

Will David Catch Up?

Facilitator's Guide

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Topic: Global Delay

Abstract:

Primary care clinicians see children for a number of well-child visits in the first three years of life and thus are in a unique position to monitor a child's development, detect delays, and make appropriate referrals for evaluation and intervention before school entry. Clinicians should be able to screen for developmental delay at each visit and list a differential diagnosis when delays are found. The evaluation and subsequent management plan should include consideration of medical and psychosocial factors that influence development. This case describes a four year old youngster, David, who presents with developmental delay in the setting of a complex psychosocial situation.

Goals:

To provide learners with a basic understanding of global developmental delay.

Objectives:

By the end of this session, learners will be able to:

1. Describe the role of social, environmental, physical, and emotional factors in child development.
2. List a differential diagnosis for a child with global developmental delay.
3. Outline a plan for the assessment and management of the child with developmental delay.

Prerequisite Case:

"When to Watch, When to Refer, When to Reassure" (Using the DENVER-II)

Related Cases:

"The Tongue Tied Toddler" (Language Delay)

"Jose's New Family" (Atypical Behaviors)

Theme: Child Development and Behavior

Key Words: Developmental delay, mental retardation, disabilities



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Bright Futures Core Concepts:

While all of the Core Concepts are included in each case, this particular case can be used to highlight communication, partnership, and prevention/health promotion.

Materials Provided:

- Facilitator's Guide
- 3-part Case Narrative: Part I, Part II, Epilogue
- Handout #1: DENVER-II
- Handout #2: David's Growth Chart
- Handout #3: Head Circumference Chart
- Bibliography

Facilitator Preparation:

Facilitators should thoroughly review this guide and the other materials provided. At the end of the guide we have included a section entitled, "**Independent Learning/Prevention Exercises**," that will further stimulate group and individual education on this topic.

Suggested Format for a One Hour Session:

We anticipate that case facilitators will modify implementation of the case session to best fit their educational setting and learners. For detailed recommendations on case facilitation, please see the chapter entitled, "A Brief Guide to Facilitating Case-Discussion," found in *The Case Teaching Method; and Growth in Children and Adolescents* (book 1 of this series).

Open the Discussion: Introduce the case title and the session goal. Explain that this will be an interactive case discussion and not a lecture.

Introduction: According to the Bright Futures Guidelines, primary care clinicians should include developmental surveillance in every well-child visit. For the four-year visit, the screening questions include the following:

- *Do you have any specific concerns about David's development or behavior?*
- *How does David communicate what he wants?*
- *What do you think David understands?*
- *How does David get from one point to another?*
- *How does David act around others?*
- *To what extent has David developed independence in eating, dressing and toileting?*
- *Tell me about David's typical play.*

Delay exists when a child does not reach developmental milestones at the expected age. Potential etiologies range from biological factors, such as chromosome disorders or intrauterine insults, to environmental factors such as maternal depression. In many young children, a specific diagnosis cannot be made. However, even in the absence of an etiologic explanation, early identification and intervention help both children and their parents.

Given the wide variation in age at which normal children will reach their developmental milestones, detection of delay can be challenging. Ongoing surveillance provides a far greater yield in developmental assessment than a single screening at a particular visit. Additionally, the context of an ongoing relationship between the caregiver and family provides an efficient evaluation and transition into intervention.

Focused developmental screening should be performed in the following four situations:

1. Children with known high-risk medical conditions (e.g., Down Syndrome)
2. Children with biological risk factors for developmental problems (e.g., birth weight < 1500 grams, intrauterine growth retardation (IUGR), meningitis, seizure disorder, severe chronic illness)
3. Children with significant environmental stresses (e.g., substance abusing parents, lack of stable housing, parental mental illness or mental retardation, family violence)
4. Children whose parents indicate concerns on prescreening questionnaires or in whom physicians, teachers, daycare providers or social workers suspect problems.

A screening test such as the DENVER-II is useful in screening the developmental status of a patient. It is important to remember the lack of predictive value of such an evaluation. A child identified with delay requires detailed physical examination (noting growth abnormalities, congenital anomalies, skin findings, and detailed neurologic exam), hearing and vision screening, and a comprehensive psychosocial history.

Global Developmental Delay is a term used when a child has delays in two or more areas of development and functioning (motor, language, social-emotional, self-care, behavior). Developmental delay is a descriptive term rather than a specific diagnosis. It is rarely an accurate designation beyond 3 years of age. At that time, more predictive evaluation tools are available. It is appropriate to use specific diagnoses with families whenever possible for anticipatory guidance as well as school planning. For example, if a child is diagnosed with cerebral palsy, mental retardation or autism, developmental delay would not be an appropriate primary diagnosis although it may help describe the child's functioning. By age 3 years, full scale IQ scores can be determined which give a current assessment of intellectual functioning and are more predictive of future functioning than developmental tests. Intelligence testing is *most* predictive once the child is school aged, however, so continued reassessments are indicated.

Mental Retardation is defined as

- IQ below 70
- Deficits result from injury, disease or abnormality that existed before age 18
- Limitations exist in at least 2 of the following 10 areas of adaptive behavior: communication, self-care, home living, social skills, community use, self direction, health and safety, functional academics, leisure and work.

Mild mental retardation is often an isolated disability, whereas severe mental retardation is often accompanied by associated deficits such as cerebral palsy, visual deficits, seizure disorder,

communication deficits, feeding problems, psychiatric or pervasive developmental disorders, and attention-deficit hyperactivity disorder. The differential diagnosis of the child with significant delay includes all of the associated deficits. An individual may have one or a combination of disabilities.

Distribute Part I of the case and ask one or more of the participants to read it aloud.

Part I

David, a 4 year old male, comes for his first clinic visit with his maternal grandmother, Ms. Donovan. She gained custody of David and his 3 year old brother John after her daughter, an IV drug user, lost custody due to extreme neglect. David and John were in several foster homes prior to living with their grandmother. When you inquire about David's father, Ms. Donovan says, "*All I know is he uses needles and is sick.*" She then tells you, "*David was always a handful in foster care, fighting with everyone except John.*" She goes on to describe her concern about David's development, "*His younger brother John seems more mature.*"

David is an adorable youngster. He only lets you examine him, however, when his younger brother John sits next to him and is examined first. David doesn't speak during your exam but is able to cooperate once he is more comfortable. David is a small, nondysmorphic child, who is 5th percentile for weight and height, and 50th percentile for head circumference. Other than poor dentition, he has normal head and neck, cardiac, pulmonary, abdominal, genitourinary and neurologic exams.

Using the Denver Developmental Screening Test (DENVER-II), you find that he throws a ball overhand, does a broad jump, hops, balances on each foot for 3 seconds, but is unable to heel-toe walk. In the exam room he says only "*bye-bye*" and "*Day*" (his name for himself); his grandmother reports that he uses several other words at home with occasional two word combinations. He answers simple questions but has no conversations. David identifies body parts for you but not colors, and he can name only one of the pictures that you show him. He cannot identify actions or demonstrate understanding of adjectives. His speech is half understandable. John tries to "*help out*" by answering some of the questions for David. David builds a tower of four cubes (but not higher). When you give him a crayon he smiles and scribbles. He imitates a vertical line but cannot copy a circle or cross. He cannot wiggle his thumb.

Ms. Donovan reports that David does not play with board games or with cards. He enjoys banging blocks together as well as "pop up" toys and books, his favorite ones having a train theme. He does not engage in pretend play, and prefers to play alone or with his brother rather than in a group. He occasionally bangs his head. He is able to pull off elastic waist pants but cannot dress himself or undo buttons. He uses a spoon but cannot brush his teeth or wash his hands independently. "*Toilet training has been terrible - he doesn't get it.*"

Following this reading, ask all participants "So what do you think about this case? What would you like to focus on during our discussion today?" List agenda items on a blackboard or flipchart. Then use the questions below to guide the discussion. Remember that the key to successfully leading a small group is facilitation of the discussion rather than lecture. Draw as many participants as possible into the discussion. Allow silences while group members think about questions. Present material from the discussion guide only when needed to complement or redirect the group discussion.

Distribute Handout #1: DENVER-II, Handout #2: David's Growth Chart and Handout #3: Head Circumference Chart, as the discussion touches on these points.

Guiding Questions for Discussion:

What is your interpretation of David's development based on the history and DENVER-II results? David has delays in several areas. The history obtained addresses most of the Bright Futures surveillance questions. Clearly, Ms. Donovan has concerns regarding David's development. Parental concerns regarding child development are strongly correlated with developmental delays. It is imperative to listen to these concerns seriously and perform a focused office screening when they are raised. In reviewing the history, David communicates and understands simple ideas, though his lack of conversation and abstract thought are concerning for language and cognitive deficiencies. His history of aggressive behavior and isolated play suggest delay in his social skills, while his lack of independence in dressing and eating may reflect fine motor delay. By age four, David's lack of toileting skills represents a delay which may be due to delayed social-adaptive and/or motor skills. Head banging is a behavior seen normally in some younger children but is clearly abnormal in a four year old. It may indicate frustration secondary to limited communication and coping skills or neurologic dysfunction.

Using the DENVER-II, the sense of delay is confirmed and clarified.

Personal-Social: David has 1 caution (dress-no help) and 5 delays (put on T-shirt, wash and dry hands, brush teeth with help, put on clothing, feed doll).

Fine motor-Adaptive: David has 1 caution (copy circle) and 3 delays (thumb wiggle, tower of 8 cubes, tower of 6 cubes).

Language: David has at least 5 delays (name 1 color, know 2 adjectives, know 2 actions, name 4 pictures, point 4 pictures).

Gross motor: David started walking late but can now do what is expected of a 4-year old (throw overhand, balance on each foot for 3 seconds, broad jump). At this time, David has language, fine motor and social delays.

What factors may have led to David's developmental delay? Using a "contextual approach," describe how health, social and educational elements are contributing to his current profile.

The differential diagnosis of David's developmental delay includes both intrinsic and extrinsic etiologies.

- A. Vision and hearing deficits commonly contribute to both language and social delays.
His poor dentition may exacerbate a speech problem.
- B. Intrauterine drug exposure or perinatal HIV acquisition could contribute to David's delays.
- C. Social chaos in previous homes and numerous transitions may have created a state of sensory deprivation and lack of attachment to caregivers which could contribute to David's development.
- D. David's isolation and aggression and low growth parameters may reflect stress and depression, which may also be significant contributors to David's delayed development, particularly speech and language.
- E. Mental retardation could account for David's global delays, with one or more of the

above factors enhancing the severity of his presentation.

What further evaluation would you like at this time? At this time, David requires further evaluation to elucidate the etiology of his delays. Medical work-up should include hearing and vision testing. An HIV test could also be sent, given David's high risk parents, low growth parameters and delays. As his poor dentition may contribute to his language delay, referral to a pediatric dentist should be arranged.

David should have a full assessment either by the school system or a developmental evaluation program. Psychological, educational, developmental, behavioral, motor, speech and language evaluations should be completed by qualified individuals. If medical problems are strongly suspected, a hospital-based clinic may be preferable.

Further medical testing:

If there were a history of seizures or seizure-like episodes, an EEG would be indicated. The prevalence of seizure disorders ranges from 12-58% of individuals with developmental disabilities in residential facilities, but they are not as common in children with less severe developmental disabilities.

Likewise, neuroimaging would be indicated in the case of unexpected change in behavior, head circumference, motor status, cognitive abilities (i.e. loss of milestones), or neurologic exam. Neuroimaging should also be obtained in children with micro- or macrocephaly or focal neurologic findings.

Chromosome testing would be considered for children with dysmorphic features or significant delays. Fragile X syndrome is the most common identifiable genetic condition causing mental retardation and language delays. Finally, metabolic screening is considered with a history of intermittent vomiting and lethargy, progressive loss of skills, unusual food intolerance, difficulty handling minor illnesses, suggestive body odor or family history of metabolic disorders.

At this time, there is no indication for EEG, neuroimaging or metabolic testing of David. Need for chromosome testing should be based on results of formal developmental evaluation as David has no specific dysmorphic features.

Distribute Part II of the case and have participant(s) read it aloud. The facilitator may want to have participants role play talking to David's grandmother.

Part II

David and his grandmother return to your office in 6 weeks with the results of the tests you requested. His hearing and vision are normal and he is HIV negative. A comprehensive dental plan has been initiated. Results from his school evaluation show that his IQ is 65 on the WPPSI. On the Vineland Scales, David's daily functioning (self care, communication, behavior at home) is that of a 2 to 2½ year old. His language skills are at a 2 year old level, with difficulties noted in understanding and producing language. His motor skills are at a 3 year old level. Reportedly, David wanted to please the examiners, but got easily frustrated when he couldn't do activities. His grandmother wants to know, *"What do all these tests mean? Do you*

think I should send David to the “special class” the school recommended?” She is worried about how much help David will need now and in the future. “I’m no spring chicken, doc!”

What is the most likely diagnosis at this point? At this time, David can be diagnosed as mentally retarded. The WPPSI (Wechsler Preschool and Primary Scale of Intelligence) is used for children age 3-7 years. It includes multiple subtests and yields verbal, performance and full scale IQ scores. The Vineland Adaptive Behavior Scale is used to assess communication, daily living, motor and socialization skills from birth to adulthood based on caregiver report. Both David's IQ and limitation in daily functioning allow a diagnosis of mild mental retardation to be made. Nonetheless, several associated factors may have impacted his delay. Initial social deprivation and chaos as well as his dentition and possibly poor nutrition may have exacerbated his delay in developing. Therefore consistent follow up is indicated as David's developmental profile may change over time.

What specific supports and interventions would you recommend now? Use a contextual approach in developing your management plan. David should be placed in special education classes for children with similar disabilities. Instructors can focus on developing motor and academic skills appropriate to his level. Speech therapy and counseling should be incorporated. A structured after school program which includes his brother may benefit David. Additionally, his brother may be included in some therapy sessions as well. A stable home environment with parental guidance and social support is mandatory. At this time, testing for Fragile X may be performed so that associated problems (scoliosis, language disorder, anxiety, mitral valve prolapse) can be identified.

What is your prognosis for David? What will you say to his grandmother? Though David's prognosis is imprecise at this young age, his grandmother can be assured that ongoing evaluation, support and intervention will maximize his potential. It is reasonable to think that he could achieve at least 6th grade academic skills and be able to live independently. He should have regular hearing and vision screening as mild sensory deficits can have magnified effects on his delays. David should have continued psychologic monitoring as he is at risk for emotional problems which may be difficult to ascertain. His family history may increase his risk for problems with addiction. He may benefit from participating in sports teams or Special Olympics, both for social skill reinforcement and for self esteem. Eventually, vocational rehabilitation may be appropriate for him as a predictable and well supervised job would suit him. He should have repeat developmental assessments as his progress may be altered by an improved social environment and his individualized intervention plan.

It is challenging to deliver the diagnosis of mental retardation to parents and family members. The following are suggestions for presenting difficult news to parents and families:

- Listen to caretaker's concerns and questions
- Speak clearly and avoid euphemistic or vague terminology
- Be honest yet hopeful
- Say something personal and positive about the child
- Remember to use the child's name
- Pause frequently to allow caretakers to take in what you are saying and ask

questions

- Be prepared for a variety of emotions including anger, shock, sadness or denial; it is more helpful to acknowledge these feelings than try to change or challenge them
- Offer support and long term follow up

The following is an example of how you might answer Ms. Donovan's questions.

“David’s testing shows that his thinking, communication and other abilities are more like a younger child’s. His intellectual functioning, or “IQ” is below average. His abilities for thinking and daily living skills are in the mildly mentally retarded range. David can continue to make progress and learn as he gets older, but he will learn more slowly, and will always be “behind” other kids his own age; he won’t fully “catch up”. We don’t know what causes mild mental retardation in most kids. Sometimes we can identify the cause through blood or other laboratory tests. In David’s case, I would like to do a chromosome test. I would also like to reevaluate David’s progress over time, as he is young and has not had any special education yet. When he is school-aged, testing will provide a better prediction about his future potential and learning needs.”

“The term mental retardation is helpful because it explains why David’s development has been “delayed” or “slow” in the past. David’s school will be better able to address his individual learning needs. David will be able to learn to read and write and should be able to work and live independently as an adult if he gets the right kind of help now. It’s important for him to receive special education so that he can reach his full potential. I’d like to meet with you again after David has started in his new class. We can review the results of the blood test and talk more about his diagnosis. Please call me if you want to talk sooner or have other questions.”

****Optional Exercise:** Facilitator’s may wish to have learners role play this conversation, with one participant taking the part of the clinician and the other taking the part of David’s grandmother.

Distribute the Bibliography page and Epilogue. Ask someone to read the Epilogue aloud.

Epilogue

David was enrolled in a special education program for children with mild mental retardation. His grandmother meets regularly with a psychologist for supportive counseling and behavioral guidance and reports *“things are much better now at home.”* David is being evaluated by a psychiatrist because his teachers are concerned about depression. He has otherwise adjusted well to his new class and follow up testing showed improved functioning in a number of areas.

Refer back to group’s learning agenda and summarize the key teaching points that were made. This will give the group a sense of accomplishment, and emphasize the

important messages. Suggest further sources of reading or other information if there are agenda items that were not covered in the discussion.

Independent Learning/Prevention Exercises: Facilitators may wish to assign “Independent Learning/Prevention Exercises” to the group, particularly if time constraints hinder the completion of the case. The following list includes suggestions to explore the available community resources that focus on Global Delay and other pertinent areas of interest that can be integrated during or after the session. If the exercise is done in the absence of the facilitator, learners should take notes on their experience, then discuss with a faculty member for feedback.

1. Visit a Special Needs classroom for children with global delay.
2. Call the local Department of Mental Retardation (DMR) (or other similar government agency) and ask what supports they can provide to children with mental retardation.

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Epilogue

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Will David Catch Up? Handout #1: Denver II

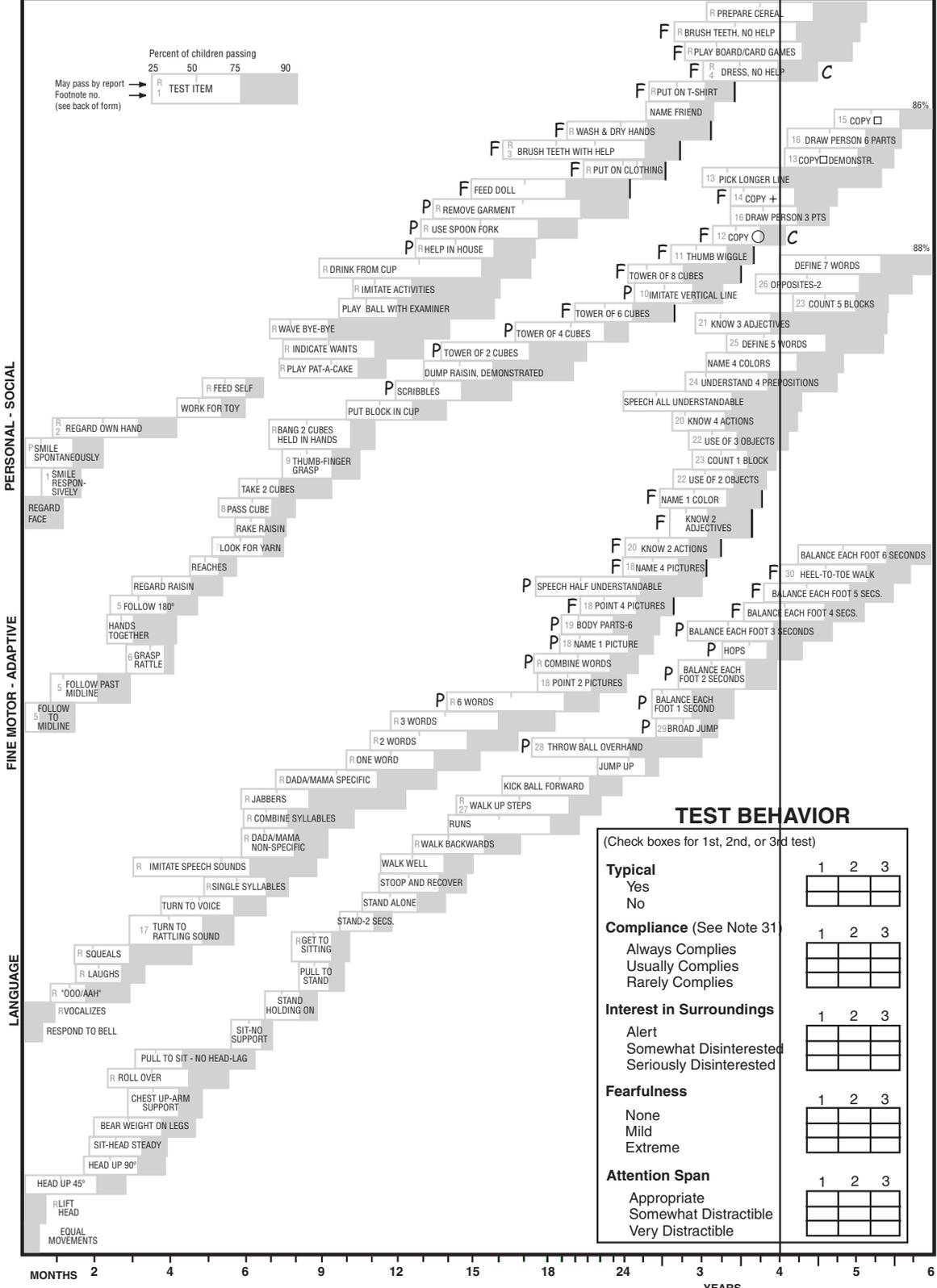
DA FORM 5694, MAY 1988

Examiner:
Date:

Name: David
Birthdate:
ID No.:

Denver II

MONTHS 2 4 6 9 12 15 18 24 3 4 5 6 YEARS



FOR USE OF THIS FORM, SEE AR 600-75

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Will David Catch Up?

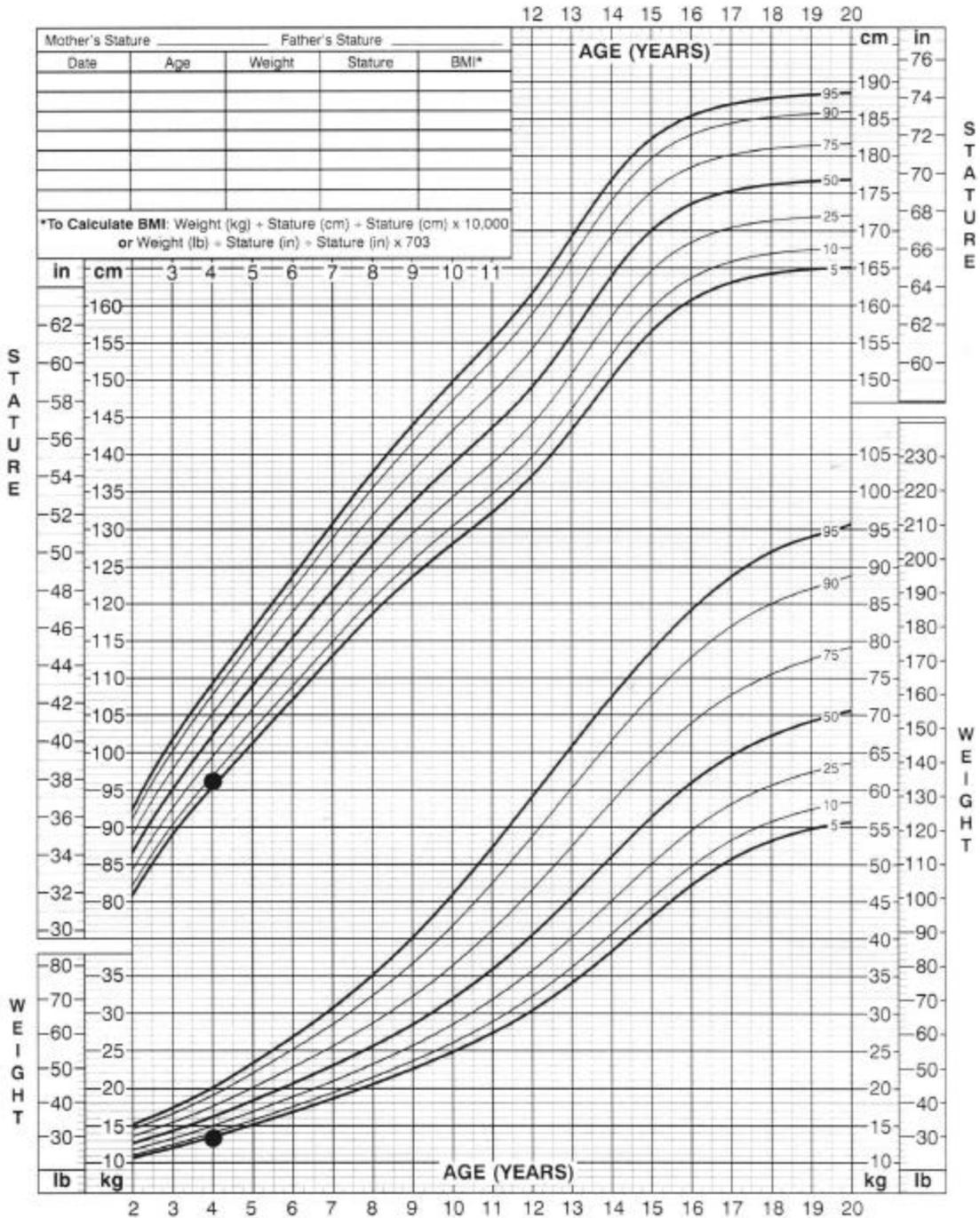
Handout #2: David's Growth Chart

2 to 20 years: Boys

NAME David

Stature-for-age and Weight-for-age percentiles

RECORD # _____



Revised and corrected November 28, 2000.

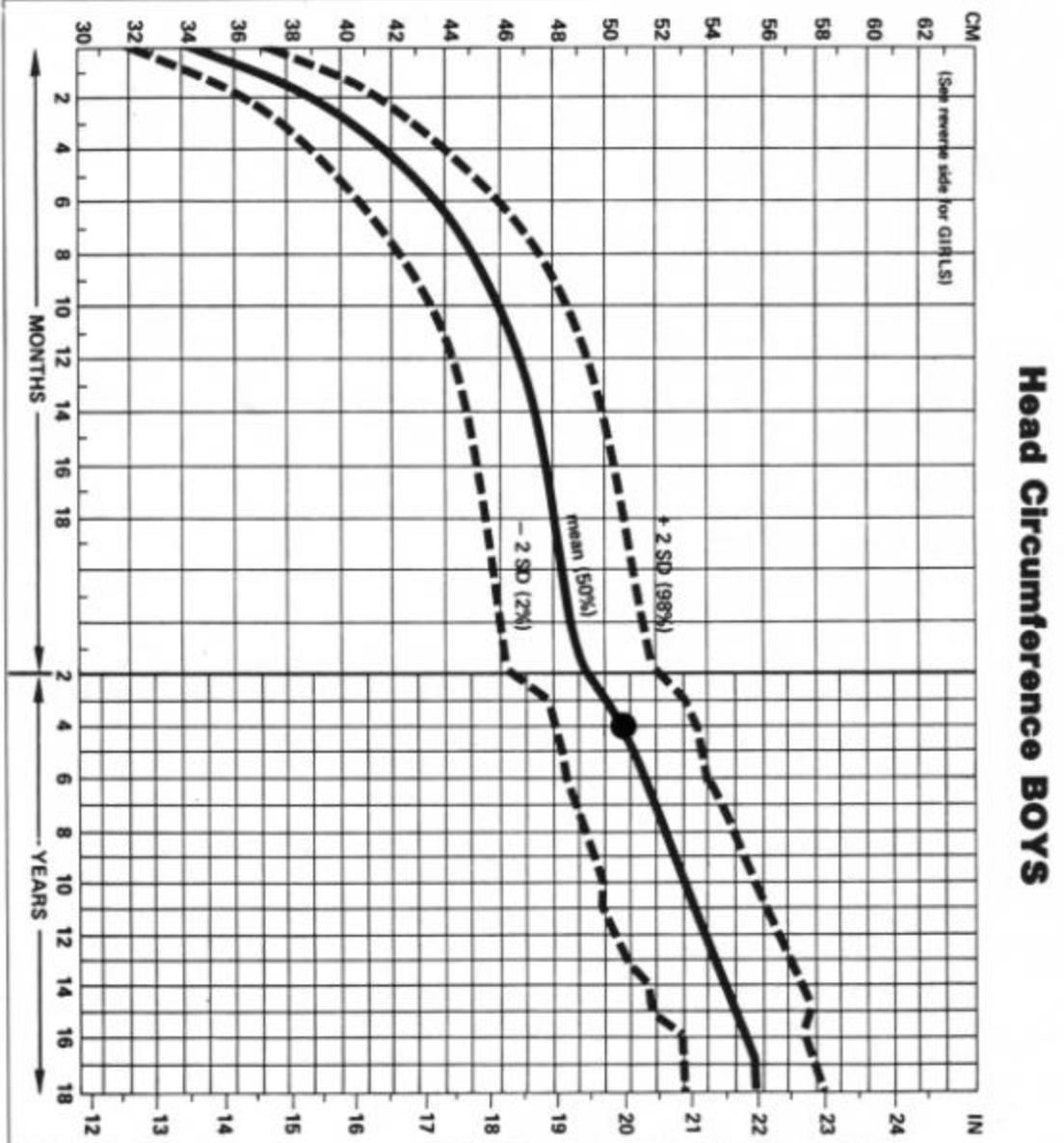
SOURCE: Developed by the National Center for Health Statistics in collaboration with the National Center for Chronic Disease Prevention and Health Promotion (2000).
<http://www.cdc.gov/growthcharts>



Will David Catch Up?
Handout #3: Head Circumference Chart

Head Circumference BOYS

SEX: _____ DATE: _____
 NAME: David
 GRADE: _____
 ADDRESS: _____
 DATE OF BIRTH: _____ A.C. No. _____
 Age: _____ Sex: _____



Head Circumference BOYS Ref: NELLHAUS, G., Pediatrics 41: 106, 1968
 © American Academy of Pediatrics, 1968.

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Suggested Readings (Annotated):

Batshaw ML. Mental retardation. *Pediatric Clinics of North America* 1993;40:507-521. This review article addresses the differential diagnosis and diagnostic evaluation of significant developmental delay, as well as intervention strategies which can be applied once the diagnosis of mental retardation is made. Intervention strategies may be particularly helpful to the primary care clinician.

First LR, Palfrey JS. The infant or young child with developmental delay. *The New England Journal of Medicine* 1994;330:478-483. This review article reinforces the importance of early identification of developmental delay and provides a step by step approach in developmental assessment appropriate for the primary care clinician.

Levy SE, Hyman SL. Pediatric assessment of the child with developmental delay. *Pediatric Clinics of North America* 1993;40:465-477. This article has a brief review of developmental assessment with a lengthier section on medical testing. It includes useful tables of physical exam findings and their associations with developmental disabilities and syndromes.