbal and Nonverbal Communication, and Restricted, Repetitive, and Stereotyped Patterns of Behavior, and combine for a cut-off score for autism spectrum disorder. The ADI-R takes between 1.5 and 2 hours to administer and requires training. Current revised algorithms have improved diagnostic accuracy for younger children. The algorithms have been detailed in published reports (Kim, Thurm, Shumway, & Lord, 2013; de Bildt et al, 2009). A revision of the ADI-R is underway which will use a module approach like the ADOS, and reduce the time it takes to administer, but is likely not to be available for several years.

66. The Autism Diagnostic Interview-Revised (ADI-R) may be useful in assessments for young children with ASD. It is an evidence-based parent interview instrument for children starting at 30 months and up through adulthood. It collects information in detail about the child's development, emergence of ASD symptoms, and current symptoms across all symptom domains. [E]

67. The ADI-R requires an investment of training (attending sponsored workshops and administering the instrument until coding reliability has been attained) to use it appropriately. [PO]

CHAPTER 4. EARLY INTERVENTION FOR YOUNG CHILDREN WITH AUTISM SPECTRUM DISORDERS AND THEIR FAMILIES

4.A Overview of Effective Intervention Strategies for Young Children with ASD and Their Families

This section provides recommendations on effective intervention strategies for children with ASD and their families. In developing these recommendations, the panel used information from the extensive review of the scientific literature and systematic review of the evidence for intervention methods commonly used or proposed for toddlers with ASD. In the years since the 1999 publication of the NYSDOH ASD Guideline, tremendous progress has been made in developing and researching early intervention strategies for young children with ASD. The following provides a summary of major areas of focus and evidence development from 1999 through 2015.

Earlier is Better

There is a consensus by experts that the earlier the intervention, the better. This consensus is based on rationales regarding early brain plasticity and the value of addressing very early learning deficits to prevent a developmental cascade of secondary ASD symptoms (Garon, Zwaigenbaum, Smith, Brian, & Roberts, et al., 2009; Masten & Cicchetti, 2010). An example of the latter is that research has suggested that, starting very young, even before their first birthday, some infants who will go on to be diagnosed with ASD have important differences in how much they tune in to social information from the faces and voices of their parents (Dawson, Raphael, & Ring, 2012). Given that social and communication interaction (including "joint attention") with parents and others are the major way that infants and toddlers develop their social and language skills, a child with this early lack of social attention is at high risk for subsequent profound social and communication delays. Most early intervention strategies endeavor to put the most fundamental learning processes, such as attention to others, imitation, joint attention, and responding to a prompt or request, in place so the child can acquire language, social skills, and play skills in a way more like same-age peers. Other important areas of focus for early intervention include reducing problem behaviors, promoting early learning skills and development of basis self-care skills. Only recently have intervention studies added analyses about predictors and moderators to reveal that starting intervention earlier leads to greater skill gains (Flanagan, Perry, & Freeman, 2012; Rogers et al., 2012; Orinstein, Helt, Troyb, et al., 2014; Smith, Klorman, & Mruzek, 2015).

Learning How to Measure Success of Intervention

There has been a great expansion not only in type of interventions developed for and applied to young children, but also in understanding how the research should be conducted. The research questions have expanded from "does this intervention work?" to:

- *What child characteristics are associated with more or less response (positive change over time) to the intervention*? Studies in this area examine child characteristics such as cognitive level, language acquisition, severity of symptoms, social interaction skills, and other child moderators associated with a child's response to intervention approaches.

- *What intervention characteristics are associated with more or less response to the intervention (program/intervention, fidelity, and parent characteristic predictors or moderators)*? The variables investigated include intervention moderators of length of time, how many hours, intensity, and setting, e.g., home, clinic, program-based (intervention predictors or moderators). For program intervention: How faithfully did the providers learn

and administer the specific treatment strategies (fidelity)? For parent-mediated intervention: parent characteristics such as responding to their child, learning the interventions, and applying them effectively and consistently (parent predictors/moderators and treatment fidelity).

- *What are the "active ingredients" of the intervention?* Since most interventions apply numerous strategies as part of a whole program (that nonetheless are assembled based on clinical and theoretical rationales), studies often endeavor to sort out which parts of the intervention may be making the most difference.

- *What child outcomes should be measured and how?* The earliest research looked at IQ, language level, and school program placement, but increasingly research studies have added outcome variables of autism severity, specific symptoms in the areas of social communication and repetitive behaviors, and adaptive behavior. In addition, many areas of functioning—adaptive, motor, problem-solving, are important outcome areas for intervention research.

While program development and evaluation has expanded greatly, research that addresses these questions to interventions for the youngest children (below age three years) does not yet answer them definitively. Studies are still being conducted, and existing studies have strengths and weaknesses. Many studies differ in methods such as who was enrolled (child age and inclusion characteristics) and how the intervention was conducted (how many weeks, what behaviors were targeted, how much provider or parent training, etc.), making comparisons difficult. This guideline update is based on a review of the evidence-base that included infants, toddlers and preschool age children. Recommendations are based on available current evidence; however, it is important to recognize the need for additional research in these areas.

Working with Families

Working with families to support their children's needs has long been an important principle in effective early intervention. Partnering with and supporting parents during intervention efforts has been defined somewhat differently in the literature, depending on authors' specific fields and contexts. Yet, there are many areas of overlap. One of the broadest contexts is the "family-centered" philosophy, which, as applied to early intervention, holds that supporting the child's family vis-à-vis their child's special needs is as much a part of the intervention as child-focused treatments. Some of the most common themes associated with family-centered early intervention are parents as partners; family-centered goals that address family priorities, strengths, and concerns; the use of natural environments; cultural competence; and family empowerment. The many specific activities aligned with family-centered early intervention run on a continuum from specific child treatment goals to navigating whole systems. At the micro level, examples include helping parents learn skills to carryover intervention strategies during daily routines, as well as responding to parents' requests for help with challenges that come up or specific issues such as toilet training, feeding, behavioral challenges, and a host of sensory processing issues. Supporting parents to be effective advocates takes place as part of assessment and ongoing intervention by helping them to understand their child's diagnosis, what concerns treatments are addressing, and how to assess whether they are helping or not. Parents should be supported to know what community resources are available and how to access, evaluate, and negotiate with them. On the most macro level, it is useful for parents-as-advocates to know legal issues, local and national advocacy agencies, how our current systems came to be, and how to help grow and change them. In addition, some family caregivers, including foster parents, may be caring for the most vulnerable young children. These families may have different needs that are important to identify and address in deciding on, planning, and implementing early intervention services.

“Family training” is a term that, although more narrow in focus, may be applied differently across intervention models. In behaviorally-focused treatment, family training often refers to teaching parents behavioral techniques to use outside of provider treatment sessions when they want to teach new skills (often during daily living situations) and when challenging behaviors are present. However, each discipline has specific approaches to parent education and training that addresses treatment goals, such as positioning issues for a child with motor concerns, food selection for a child with feeding problems, and language promotion for a child with communication delays. Family training can also have a broader meaning more aligned with family-centered care that includes many aspects, such as problem-solving around any number of family concerns, gaining information and education on their child’s diagnosis, understanding and acting on the steps necessary for transition from the birth-to-three to the preschool education system.

“Parent-mediated” and “parent-coaching” interventions can have both shared and more specific connotations. Working with parents to gain certain skills to help child skill-building and behavior management certainly involves coaching the parent regardless of the model. However, parent-mediated usually refers to the effort to have the parent as the primary interventionist while the provider supplies instruction, modeling, monitoring, and feedback. This strategy is used across intervention models, i.e., behavioral, semantic-pragmatic/relationship, or discipline-specific such as language promotion programs.

The 1999 NYSDOH ASD guideline included recommendations for parent training as part of ABA-derived interventions. Parent-training and working with parents continues to be a key component of almost all interventions for children with ASD, including intensive behavioral and developmental interventions as described and recommended in Section 4.B.2.

There is growing literature in the last 20 years that emphasizes working with parents and caregivers to support families in how they interact with their children that has arisen from a somewhat different background than much of the well-established ABA literature. The focus and methods of these parent-mediated approaches overlaps with past and present ABA intervention approaches. The panel elected to develop recommendations on parent-mediated approaches in Section 4.C.3, both to highlight the importance of working directly with parents and caregivers, and the somewhat different approaches, in terms of goals and methods, used in current in published research about these interventions.

See Appendix C -The DEC Recommended Practices (Division for Early Childhood, 2014) provide guidance to practitioners and families about the most effective ways to improve the learning outcomes and promote the development of young children, birth through age 5, who have or are at-risk for developmental delays or disabilities.

The DEC Recommended Practices support children’s access and participation in inclusive settings and natural environments and address cultural, linguistic, and ability diversity.

Division of Early Childhood (2014)

Goals for Early Intervention for Young Children with ASD

First and foremost, early intervention services for children with ASD and their families must be directed at ASD-specific issues, as well as strategies to promote children’s overall development in home and community settings. For very young children, intervention strategies should prioritize developing and improving social-communication skills and reducing restricted and repetitive behaviors and interests. Lack of progress in developmental domains that have well-known

sequences (such as in early expressive language: canonical babbling, then variegated babbling, jargon, single words, and then two-word phrases) are often attributable in part to lack of engagement with, imitation of, and attention to others (core ASD symptoms). However, because children with ASD have different learning rates both early and persistently in their lives, ameliorating ASD symptoms to the greatest degree possible will not guarantee age-level functioning.

4.B. Early Intervention Approaches for Young Children with ASD and Their Families

4.B.1 Recommendations on Choosing and Planning Interventions

Much progress has been made in defining and testing early intervention methods and thus creating an evidence base. Ideally practitioners would all be able to access, train for, and carry out manualized, evidence-based programs with a high level of skill. Ideally, all parents would be highly motivated to participate, have a lot of time to devote to it, and none would move away or drop out of programs. However, evidence-based practice involves integrating interventions that have the strongest empirical support with family preferences and needs, practitioner judgement, and other contextual factors. Clinical endeavors also rely on nuanced assessment of the child within a given context to make treatment decisions in collaboration with parents. The recommendations in this section reflect that:

- Plans for type, length, and setting of intervention is highly individualized and done in collaboration with caregivers in the context of their local resources.
- Intervention reflects a thorough assessment of child characteristics and current behaviors and developmental levels; as well as parent/caregiver preferences, resources, and goals.
- Different providers from a variety of disciplines and different agencies involved with the child and family form a collaborative team with the caregiver.
- Setting and methods chosen for intervention reflect consideration of a continuum, from the most similar to what same-age peers without special needs may be experiencing, to more focused and restricted settings and methods, while always working toward the most natural setting possible.
- Intervention methods are continually assessed for progress toward specified goals and adjustments made accordingly.

These recommendations refer to the highly important process of initiating interventions and planning and choosing them; developmentally appropriate practices; natural learning environments; and, monitoring for effectiveness. The recommendations apply across all approaches to interventions regardless of the theoretical basis of the intervention.

Recommendations with an "[E]" designation were determined to be supported by the scientific literature reviewed by expert reviewers.

Recommendations with a "[PO]" represent panel opinion based on current best practices.

Starting, Choosing, and Carrying Out Interventions

1. It is important to identify children with ASD and begin appropriate interventions as soon as possible. Early intervention may help through advancing the child's overall development, accomplishing immediate goals, and increasing appropriate behaviors, and may lead to better long-term functional outcomes. [E]

2. If a child has identified developmental delays and ASD is suspected but not confirmed, it is still important to initiate appropriate early intervention services to address identified developmental delays as soon as possible. [PO]

3. It is recommended that comprehensive and intensive early intervention services that address core ASD deficits and other developmental delays or health concerns begin as soon as a child is suspected of having ASD. [PO]

4. It is recommended that the nature of children's comprehensive and intensive early intervention services be determined on an individual basis, depending on characteristics of both the child and the family. [E]

5. When making decisions about interventions for a child with ASD, it is recommended that parents partner with qualified professionals with experience in treating children with ASD and supporting families. [PO]

6. It is important to recognize that children with ASD have different strengths and needs, and may respond differently to specific intervention methods or techniques. [PO]

7. It is recommended that intervention outcomes for each child be clearly identified, appropriate for the child's age and developmental status, and include criteria for intervention outcomes that are measurable. [E]

8. Depending on the specific outcomes that are targeted (e.g., social, communication, behavior, joint attention, play, cognitive, school readiness, academic, motor, adaptive), it is recommended that a range of evidence-based practices be used. [E]

9. It is recommended that interventions address behaviors and skills that are appropriate for the child's age and developmental status. This includes:

    - Using developmental sequences to guide goal development. For example, intervention services that aim to enhance language may begin by targeting joint attention, gestures, and shared affect.
    - Focusing on skills that are foundational for learning across a broad range of outcomes and contexts. Examples include:
        - Attending to others.
        - Imitating others.
        - Sharing emotions and interests via joint attention.
        - Sharing a common frame of reference with a parent, sibling, or another person about an environmental event.
        - Engaging in coordinated, reciprocal activities with others, and understanding that meanings are transmitted between people via gestures, sounds, expressions, and words. [E]

10. It is recommended that generalization of skills be assessed and promoted during every stage of the intervention process. This includes the selection of treatment targets that (1) promote the socially appropriate and functional use of new skills, and (2) support children's adaptive functioning in natural contexts and environments. [PO]

11. It is important to include parents as active participants in the intervention team to the extent of their interests, resources, and abilities. Parental involvement is important to ensure that the

behavioral and developmental outcomes, goals, and strategies most important to the family are incorporated in the intervention, and to promote generalization of new skills. [E]

EI Policy: An individualized family service plan (IFSP) must be in place for eligible children and their families by 45 days from the child's referral to the Early Intervention Program. The IFSP must include measurable outcomes to be achieved for the child, and services and strategies needed by the child and family to enhance the child's development. The team to develop the IFSP team includes the parent, the Early Intervention Official, the service coordinator, the evaluator, and others invited by the parent or service coordinator, with the parent's consent. Early intervention services included in the child's and family's IFSP must be provided at no cost to parents.

Natural Learning Environments

12. It is recommended that whenever possible and appropriate, learning opportunities are embedded within child-directed play or familiar daily life routines. Contingency-based skill building is most effective when it is embedded in social interactions and activities that are motivating, meaningful, and allow the child to experience the natural contingencies of their own behavior. [PO]

13. It is recommended that generalization of skills is assessed and promoted during every stage of the intervention process. This includes that skills are taught during the child's typical daily interactions, experiences, and routines, with multiple materials and by multiple people. [PO]

14. It is recommended that children's parents, caregivers, and teachers are sufficiently supported to implement intervention strategies during a broad range of familiar daily life routines. Such routines include caregiving activities (e.g., meals, bath time), play (e.g., toy play, physical play, book reading), household chores (e.g., feeding pets, getting the mail), and activities in the community (e.g., going to a store, visiting a park). [PO]

15. It is recommended that to the extent that it leads to improvements in systematically planned learning outcomes (e.g., peer interaction skills, play skills, independent participation in group activities), intervention strategies are embedded in settings in which ongoing interactions occur with typically developing children. [PO]

Early Intervention Policy: Early intervention services must be delivered in natural environments to the maximum extent appropriate for the child and family. Natural environments are settings that are natural or normal for the child's age peers who have no disability, including the home, child care setting, or other community setting in which children without disabilities participate. Under the Early Intervention Program, early intervention services can be delivered in a wide variety of home and community-based settings.

Developmentally Appropriate-Enhancing Strategies

16. It is recommended that developmentally appropriate practice is incorporated into intervention strategies for young children with ASD. Developmentally appropriate practices:
    - Are based on research on how young children develop and learn.
    - Recognize and incorporate individual characteristics of the child when intervening.
    - Recognize and incorporate the values, expectations and factors that shape the child's home and family environment. [E]

17. It is also important to recognize that not all children develop and learn in the sequence generally found in typical development. [PO]

18. It is recommended that interventions incorporate (but not be limited to) strategies to increase the child's motivation such as following the child's lead, giving the child choices about the intervention activities and materials, shared turn-taking within object or social play routines, or adult imitation of the child's language, play, or body movements. [E]

19. It is recommended that interventions incorporate a range of strategies to provide feedback to the child. To the extent possible, clinicians should use reinforcement that has a meaningful link to the child's goals and target behavior. [PO]

Early Intervention Policy: Early Intervention Program providers are responsible for using a child development emphasis in intervention strategies, incorporating quality child development practices with necessary adaptations to enhance the child's development.

Training, Supervision, and Professional Development

20. It is recommended that interventions be implemented by appropriately credentialed, qualified professionals with expertise and experience in the delivery of the intervention being provided. [PO]

21. It is recommended that professionals delivering services to young children with ASD and their families be trained in the use and delivery of evidence-based interventions approaches. [PO]

22. It is recommended that professionals implementing interventions participate in ongoing professional development opportunities to learn about advances in evidence-based practice. [PO]

23. It is recommended that professionals implementing interventions participate in ongoing professional supervision. [PO]

EI Policy: In New York State, the term used for professionals who are qualified to deliver early intervention services is "qualified personnel". The term "qualified personnel" is defined in program regulations and includes those individuals who are approved to deliver Early Intervention Program services, to the extent authorized by their licensure, certification, or registration in the area where they are providing services.

Collaboration and Coordination

24. It is important that techniques and approaches be coordinated, integrated, and collaborative across all individuals working with the child and family. [PO]

25. Frequent team meetings between providers and families and co-treating opportunities are essential to effective coordination of care and collaboration. [PO]

26. It is important that team members communicate with each other regularly about the child's progress and interventions. This could be accomplished by a variety of methods, such as communication book or secure email. [PO]

27. It is recommended that all intervention providers supporting the child and his/her family collaborate on an ongoing basis (i.e., at least monthly) to coordinate intervention targets and strategies. [PO]

28. If a paraprofessional is a member of the team, training and close supervision should be provided by professionals to ensure that the service provided by the paraprofessional is consistent with agreed-upon intervention goals and methods. [PO]

29. When planning comprehensive intervention services for a child with ASD, it is recommended that if multiple intervention components are used, careful consideration be given to integrating the intervention approaches and/or components to make sure they are compatible and complementary. [PO]

30. If an intervention is being considered that is time intensive for the child and/or parents, caregivers, or other family members, it is important to consider the total time involved across all intervention services and ensure coordination of intervention services and approaches. [PO]

Early Intervention Policy: Early Intervention Program providers are responsible for consulting with parents, other service providers (including primary health care providers and child care providers) and representatives of appropriate community agencies to ensure the effective provision of services to the child and family. Providers are also responsible for providing support, education, and guidance to parents and other caregivers regarding the provision of early intervention services.

Monitoring Progress

31. It is recommended that the child's progress be monitored on an ongoing basis by the provider(s) delivering early intervention services and that intervention techniques be modified as appropriate based on the child's progress. This should include collection of data on the child's skill acquisition that can be used on an ongoing basis to guide decisions about intervention. [PO]

32. It is recommended that clinicians use standardized assessments with established reliability and validity, observations, and developmental checklists to guide the development and selection of individualized intervention goals. [PO]

33. To track progress regarding children's individualized treatment goals, it is recommended that measurable criteria for mastery are established and progress is evaluated through ongoing measurement. This may include curriculum-based assessments to examine progress at specific time periods (for example, monthly or quarterly). [E]

34. It is recommended that a lack of objectively documentable progress over a three-month period be taken to indicate a need to revise the intervention approach, increase individualized attention or programming time, reformulate the learning targets, or provide additional training and consultation. For very young toddlers, parents and interventionists may want to consider lack of progress in a two-month period suggests the need to revise the intervention approach. [PO]

35. It is recommended that parents and professionals consider modification of an intervention when:
    - The child has progressed and target objectives have been achieved.
    - The therapist-child/family match is not an effective working partnership.
    - Progress is not observed after an appropriate trial period.
    - The child has shown some progress but target objectives have not been achieved after an appropriate trial period.
    - There is an unexpected change in a child's behavior or health status.
    - There is a change in the intervention setting (for example, moving from the home to a preschool setting).
    - There is a change in family priorities. [PO]

Early Intervention Policy: A child's and family's IFSP must be reviewed every six months and evaluated annually, and revised as appropriate. The results of any current evaluations and other information available from ongoing assessment of the child and family must be used in determining the services that are needed and will be provided.

Periodic In-Depth Re-Assessment

36. In addition to ongoing monitoring, it is recommended that periodic, formal appropriate re-assessment of the child's progress and developmental status be done at least once every 6 to 12 months, and, as appropriate, compare the child's progress and functional level with age-expected levels of development and functioning. [PO]

37. In conducting the periodic re-assessment, it is important for professionals to use good clinical judgment and current best practice, and individualize the assessment to the child. As appropriate, the re-assessment may include:
    - A curriculum-based assessment
    - A functional behavioral assessment if interfering behaviors continue
    - Assessment of social (pragmatic) communication and expressive and receptive language
    - Standardized testing to help assess the child's progress
    - Diagnostic testing to assess the child's status. [E]

4.B.2 Recommendations on Early Intensive Behavior and Developmental Approaches

The 1999 NYSDOH ASD Guideline established evidence based standards of care for children with an autism spectrum disorder receiving early intervention services in NY. The report recommended "…the principles of ABA be included as an important element of any intervention program for young children with autism." Since the publication of the NYSDOH ASD Guideline, numerous studies and reports have been published evaluating the impact of behavioral interventions for individuals with ASD. Weitlauf et al. (2014, Executive Summary, page 11) in their discussion of key findings resulting from their systematic review of behavioral interventions for children with ASD concluded that evidence from research continues to support early behavioral and child development intervention based on the principles of applied behavior analysis (ABA) delivered in an intensive and comprehensive way (addressing numerous areas of functioning) can positively affect some children with ASD. Specifically, based on their review, the authors concluded that "Across approaches, children receiving early intensive behavioral and developmental interventions demonstrate improvements in cognition, language, adaptive, and ASD impairments compared with children receiving low intensity and eclectic non-ABA-based approaches (Weitlauf et al., 2014, Executive Summary, page 11). In conducting their review, Weitlauf et.al. operationalized early intensive behavioral and developmental interventions as having their basis in, or drawing upon principles of ABA (Weitlauf et al., 2014, pg. 6). The interventions reviewed differed in methods and settings, and included the Early Start Denver Model, University of California/Lovaas Model, and interventions that focus on key pivotal or foundational skills and behaviors, such as Pivotal Response Training and Hanen More than Words (Weitlauf et al., 2014, pg. 6). The review of research published after Weitlauf et al. (2014), completed by Dr. Michael Siller to assist panelists in updating of this guideline, supports the conclusion of this review (NYSDOH ASD Guideline Update: Report of the Research, 2017).

Intensive behavioral models often rely heavily on one-on-one therapy sessions during which a trained therapist uses discrete trial teaching. Other models blend ABA principles with naturalistic/developmental principles with developmental and relationship-based approaches. Other intervention approaches which are also ABA-based interventions focus on key pivotal or foundational skills and behaviors (such as motivation to communicate) rather than global improvements. These approaches often emphasize parent training as a modality for treatment delivery (e.g., Pivotal Response Training, Enhanced Milieu Training, and Natural Environment teaching, as well as classroom-based models such as LEAP). The term ABA-based interventions refers to this overarching, broad grouping of early intensive behavioral and developmental interventions throughout this guideline.

Evidence continues to substantiate that interventions based on principles of ABA and child development and delivered in an intensive (greater than or equal to 15 hours per week) and comprehensive (i.e., addressing numerous areas of functioning) approach can positively affect a subset of children with ASD (Weitlauf et. al., 2014). Across intervention approaches, children receiving early intensive interventions based on principles of applied behavior analysis and child development demonstrate improvements in cognitive, language, adaptive, and ASD impairments compared with children receiving low-intensity interventions and eclectic non-ABA-based intervention approaches (Weitlauf et al., 2014).

Applied Behavior Analysis (ABA) and the Developmental Perspective

Early Intervention Policy: Early Intervention services include applied behavior analysis (ABA). ABA means "the design, implementation, and evaluation of systematic environmental changes to produce socially significant change in human behavior through skill acquisition and the reduction of problematic behavior. ABA includes direct observation and measurement of behavior and the identification of functional relations between behavior and the environment. These include contextual factors such as establishing operations, antecedent stimuli, positive reinforces, and other consequences that are used to produce the desired behavior change.

ABA is the most well-researched and validated general approach to treatment for ASD. Behavior analytic strategies were first found in the 1960's to lead to effective learning and development for typical young children (Birnbrauer, Bijou, Wolf, & Kidder, 1965; Hart & Risley, 1968; Hawkins, Peterson, Schweid, & Bijou, 1966) as well as children with autism (e.g. Wolf, Risley, & Mees, 1964) and extended over time to addressing skill development and challenging behavior for school-aged children, adolescents, adults, and the full range of diagnostic conditions.

Professionals that practice ABA are called Behavior Analysts, and if they are Board Certified will use the designation BCBA (Board Certified Behavior Analyst). Behavior Analysts practice in a variety of conceptual, experimental and applied areas but a specific set of techniques and strategies have been applied to autism interventions. As children were diagnosed at very young ages, the concepts were adapted and successfully applied to skill acquisition, behavior management, emotional development, and all areas of important child development.

One reason that there is an abundance of scientific evidence for ABA-based interventions is that

measurement is a core element of the discipline. Built into ABA strategies are precise and objective procedures for defining behaviors, interventions, and progress, and for simultaneously taking data to document each step. It is critical that ABA interventions for children with ASD are based on the parameters established in this research base to be effective. Use of isolated procedures or techniques alone is insufficient. It is the specific concepts and parameters, comprehensively employed, that determine the effectiveness of intervention.

ABA interventions occur in many different contexts and settings ranging from highly controlled therapeutic situations (often referred to as Discrete Trial Format) to natural contexts such as play, home, community, and group settings. The context chosen for intervention is based on a consideration of many variables including the child's age, developmental level, and attention. All ABA programs must explicitly include a generalization procedure so that the skill is practiced in more and more settings until the child can show the skill (or have an alternative response for a challenging behavior) reliably in his/her daily life. If there is a challenging behavior, it might be addressed in a natural setting after a detailed analysis has been carried out in a controlled setting to understand what tends to happen before and after the behavior, and what factors may be influencing the child.

Since the 1960s, the research base and clinical strategies for ABA have expanded greatly. This has occurred to such an extent that there are descriptive names for certain 'packages' or techniques that have ABA as their base, such as the Picture Exchange Communication System (PECS - Bondy & Frost,1994), Verbal Behavior Approach (Sundberg, 2001), and Pivotal Response Training (PRT) (Koegel & Koegel, 2006; Coolican, Smith, and Bryson, 2010; Steiner, Gengoux, & Klin, 2013).

A general trend over the last 20 years in ABA has been an emphasis on "naturalistic" or incidental teaching (e.g., Hart & Risley 1975). Naturalistic teaching embeds the key features of behavior analytic intervention in the child's daily activities and routines. A commonly used example is that in a discrete trial format, the provider may ask the child to point to a picture of a cookie or an actual cookie, and then give a reward such as a bit of cookie when the child does it. In a naturalistic format, during snack time, the provider may ask the child to say "cookie, please," and the child is given the cookie as the reward/consequence. In this way, the task itself is set in what would be occurring during the day in a typical schedule, and the child behavior and reward are functionally linked. These two formats are complementary, and the proportion of how much one vs the other is used depends on the child's skill level and learning characteristics.

Also over the last 20 years, ABA research and application for infants and toddlers with ASD have utilized information about children's physical and cognitive capacities and ability to engage in social relationships. The younger the child, the more critical is the need to adjust to the child's developmental level and to carefully sequence the specific component skills to be taught. For example, the youngest preverbal child might be prompted with a combination of gestures, objects and very short phrases. Young children also would be expected to play with toys on the floor as part of their skills training. On the other hand, an older child might be expected to sit at a play table or desk in a "school-like" setting for a series of tasks.

A developmental perspective integrates into the intervention method the science of child development, which informs choice of activities based on the sequence of skills as they unfold in a typical sequence. However, many skill domain sequence steps have very different forms and thus are not linear. For example, before single words would be taught, perhaps attention to others' language, production of phonemes/babbling, and vocal imitation might be the focus. On the other hand, for a particular child, emphasis might be placed on word imitation directly. These are decisions that must be made based on the child's unique pattern of skills and learning challenges.

Schreibman et al. (2015) have used the term "Naturalistic Developmental Behavioral Interventions

(NDBI)" to denote the best-practice blending of behavioral and developmental strategies for infants and toddlers with ASD. Principles they outline can be summarized as follows:

- Three-part contingency (antecedent, behavior, and consequences).
- Manualized practice.
- Fidelity checks and demonstration.
- Individualized treatment goals.
- Ongoing measurement of progress.
- Child initiated teaching.
- Motivate and engage children.
- Natural reinforcement.
- Using prompting and prompt fading.
- Balancing turns within objects and social play routines.
- Modeling.
- Adult imitation of the child's language, play, and body movements.
- Broadening the attentional focus of the child.

Recommendations with an "[E]" designation were determined to be supported by the scientific literature reviewed by expert reviewers.

Recommendations with a "[PO]" represent panel opinion based on current best practices.

Early Intervention Policy: The child's and family's IFSP must include a statement of specific early intervention services, based on peer-reviewed research, to the extent practicable, necessary to meet the unique strengths and needs of the child and family. It is important to note that a diagnosis of ASD is not necessary to consider these intervention strategies for toddlers and their families. If there is a concern about suspected ASD, the IFSP team can consider including ASD services as appropriate to meet the needs of the child and family.

Early Intensive Behavioral and Developmental Approaches

38. It is recommended that early behavioral and developmental interventions based on principles of ABA be incorporated as an important element of any intervention approach for young children with autism spectrum disorder. These interventions use research-based procedures and parameters and are based upon basic principles of learning. [E]

39. In deciding upon the intensity and duration of intervention for young children with ASD, it is important to recognize that based on available scientific evidence, it is not possible to accurately predict the optimal intensity that will be effective for any given child and family. However, it is recommended that behavioral programs include a minimum of approximately 20 hours per week of individualized intervention. [E]

40. It is recommended that the precise number of hours and duration of behavioral intervention be determined based on a range of child and family characteristics, including severity of autistic symptoms, rate of progress, health considerations, the child's tolerance for the intervention, and

family participation.

- In the recent studies reviewed, effective interventions based on ABA techniques ranged in intensity between 14-28 hours per week (Weitlauf et al., 2014).
- In the recent studies reviewed effective interventions based on ABA techniques extended over a duration of 8 months to 2 years (Weitlauf et al, 2014). [E]

41. It is recommended that intensive early intervention approaches be used to address a range of child outcomes including improvements in cognitive abilities, adaptive behaviors, language and communication, and social skills/social behavior, and amelioration of ASD core symptoms. [E]

42. It is recommended that the selection of the early intervention approach be guided by scientific evidence on the effectiveness of the intervention strategy, including child outcomes, parental resources, priorities, and concerns and values, and provider training and available training resources. [E]

43. It is recommended that intervention approaches be tailored to the child's learning style. Some children learn more quickly using a more structured teaching approach where skills are broken down into small steps for learning and each step is taught very systematically typically in a highly structured situation (e.g., Discrete Trial Training), while other children improve with approaches that emphasize less structured natural situations that focus on the child's interest and natural consequences (e.g., Incidental Teaching, Pivotal Response Training). [PO]

Early Intervention Policy: The type, intensity, frequency, and duration of early intervention services are determined through the IFSP process. All services included in the IFSP must be agreed upon by members of the IFSP team, including the parent. If disagreements arise about the services to be included in the IFSP, parents have the right to due process procedures, including mediation and/or an impartial hearing.

Early Intervention Program providers are responsible for using an individualized approach for both children and families, including consideration and respect for cultural, lifestyle, and other child and family characteristics.

Training and Supervision of Providers

44. It is recommended that ABA interventions are supervised and delivered by appropriately credentialed, qualified personnel with the requisite training and experience. [PO]

45. It is recommended that all professionals who design, oversee, and supervise children's intensive intervention services based on principles of applied behavior analysis and child development participate regularly in professional development opportunities to learn about current advances in interventions for young children with ASD. [PO]

EI Policy: In New York State, the term used for professionals who are qualified to deliver early intervention services is "qualified personnel". The term "qualified personnel" is defined in program regulations and are those individuals who are approved to evaluate children and deliver early intervention services to the extent authorized by their licensure, certification, or registration in the area where they are providing services. To diagnose ASD, the multidisciplinary evaluation team must include a professional qualified to do so under his or her professional scope of practice.

Parent Training

46. It is recommended that parent training and education be included as an important component of comprehensive intervention programs for children with ASD. 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 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 strategies used by interventionists and parents.
    - Improve the interaction between the parents and their child.
    - Increase parent satisfaction and reducing parent stress.
    - Promote reinforcement to enhance the occurrence and generalization of desired behaviors. [E]

47. It is recommended that consideration be given on how to include siblings and other family members the parent training program. [E]

Early Intervention Policy: Early Intervention Program providers are responsible for providing support, education, and guidance to parents and other caregivers regarding the provision of early intervention services.

4.B.3 Recommendations on Parent-Mediated Approaches

Parent-mediated interventions in this section are defined broadly as interventions where parents are responsible for carrying out some or all of the intervention with their own child (Wong et al., 2013). Researchers and clinicians involved with these interventions are specifically interested in promoting strong parent-child relationships and child attachment, enhancing positive early social interaction and communication, and fostering skills the child is not naturally developing on his/her own. The approach also focuses on intervention strategies to help the child attend to and become more fundamentally engaged with parents, thought of as the key issue in addressing ASD symptoms in young children. The assumption is that the more a child is engaged with his or her parents, the more the child will then learn

language and play as well as develop socially through ongoing interactions during critical developmental periods. Although this can be accomplished through direct intervention by an experienced provider, part of the theoretical model is that the parent is the best interventionist. This is because of the amount of time parents have with their children across multiple contexts, and the strong motivation of parents to address their children's needs and promote and enhance development.

Different parent-mediated approaches share several perspectives and intervention goals (following the child's lead, responding in ways that shape child behaviors into communicative acts, promoting positive affective exchanges, matching the child's interests while promoting the next development steps, endeavoring to have the child initiate more interactions rather than having the parent lead a learning task). Many intend for the caregivers to spend from 15 to 25 hours a week with the play strategies. Currently, parent-mediated intervention research studies are highly variable in how they are implemented. Some intervention programs last 12 weeks while other programs continue for 12 months. Some add the parent coaching program to all the other therapies or programs the children are receiving, some do the parent coaching alone with one group and a group receiving community "treatment as usual." The research base for this approach is currently building.

Recommendations with an "[E]" designation were determined to be supported by the scientific literature reviewed by expert reviewers.

Recommendations with a "[PO]" represent panel opinion based on current best practices.

Parent-Mediated Approaches

48. 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. [E]

49. 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. [PO]

50. 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. [E]

51. 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. [PO]

52. 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. [PO]

Early Intervention Policy: The type, intensity, frequency, and duration of early intervention services are determined through the IFSP process. All services included in the IFSP must be agreed upon by members of the IFSP team, including the parent. If disagreements arise about the services to be included in the IFSP, parents have the right to due process procedures, including mediation and/or an impartial hearing.

Selecting Evidence-based Parent-Mediated Intervention Approaches

Early Intervention Policy: The child's and family's IFSP must include a statement of specific early intervention services, based on peer-reviewed research, to the extent practicable, necessary to meet the unique strengths and needs of the child and family.

53. It is recommended that parent-mediated intervention approaches be used to target a range of child outcomes including communication and language, adaptive behaviors, ASD symptom severity, joint attention, play skills, social behaviors, and sensory-regulation. [E]

54. It is recommended that parent-mediated interventions address the parents' informational needs and promote the parents' capacity to meet the needs of a young child with ASD. Important parent outcomes include: parenting practices that promote children's learning, parent self-efficacy and knowledge of child development, parental acceptance of their child's ASD diagnosis and reductions in parenting-related stress, and parental understanding of their child's inner life (what their child may be thinking or feeling). [PO]

55. It is recommended that the selection of parent-mediated approaches is guided by (1) scientific evidence (including target outcomes), (2) parental values, resources, and priorities, and (3) provider training and available training resources. [PO]

4.B.4 Recommendations on Family Well-Being and Support

Recommendations with an "[E]" designation were determined to be supported by the scientific literature reviewed by expert reviewers.

Recommendations with a "[PO]" represent panel opinion based on current best practices.

56. It is important to recognize that parents with children with ASD often experience high levels of stress. [E]

57. 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. [PO]

58. Families may benefit from referrals to other resources in their community, and information and support that may be of assistance. [PO]

59. 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. [PO]

60. It is recommended that families who are experiencing stress in raising their children with ASD be referred to mental health support services. [PO]

Early Intervention Policy: Family training, counseling, home visits, and parent support groups to assist the family in understanding the special needs of the child and enhancing the child's development are defined as early intervention services. Family support groups and individual family counseling are paid for by the Early Intervention Program.

All early intervention services must be provided at no cost to parents.

See Appendix C - The DEC Recommended Practices (Division for Early Childhood, 2014) provide guidance to practitioners and families about the most effective ways to improve the learning outcomes and promote the development of young children, birth through age 5, who have or are at-risk for developmental delays or disabilities.

The DEC Recommended Practices support children's access and participation in inclusive settings and natural environments and address cultural, linguistic, and ability diversity.

Division of Early Childhood (2014)

Chapter 5. Medical Management of Young Children with Possible or Established ASD

5.A. Health Evaluations for Young Children with Possible or Established ASD

This section provides recommendations about both general and specific evaluations of health status for children with ASD. In contrast to the behavioral diagnostic assessment and evaluation methods reviewed in Chapter 3, the health assessment methods evaluated in this section are not used to identify or diagnose ASD. There is currently no specific laboratory, imaging, electrophysiological or other medical tests that can be used to establish the diagnosis of ASD. There are current research studies that suggest that with further study, neurophysiologic measures in early childhood might be eventually shown to have utility in early diagnosis.

There are several well-accepted reasons why it is important for young children with possible or established ASD to be seen by a medical professional. Associated medical conditions need to be considered that might impact the child's health and response to early intervention. In addition, considering the etiology or cause of the developmental disorder is important as it may impact the child's prognosis or need for further medical or genetic work-up and other identifiable conditions that might impact the child's health.

Primary care providers (PCP) need to be aware of co-morbid conditions seen more frequently in young children with ASD, and provide surveillance in the context of anticipatory guidance for parents. In addition, these conditions should be monitored by primary care providers to recommend indicated medical interventions to parents in the context of well-child care, or to refer a child and family for specialty care. PCPs can also help families understand findings resulting from specialized diagnostic assessments and evaluations, and recommend a second opinion if necessary. A trusted PCP who takes time to listen to families and review recommendations made by specialists can help parents make more informed decisions about their children's health and development.

Primary care providers may be asked by parents about vaccinations and ASD, and may have concerns they wish to discuss about whether vaccines cause autism. It is important to note that there is no evidence in the peer reviewed scientific literature that childhood vaccination causes or exacerbates autism (Institute of Medicine, 2004; Maglione, M.A, Das L., Raaen, L. et al 2014). For more information about vaccine safety, visit the New York State Department of Health website, https://www.health.ny.gov/prevention/immunization/vaccine_safety/truth_about_autism.htm.

Children with ASD are susceptible to the same health problems as children without ASD. It is important to note that the assessment and intervention for these general medical conditions is outside the scope of this guideline and, therefore, not addressed in this document.

The review of health evaluation in this chapter is limited to recommendations for the primary care provider to ensure that associated medical conditions are appropriately identified and treated, a description of an appropriate evidence based evaluation for etiologies, and discussion of controversial evaluations that families may ask their primary care providers about. Review was limited to health-related topics associated with ASD published in the peer reviewed literature since the initial document. A more extensive review of standard pediatric care was not undertaken, since the established AAP recommendations, contained in *Bright Futures* (Hagan, Shaw, and Duncan, 2017*)*, are the standard of care for the field.

This section on health evaluations of children with possible ASD is divided into the following parts:

A. Medical Home
B. Strategies for the Health Evaluation
C. Monitoring for Common Co-occurring conditions
D. Assessment of Immune Status, Food-Allergy and Diet Assessment, and Metabolic Testing.

5.A.1 Recommendations on Medical Homes (Consistent and Accessible Primary Care)

Recommendations with an "[E]" designation were determined to be supported by the scientific literature reviewed by expert reviewers.

Recommendations with a "[PO]" represent panel opinion based on current best practices.

The American Academy of Pediatrics defines the Medical Home to be medical care provided to children that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective (Sia et al., 2002). Characteristics that define a Medical Home include health care that is delivered or directed by well-trained physicians, nurse practitioners, and physician assistants who are known to the family and can develop partnerships with families based on mutual responsibility and trust. In a Medical Home, these clinicians deliver or direct primary health care provided to the child, and manage and facilitate all aspects of pediatric care. (Sia et al., 2002).

See Appendix C - The DEC Recommended Practices (Division for Early Childhood, 2014) provide guidance to practitioners and families about the most effective ways to improve the learning outcomes and promote the development of young children, birth through age 5, who have or are at-risk for developmental delays or disabilities.

The DEC Recommended Practices support children's access and participation in inclusive settings and natural environments and address cultural, linguistic, and ability diversity.

Division of Early Childhood (2014)

Primary health care in a medical home encompasses the following services:
Provision of family-centered care through developing a trusting partnership with families, respecting their diversity, and recognizing that they are the constant in a child's life.

1. Sharing clear and unbiased information with the family about the child's medical care and management and about the specialty and community services and organizations they can access.
2. Provision of primary care, including but not restricted to acute and chronic care and preventive services, including breastfeeding promotion and management, immunizations, growth and developmental assessments, appropriate screenings, health care supervision, and patient and parent counseling about health, nutrition, safety, parenting, and psychosocial issues.
3. Assurance that ambulatory and inpatient care for acute illnesses will be continuously available (24 hours a day, 7 days a week, 52 weeks a year).
4. Provision of care over an extended period of time to ensure continuity. Transitions, including those to other pediatric providers or into the adult health care system, should be planned and organized with the child and family.
5. Identification of the need for consultation and appropriate referral to pediatric medical subspecialists and surgical specialists. (In instances in which the child enters the medical system through a specialty clinic, identification of the need for primary pediatric consultation and referral is appropriate.) Primary, pediatric medical subspecialty, and surgical specialty care providers should

collaborate to establish shared management plans in partnership with the child and family and to formulate a clear articulation of each other's role.

6. Interaction with early intervention programs, schools, early childhood education and child care programs, and other public and private community agencies to be certain that the special needs of the child and family are addressed.
7. Provision of care coordination services in which the family, the physician, and other service providers work to implement a specific care plan as an organized team.
8. Maintenance of an accessible, comprehensive, central record that contains all pertinent information about the child, preserving confidentiality.
9. Provision of developmentally appropriate and culturally competent health assessments and counseling to ensure successful transition to adult-oriented health care, work, and independence in a deliberate, coordinated way. (Sia et al., 2002, pg. 2)

Bright Futures (Hagan & Duncan, 2017) advocates for health monitoring and anticipatory guidance for all children, including children with ASD and other special health care needs. Children with ASD are susceptible to all the same health problems as children without ASD. While there is extensive scientific literature on the general health evaluation of young children, a systematic literature evaluation was not done for this topic since it was outside the scope of the guideline. However, the panel felt it was important to make some consensus recommendations about general health care for children with ASD. In some cases, these recommendations were derived from evidence reviewed in other parts of the guideline.

General Health Care for Children with ASD

1. It is recommended that children with ASD, like other children with special health care needs, receive their primary care in a Medical Home that offers a trusting and collaborative working partnership with families and provides developmentally appropriate health care that continues uninterrupted as the child moves within and across systems of care. [PO]

2. It is important to recognize that children who receive care in a Medical Home have improved access to primary and specialty care and the families report improved quality of life. [E]

3. The need for a health evaluation may be triggered by findings identified in primary care, through recommended screening, or because of concerns raised by a parent, or if a developmental problem may exist in the context of ongoing developmental surveillance. [PO]

4. It is important that children with possible ASD have a thorough health evaluation to identify and assess:
   - Medical conditions or developmental problems that are sometimes mistaken for ASD.
   - Associated medical conditions or genetic syndromes often seen in children with ASD. [E]

EI Policy: An assessment of physical development, including a health assessment, is a required component of the child's multidisciplinary evaluation and assessment. Whenever possible, the health assessment for the program should be completed by the child's primary care provider.

Health Evaluation of Children with ASD

5. It is important to carry out a comprehensive health evaluation for children with possible ASD to:
   - Provide a general assessment of the child's health status (as is recommended for all children with possible developmental delays or concerns).
   - Evaluate for disease and assess suspected health problems.
   - Look for associated medical conditions or genetic syndromes that are seen more frequently in children with ASD.
   - Look for evidence of other developmental problems, since these are more frequently seen in children with ASD than in typically developing children.
   - Identify other medical conditions (such as hearing loss) that sometimes result in symptoms mistaken for ASD in a child who does not have ASD, or may complicate ASD.
   - Aide in assessing the child's level of development and in planning of interventions and assessing health outcomes from interventions. [E]

6. It is important to recognize that health care visits may present special challenges for children with ASD and their parents and healthcare providers.
   - Sensory sensitivities may cause distress and resultant behavioral challenges in the office setting. Stressors may include but are not limited to: noise from office equipment, bright lights, or touch as might be required in an examination. Being aware of sensory differences may help with cooperation by decreasing stressful stimuli or preparing a child.
   - Children with ASD may have behavioral exacerbation with unstructured wait times in the waiting room. It may be helpful to see them at a time of day when the waiting room is not busy and they can be taken to a room right away.
   - Children with ASD may not understand language in a typical fashion. It is important for providers to ask how the child communicates and what he/she understands. Use of visual schedules, sign language and clear language to let the child know what will happen next and what needs to happen before they can be done may help them understand and improve cooperation. The clinician might ask the family to review in words or pictures what the visit will entail prior to the visit so it will be familiar to the child (visual supports to inform a child what will happen).
   - Children with ASD may not report or respond to pain in typical fashions. [PO]

7. It is important that a general health evaluation for children with possible ASD include at least the following components:
   - Assessment of hearing and vision.
   - A neurological examination.
   - A skin exam (for signs of neurocutaneous disorders with increased risk for ASD like tuberous sclerosis or neurofibromatosis).
   - A search for medical conditions, genetic syndromes, or other developmental problems that are sometimes associated with ASD including completion of family history, review of medical history, measurement of growth parameters, including head circumference and dysmorphology exam.
   - Developmental screening as recommended with ongoing surveillance and general health screening appropriate for the child's age per the AAP periodicity schedule.
   - Addressing any other health concerns expressed by parents.
   - Assessment of other current health problems. [E]

8. There are problems seen with greater frequency among children with ASD that benefit from identification, assessment and initial management in primary care. Since the problems may be behavioral and the symptoms impact learning and family function, coordination of medical and other intervention systems is recommended. Common problems that impact health of children with ASD include:
   - Feeding problems and nutritional concerns. [E]
   - Sleep disorders. [E]
   - Wandering (elopement). [E]
   - Pica (eating or chewing non-food items). [PO]
   - Behavioral health disorders like Attention Deficit Hyperactivity Disorder [PO]
   - GI problems (e.g., difficulty toilet training, constipation) [E]
   - Seizures [E]

Explaining the Health assessment to Parents and Informed Consent

9. It is important that professionals carrying out the health evaluation of children with possible ASD discuss the findings of the evaluation with the child's parents and/or parents. [PO]

10. Appropriate informed consent is required for genetic testing as well as adequate safeguards for confidentiality of results. Parents need to be counseled about the risks and benefits of all testing and provide appropriate informed consent. [E]

5.A.2 Recommendations on Monitoring for Common Co-occurring Medical Concerns

One purpose of comprehensive health evaluations for children with suspected ASD is to identify and assess associated medical conditions that are seen more commonly in children with ASD than in the general population. Medical conditions associated with ASD include sleep disorders, feeding disorders, GI symptoms, wandering (elopement), seizure and genetic syndromes (for example, Fragile X syndrome).

Table 5.1 provides a list of medical conditions and syndromes that are more common in children with ASD than in the general population. While there is an increasing basic science literature examining the neurobiology of sensory processing challenges in people with ASD, the only clinical screening and evaluation of sensory differences that medical professionals have the capacity to screen and test for are related to vision and hearing. It is very important that all children with developmental delays have their hearing and vision screened. This is especially important in children being evaluated for ASD since lack of visual attention to faces may be an early symptom of vision problems as might language delays or inattention to meaningful sounds might indicate hearing difficulties.

Challenges with feeding and sleep may precede recognition of the symptoms of ASD. Appropriate management in the medical home might improve both the health of the child and quality of life for the family. Other associated disorders like seizures need active medical management. Identification of genetic disorders is important for further evaluation of associated health concerns and for genetic counseling. Medical conditions that are common in childhood such as ear infections and eczema need to be considered in children with ASD who might have a change in behavior or irritability. Children with ASD might not indicate discomfort in the same ways as other children.

Sensory symptoms, including behavioral signs of hyper- or hyposensitivity, have been added to the DSM-5 criteria of restricted and repetitive behaviors as a core symptom of ASD. The documentation of these symptoms is currently done by questionnaire by nonmedical professionals, and further discussion of screening and assessment of these symptoms is not currently part of the medical evaluation. Currently, there are no instruments for sensory processing difficulties in early childhood that have any published research with sensitivity and specificity information (Eeles, et al., 2014).

However, it is important for medical professionals to be aware of sensory and behavioral symptoms associated with ASD, and provide parents an opportunity to discuss any concerns about their children's symptoms as part of ongoing health care. Recent research suggests that children who continue to experience strong sensory aversion or interests and/or repetitive behaviors into their school years have more limited outcomes in terms of social skills, independence, and adaptive skills as they mature (Lord & Luyster, (2006), Lord, et al., 2006). Thus, attempts to address these issues as early as possible in the intervention program are important.

Interventions for reported sensory symptoms may also be proposed based on behavioral approaches or theories related to sensory integration. Behavioral approaches use principles of behavior analysis to provide competing activities, alternative behaviors, and more socially appropriate or less intrusive ways of addressing the child's sensory needs. These approaches also focus on desensitizing the child to upsetting sensations, or rearranging environments to minimize stress while the child is learning other skills. Behavioral approaches are supported by some evidence. A second approach includes both sensory-based intervention and sensory integration therapy. Interventions to address sensory integration may involve passive approaches where pressure or other adult-mediated interventions are provided to alter the sensory experience or active interventions where the child is involved in integrating sensory experiences. While the research supporting sensory approaches is emerging, the evidence is currently insufficient to recommend specific approaches. However, interventions to address sensory symptoms remain widely used (Lang et al., 2012).

There is an increased rate of both anxiety and depression in older children with ASD and anxiety and over-responsivity have been identified in toddlers with ASD. Anxiety may be associated with GI and sleep symptoms in older children with ASD and consideration of possible co-occurrence may be important in the management of the medical conditions. Screening for parental depression and mental health concerns is an increasing occurrence in primary pediatric care. Familial anxiety and depression is more common in families with ASD. Since behavioral health and wellness of other family members can impact the child, the pediatric health care provider should be aware of the need to refer families for appropriate community and mental health supports for caregivers and siblings.

Recommendations with an "[E]" designation were determined to be supported by the scientific literature reviewed by expert reviewers.

Recommendations with a "[PO]" represent panel opinion based on current best practices.

Monitoring for Common Co-Morbid Conditions

Hearing status

11. It is extremely important to establish the hearing status in a child with suspected or diagnosed ASD to rule out hearing impairment as a contributing factor for the child's communication problems. [E]

12. If there is any indication that a child with suspected or diagnosed ASD has a hearing problem either on screening or clinical presentation, it is important to refer the child for a hearing evaluation by an audiologist (including brain stem evoked response testing if appropriate). [PO]

Early Intervention Policy: Audiologic evaluations and services are covered under the Early Intervention Program.

Genetic Testing

13. In most children with suspected or diagnosed ASD, families should be counseled about the capabilities of current genetic testing and testing or referral to a geneticist should be offered. [PO]

14. Chromosomal microarray(CMA) is currently recommended as the first line genetic testing to identify genetic associations with ASD. Genetic abnormalities may be identified in up to 30% of children with ASD using this technology, although not all are etiologic.
    - CMA is recommended so appropriate counseling can be provided regarding recurrence risk and associated conditions.
    - Genetic abnormalities are found by CMA in children with both lower and higher cognitive abilities, but are more likely to be identified in the presence of dysmorphic features, seizures, or macrocephaly.
    - A positive family history may increase the likelihood of finding heritable genetic differences. [E]

15. DNA testing for Fragile X syndrome is recommended at least in boys with ASD to provide:
    - Appropriate counseling regarding recurrence risk and associated conditions.
    - Fragile X syndrome is less likely to be found in children with ASD with typical cognitive abilities.
    - Fragile X syndrome is significantly less likely to be associated with ASD in girls. It should be considered in the evaluation of a girl if there are male relatives with intellectual disability. [E]

Table 5.1 **Medical Conditions and Syndromes Associated with ASD**
This table includes medical and behavioral health conditions seen more frequently in children with ASD than in the general population. Head: Macrocephaly Ears: Hearing loss Mouth: Dental decay GI: Food selectivity Constipation Neurologic: Seizures – Intellectual disabilities – Behavioral symptoms attributed to hyper and hyposensitivity to sensory

Table 5.1
Medical Conditions and Syndromes Associated with ASD

stimuli

Behavior:

- Sleep onset and maintenance
- Attention Deficit Hyperactivity Disorder
- Anxiety and mood regulation disorders
- Pica
- Wandering

Genetic disorders associated with ASD include:

- Copy number variants (CNVs-novel mutations)
- Fragile X syndrome
- Down syndrome
- Angelman syndrome (15 q 11)
- Isodicentric duplication of chromosome 15
- PTEN abnormalities (Bannayan Riley Ruvalcaba syndrome)
- Rett Syndrome
- Smith Lemli Opitz syndrome
- Smith Magenis syndrome
- Tuberous Sclerosis
- Velocardiofacial syndrome (22q-)
- William syndrome

Metabolic disorders associated with ASD:

- Phenylketonuria
- Smith Lemli Opitz syndrome

Prenatal Infections associated with ASD:

- Rubella
- Cytomegalovirus

Environmental and prenatal associations with ASD:

- Advanced maternal and paternal age
- Maternal medication use: valproic acid, thalidomide, misoprostol
- Prematurity

Environmental and prenatal associations that need replication:

- Maternal obesity, metabolic syndrome
- Selective serotonin reuptake inhibitor exposure (SSRI)

16. Karyotype continues to have utility when specific syndromes are suspected or when there are balanced translocations (rearrangement of chromosomes without loss of genetic material). [PO]

17. The techniques of genetic testing are rapidly advancing. Whole exome sequencing and newer techniques will increase the yield of etiologic testing, and new technologies may have utility in predicting treatment response or other dynamic interactions between genotype and phenotype. [PO]

18. An EEG is not currently used for making the diagnosis of ASD. It is not obtained as a baseline study if there is no history suggesting seizures. [PO]

19. EEG (electroencephalogram) is recommended in children for whom:
    - There is a clinical history suggesting seizures.
    - There is a clinical picture of possible Landau-Kleffner syndrome (a specific condition in which the child has a late regression with loss of language; this is a form of epilepsy identified on EEG during sleep).
    - In the clinical judgment of the physician, the electroencephalogram is important to rule out seizures. [PO]

Magnetic Resonance Imaging (MRI)

20. The use of MRI scans is not recommended in the routine assessment of children with possible ASD. [E]

21. Magnetic resonance imaging (MRI) scans may be useful in certain clinical situations in assessing children with ASD when there is heightened concern about focal neurological problems, atypical regression, seizures, concern regarding microcephaly, evaluation for hydrocephalus, or children with neurologic findings for whom the clinician feels a neuroimaging study is indicated). [E]

EI Policy: Although a health assessment is a required component of the multidisciplinary evaluation, medical tests (such as MRIs, metabolic, and genetic tests) are not provided or reimbursed by the Early Intervention Program. The service coordinator is responsible for assisting the family to access these and other health care services through the child's primary care provider.

5.A.4 Recommendations on Assessment of Immune Status, Allergies, and Metabolism

There is currently no evidence to suggest immune, allergic, or metabolic tests should be used to identify subgroups of children with ASD who may respond to specific medication or dietary interventions for behavioral symptoms. The scientific literature indicates that ASD is associated with neurobiological differences in brain development typically originating during fetal development. These differences are based in genetic predisposition with environmental and perhaps immunologic factors impacting brain functioning during development. Advances in science have demonstrated that ASD is not a singular disorder. ASD may be associated with many specific genetic conditions.

Recommendations with an "[E]" designation were determined to be supported by the scientific literature reviewed by expert reviewers.

Recommendations with a "[PO]" represent panel opinion based on best practices.

Immune System

22. An evaluation of the mother or child's immune system status is not recommended in the routine assessment of otherwise healthy children with ASD. [E]

Food Allergy and Diet Assessment

23. Testing for food allergies is not recommended in the routine assessment of otherwise healthy children with possible ASD. [E]

24. It is recommended that children with possible ASD be treated no differently than other children in the assessment of food allergies. Testing for food allergies may be useful in some children if there is a clinical concern about allergies. [PO]

Metabolic Testing

25. Testing for disorders of metabolism and for mitochondrial disorders is of low yield in routine screening of children with ASD and is not recommended unless suggested by history, family history, or examination. [E]

Early Intervention Policy: Medical tests, including evaluation of the immune system and allergy and diet assessments are not covered by the Early Intervention Program. The service coordinator is responsible for assisting the family to access these and other health care services through the child's primary care provider.

5.B Health Interventions for Young Children with Possible or Established ASD

This section on health evaluations of children with possible ASD is divided into the following parts:

1. Addressing Common Health and Safety Problems in Children with ASD
2. Medication
3. Dietary Interventions for Children with ASD
4. Hormone Therapies, Immunologic Therapy, Anti-infective Agents, Hyperbaric Oxygen, and Chelation Therapy.

There has been increasing recognition that children with ASD have co-occurring health issues that impact their quality of life, behavior, development, skill acquisition, and family functioning. Some of these conditions may be related to the underlying core symptoms of ASD, some may be related to the biologic predisposition to both medical and behavioral symptoms, and some may be the manifestations of common childhood conditions that are exaggerated by the core symptoms of ASD. Some of the medical conditions that may occur with greater frequency in children with ASD may be related to the underlying genetic or etiologic disorder. Children diagnosed with ASD should be evaluated by a medical professional to identify and treat co-occurring conditions. In the past decade, there has been a focus in medical practice to provide coordinated care through a primary care source. Children with ASD, like other children with special health care needs, benefit from routine medical care through a Medical Home.

5.B.1 Recommendations on Addressing Common Health and Safety Problems in Children with ASD

Recommendations with an "[E]" designation were determined to be supported by the scientific literature reviewed by expert reviewers.

Recommendations with a "[PO]" represent panel opinion based on best practices.

26. *Sleep:* The PCP should be proactive in addressing sleep problems. The first intervention should be behavioral and include counseling regarding sleep hygiene, followed by a trial of melatonin. Referral for further evaluation is indicated if obstructive sleep apnea is suspected on history or physical examination or sleep problems impact family or child functioning after initial interventions. [E]

27. *Feeding:* The PCP should be proactive in addressing feeding problems. The first intervention should be behavioral suggestions and assessment of nutritional status. Counseling about nutrition and correcting nutritional deficits should take place in primary care with referral to a registered dietitian as appropriate. Referral for behavioral or oral motor feeding support should be considered if feeding problems persist. [E]

28. *Diet and nutrition*: Behavior, attention, and learning are supported by a well-balanced diet. The PCP should provide anticipatory guidance around nutrition in the course of well-child care for a child with ASD, especially because of the high likelihood of selective eating, and refer to specialty care including nutrition as appropriate. Adequate weight gain and growth may occur even in the presence of inadequate nutritional intake. A dietary history should be taken at well-child visits to establish that the child is taking a varied diet. [PO]

29. *Constipation:* The PCP should be proactive in addressing constipation and GI symptoms elicited in the context of primary care using conventional diagnostic and treatment methods adapted to the individual child. [PO]

30. *Seizures:* The PCP should be proactive in monitoring for the possibility of seizures. When documented, referral to a neurologist should be considered with work up and prescription of anticonvulsant medication as indicated by age, history, medical comorbidities, and seizure type. [PO]

31. *Elopement (wandering)*: It is very important for the primary health care provider to be proactive in counseling parents about elopement (wandering) and safety, including water safety, in the context of anticipatory guidance. This is important not only for toddlers and preschool age children, but also for older children with ASD who may have deficits in safety awareness and judgment. [PO]

5.B.2 Recommendations on Medication

Recommendations with an "[E]" designation were determined to be supported by the scientific literature reviewed by expert reviewers.

Recommendations with a "[PO]" represent panel opinion based on best practices.

At this time, appropriately designed studies have not demonstrated efficacy of medication for amelioration of the core features (social/communicative impairment, repetitive behaviors) of ASD in young children. Use of medication as part of a behavior management plan for children under 3 has not been adequately evaluated regarding safety and efficacy and is not currently considered the standard of care. There are, however, medications that have been shown to be effective in the management of some of the behavioral symptoms (e.g. hyperactivity, irritability, sleep problems) associated with ASD in studies that included children over 3 years of age. Pharmacologic interventions are not generally recommended until non-pharmacologic (behavioral and therapeutic) approaches have been optimized.

32. It is recommended that caution and consideration be given to the potential risks as well as the purported benefits of the use of any medication being considered to treat manifestations of ASD in young children. Medication should only be considered in young children after an adequate trial of nonpharmacologic behaviorally sound interventions. [E]

33. It is recommended that a decision to use any medication be guided by evidence of effectiveness and safety in scientific studies using adequate research designs. [PO]

34. When discussing medication for treatment of symptoms associated with ASD, it is important that professionals explain to the child's parents the potential side effects as well as potential benefits. [PO]

Experience and expertise of prescribing clinicians

35. It is recommended that, when appropriate, other qualified professionals working with the child and family facilitate consultation with a prescribing clinician (physician, nurse practitioner, or physician's assistant) who has expertise in the use of psychoactive medication to treat symptoms associated with ASD in young children. [PO]

36. It is recommended that physicians or other appropriate clinicians evaluating a young child with ASD for possible use of psychoactive medication have:
    - Expertise treating young children with ASD.
    - Knowledge about the use of both medication and non-medication interventions for ASD in young children.
    - Knowledge of the potential benefits and risks of psychoactive medications that are considered.
    - Experience in monitoring young children with ASD on psychoactive medication (including assessing the child's progress on the medication, recognizing signs of side effects or toxicity, and making appropriate increases and decreases in dosage). [PO]

Using a trial of psychoactive medication to treat symptoms associated with ASD in young children

37. Psychoactive medication may be a useful component of therapy in some young children with ASD who have severe behavior problems that have not responded to other interventions (e.g. behavioral and parent-mediated therapies) alone. Medication and behavioral interventions may produce an additive or improved outcomes. Types of medications that are sometimes considered include:
    - Stimulants.
    - Atypical neuroleptic agents.
    - Mood stabilizers/anticonvulsants.

- Benzodiazepines.
- Antihistamines.
- Selective serotonin reuptake inhibitors.
- Melatonin. [PO]

38. It is important to recognize that safety and efficacy studies for stimulants, atypical neuroleptics, and SSRIs have not included children under three years of age. Anticonvulsants, benzodiazepines, and antihistamines are used in this age group for nonbehavioral purposes. [PO]

39. In carrying out a trial of psychoactive medication to treat symptoms associated with ASD, it is recommended that selection of a specific medication be guided by evidence of its effectiveness for a particular symptom as well as its safety in scientific studies using adequate research designs with young children. [PO]

40. Some young children with ASD who have severe sleep problems that are not helped by appropriate behavioral intervention (e.g., sleep hygiene), may respond to a trial of melatonin. While antihistamines are safe for their indicated uses, they have not been evaluated as sleep aids in young children. Sedating medications such as clonidine, gabapentin, and benzodiazepines have not been studied as a treatment for sleep problems in young children. [PO]

Monitoring children taking medications for symptoms associated with ASD

41. If, in conjunction with appropriate non-pharmacologic therapeutic interventions, professionals prescribe a medication to treat symptoms associated with ASD in a young child, it is important that they regularly monitor the child to:
    - Assess the effectiveness of the medication for improving targeted behaviors.
    - Look for signs of negative or paradoxical effects.
    - Look for signs of adverse behavioral or health effects that may be related to use of the medication. [E]

42. If a child is receiving medication for symptoms associated with ASD, it is important that parents and caregivers monitor the child for potential side effects and bring any concerns to their physician's attention. [E]

43. After an adequate trial period of a medication, it is recommended that its continued use be periodically reevaluated. It is also recommended that a decision about whether or not to continue the medication be based on its demonstrated effectiveness in improving targeted behaviors in the child, balanced against concerns about side effects. [PO]

Early Intervention Policy: Medications are medical treatments, not early intervention services. Medications are not paid for or reimbursed by the Early Intervention Program.

5.B.3 Recommendations on Dietary Interventions for Children with ASD

Recommendations with an "[E]" designation were determined to be supported by the scientific literature reviewed by expert reviewers.

Recommendations with a "[PO]" represent panel opinion based on best practices.

44. Special diets that eliminate milk, gluten products or other specific foods are not adequately supported by the evidence for the treatment of symptoms associated with ASD in children to recommend their use. Although there are many favorable case reports on diets, there is no support from carefully designed studies for the use of these diets to treat core or associated features of ASD. It is recommended that caution and consideration be given to the potential risks as well as the purported benefits of the use of any special diet being considered to treat manifestations of ASD in young children. [E]

45. It is recommended that a decision to use dietary interventions to treat ASD symptoms be guided by evidence of effectiveness and safety in scientific studies using adequate research designs. [PO]

46. When discussing dietary interventions for treatment of symptoms associated with ASD, it is important that professionals explain to the child's parents the potential risks as well as potential benefits, including the limitations of scientific support for these interventions. [PO]

47. Families who elect to restrict specific foods should be aware of the impact on their child's diet and compensate for deficits with appropriate fortified foods or supplements. For example, removal of dairy products in the popular but as yet unproven gluten-free and casein-free diet, eliminates calcium and vitamin D from the diet that must be replaced. [E]

48. There may be specific medical conditions unrelated to ASD like celiac disease, lactose intolerance and others that call for specific dietary restrictions. Improved well-being in those cases will impact general health and may impact the child's behavior, sleep, and availability for learning. [PO]

49. Children with ASD may have selective diets and need to take nutritional supplements for general health. However, there are currently no data indicating that children with ASD, in general, benefit from specific dietary supplementation or restrictions, or that supplements ameliorate symptoms of ASD. [E]

50. If food allergies are documented in a child using standard allergy testing methods, appropriate dietary changes or other treatment may be needed. While this would be unrelated to the child's ASD, improvement in itching or other symptoms that lead to discomfort may decrease irritability. [PO]

Monitoring children given dietary therapies for symptoms associated with ASD

51. If dietary therapies are elected by families to attempt to alter symptoms associated with ASD in a young child, it is important that the family and their health care providers regularly monitor the child to:
    - Assess the effectiveness of the diet for improving targeted behaviors.
    - Look for signs of adverse behavioral or health effects that may be related to use of the dietary therapy.
    - Measure growth parameters. It is important to recognize that adequate or increased BMI may be present in the face of nutrient insufficiencies. [E]

52. After an adequate trial period of a dietary therapy, it is recommended that its continued use be periodically reevaluated. It is also recommended that a decision about whether or not to continue the dietary therapy be based on its demonstrated effectiveness in improving targeted behaviors in the child, balanced against concerns about side effects. [PO]

53. Administering high doses of any type of vitamin or mineral is not recommended as a treatment for symptoms of ASD in young children, unless specifically prescribed as a treatment for a documented deficiency or specific metabolic disorder by an appropriate, licensed health care professional. [PO]

54. If a child with ASD has a documented vitamin or mineral deficiency, it is recommended that this be treated as appropriate. [PO]

Early Intervention Policy: Nutrition services are considered early intervention services under the Early Intervention Program. However, the program does not pay or provide reimbursement for special foods or dietary supplements, such as vitamins or minerals. The service coordinator is responsible for assisting the family to access these and other health care services through the child's primary care provider or other service providers as appropriate.

5.B.4 Recommendations on Hormone Therapies, Immunologic Therapy, Anti-Infective Agents, Hyperbaric Oxygen, and Chelation Therapy

Recommendations with an "[E]" designation were determined to be supported by the scientific literature reviewed by expert reviewers.

Recommendations with a "[PO]" represent panel opinion based on current best practices.

Hormone Therapies

55. The use of hormones intended for other medical conditions (such as ACTH, gonadotropin hormones, and secretin) is not recommended as treatment for symptoms of ASD. [PO]

56. Secretin has been thoroughly studied and found to be ineffective [E].

57. Other hormones have not been definitively studied. The evidence currently available does not support their use as a treatment for symptoms of ASD. [E]

58. Oxytocin is a hormone associated with social behaviors. Administration of oxytocin in clinical research settings suggests potential future applications. The use of over the counter oxytocin is not recommended. [PO]

Immunologic Therapy

59. The use of immune or immunologic therapies for treatment of ASD is not recommended based on currently available evidence. [E]

60. Immunologic testing is only recommended in children with ASD in the setting of clinical symptomatology suggestive of allergic and immunologic disorders. [PO]

61. Stem cell therapies are considered experimental at the time of this review and are not recommended. [PO]

Anti-Infective Agents

62. Anti-infective agents including anti-yeast and antifungal agents and antibiotics are not recommended for treatment or prevention of symptoms of ASD in young children based on currently available evidence. [PO]

Hyperbaric Oxygen Therapy

63. Current evidence does not support the use of hyperbaric oxygen therapy for either prevention or treatment of the symptoms of ASD. [E]

Chelation Therapy

64. There is no evidence in the peer reviewed literature to support chelation for heavy metals, including mercury, as an intervention for prevention or treatment of ASD using any (oral, transcutaneous, or intravenous) route of administration. [PO]

65. Families need to be counseled regarding the potential risks of this unproven therapy. [PO]

EI Policy: Hormone therapies, immunological therapies, vitamin therapies, and medical treatments are not included in the definition of early intervention services and are not paid for or reimbursed under the program. The service coordinator is responsible for assisting the family to access these and other health care services through the child's primary care provider or other service providers as appropriate.

Hyperbaric oxygen and chelation therapy are medical treatments, not early intervention services. These treatments are not paid for or reimbursed by the Early Intervention Program.

Appendix A. Early Intervention Program Information

EARLY INTERVENTION PROGRAM DESCRIPTION

The Early Intervention Program is a statewide program that provides many different types of early intervention services to infants and toddlers with disabilities and their families. In New York State, the Department of Health is the lead state agency responsible for the Early Intervention Program.

Early Intervention services can help families:

- Learn the best ways to care for their child
- Support and promote their child's development
- Include their child in family and community life

Early Intervention services can be provided anywhere in the community, including:

- A child's home
- A child care center or family day care home
- Recreational centers, play groups, playgrounds, libraries, or any place parents and children go for fun and support
- Early childhood programs and centers

Parents help decide:

- What are appropriate early intervention services for their child and family
- The outcomes of early intervention that are important for their child and family
- When and where their child and family will get early intervention services
- Who will provide services to their child and family

Early Intervention Officials (EIO)

In New York State, all counties and the City of New York are required by public health law to appoint a public official as their Early Intervention Official.

The EIO is the person in the county responsible for:

- Finding eligible children
- Making sure eligible children have a multidisciplinary evaluation
- Appointing an initial service coordinator to help families with their child's multidisciplinary evaluation and Individualized Family Service Plan (IFSP)
- Making sure children and families get the early intervention services included in their IFSPs
- Safeguarding child and family rights under the Program

The EIO is the "single point of entry" for children into the Program. This means that all children under three years of age who may need early intervention services must be referred to the EIO. In practice, Early Intervention Officials have staff who are assigned to take child referrals.

Parents are usually the first to notice a problem. Parents can refer their own children to the Early Intervention Official. Sometimes, someone else will be the first to raise a concern about a child's development. New York State public health law requires certain professionals (primary referral sources) to refer infants and toddlers to the Early Intervention Official if a problem with development is suspected. However, no professional can refer a child to the EIO if the child's parent says no to the referral.

Service Coordinators

There are two types of service coordinators in New York State: initial service coordinators and ongoing service coordinators. The initial service coordinator is appointed by the Early Intervention Official. The initial service coordinator helps with all the steps necessary to get services from referral to the early intervention program, through the child's multidisciplinary evaluation and development of the first Individualized Family Service Plan (IFSP).

Parents are asked to choose an ongoing service coordinator as part of the first IFSP. The main job of the ongoing service coordinator is to make sure the child and family get the services included in the IFSP. The ongoing service coordinator will also help change the IFSP when necessary and make sure the IFSP is reviewed on a regular basis. Parents may choose to keep the initial service coordinator, or they can choose a new person to be the ongoing service coordinator.

Eligibility

Children are eligible for the Early Intervention Program if they are under 3 years old AND have a disability OR developmental delay. A disability means that a child has a diagnosed physical or mental condition that often leads to problems in development (such as Down syndrome, autism, cerebral palsy, vision impairment, or hearing impairment).

A developmental delay means that a child is behind in at least one area of development, including:

- Physical development (growth, gross and fine motor abilities)
- Cognitive development (learning and thinking)
- Communication (understanding and using words)
- Social-emotional development (relating to others)
- Adaptive development (self-help skills, such as feeding)

A child does not need to be a U.S. citizen to be eligible for services. And, there is no income "test" for the Program. The child and family do have to be residents of New York State to participate in the Early Intervention Program.

How is Eligibility Decided?

All children referred to the Early Intervention Official have the right to a free multidisciplinary evaluation to determine if they are eligible for services. The multidisciplinary evaluation also helps parents to better understand their child's strengths and needs, and how early intervention can help.

A child who is referred because of a diagnosed condition that often leads to developmental delay, such as Down syndrome, will always be eligible for early intervention services.

If a child has a diagnosed condition, he or she will still need a multidisciplinary evaluation to help plan for services. If a child has a delay in development and no diagnosed condition, the multidisciplinary evaluation is needed to find out if the child is eligible for the Program. A child's development will be measured according to the "definition of developmental delay" set by New York State.

Services

Early intervention services are:

- Aimed at meeting children's developmental needs and helping parents take care of their children
- Included in an Individualized Family Service Plan (IFSP) agreed to by the IFSP team.

Early intervention services include:

- Assistive technology services and devices

- Audiology
- Applied behavior analysis
- Family training, counseling, home visits, and parent support groups
- Medical services for diagnostic or evaluation purposes only
- Nursing services
- Nutrition services
- Occupational therapy
- Physical therapy
- Psychological services
- Service coordination services
- Social work services
- Special instruction
- Speech-language pathology
- Vision services
- Health services needed for children to benefit from other early intervention services
- Transportation to and from early intervention services

Provision of Services

Only qualified professionals, i.e. individuals who are licensed, certified, or registered in their discipline and approved by New York State, can deliver early intervention services. All services can be provided using any of the following service models:

- Home- and community-based visits. In this model, services are given to a child and/or parent or other family member or caregiver at home or in the community (such as a relative's home, child care center, family day care home, play group, library story hour, or other places parents go with their children).
- Facility- or center-based visits. In this model, services are given to a child and/or parent or other family member or caregiver where the service provider works (such as an office, a hospital, a clinic, or early intervention center).
- Parent-child groups. In this model, parents and children get services together in a group led by a service provider. A parent-child group can take place anywhere in the community.
- Family support groups. In this model, parents, grandparents, siblings, or other relatives of the child get together in a group led by a service provider for help and support and to share concerns and information.
- Group developmental intervention. In this model, children receive services in a group setting led by a service provider or providers without parents or caregivers present. A group means two or more children who are eligible for early intervention services. The group can include children without disabilities and can take place anywhere in the community.

REIMBURSEMENT

All services are at no cost to families. The program accesses Medicaid and commercial third party insurance when parents' policies are regulated by the state. County and state funds cover the costs of services not covered by other payers.

For more information about the New York State laws and regulations and administrative guidance documents that apply to early intervention services, contact the Bureau of Early Intervention.

New York State Department of Health
Bureau of Early Intervention
Corning Tower Building, Room 287
Empire State Plaza
Albany, NY 12237-0660
(518) 473-7016

http://www.nyhealth.gov/community/infants_children/early_intervention/

Appendix B. Early Intervention Steps

Early Intervention Steps For Families and Professionals

Family Concern

1. Referral (Unless parent objects)

- Referral source or parent suspects child of having developmental delay or disability
- Family informed of benefits of Early Intervention Program (EIP)
- Child referred to Early Intervention Official (EIO) within two days of identification
- EIO assigns Initial Service Coordinator

2. Initial Service Coordinator

- Provides information about EIP
- Informs family of rights
- Reviews list of evaluators
- Obtains insurance/Medicaid information
- Obtains other relevant information

3. Evaluation*

- Determine eligibility
- Family assessment (optional)
- Gather information for Individualized Family Service Plan (IFSP)
- Summary and report submitted

prior to IFSP

4. The IFSP Meeting*

(If child is eligible)

- Family identifies desired outcomes
- Early Intervention services specified
- Develop written plan
- Family and EIO agree to IFSP
- Identify Ongoing Service Coordinator (OSC)
- EIO obtains social security number(s)

Early Intervention Services*

- Assistive technology devices and services
- Audiology
- Family training, counseling, home visits, and parent support groups
- Medical services only for diagnostic or evaluation purposes
- Nursing services
- Nutrition services
- Occupational therapy
- Physical therapy
- Psychological services
- Respite services
- Service coordination
- Social work services
- Special instruction
- Speech-language pathology
- Vision services
- Health services
- Transportation and related costs

AREAS OF DEVELOPMENT

- Cognitive
- Physical (including vision and hearing)
- Communication
- Social/emotional
- Adaptive development

5. IFSP Review Six Months, Evaluate Annually

- Decision is made to continue, add, modify or delete outcomes, strategies and/or services
- If parent requests, may review sooner (If parent requests an increase in services, EIO may ask for supplemental evaluation)

6. Transition

- Plan for transition included in IFSP
- Transition to:
  - Services under Section 4410 of Education Law (3-5 system)

    OR
  - Other early childhood services, as needed

From Early Intervention Program Parent Guide
http://www.health.ny.gov/publications/0532.pdf

Appendix C. Division of Early Childhood (DEC) Recommended Practices

The DEC Recommended Practices (Division for Early Childhood, 2014) provide guidance to practitioners and families about the most effective ways to improve the learning outcomes and promote the development of young children, birth through age 5, who have or are at-risk for developmental delays or disabilities.

The DEC Recommended Practices support children's access and participation in inclusive settings and natural environments and address cultural, linguistic, and ability diversity.

The following are DEC Recommended Family Practices. The full set of DEC recommended practices can be accessed here: www.dec-sped.org/dec-recommended-practices

Family

Family practices refer to ongoing activities that (1) promote the active participation of families in decision-making related to their child (e.g., assessment, planning, intervention);
(2) lead to the development of a service plan (e.g., a set of goals for the family and child and the services and supports to achieve those goals); or (3) support families in achieving the goals they hold for their child and the other family members.

Family practices encompass three themes:

1. ***Family-centered practices:*** Practices that treat families with dignity and respect; are individualized, flexible, and responsive to each family's unique circumstances; provide family members complete and unbiased information to make informed decisions; and involve family members in acting on choices to strengthen child, parent, and family functioning.
2. ***Family capacity-building practices:*** Practices that include the participatory opportunities and experiences afforded to families to strengthen existing parenting knowledge and skills and promote the development of new parenting abilities that enhance parenting self-efficacy beliefs and practices.
3. ***Family and professional collaboration:*** Practices that build relationships between families and professionals who work together to achieve mutually agreed upon outcomes and goals that promote family competencies and support the development of the child.

We recommend the following family practices for practitioners:

F1. Practitioners build trusting and respectful partnerships with the family through interactions that are sensitive and responsive to cultural, linguistic, and socio- economic diversity.

F2. Practitioners provide the family with up-to-date, comprehensive and unbiased information in a way that the family can understand and use to make informed choices and decisions.

F3. Practitioners are responsive to the family's concerns, priorities, and changing life circumstances.

F4. Practitioners and the family work together to create outcomes or goals, develop individualized plans, and implement practices that address the family's priorities and concerns and the child's strengths and needs.

F5. Practitioners support family functioning, promote family confidence and competence, and strengthen family-child relationships by acting in ways that recognize and build on family strengths and capacities.

F6. Practitioners engage the family in opportunities that support and strengthen parenting knowledge and skills and parenting competence and confidence in ways that are flexible, individualized, and tailored to the family's preferences.

F7. Practitioners work with the family to identify, access, and use formal and informal resources and supports to achieve family-identified outcomes or goals.

F8. Practitioners provide the family of a young child who has or is at risk for developmental delay/disability, and who is a dual language learner, with information about the benefits of learning in multiple languages for the child's growth and development.

F9. Practitioners help families know and understand their rights.

F10. Practitioners inform families about leadership and advocacy skill-building opportunities and encourage those who are interested to participate.

Appendix D. Early Intervention Program Resources

The New York State Department of Health, Early Intervention Program website has comprehensive information for families and professionals. To access this website, go to www.health.ny.gov, and search for the Early Intervention Program, or use the following web addresses for specific information.

Early Intervention Home Page

www.health.ny.gov/community/infants_children/early_intervention/index.htm

List of Local Early Intervention Officials

www.health.ny.gov/community/infants_children/early_intervention/county_eip.htm

Autism

www.health.ny.gov/community/infants_children/early_intervention/autism/

Families

www.health.ny.gov/community/infants_children/early_intervention/families.htm

Child and Family Outcomes

www.health.ny.gov/community/infants_children/early_intervention/outcomes_survey/

Memoranda, Guidance, and Clinical Practice Guidelines

www.health.ny.gov/community/infants_children/early_intervention/memoranda.htm

Regulations, Laws, and Reimbursement Rates

www.health.ny.gov/community/infants_children/early_intervention/regulations.htm

Links to State and National Resources

www.health.ny.gov/community/infants_children/early_intervention/related_links.htm

Early Intervention Program Service Providers

www.health.ny.gov/community/infants_children/early_intervention/service_providers/

Training

www.health.ny.gov/community/infants_children/early_intervention/training.htm

Early Intervention Coordinating Council

http://www.health.ny.gov/community/infants_children/early_intervention/eicc_members.htm

Appendix E. Consensus Panel Member Biographies

Name	Discipline	Biography
Stephen R. Anderson, Ph.D., LBA, BCBA-D	Licensed Psychologist	Dr. Anderson received his Ph.D. in Developmental and Child Psychology from the University of Kansas. He has served as Adjunct Assistant Professor at a number of colleges and universities including the University of Kansas, Northeastern University, and the State University of New York at Buffalo, Canisius College, and Buffalo State College. Dr. Anderson currently is the Chief Executive Officer of The Summit Center in Amherst, New York. He is a reviewer for a number of professional journals and has published journal articles, book chapters, and one book on the education and treatment of children with developmental disabilities. Dr. Anderson is the Past President of the Association of Professional Behavior Analysts and has served in other leadership roles at the state and national level. As a licensed psychologist and Licensed Behavior Analyst, Dr. Anderson has worked in the autism field for more than 35 years and has served as an expert witness and consultant.
Ira Cohen, Ph.D., F.A.P.S.	Clinical Psychologist	Ira Cohen Ph.D., F.A.P.S. is the former Chairman of the Dept. of Psychology at the NYS Institute for Basic Research in Developmental Disabilities and, since 2014, holds the title of Visiting Research Scientist. Prior to being Chairman, he was the Head of the Division of Behavioral Assessment and Research, as well as a Research Scientist. Dr. Cohen has been part of numerous Professional Organizations, some of which include the American Association on Mental Retardation, Association for Psychological Science, Autism Society of America, International Society for Autism Research and Society for Research in Child Development. For the past 39 years Dr. Cohen has contributed to over 170 various Posters and Professional Presentations involving a wide variety of topics, many of which were focused on autism, and is author or co-author of over 100 peer-reviewed publications on autism and related conditions. He is a member of the editorial board of the Journal of Autism and Developmental Disabilities.
Shirley Cohen, Ph.D.	Special Educator	Shirley Cohen, Ph.D was a professor in the Department of Special Education at Hunter College, of the City University of New York for many years before becoming Professor Emerita in 2011. In 2001 Professor Cohen created an Early Childhood Special Education Certification program for master degree students. For three years, Dr. Cohen directed a training program on autism funded by the NYS Education Department, followed for six years by the ASD Nest training program funded by the NYC Department of

Name	Discipline	Biography
		Education. Dr. Cohen co-developed the ASD Nest, an inclusion program now in multiple NYC public schools, and its partner, the Intensive Kindergarten, a one year transitional program. She also served as the first director of the Regional Center for Autism Spectrum Disorders at Hunter College and is the author of the book *Targeting Autism.* Dr. Cohen also served as Assistant, Associate, and Interim Dean of the School of Education at Hunter.
Tara Cook	Parent	Tara Cook is the parent of a child who was diagnosed with Autism in 2010. Mrs. Cook is a graduate of the Early Intervention Partners in Policymaking program and has worked with Dr. Siller and Hunter College on several events on how to get at-risk children identified earlier. Mrs. Cook participates in a local group for parents of children with special needs and worked for Pearson, Inc where she was a member of the committee for Diversity and Inclusion in the workplace.
Lynn Decker	Parent	Lynn Decker is the parent of 2 sons who have received services from the Early Intervention Program including ABA, speech, occupational therapy, and physical therapy. Since 2000 Mrs. Decker has been a convener of the Downtown Spectrum Parent Support Group. She has also been a resource for Parent to Parent of NYS and a member of the Advisory Board of the Hunter College Center for Autism and Related Disorders. Mrs. Decker has a BA in Political Science and an MPA in Public and Nonprofit Management and Policy. From 2007 to 2010 she worked at Job Path, Inc. as a Medicaid Service Coordinator and a Program Director of the Life Coaching Project.
Carroll Grant, Ph.D.	Clinical Psychologist	Carroll Grant, Ph.D. has a Certificate of Advance Study in School Psychology, Doctor of Philosophy in Special Education Area of Emotional Disturbance, a Bachelor of Arts in Child Study and Special Education, and a Master of Education in Special Education. Since 1982 Dr. Grant has been the Executive Director of the Margaret L. Williams Developmental Evaluation Center Golisano Children's Hospital. Dr. Grant created KidSpeak: Puppet Workshop about Autism and authored KidSpeak Curriculum about Autism and the companion book Carey and Sally: Friends with Autism. Within the community, Dr. Grant is a member of Central NY Coalition for Young Children with Disabilities, Onondaga County LEICC and a Board Member of the Central NY Autism Society of America.
Susan Hyman, M.D.	Developmental and Behavioral Pediatrician, Professor of Pediatrics and Division Chief of	Dr. Susan Hyman is a Developmental and Behavioral Pediatrician and co-PI of the Autism Treatment Network site at the University of Rochester Medical Center. As Division Chief of Developmental and Behavioral Pediatrics at the Golisano Children's Hospital, Dr. Hyman has worked with Director of Clinical Services, Lynn Cole PNP, to

Name	Discipline	Biography
	Development and Behavioral Pediatrics	implement the ATN chronic care model as their standard of care. Dr. Hyman is also an author of the Autism Toolkit (AAP, 2007) and past chair of the American Academy of Pediatrics Autism Subcommittee. She is a current member of the Executive Committee of the Council on Children with Disabilities of the American Academy of Pediatrics and is a member of the sub board of Developmental and Behavioral Pediatrics of the American Board of Pediatrics. Her professional memberships include the American Academy of Pediatrics, (Committee on Children with Disabilities, Section on Developmental and Behavioral Pediatrics, Committee on Holistic and Integrative Medicine) and the Society for Developmental and Behavioral Pediatrics. Dr. Hyman has contributed to over 50 Peer Reviewed Publications. Her funded research focused on diet and nutrition of children with ASD and the effectiveness of pharmacologic, behavioral and dietary interventions.
Harold Kanthor, MD	Primary Care Pediatrician	Hal Kanthor MD is a pediatrician in Rochester NY. Dr. Kanthor is a former chair of the Committee for Children with Disabilities of Chapter 1, District II of the American Academy of Pediatrics. He was also the Chair of the Consensus Panel on Autism and Pervasive Developmental Disorders for the New York State Health Department Early Intervention Program from 1997-1998.
Catherine Lord, Ph.D.	Clinical Psychologist	Catherine Lord Ph.D. is an Affiliated Professor of Clinical Psychology in the Teachers College at Columbia University, Director of the Center for Autism and the Developing Brain, and Professor of Psychology and DeWitt Wallace Senior Scholar at Cornell Medical College. Dr. Lord is currently a member of the DSM-5 Neurobiological Disorders committee and has contributed to 15 publications and 18 various Research projects and research support focused on Autism.
Gloria Lucker, MS, OTR/L, FAOTA, Board Certified Pediatric Specialist.	Occupational Therapist	Gloria Lucker is Founder and CEO of Optimal Occupational and Physical Therapy Associates Services (OTAS), and is Board Certified in Pediatric Occupational Therapy. Gloria has been working as a pediatric therapist for more than thirty years and has provided services to children and families throughout Western New York. As an advocate for children, Gloria has developed innovative programs for early intervention services. Gloria is a specialist in the area of sensory integration and, particularly, sensory processing dysfunction. Gloria is currently President of the New York State Occupational Therapy Association and was the New York State Representative to the Representative Assembly of AOTA A graduate of New York University and State University of New York at Buffalo, Gloria is a Fellow of the American Occupational Therapy Association.

Name	Discipline	Biography
		Gloria taught in the occupational therapy assistant program at Erie Community College for nine years and at the University of Buffalo for five years. She has been a field work supervisor and mentor to many students. Gloria is recognized as a specialist in the provision of occupational therapy services to students on the autism spectrum.
Stacey Orzell	Parent	Stacey B. Orzell is the proud parent of two wonderful boys. Her younger son was diagnosed with Autism in 2009. Since then she has attended Parent Trainings, conferences, and became Parent Member for Special Education. Stacey was trained as an Early Intervention Partner and has been a part of the LEICC for 3 years. Currently Mrs. Orzell is a Consultant/Volunteer for the Autism Move-A-Thon of Orange County in Partnership with Mental Health Association in Orange County. From 2011-2014 she was an Ongoing Service Coordinator for Early Intervention. In 2013, Stacey graduated from the Partners in Policymaking program with the Advocacy Center and Cornell University. Recently, Stacey has been named the recipient of the 2016 MHANYS Family Advocate of the Year Award. Also in 2016 she has become a Certified Special Olympics Swim Coach and is training a team in Orange County, New York. The Thunderbolts will compete at West Point, Marist and SUNY New Paltz in 2017. Stacey was unanimously voted to serve as Public/Parent member for the NYSOTA organization. She volunteers for the LEND program with WIHD offering mentorship and experience as a family affected with autism to trainees. She is a *"Yes I Can"* family advocate always willing to help others. Stacey is a photographer *"Raising Autism Awareness One Smile at a Time"!*
Christine Radziewicz, Doctor of Arts, CCC-SLP	Speech Language Pathologist	Dr. Christine Radziewicz, Doctor of Arts, CCC-SLP, Teacher of the Deaf and Hearing Impaired, NY State School Administrator, is currently the Chief Operating Officer for the School for Language and Communication Development and ABLE Community services whose programs serve children preschool through age 21 and adults with language and autism spectrum disorders. Dr. Radziewicz was part of the Consensus Panel on Autism and Pervasive Developmental Disorders for the New York State Health Department Early Intervention Program and had been a professor and Clinical Director of the Hy Weinberg Center for Communication Disorders at Adelphi University in Garden City, New York. She has co-authored three books and contributed several chapters in other professional publications. Dr. Radziewicz' clinical interests include parent child communication and the patterns of language development in children with autism.

Name	Discipline	Biography
Ray Romanczyk, Ph.D.	Clinical Psychologist	Raymond G. Romanczyk, PhD is a SUNY Distinguished Service Professor, Executive Director of the Institute for Child Development, at Binghamton University, and adjunct professor of psychiatry at SUNY Health Sciences Center. He is a licensed clinical psychologist and has 45 years of clinical and research experience related to individuals with ASD. In addition to diagnostic evaluations and service provision for early intervention, preschool, and school age children, he teaches undergraduate, graduate, and medical students. He has served on numerous panels and boards addressing quality assurance and ethical conduct, has consulted to the Civil Rights Division of the US Department of Justice, and served as the Chair of the IRB at Binghamton University. Dr. Romanczyk is an Associate Editor for the Child and Family Behavior Therapy journal, serves on the Editorial Board of the Focus on Autism & Other Developmental Disabilities journal, and was one of the founders of the Council on Autism Services. Dr. Romanczyk has contributed to over 100 publications and given over 600 professional conference presentations and keynote speeches, primarily in the field of autism.
Beth Rosenberg	Parent	Beth Rosenberg is a parent of a child who received early intervention, CPSE and CSE therapies starting at age 18 months. Ms. Rosenberg is an educator and holds an MS in Education Technology. In 2009 she founded TechKidsUnlimited.org which teaches youth and teens who learn differently about computer science principles and technology skills. Ms. Rosenberg also works as a consultant to various not-for-profits on technology, access and special needs including the UJA Federation's annual Hillibrand Autism Symposium.
Lisa Shulman, M.D.	Developmental and Behavioral Pediatrician	A graduate of Brown University and University of Pennsylvania School of Medicine, Lisa H. Shulman M.D. completed Pediatric residency training at the Mount Sinai Medical Center of New York and fellowship training in Child Development at the Rose F. Kennedy Center Children's Evaluation and Rehabilitation Center (CERC) at MONTEFIORE. She is board certified in Pediatrics, Neurodevelopmental Disabilities, and Developmental and Behavioral Pediatrics. Since 1992, Dr. Shulman has been a member of the Pediatric Attending staff of CERC and an Associate Professor of Pediatrics at the Albert Einstein College of Medicine. From 1996 to the present, Dr. Shulman has been the Director of the Infant/Toddler Team at CERC, a program with a 17-year history as a certified Early Intervention Program performing approximately 400 evaluations per year. Since 2004, Dr. Shulman has been the director of the RELATE program at Einstein, a state of

Name	Discipline	Biography
		the art evaluation and treatment program for toddlers through teens with autism spectrum disorders. The program follows approximately 1600 children with autism spectrum disorders. Dr. Shulman's clinical and research interests include: early identification of autism and Asperger's syndrome, language and social regression, overcoming healthcare disparities, use of complementary and alternative medicine in autism, and developmental implications of idiopathic toe-walking.
Michael Siller, Ph.D.	Developmental Psychologist	Dr. Siller received his doctorate in developmental psychology from the University of California at Los Angeles in 2006. Prior to joining the faculty at Emory University in 2016, Dr. Siller held a position as Associate Professor of Psychology at Hunter College of The City University of New York. Dr. Siller published the first pair of longitudinal studies to show that responsive parental behaviors reliably predict the long-term (16-year) language gains in children with autism, and completed two clinical trials evaluating the efficacy of Focused Playtime Intervention, a parent-coaching intervention that aims to improve the quality of parent-child communication during shared toy play. In addition, Dr. Siller has collaborated with primary care and Early Head Start providers to enhance early identification of autism in ethnically diverse and low resource communities. His articles have been published in a number of leading journals including Developmental Psychology, the Journal of Autism and Developmental Disorders, and the Journal of Early Intervention. Currently, Dr. Siller serves as Acting Associate Professor of Pediatrics at Emory University and Co-Director of the Educational Science Research Core at the Marcus Autism Center. Marcus Autism Center is one of three National Institutes of Health (NIH) Autism Centers of Excellence in the U.S., as well as the largest provider of diagnostic and treatment services for children with autism and related disorders in the country. In this capacity, Dr. Siller develops, evaluates, and implements community-viable educational innovations for children, adolescents, and young adults with autism in Georgia and beyond.
Patty Towle, Ph.D.	Clinical Psychologist	Dr. Patricia Towle is the Co-Director of Psychology Training and senior LEND Faculty at the Westchester Institute for Human Development, with faculty appointment in Public Health, Pediatrics, and Psychiatry at the New York Medical College She has been practicing, teaching, and conducting research in the area of early intervention, pediatric developmental disabilities, disability policy, and autism spectrum disorder for the last 30 years. Her doctorate is in clinical psychology from the University of Connecticut. She

Name	Discipline	Biography
		completed a post-doctoral fellowship at the University Affiliated Program at the University of North Carolina Medical School while supported by a NIMH Research Training fellowship. At the Westchester Institute for Human Development (WIHD) she has been the recipient of several grants for training and research in the area of early intervention. Dr. Towle has a wide-ranging clinical experience with diagnostic evaluation of young children, having specialized in those with autism spectrum disorders over the two decades. She has authored and co-authored two books, several research articles, and a DVD. Dr. Towle has conducted many training sessions on these topics across numerous venues, ranging from academic to community.
Bob Trapani, O.T.	Occupational Therapist	Bob Trapani is the owner and manager of Thrive By 5, supplying OT, PT, Speech, Social Work, and Special Education treatments and assessments to children in Onondaga, Cayuga, Wayne, Seneca, Broome, and Oswego counties. Mr. Trapani has worked with children for the past 36 years, the past 23 years with children enrolled in the NYS Early Intervention Program. He has been a part of numerous professional organizations including Sensory Integration International, the Interdisciplinary Council on Developmental & Learning Disorders, and Profectum.
Amy Wetherby, Ph.D., CCC-SLP	CCC-SLP	Amy M. Wetherby, Ph.D., CCC-SLP, is a Distinguished Research Professor in the Department of Clinical Sciences and Director of the Autism Institute in the College of Medicine and the Laurel Schendel Professor of Communication Disorders at Florida State University. She has 30 years of clinical experience and is a Fellow of the American Speech-Language-Hearing Association. Dr. Wetherby has published extensively and presents regularly at national conventions on early detection of children with autism spectrum disorder and intervention for children with autism spectrum disorder using the SCERTS model. She served on the National Academy of Sciences Committee for Educational Interventions for Children with Autism and is the Executive Director of the Florida State University *Center for Autism and Related Disabilities*. She is the project director of research grants funded by U.S. Department of Education, National Institutes of Health, Centers for Disease Control and Prevention and Autism Speaks.
Serena Wieder, Ph.D.	Clinical Psychologist	Dr. Serena Wieder is the Clinical Director and a founding member of the Profectum Foundation, dedicated to advancing the development and infant mental health of children with autism and special needs through training and educational programs focusing on the importance of relationships and parent mediated intervention. Prior to this

Name	Discipline	Biography
		she was the co- founder and associate chair of the Interdisciplinary Council on Developmental and Learning Disorders (ICDL). She and the late Dr. Stanley Greenspan co-developed the DIR (Developmental, Individual Difference and Relationship based) Model and co-authored Engaging *Autism*, *The Child with Special Needs, and Infant and Early Childhood Mental Health*, and chaired and edited two diagnostic manuals. She co-authored *Visual/Spatial Portals to Thinking, Feeling and Movement* with Dr. Harry Wachs, a pioneer of developmental vision cognitive therapy. Dr. Wieder also publishes extensively in books and journals, has co-chaired and organized national and international conferences, and lectures worldwide on the importance of relationships, symbolic play and sensory processing in development. She serves on the Board of Zero to Three and other advisory boards related to infant mental health and special needs. Dr. Wieder continues to provide consultation and treatment services in NYC.

Appendix F. Peer Reviewers

Grace Baranek, PhD, OTR
Chan Division of Occupational Science and Occupational Therapy, University of Southern California
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Department of Audiology & Speech Pathology
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New York State

Amy De Vito
Parent Member
NYS Early Intervention Coordinating Council

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University of Connecticut

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San Diego, CA

Maureen Greer
Executive Director, ITCA
Indianapolis, IN

Catherine Hancock, MS, RN, PMHCNS, BC
Part C Coordinator
ITCA Board Member
Virginia

Elizabeth Isakson, MD, FAAP
Executive Director, Docs for Tots
Astoria, NY

Michele Kohler, LCSW
Evaluation Unit Supervisor
New York League For Early Learning/LIFESTART Program

Lynn Skene Johnson, EdD
Part C Coordinator and President, Infant-Toddler Coordinators Association
Connecticut

Paola Jordan
Parent Member
NYS Early Intervention Coordinating Council

Anthony Malone
Developmental Pediatrician and Chair of Committee on Children with Disabilities, NYS Ch. 1, District II, AAP
Albany, NY

Lucy Jane Miller, PhD, OTR/L
Director, STAR Institute for Sensory Processing Disorder Denver, CO
Clinical Professor, University of CO,
Denver, Dept. of Pediatrics
Professor; Rocky Mountain University of Health Professions, Pediatrics, Provo UT.

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Clinical Professor of Pediatrics
Keck School of Medicine at USC
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Haggerty-Friedman Professor of Developmental/Behavioral Pediatric Research at the University of Rochester Medical Center Rochester,

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