

# Guidelines for the Care of Children and Adolescents with Autism and Pervasive Developmental Disorders

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## **Basic Team**

The special care needs of children with autism can be met by the primary care physician working collaboratively with parents, an experienced child development team, early childhood educators, teachers, and other school staff. Some children and families require referral to a child neurologist or child psychiatrist, and other children may need referral to a behavioral consultant. Please note that the primary care physician continues to be responsible for coordinating the special services that these children require.

Regular members of the child development team include a developmental pediatrician, a psychologist, a speech-language pathologist, an occupational therapist, an audiologist, and a medical social worker. Many children do not see all members of the team, and some children require additional evaluations (e.g., nutritionist, behavioral specialist).

## **Initial Evaluation**

The objectives of the initial evaluation by the child development team are to confirm the diagnosis of autism, to determine the presence of other developmental and behavior problems, to establish the cause of the child's developmental problems if possible, and to review the support needs of the child's family. The responsibilities of the primary care physician and the nurse are to identify and refer children who are suspected of having autism; to perform a complete medical examination of such children including evaluation for minor anomalies; to evaluate and treat associated medical problems; and to counsel the parents and children about the diagnosis and recommended treatment.

## **Frequency of Visits**

The child and family are best followed monthly in the primary care office following the initial evaluation until associated medical problems are evaluated, family support needs have been addressed and discussed, and the child is receiving needed educational services. Reevaluate the child and family in the office at least yearly to monitor his or her progress and review the treatment of associated behavior and medical problems, and more frequently for younger children and children in the first year after beginning treatment. Some children may need to be seen more often by the primary care physician (e.g., children with seizures who are taking anticonvulsants). Many children benefit from reevaluation by the child development team. Some children require regular follow-up by a child neurologist or a child psychiatrist. The management plan should be updated as needed at each reevaluation and not less than yearly.

# Guidelines for the Care of Children and Adolescents with Autism and Pervasive Developmental Disorders

The following elements are recommended by age group, and the listing is cumulative. Review all items indicated up through the actual age group of a child entering your practice for the first time as part of the initial evaluation.

AGE	KEY CLINICAL ISSUES/CONCERNS	EVALUATIONS/KEY PROCEDURES	SPECIALISTS
Birth–5 years (pre–school age)	<p><i>Growth/Nutrition</i></p> <p><i>Associated Medical Problems</i> Hearing/vision</p> <p>Gastroesophageal reflux (GER)</p> <p>Seizures</p> <p>Neuromotor concerns (e.g., hypotonia, dyspraxia, toe walking)</p> <p>Sleep problems</p> <p>Constipation</p> <p>Toilet training</p> <p>Drooling</p>	<p>Growth parameters, diet record</p> <p>Audiologic testing, vision testing, referral to ophthalmologist as needed</p> <p>Workup for GER, trial of medication, positioning, and diet change</p> <p>Electroencephalogram (EEG), referral to child neurologist as needed</p> <p>Detailed neuromotor evaluation as needed</p> <p>Behavioral management, occasional short-term medications</p> <p>Diet, medication (e.g., bulk agent)</p> <p>Behavioral management, occasional medications</p>	<p>Nutritionist, feeding specialist as needed</p> <p>Audiologist, ophthalmologist as needed</p> <p>Pediatric gastroenterologist as needed</p> <p>Child neurologist as needed</p> <p>Physical/occupational therapist as needed</p> <p>Developmental pediatrician (DPed), nurse specialist as needed</p> <p>Speech-language pathologist, DPed as needed</p>
<b>Note any side effects of medications.</b>			
	<i>Dental Care</i>	Review oral hygiene	Dentist
	<i>Cause of the Developmental Disability</i> Consider pervasive developmental disorder (PDD), fragile X syndrome, or Landau-Kleffner syndrome	<p>Evaluation for minor anomalies</p> <p>Fragile X study, chromosomes, magnetic resonance imaging (MRI) scan, and so forth as needed</p> <p>Obtain EEG with prolonged sleep record if regression in skills occurs</p>	DPed, medical geneticist as needed
	<i>Associated Behavior or Mental Health Problems</i> Aggression Hyperactivity or inattention Oppositional behavior Avoidant behavior Anxiety Perseverative behaviors Self-injurious behaviors (SIBs) or stereotypes	<p>Family and teacher interviews, behavior rating scales, functional analysis of behavior</p> <p>Parent training in behavior management</p>	<p>DPed, child psychiatrist, or other mental health professional as needed</p> <p>Referral to child development team, behavioral consultant as needed</p>

## Guidelines for the Care of Children and Adolescents with Autism and Pervasive Developmental Disorders (continued)

The following elements are recommended by age group, and the listing is cumulative. Review all items indicated up through the actual age group of a child entering your practice for the first time as part of the initial evaluation.

AGE	KEY CLINICAL ISSUES/CONCERNS	EVALUATIONS/KEY PROCEDURES	SPECIALISTS
Birth–5 years (pre–school age) (continued)	<p><i>Developmental Progress, Early Intervention/Early Childhood Special Education (EI/ECSE) Services</i></p> <p>Need for physical therapy, occupational therapy, speech–language therapy, behavioral support</p> <p>Developmental delay or mental retardation</p> <p>Speech–language disorder</p> <p>Dyspraxia</p>	<p>Developmental surveillance</p> <p>Request EI/ECSE report, review individualized family service plan (IFSP) with family</p>	<p>Referral to child development team as needed</p> <p>Speech–language pathologist, physical and occupational therapists as needed</p>
	<p><i>Review of Diagnosis and Anticipatory Guidance</i></p> <p>Review IFSP with family</p> <p>Need for parent training in behavior management</p> <p>Discuss alternative therapies</p> <p>Transition from EI to ECSE and from ECSE to grade school</p> <p>Sibling programs</p>	<p>Family interview, educational materials (e.g., handouts on alternative therapies), initiate care notebook</p> <p>Teacher interview, school conference</p>	<p>Primary care office; collaborate with child development team and EI/ECSE staff as needed</p>
	<p><i>Family Support Services</i></p> <p>Respite care</p> <p>Parent group</p> <p>Community health nurse</p> <p>Advocacy (e.g., Autism Society of America)</p> <p>Financial services (Supplemental Security Income [SSI])</p> <p>Other enabling services</p>	<p>Family interview, use parent questionnaire (e.g., Family Needs Survey) as needed; provide resource information</p> <p>Care coordination; collaboration with school, Developmental Disability (DD) services, and other agencies</p>	<p>Medical social worker, community health nurse, and other community services as needed</p>

## Guidelines for the Care of Children and Adolescents with Autism and Pervasive Developmental Disorders (continued)

The following elements are recommended by age group, and the listing is cumulative. Review all items indicated up through the actual age group of a child entering your practice for the first time as part of the initial evaluation.

AGE	KEY CLINICAL ISSUES/CONCERNS	EVALUATIONS/KEY PROCEDURES	SPECIALISTS
6–12 years (school-age)	<p><i>School Progress</i> Need for ancillary services Physical therapy, occupational therapy, speech-language therapy</p> <p><i>Associated Behavior or Mental Health Problems</i> Sleep disorder Hyperactivity or inattention Oppositional behaviors Anxiety Depression Aggression Obsessive-compulsive behaviors SIBs or stereotypies</p>	<p>Family and teacher interviews, behavior rating scales, school report as needed; review individualized education program (IEP) with family</p> <p>Interviews, behavior rating scales, functional analysis of behavior Medication management as needed</p>	<p>Evaluation by child development team as needed; collaborate with school staff</p> <p>Referral to child development team or individual appointments with DPed, psychologist, behavioral consultant, and child psychiatrist as needed</p>
13–21 years (adolescent–young adult)	<p><i>Social Skills, Recreation and Leisure Activities</i> Involvement in peer group activities at school and in the community (determine which supports are needed)</p> <p><i>Self-Care/Independent Living</i> Determine which supports are needed</p> <p><i>Anticipatory Guidance</i> Transitions to middle school and high school Sexuality, menstrual hygiene, and birth control Vocational training Life skills programs Encourage healthy behaviors (e.g., diet, exercise) Transition to adult services</p>	<p>School-based program and referral to community services as needed</p> <p>Outpatient occupational therapy and physical therapy services as needed Independent living skills program, social skills training as needed</p> <p>Adolescent, family and teacher interviews, school conference as needed; review IEP with family Social skills training regarding sexuality, menstrual hygiene; birth control as needed (e.g., Depo-Provera) Career counseling, evaluation by vocational specialist as needed Care coordination; collaboration with school staff, DD services, other agencies</p>	<p>Physical therapist, occupational therapist, adaptive PE specialist, psychologist, and behavioral consultant as needed; collaborate with school staff</p> <p>Medical social worker, physical therapist, occupational therapist, psychologist as needed</p> <p>Primary care office in collaboration with child development team and school staff Referral to gynecologist as needed Referral to Department of Vocational Rehabilitation</p>



## **Family and Physician Management Plan Summary for Children and Adolescents with Autism and Pervasive Developmental Disorders** *(continued)*

6. Do you also receive services from a child development team of specialists?

Contact person \_\_\_\_\_

Location \_\_\_\_\_

7. Have you/has your child had any blood tests, radiologic (X-ray) examinations, or other procedures since your last visit? If yes, please describe.

8. Have you/has your child been hospitalized or received surgery since your last visit? If yes, describe.

9. Please note your child's accomplishments since your last visit. Consider activities at home, in your neighborhood, or at school, as well as success with treatments.

10. What goals (skills) would you/your child like to accomplish in the next year? Consider activities at home, in your neighborhood, or at school, as well as success with a treatment.

11. What questions or concerns would you like to address today?

# Family and Physician Management Plan Summary for Children and Adolescents with Autism and Pervasive Developmental Disorders

The Management Plan Summary should be completed at each annual review and more often as needed. It is intended to be used with the Guidelines for Care, which provide a more complete listing of clinical issues at different ages and recommended evaluations and treatments.

Child's name \_\_\_\_\_ Person completing form \_\_\_\_\_ Today's date \_\_\_\_\_

Clinical issues	Currently a problem?	Evaluations needed	Treatment recommendations	Referrals made	Date for status check
<i>Family's Questions</i>					
<i>Cause of the Developmental Disability</i> Fragile X DNA testing results					
<i>Growth/Nutrition</i>					
<i>Dental Care</i>					
<i>Other Medical Issues</i> Hearing or vision concerns Seizures Neuromotor concerns (e.g., hypotonia, toe walking) Drooling Sleep disorder Constipation or diarrhea Toilet training Sexuality, menstrual hygiene <b>Note any side effects of medications.</b>					

# Family and Physician Management Plan Summary for Children and Adolescents with Autism and Pervasive Developmental Disorders *(continued)*

Child's name \_\_\_\_\_ Person completing form \_\_\_\_\_ Today's date \_\_\_\_\_

Clinical issues	Currently a problem?	Evaluations needed	Treatment recommendations	Referrals made	Date for status check
<p><i>Associated Developmental or Learning Issues</i></p> <p>Current school progress Review early intervention (EI) or school services (individualized family service plan [IFSP] or individualized education program [IEP]) Developmental delay or mental retardation Speech-language disorder; assess need for augmentative communication</p>					
<p><i>Need for Physical and Occupational Therapy Services</i></p> <p>Hypotonia or toe walking Associated dyspraxia or cerebral palsy Fine motor or visual motor concerns</p>					
<p><i>Associated Behavior or Mental Health Issues</i></p> <p>Aggression Inattention or hyperactivity Oppositional behavior Anxiety, depression Obsessive-compulsive behaviors Stereotypies Self-injurious behaviors (SIBs)</p>					

## Family and Physician Management Plan Summary for Children and Adolescents with Autism and Pervasive Developmental Disorders *(continued)*

Child's name \_\_\_\_\_ Person completing form \_\_\_\_\_ Today's date \_\_\_\_\_

Clinical issues	Currently a problem?	Evaluations needed	Treatment recommendations	Referrals made	Date for status check
<i>Behavior Management in the Home</i>					
<i>Behavior Management in the School</i>					
<i>Discussion of Alternative Therapies</i>					
<i>Social Skills</i> Involvement in group activities at school, in community (determine which supports are needed)					
<i>Promote Self-Care/Independence</i>					
<i>Family Support Services</i>					
<i>Anticipatory Guidance</i> List issues discussed and materials provided					

# Family and Physician Management Plan Summary for Children and Adolescents with Autism and Pervasive Developmental Disorders *(continued)*

Child's name \_\_\_\_\_ Person completing form \_\_\_\_\_ Today's date \_\_\_\_\_

Clinical issues	Currently a problem?	Evaluations needed	Treatment recommendations	Referrals made	Date for status check
<i>Collaboration with Community Agencies Schools</i>					
Comments					

Next update of the Management Plan Summary \_\_\_\_\_

Signature \_\_\_\_\_ Date \_\_\_\_\_  
(Child and parent)

Signature \_\_\_\_\_ Date \_\_\_\_\_  
(Health professional)

### ***Questions for Parents to Ask Themselves Regarding Specific Treatments***

Child's name \_\_\_\_\_ Date of birth \_\_\_\_\_ Person completing form \_\_\_\_\_

1. What characteristic behaviors of autism am I trying to target? Does the treatment that I am considering target these characteristic behaviors?
2. Are there any harmful side effects associated with this treatment?
3. What positive effects of treatment would I hope to see?
4. What short-term and long-term effects might I see with this treatment?
5. Can this treatment be integrated into my child's current program?
6. What is the cost of the treatment?
7. Will my insurance company pay for the treatment?
8. How much time does the treatment take? Can I realistically devote the time required to the treatment?
9. Has this treatment been validated scientifically?
10. Have I researched the treatment?
11. Was I able to interview other parents and professionals about the treatment? If so, list stated pros, cons, and other areas of interest.
12. Do proponents of the treatment claim that this procedure can help nearly everyone? Do proponents offer the possibility of a "cure," state that treatment must be done early or else is not effective, claim that treatment benefits a variety of conditions? If so, these should be seen as "red flags" to be more careful in considering this technique.
13. What do my pediatrician and other professionals involved with my child think about the treatment's appropriateness?

From Fields, V. (1994). *Autism advocacy in Lane County: A handbook for parents and professionals*. Unpublished master's thesis, University of Oregon, Eugene; reprinted by permission.

## ***Observation of Play***

The purpose of the play observation is to improve the quality of behavioral observations in the primary care office. It is not a screening test. It provides a structure to look for specific social, communicative, and play behaviors to assist in the identification of children through 3 years of age who are suspected of having autism or other pervasive developmental disorders (PDDs).

The play observation is best incorporated at the end of the physician's interview with the parents and prior to the physical examination. Look for the target behaviors while the child is playing during the interview, then allow 10–15 minutes for the structured observation of play.

**TOYS:** Have books and a number of toys available, including toys that can be used for pretend or make-believe play and reciprocal play, and "cause-and-effect" toys such as a Jack-in-the-Box or a See 'n Say toy (a pull-string toy). Your toy box can include a toy telephone with push buttons or a dial that spins, a doll with removable clothes, two plastic bowls or cups and two spoons, a 6-inch-diameter ball, a toy car, a pull toy (e.g., a train), a tower and plastic rings, blocks, a shape sorter, and books.

### **METHODS**

1. Begin by telling the parents that you want to watch them play with their child to learn more about their child's behavior. Ask the parents if they have brought any of the child's toys from home. Then encourage the parents to play as if they were at home and use the child's own toys as well as those in the toy box.

Wait and observe (several minutes).

*[Skip Item #2 if the parents and the child are already playing actively on the floor near the toy box.]*

2. Next, ask the parents to sit down next to the box of toys. If the child is not engaged actively in playing near the toy box, ask one of the parents to pick up a toy to show the child and to call the child by name. If the child does not come in response to being called, ask one of the parents to place the child next to the toys.

Wait and observe.

3. Now instruct one of the parents to show the child the toy telephone (or a bowl and a spoon). If the child does not begin to play with the toy telephone (or the bowl and the spoon), instruct one of the parents to model dialing, pretend to talk on the telephone (or pretend to eat from the bowl with the spoon), and then offer the telephone receiver (or the pretend spoonful) to the child.

Wait and observe.

If the child begins to play with the toy telephone, ask one of the parents to imitate the child (do whatever the child does right after the child does it) and/or to elaborate slightly on the child's play.

4. Next, ask one of the parents to show the child a book. If the child does not begin to look at the book, instruct the parent to begin talking about a picture in the book and to show that picture to the child while pointing at it. If the child begins to look at the book, ask the parent to follow the child's lead and imitate and/or elaborate slightly on what the child is doing.

Wait and observe.

5. Next, ask one of the parents to call the child's name, point to an easily observed toy or object in the room, and say, "Look at the [name of toy]!" Does the child look where his or her parent is pointing, not just at the parent's hand? If the child does not look at the parent when the child's name is called, ask the parent to touch the child on the shoulder and again call the child's name, point at an object, and say, "Look at the [name of toy]!"

6. At some point during the child's play, pretend that you (the examiner) hurt your finger and feign crying loudly. Does the child notice? Look concerned? Try to comfort?

7. Demonstrate blowing bubbles, then close the jar of bubbles and hold the jar in front of you. Wait and observe how the child responds. Does the child request more? If so, how? Next, make sure the lid is tightly closed and hand the jar to the child. Does the child request help? If so, how? Alternatively, show the child an attractive toy or food item, then place it into a clear plastic jar and screw the lid on tightly so that the child cannot open it. Hand the jar to the child, and observe how the child responds. Does the child request help? If so, how?

## **Observation of Play**

Name \_\_\_\_\_ Date of birth \_\_\_\_\_ Today's date \_\_\_\_\_

Examiner \_\_\_\_\_

Family's concerns \_\_\_\_\_

<b>Scoring</b> ( <i>check [✓] each time behavior occurs</i> )	<b>Description</b> ( <i>circle and add description as needed</i> )
<p><b>1. Communication</b></p> <p><input type="checkbox"/> Uses gestures (please list)</p>   <p><input type="checkbox"/> Uses words (please list)</p>   <p><input type="checkbox"/> Makes requests (e.g., "help" or "more")</p>	<p>In imitation                      To request</p>   <p>In imitation                      To request</p>   <p>Looks at examiner's or parent's face                      With vocalization</p>
<p><b>2. Social</b></p> <p><input type="checkbox"/> Seeks contact with parent</p>   <p><input type="checkbox"/> Looks at parent's face</p>   <p><input type="checkbox"/> Looks at examiner's face</p>   <p><input type="checkbox"/> Responds to name</p>	<p>Then looks at parent's face      With vocalization</p>   <p>And smiles with parent</p>   <p>And smiles with examiner</p>

*(continued)*

<p><b>Observation of Play (continued)</b></p> <p><b>Scoring</b> (check [✓] each time behavior occurs)</p> <p><input type="checkbox"/> Shows (i.e., brings) toy to parent</p> <p><input type="checkbox"/> Points to toy or book</p> <p><input type="checkbox"/> Looks where parent has pointed</p> <p><input type="checkbox"/> Notices the examiner crying (typical by 1 year of age)</p>	<p><b>Description</b> (circle and add description as needed)</p> <p>Then looks at parent's face      With vocalization</p> <p>Then looks at parent's face      With vocalization</p> <p>Looks concerned (typical by 2 years of age)      Tries to comfort (typical by 2–4 years of age)</p>
<p><b>3. Play</b></p> <p><input type="checkbox"/> Imitates</p> <p><input type="checkbox"/> Pretends</p>	

(continued)

**Observation of Play (continued)**

**General observations** (e.g., very active, tantrums, passive or stares into space, flat affect, perseverative play such as spinning toys, stereotypic behavior such as hand flapping):

Impression (*please circle*):          Autism is present                  Suspected                  Not present

Action taken:

**REFERENCES**

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- Osterling, J., & Dawson, G. (1994). Early recognition of children with autism: A study of first birthday home videotapes. *Journal of Autism and Developmental Disabilities*, *24*(3), 247–257.
- Siegel, B. (1996). *The world of the autistic child: Understanding and treating autistic spectrum disorders* (pp. 94–95). New York Oxford University Press.