

Guidelines for the Care of Children and Adolescents with Developmental Delay or Intellectual Disability

Basic Team

The special care needs of children with developmental delay can be met by an experienced primary care physician working collaboratively with parents, early childhood educators, teachers, and other school staff. Some children and families require referral to an experienced child development team headed by a developmental pediatrician, and other children may need referral to a medical geneticist. 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 require evaluation by all members of the team, and some children require additional evaluations (e.g., nutritionist, behavioral specialist).

Initial Evaluation

The objectives of the initial evaluation are to document the child's performance level in different developmental domains, make service recommendations, determine the cause of the disability, and identify associated medical problems. The responsibilities of the primary care physician and nurse are to complete family, developmental, and medical histories; perform a complete medical examination, including a surface evaluation for minor congenital anomalies; determine the needs for referral and for laboratory tests; and counsel the parents and the child about the diagnosis and recommended treatment.

Frequency of Visits

The child and the family are best followed monthly in the primary care office following the initial evaluation until associated medical problems are determined, the cause of the disability is identified and discussed, and the child is receiving general education services. Then reevaluate the child and the family in the office at least yearly to monitor his or her progress and to review the treatment of associated medical problems and more often for younger children and in the first year after the diagnosis. Some children may need to be seen more often by the primary care physician (e.g., children with seizures who are taking anticonvulsants). Some children require regular follow-up by the child neurologist, and other children may require reevaluation by the child development team. The management plan should be updated at each reevaluation and not less than yearly.

Guidelines for the Care of Children and Adolescents with Developmental Delay or Intellectual Disability

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> <ul style="list-style-type: none"> Failure to thrive Oral motor dysfunction Gastroesophageal reflux (GER) Microcephaly or macrocephaly <p><i>Associated Medical Problems</i></p> <ul style="list-style-type: none"> Hearing/vision Seizures Hypotonia Musculoskeletal: Hip dysplasia, scoliosis Sleep problems Constipation Toilet training Drooling 	<ul style="list-style-type: none"> Growth parameters, diet record, nutrition and feeding assessment, workup for GER Special diet and feeding program, treatment for GER Cranial computed tomography (CT) or magnetic resonance imaging (MRI) scan as needed Hearing and vision testing Electroencephalogram Detailed neuromotor examination Hip ultrasound, X rays as needed Behavior management, occasional short-term medications Diet, medications (e.g., bulk agent), timed toilet training, adaptive seat as needed Behavioral therapy, occasional medication 	<ul style="list-style-type: none"> Nutritionist, feeding specialist or team, pediatric gastroenterologist as needed Audiologist, ophthalmologist Child neurologist as needed Physical therapist, orthopedist as needed Developmental pediatrician (DPed), nurse specialist as needed Speech-language pathologist, rarely referral to otolaryngologist for older school-age children
Note side effects of any medications.			
<i>Cause of the Disability</i>			
<i>Dental Care</i>		Review oral hygiene	Dentist
<i>Associated Behavior/Mental Health Problems</i>			
Autism spectrum disorder		Interview, behavior rating scales	Referral to child development team or psychologist, behavioral consultant, child psychiatrist as needed
Aggression		Functional analysis of behavior as needed	
Hyperactivity/inattention		Behavior management programs at home and school	
Oppositional behavior		Medication as needed	
Anxiety			

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Guidelines for the Care of Children and Adolescents with Developmental Delay or Intellectual Disability *(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) <i>(continued)</i>	<p><i>Developmental Progress, Early Intervention (EI)/Early Childhood Special Education (ECSE) Services</i></p> <p>Need for ancillary services: Physical therapy (PT), occupational therapy (OT), speech–language therapy</p> <p>Speech disorder</p> <p>Dyspraxic gait, ataxia, hypotonia, or cerebral palsy</p> <p>Fine motor and visual motor concerns</p>	<p>Request EI/ECSE report, review individualized family service plan (IFSP) with family</p> <p>Detailed musculoskeletal and neuromotor examinations</p>	<p>Referral for PT, OT, speech–language therapy as needed or for evaluation by child development team</p> <p>Collaborate with EI/ECSE staff</p>
	<p><i>Review of Diagnosis and Anticipatory Guidance</i></p> <p>Review IFSP or individualized education program (IEP) with family</p> <p>Transition from EI to ECSE and from ECSE to elementary school</p> <p>Sibling programs</p> <p>Discussion of alternative (controversial) therapies</p> <p>Promotion of self-care/independence</p> <p>Accident prevention</p>	<p>Family interview, educational materials, resource information, initiate care notebook</p> <p>Teacher interview, school conference as needed</p>	<p>DPed as needed</p> <p>Collaborate with EI/ECSE staff, child development team</p>
	<p><i>Family Support Services</i></p> <p>Respite care</p> <p>Parent groups</p> <p>Community health nurse</p> <p>Advocacy (e.g., The Arc)</p> <p>Financial services (e.g., Supplemental Security Income [SSI])</p> <p>Other enabling services</p>	<p>Family interview, parent questionnaires (e.g., Family Needs Survey), provide resource information</p> <p>Care coordination</p>	<p>Medical social worker, referral to community health nurse, other community services as needed</p>
	<p><i>Collaboration with Community Services</i></p> <p>School</p> <p>Community health nurse</p> <p>Other service providers</p>	<p>Comprehensive care coordination with regular exchange of written information (at least yearly) with other service providers</p>	<p>Primary care office in collaboration with child development team</p>

Guidelines for the Care of Children and Adolescents with Developmental Delay or Intellectual Disability *(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: PT, OT, speech-language therapy</p> <p><i>Communication or Speech-Language Disorder</i></p> <p><i>Associated Behavior/Mental Health Problems</i> Autism Attention-deficit/hyperactivity disorder (ADHD) Oppositional behavior Anxiety Depression Aggression Obsessive-compulsive behavior Self-injurious behaviors (SIBs) and stereotypes</p> <p><i>Social Skills</i> Promote social competence Determine which supports are needed for involvement in peer group activities at school and in the community</p> <p><i>Anticipatory Guidance</i> Sports and leisure activities Transition to middle school</p>	<p>Behavior rating scales; school report; review IEP with family Detailed musculoskeletal and neuromotor examinations</p> <p>Evaluate need for augmentative and alternative communication (AAC) devices</p> <p>Behavior rating scales; functional analysis of behavior Behavior management programs at home and at school Medication management as needed Collaborate with school staff</p> <p>Social skills program at school; encourage participation in community services</p> <p>Provide resource information on community services Determine which supports are needed to encourage participation in community recreation and leisure activities</p>	<p>Referral to child development team or individual evaluations by physical therapist, occupational therapist, speech-language therapist Collaborate with school staff</p> <p>Speech-language pathologist, AAC specialist as needed</p> <p>Referral to child development team, behavioral consultant, or mental health professional as needed</p> <p>Psychologist, behavioral consultant, physical therapist, occupational therapist, adaptive physical education specialist as needed Collaborate with school staff</p> <p>Primary care office in collaboration with child development team</p>

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Guidelines for the Care of Children and Adolescents with Developmental Delay or Intellectual Disability *(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
13–21 years (adolescent and young adult)	<p><i>Self-Care/Independent Living</i> Determine which supports are needed to promote self-care and independent living skills</p> <p><i>Anticipatory Guidance</i> Transitions to middle school and to high school Sexuality and birth control, menstrual hygiene Vocational training Life skills programs (independent living) Encourage healthy behaviors (e.g., diet, exercise) Transition to adult services</p>	<p>PT and OT services as needed Independent living skills program, social skills training as needed Service coordination</p> <p>Adolescent, family, and teacher interviews; school conference as needed; review IEP with family</p> <p>Social skills training regarding sexuality, menstrual hygiene, birth control (e.g., Depo-Provera) as needed Evaluation by vocational specialist, life skills training program as needed</p>	<p>As needed, refer to physical therapist, occupational therapist, psychologist, medical social worker Collaborate with school, Developmental Disability Services</p> <p>Primary care office in collaboration with child development team Gynecologist as needed Referrals to Developmental Disability Services, Department of Vocational Rehabilitation</p>

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Family and Physician Management Plan Summary for Children and Adolescents with Developmental Delay or Intellectual Disability *(continued)*

6. Do you/does your child also receive services from a child development team of specialists?
Contact person _____
Location _____
7. Have you/has your child had any blood tests, radiologic (i.e., X-ray) examinations, or other procedures since your/your child's last visit? If yes, please describe.
8. Have you/has your child been hospitalized or undergone surgery since your/your child's last visit? If yes, describe.
9. Please note your/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 (i.e., 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 treatments.
11. What questions or concerns would you like addressed today?

Family and Physician Management Plan Summary for Children and Adolescents with Developmental Delay or Intellectual Disability

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>Growth/Nutrition</i> Feeding problems Slow weight gain Gastroesophageal reflux Obesity Short stature					
<i>Associated Medical Problems</i> Hearing loss Strabismus/vision problems Seizures Hypotonia Musculoskeletal issues (e.g., scoliosis, foot deformity) Drooling Sleep disorder Constipation Toilet training Sexuality, menstrual hygiene Note any side effects of medications.					
<i>Cause of the Disability</i>					

Family and Physician Management Plan Summary for Children and Adolescents with Developmental Delay or Intellectual Disability *(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>Dental Care</i>					
<i>Associated Behavior/ Mental Health Problems</i> Autism Aggression Inattention/hyperactivity Oppositional behavior Anxiety, depression Obsessive-compulsive behaviors Stereotypies Self-injurious behaviors (SIBs)					
<i>Associated Developmental or Learning Issues</i> Current school achievement Review early intervention (EI) or school services (individualized family service plan [IFSP] or individualized education program [IEP]) Speech-language disorder (need for augmentative and alternative communication devices)					
<i>Need for Physical Therapy or Occupational Therapy Services</i> Hypotonia Associated dyspraxia or cerebral palsy Fine motor/visual motor concerns					

Family and Physician Management Plan Summary for Children and Adolescents with Developmental Delay or Intellectual Disability *(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 (Controversial) Therapies</i>					
<i>Social Skills</i> Determine which supports are needed to promote involvement in peer group activities at school and in the community					
<i>Self-Care/Independence</i>					
<i>Anticipatory Guidance</i> List issues discussed and materials provided					
<i>Family Support Services</i>					

Family and Physician Management Plan Summary for Children and Adolescents with Developmental Delay or Intellectual Disability (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</i> School Developmental Disability Services Vocational Rehabilitation					
Comments					

Next update of the Management Plan Summary _____

Signature _____ Date _____
(Child and parent)

Signature _____ Date _____
(Health professional)

Family and Physician Management Plan Summary for Children and Adolescents with Down Syndrome *(continued)*

6. Do you/does your child also receive services from a child development team of specialists?
Contact person _____
Location _____
7. Have you/has your child had any blood tests, radiologic (i.e., X-ray) examinations, or other procedures since your last visit? If yes, please describe.
8. Have you/has your child been hospitalized or undergone surgery since your last visit? If yes, describe.
9. Please note your/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 (i.e., 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 treatments.
11. What questions or concerns would you like addressed today?

Family and Physician Management Plan Summary for Children and Adolescents with Down Syndrome

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> Growth/Nutrition Feeding problems Obesity					
<i>Associated Medical Problems</i> Congenital heart defect Visual concerns (e.g., strabismus, cataracts) Hearing concerns (e.g., recurrent acute otitis media, persistent serous otitis) Recurrent respiratory infections Hypothyroidism Musculoskeletal problems (e.g., hip dysplasia, atlantoaxial instability) Seizures Gastrointestinal problems (e.g., bowel atresia, Hirschsprung disease) Constipation Toilet training (determine need for adaptive seating) Sleep apnea Leukemia (rare) Sexuality, menstrual hygiene Note any side effects of medications.					
<i>Dental Care</i> Periodontitis					

Family and Physician Management Plan Summary for Children and Adolescents with Down Syndrome *(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 Behavior/Mental Health Problems</i></p> <ul style="list-style-type: none"> Autism Aggression Inattention/hyperactivity Oppositional behavior Anxiety, depression Obsessive-compulsive behavior Stereotypies Self-injurious behaviors (SIBs) 					
<p><i>Associated Developmental Problems</i></p> <ul style="list-style-type: none"> Current school progress Review early intervention or school services (individualized family service plan [IFSP] or individualized education program [IEP]) Speech-language disorder (determine need for augmentative and alternative communication devices) 					
<p><i>Need for Physical or Occupational Therapy Services</i></p> <ul style="list-style-type: none"> Hypotonia Associated dyspraxia or cerebral palsy Fine motor/visual motor concerns 					

Family and Physician Management Plan Summary for Children and Adolescents with Down Syndrome *(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 (Controversial) Therapies</i>					
<i>Social Skills</i> Determine which supports are needed to promote involvement in peer group activities at school and in the community					
<i>Anticipatory Guidance</i> List issues discussed and materials provided					
<i>Promote Self-Care/Independence</i>					
<i>Family Support Services</i>					

Family and Physician Management Plan Summary for Children and Adolescents with Down Syndrome *(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</i> Communication with schools Developmental Disability Services Vocational Rehabilitation					
Comments					

Next update of the Management Plan Summary _____

Signature _____ Date _____
 (Child and parent)

Signature _____ Date _____
 (Health professional)

Surface Evaluation for Minor Congenital Anomalies

The purpose of this examination is to provide a structure for making skilled observations to assist with the identification of children with birth defect syndromes and genetic problems. This examination is best integrated into the general physical examination. When first learning to evaluate a child thoroughly for minor anomalies, however, it is useful to conduct the examination from start to finish to become comfortable with every aspect of the examination.

Starting with the head and face, follow the sequence presented below. For each stage of the examination, a list of the most common anomalies is provided. Please remember to measure whatever can appropriately be measured (e.g., ear length, hand length, palpebral fissure length). Circle the anomalies that are present and describe or write in the measurements in the righthand column. Please also describe any anomalies next to the appropriate category that are not listed on the form.

Child's name _____ Date of birth _____ Today's date _____

Diagnosis or referral concerns _____

1. Craniofacial

- Flat or prominent nasal bridge
- Small mandible
- Flat or prominent occiput
- Metopic ridge
- Large posterior fontanelle
- Malar hypoplasia
- Anteverted nose
- Synophrys

2. Ears

- Preauricular tags or sinus
- Large or small ears
- Asymmetric size
- Low-set ears
- Posterior rotation (> 10%)
- Lack of usual fold of helix

3. Eyes

- Epicanthal folds
- Hypo- and hypertelorism
- Ptoxis
- Short palpebral fissures
- Upward slant to palpebral fissures
- Downward slant to palpebral fissures

4. Mouth

- Bifid uvula
- High-arched palate
- Wide alveolar ridges
- Large tongue
- Thin upper lip
- Flat philtrum

5. Skin/hair

- Low hairline
- Frontal upsweep/aberrant hair whorl
- Alopecia of scalp
- Extra posterior cervical skin
- Large capillary hemangioma (other than on posterior neck)
- Café au lait spots
- Hypopigmented macules
- Deep sacral dimple
- Aplasia cutis congenita

(continued)

Surface Evaluation for Minor Congenital Anomalies (continued)

6. Chest

- Short sternum
- Depressed sternum
- Wide-set or high-located nipples
- Shield chest

7. Abdominal/perineal

- Diastasis recti (> 3 centimeters)
- Umbilical hernia
- Inguinal hernia
- Small testes
- Hypospadias
- Small or hypoplastic genitals

8. Hands

- Single palmar crease
- Clinodactyly
- Other unusual crease pattern
- Camptodactyly
- Partial cutaneous syndactyly
- Proximally placed thumb
- Broad thumb
- Duplication of thumbnail
- Small or dysplastic nails
- Overlapping fingers
- Long fingers
- Small or large hands
- Short metacarpals

9. Feet

- Syndactyly of toes
- Overlapping toes
- Wide gap between toes
- Prominent heel
- Broad hallux
- Hallux valgus
- Hypoplastic nails
- Duplication of nail (rudimentary polydactyly)

Length _____ Weight _____ Head circumference _____

Comments _____

(continued)

Surface Evaluation for Minor Congenital Anomalies (continued)

Reference

Jones, K.L. (Ed.). (1997). *Smith's recognizable patterns of human malformation* (5th ed.). Philadelphia: W.B. Saunders Co.

Normal standards

Outer canthal distance (Jones, p. 764)
Inner canthal distance (Jones, p. 765)
Palpebral fissure length (Jones, p. 766)
Ear length (Jones, p. 768)
Total hand length (Jones, p. 760)
Palm length (Jones, p. 761)
Middle finger length (Jones, p. 761)
Foot length (Jones, p. 763)
Penile length (Jones, p. 769)

Notes (please review Jones, pp. 727–746)

1. Measure the outer and inner canthal distance with a plastic see-through ruler.
2. A flat nasal bridge and anteverted nose typically go together. Consider a nose anteverted if you can see straight into the nostrils when looking at the child from the front.
3. Ears are posteriorly rotated (slanted away from eye) if there is 15% slant away from the perpendicular (Jones, p. 730).
4. A sacral dimple is considered deep if the bottom cannot be seen without considerable stretching. It should be distinguished from a pilonidal sinus.
5. Measure penile length by resting one end of a ruler on the pubic bone and stretching the penis as much as possible. Measure to the tip of the glans.
6. Hypoplastic testes refers to small size and/or abnormal consistency. Hypoplasia of the labia majora may give the impression of a large clitoris (Jones, p. 734).
7. If the first metacarpal bone is short, the thumb will be proximally placed. If other metacarpals or metatarsals are short, the corresponding finger or toe will appear short. To check for a short metacarpal, have the child make a fist and check the knuckles. If a short metacarpal bone is present, the knuckle will be absent. A common example is relative shortness of the fourth or fifth metacarpal or metatarsal (Jones, p. 732).
8. Dysplastic nails are spoon-shaped, ridged, or otherwise malformed nails. The nails generally reflect the size and shape of the underlying distal phalanx (Jones, p. 731).
9. Partial syndactyly most commonly occurs between the third and fourth fingers and second and third toes. Less than 25% syndactyly between the second and third toes is considered normal.