Jose's New Family
Facilitator's Guide

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Topic: Atypical Behaviors

Abstract:
International adoption is an increasingly common way to build families in the U.S. Many adopted children arrive from other countries with little or no background information and a host of potential medical, developmental, behavioral, and psychosocial problems. Families may consult their primary care clinician when considering adoption, or just after a child comes to live with them. Clinicians should know how to evaluate these children, assist families, and provide linkage to appropriate resources for early treatment. This is the story of Jose, a 2-year-old boy from Central America, who is being adopted by a couple in the United States. He has some unusual behaviors and developmental delays, and has likely come from a background of deprivation, malnutrition and maltreatment. Clinicians will discuss the appropriate work-up and interpretation of Jose's current problems in the context of his difficult past life and present transition.

Goal:
To provide learners with an understanding of how to evaluate unusual behaviors in the context of adoption.

Objectives: By the end of this session, learners will be able to:
1. Define adoption and discuss how it affects children and families.
2. Discuss the appropriate medical, developmental and psychosocial assessment of an adopted child with unusual behaviors.
3. Describe the role of the clinician in pre-adoptive assessment and in assisting children and families throughout the adoption process.

Prerequisite Cases:
"When to Watch, When to Refer, When to Reassure" (Using the Denver II)
"The Tongue Tied Toddler" (Language Delay)

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Related Case:
"The Pain that Just Wouldn't Go Away" (Recurrent Abdominal Pain)
"The Father's Handprint" (Physical Abuse)
"Margaret's Secret' (Sexual Abuse)
"The Silent Cry" (Neglect, Parental Alcoholism)

Themes: Child Development and Behavior, Growth in Children and Adolescents

Key Words: Adoption, unusual behaviors, atypical behaviors, developmental delay, speech/language delay, child abuse, international health, tuberculosis, parasites, iron deficiency

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, advocacy, and prevention/health promotion.

Materials Provided:
- Facilitator's Guide
- 3-part Case Narrative: Part I, Part II, Epilogue
- Handout #1: Denver II
- Handout #2: Growth Chart
- Handout #3: Head Circumference
- 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).

Introduction: Adoption is a legal mechanism allowing for full family membership and privileges to children not born into the family. Approximately 2% of children in the U.S. are adopted. In 1986, there were about 115,000 total adoptions in the U.S., with approximately one half involving adoption by non-birth-family members. Over 12,000 children were adopted from outside of the United States in 1997 and many of these adoptions involved children with special needs. Risks inherent in adoption, whether domestic or international, include both legal risk and medical risk. Legal risk refers to problems that can prevent the adoption from becoming final (e.g., a birth mother changing her mind, a judge awarding custody to a previously unknown or

disinterested family member). Medical risk refers to problems that are known or as yet undiscovered. In either case, adopted children may require more time and attention from health care providers. A pre-adoption visit is highly recommended to assist parents in interpreting medical and developmental information and to help them anticipate problems and special situations. Very often, children arrive with little or no background information. One study has shown that the most common problems among international adoptees are: deficient immunizations (37%), intestinal parasites (29%), emotional or behavioral problems (22%), skin diseases (16%), uncertain age (12%), scabies and/or lice (10%), and congenital anomalies (10%). Other problems that have been identified among these children include developmental delay, lactose intolerance, vision and hearing deficits, hepatitis B, hepatitis C, HIV, rickets and fetal alcohol syndrome. A child's risk of these medical conditions varies greatly depending on their country of birth.

Open the Discussion: Introduce the case title and the session goal. Explain that this will be an interactive case discussion and not a lecture. Distribute Part I of the case and ask one or more of the participants to read it aloud.

Part I

Jose, a Central American boy who is reported to be 2 years old, is brought to your office for an initial assessment. He has been living with the Cohens, his adoptive parents, for one month. While the adoption has been completed in his home country, it has not yet been made final in the U.S. Mr. and Mrs. Cohen have little medical history or background information on Jose. According to papers from the orphanage where he was living, he received one set of immunizations before being released for travel to the United States. Little is known about his birth parents, but authorities suspected that his mother was a cocaine addict. When he was approximately 10 months old, Jose was found with his 7-year-old sister on the street. Both of them were placed in the orphanage. His sister subsequently ran away.

Mrs. Cohen says, "*Jose doesn't talk very much and it worries me. I try to speak to him in Spanish, but he doesn't always answer. I don't even know if he understands me.* "
You ask, "*How many words do you think he can say in Spanish?*"
"*Probably 5 or 10*," she responds. "*Sometimes I've heard him singing to himself in Spanish, though.*"
"*How does he let you know when he wants something?*"
"*He either cries or points.*"
You then ask, "*How does Jose act around other children?*"

Mr. Cohen tells you that both he and his wife work, so Jose spends several hours a day in a home-based day care center. The day care provider told them that Jose rarely plays with the other children. Mrs. Cohen states that Jose seems to prefer to be by himself when at home, too. Her two older children, ages 8 and 10, are eager to play with him, but Jose rarely acknowledges them. He does seem interested in toys, but doesn't always know what to do with them. For example, he likes to sit and hold toy trucks, rather than "driving" them around. He likes to bang blocks together, but doesn't stack them.

Mrs. Cohen states that Jose seems quite different from her other children when they were his age. She and her husband want to know if his unusual behavior is "*a phase that he will grow out of, or a more serious problem.*" During this conversation, Jose has been sitting in Mrs. Cohen's lap holding a Big Bird doll. He has not made any sounds, nor has he looked at any of you.

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.

Guiding Questions for Discussion:

What is your impression of Jose's behavior? Some of Jose's behaviors are concerning. He has limited speech. A normal 2-year-old should have a vocabulary of at least 50 words and should be starting to create 2-word phrases. The fact that Jose points when he wants something is somewhat reassuring. Children with Pervasive Developmental Disorders (PDD) or autism do not usually do this. Jose's receptive language ability is unclear. Most 2-year-olds should be able to follow simple commands. However, an English-Spanish language barrier may influence Mrs. Cohen's observations of Jose. He could have developed language to an age appropriate level in Spanish and not be understood, or he may have delayed primary language acquisition. In either case, his facility learning a second language (English) will be impacted by his degree of language development in his primary language. (For more information on language delay, see the case of the "*Tongue Tied Toddler*.") In early childhood, play reflects cognitive and social development. Abnormal play may indicate deficits in either area. Normal 2-year-olds have not grasped the concept of reciprocal (interactive) play, but like to play alongside other children (parallel play). Regarding use of toys, most 2 year olds engage in simple symbolic play (running a toy car along the ground and saying "vroom vroom") and should be able to stack at least 4 blocks. Jose demonstrates developmental lags in his play and fine motor skills. (See the Denver II case, "*When to Watch, When to Refer, When to Reassure*," for more information on developmental screening and interpretation.)

What is your preliminary differential diagnosis? Environmental factors can cause developmental delays. Important examples include inadequate stimulation, deficient interpersonal nurturing, physical abuse or neglect, poverty, malnutrition, family chaos, and cultural adjustment. Given his turbulent early life, Jose may also have difficulty with attachment or suffer from post traumatic stress disorder (PTSD) or depression. These conditions may make him appear to have greater delays than is actually the case. In particular, children who have spent significant periods of time in an institution (e.g., orphanage) may not have the opportunity to form a positive bond with a primary caregiver, and therefore appear aloof and disinterested when first coming to live with their new families. Other possibilities should also be considered. Medical causes of developmental delay include impairment of vision or hearing, plumbism, genetic abnormalities (e.g. Fragile X, Down syndrome), intrauterine infection or drug exposure, fetal alcohol syndrome, acquired infections, CNS trauma, hypothyroidism, neurocutaneous syndromes (e.g. Tuberous Sclerosis, Neurofibromatosis), seizure disorders,

prematurity, perinatal complications, and inborn errors of metabolism. Behavioral syndromes associated with developmental delay include Pervasive Developmental Disorder (PDD), autism, and childhood psychosis.

What further information would you like? Under ordinary circumstances, one would like a full prenatal and birth history, details of early developmental milestones, history of illnesses, hospitalizations, and absence or presence of seizure activity. Since Jose is being adopted internationally, information on his birth and early development may be very limited. However, families can often provide valuable information about their child's situation just prior to the adoption. The Cohens should be asked to describe the orphanage (e.g., caregiver to child ratio, presence or absence of toys) and to relay any reports that they were given by orphanage staff. They can also provide information regarding their direct observations of Jose for the past month. They should be asked about Jose's response to sound, his apparent vision, impression of gross and fine motor skills, and possible seizure activity. Also important are questions about adaptive skills, i.e., toileting, eating, dressing and undressing, sleep, and any odd behaviors. Regarding social history, one would usually ask: 1) What is the family structure? 2) Who are the primary caregivers? 3) How does this child spend his/her day? (home, type of daycare, etc.) 4) Have there been any stresses in the home? (chaotic daily schedule, marital discord, substance abuse, violence, neglect, financial problems, etc.).

Jose will, of course, need a complete physical examination.

Distribute Part II of the case and have participant(s) read it aloud. The facilitator should also distribute Handout #1: Denver II, Handout #2: Growth Chart and Handout #3: Head Circumference.

Part II

You ask the Cohens, "*Do you have any concerns about Jose's hearing or vision?*"

Mrs. Cohen answers, "*He seems to hear everything. He always runs to the window if a truck goes by and will usually go into the den if he hears the TV is on. I also think his vision is fine. He finds "M&M"s and other tiny things on the floor even when I wish he wouldn't!* "

You ask about unusual behaviors. Mrs. Cohen reports that she has seen Jose "*staring into space,*" but has never seen repetitive or tonic clonic movements. He has a fairly restricted diet, clearly preferring bland starches such as bread, rice, pasta, crackers, and french fries. On several occasions, Mrs. Cohen has found stashes of food hidden in his room. The Cohens have seen no repetitive self-stimulatory activities (e.g., rocking, head-banging, spinning around, hand-flapping).

You perform the Denver II developmental screening test. *(See Handout #1)*

On physical examination, Jose appears somewhat small for his presumed chronological age. *(See Handouts #2 and #3.)* He has no dysmorphic features. Examination of the skin reveals a small circular scar over the left deltoid, and well-healed linear scars on his lower back, buttocks, and posterior thighs. He has normal appearing tympanic membranes and normal oro-motor structure and function. Thyroid is nonpalpable. Heart and lungs are normal, and there is no hepatosplenomegaly. Genitalia are that of a normal

uncircumcised male. He has no sacral dimple or tuft. Examination of the extremities reveals normal bulk and muscle tone. His DTR's are brisk but symmetrical. His gait is well coordinated.

What factors might have influenced Jose's development? When assessing developmental delay, clinicians must remember that child behavior and development results from a complex interaction of **intrinsic** and **extrinsic** factors. Intrinsic factors (in the child) include biomedical problems, genetic syndromes, and innate temperament. Extrinsic factors (in the environment) include family structure and stability, economic status, cultural values, and caregiver response to perceived problems in the child. Children who are adopted are at increased risk for both intrinsic and extrinsic problems. For example, children who have special needs may be more likely to be abandoned, neglected, or mistreated by their families of origin - and thus made available for adoption. Conversely, children who are abandoned or removed from their families of origin are at increased risk of developing problems of adjustment and attachment, which may manifest themselves as abnormalities of development or behavior.

What is the most likely cause of Jose's unusual behaviors? Jose has just undergone a major life transition by moving in with his new family and being suddenly immersed in a new language and culture. His history of deprivation and loss has also had a significant effect on his development. These are the most likely causes of his unusual behaviors, but other possibilities cannot be completely excluded. Jose's gross motor skills are age-appropriate. Some of his fine motor and adaptive delays (not using a spoon, not "helping" to put on clothing) are concerning, but may be explained by lack of exposure. However, he clearly has a delay in language skills. Language development is dependent on early stimulation and interpersonal interaction, and thus tends to be the more delayed than the personal-social or gross/fine motor domains among children who experience deprivation. Therefore, all of Jose's problems, including inappropriate use of toys and lack of peer interaction, could be due to early social deprivation and instability. One cannot exclude a primary language disorder, however. PDD and autism remain possibilities as well, but are less likely given the absence of stereotypical behaviors and presence of early play skills. Close monitoring, with early referral to a specialist and intervention program, is warranted.

What further evaluations are needed? All international adoptees should undergo a standard medical screening. This should include Hepatitis B and C profile, stool for ova and parasites, PPD, CBC, HIV test, RPR or VDRL, lead and urinalysis. Immunization should be reviewed and the possibility of sickle-cell disease considered. All adopted children should have rigorous developmental screening with documentation of delays, and assessment of hearing and vision. This will allow for early intervention, and can assist parents in gaining access to state sponsored special education programs and other treatment services. Jose will also require close developmental and behavioral monitoring. Lack of progress in his new home would indicate a need for reconsideration of other etiologies (e.g., Fragile X). The pattern of scarring on his back may be a result of physical abuse and a skeletal survey is indicated. If this confirms the diagnosis, he and his parents should be promptly referred to a child mental health professional with expertise in this area for therapeutic interventions (e.g., parental guidance, play therapy).

Unfortunately, histories of physical and sexual abuse, and resulting PTSD, are now being reported more often among international adoptees.

What will you say to Jose's parents about his prognosis? While the majority of internationally adopted children do quite well, those who have been institutionalized have a higher incidence of attachment disorders, intellectual impairment, delays in language development, sensory hypersensitivity, and poor social skills. These children make progress following adoption, but long term prognosis is unknown. The clinician should present both an honest and optimistic view of the situation. Increasing an awareness of the child's strengths will foster the parent-child bond, which can only help promote optimal development. One way of presenting this to the parents is as follows:

"Thanks for bringing Jose in today. I really enjoyed meeting him and seeing all of you together. You are a very special family. I'm happy to report that Jose has many wonderful strengths. Overall, he appears to be in good physical health. I've found no evidence of any current infections, and we'll do a few tests today to make sure we haven't missed anything. He appears well nourished, strong, and coordinated. I have no reason to believe there's anything wrong with his vision or hearing, and the fact that he sings to himself probably indicates he can remember things he has heard. He has no odd behaviors that would lead me suspect a serious developmental disorder like autism. The things he has trouble with - playing with other children, using toys and silverware appropriately, and talking - may all be explained on the basis of the difficult circumstances of his early life. I am concerned that, at some point, someone might have physically mistreated Jose. I'm going to order x-rays today that may show old fractures. In any case, he has undergone a lot of recent changes - a new family, a new language, and a new country. Once he's adjusted to these things, I would expect him to begin to catch up. Whether or not he will catch up completely is something only time will tell. In the meantime, we can help to work on his language and social skills by enrolling him in a special program. While early intervention programs are important, his new family is much more important. The loving, nurturing environment that only you can provide is critical to his future growth and development.

There may be some ups and down along the way. There may be some times that you are still worried about Jose. You can always call me. I will want to see you again in two weeks. We can review some of the test results and the progress you are making. And we'll arrange regular visits after that."

Clinicians may also offer anticipatory guidance regarding the most common problems that are seen early on among internationally adopted children. These include sleeping difficulties, hoarding of food (pouching), and oppositional behaviors, rocking and head banging. Be sure as well that the new parents are receiving appropriate guidance and support. These services are often provided by the adoption agency, but clinicians should ask about the precise nature of such assistance and determine if additional help is needed.

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

Epilogue

Jose returns with his parents 2 weeks later. Hearing and vision screens were normal. His Hepatitis B profile, syphilis serology, and HIV test are all negative. His CBC reflects a mild microcytic anemia suggestive of iron deficiency, and his lead level is <10 mcg/dl. Sickle cell screen is negative. The urinalysis is normal. There is a 10 mm. area of induration at the site of his Mantoux test. You telephone the orphanage in Central America and discover that he had received BCG even though this was not recorded in his overseas medical record (thus the circular scar over his left deltoid). A follow-up chest X-ray shows no evidence of tuberculosis. His stool examination reveals a few ova consistent with infection by *Schistosoma mansoni*. The skeletal survey shows healed fractures of both femurs and 4 ribs.

After obtaining an Infectious Disease consultation, you treat Jose with INH for 9 months. You prescribe a 3-month course of therapeutic iron and praziquantel (40 mg/kg divided into 2 doses over 1 day). You refer Jose to the *Brownville Early Intervention Center*, and he enjoys going to the *Toddler Group* immensely. He develops good rapport with his speech and occupational therapists. Because of the positive skeletal survey, you also refer Jose and his parents to a child psychologist with particular expertise in child abuse treatment.

Jose's adoption in the U.S. is finalized during the following year. As he approaches his 3rd birthday, you refer him for a school-based evaluation so his special services can be continued. By the time he is ready to enter kindergarten, Jose has made tremendous progress. He now enjoys playing with the other children and his unusual behaviors have gradually disappeared. He is still at risk for learning difficulties, but does not need special services at this time. He is closely monitored at school and is seen by you on a regular basis.

Jose is a happy child and the Cohens are thrilled with him.

Facilitators may wish to review the American Academy of Pediatrics' *Red Book* guidelines for "*Medical Evaluation of Internationally Adopted Children*," as well as treatment recommendations for Tuberculosis and Schistosomiasis. Copies of these sections may be used as handouts, and distributed at the end of the session. If there is sufficient time, learners may also wish to discuss how and when adoption should be discussed with a child, and how primary care clinicians can assist parents with developmentally appropriate disclosures.

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 International Adoption, as well as other areas of pertinent 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.

1. Invite an adoptive family to come in and speak to the group about their experiences.
2. Invite a public health specialist to talk about screening for infections diseases in foreign adoptees.

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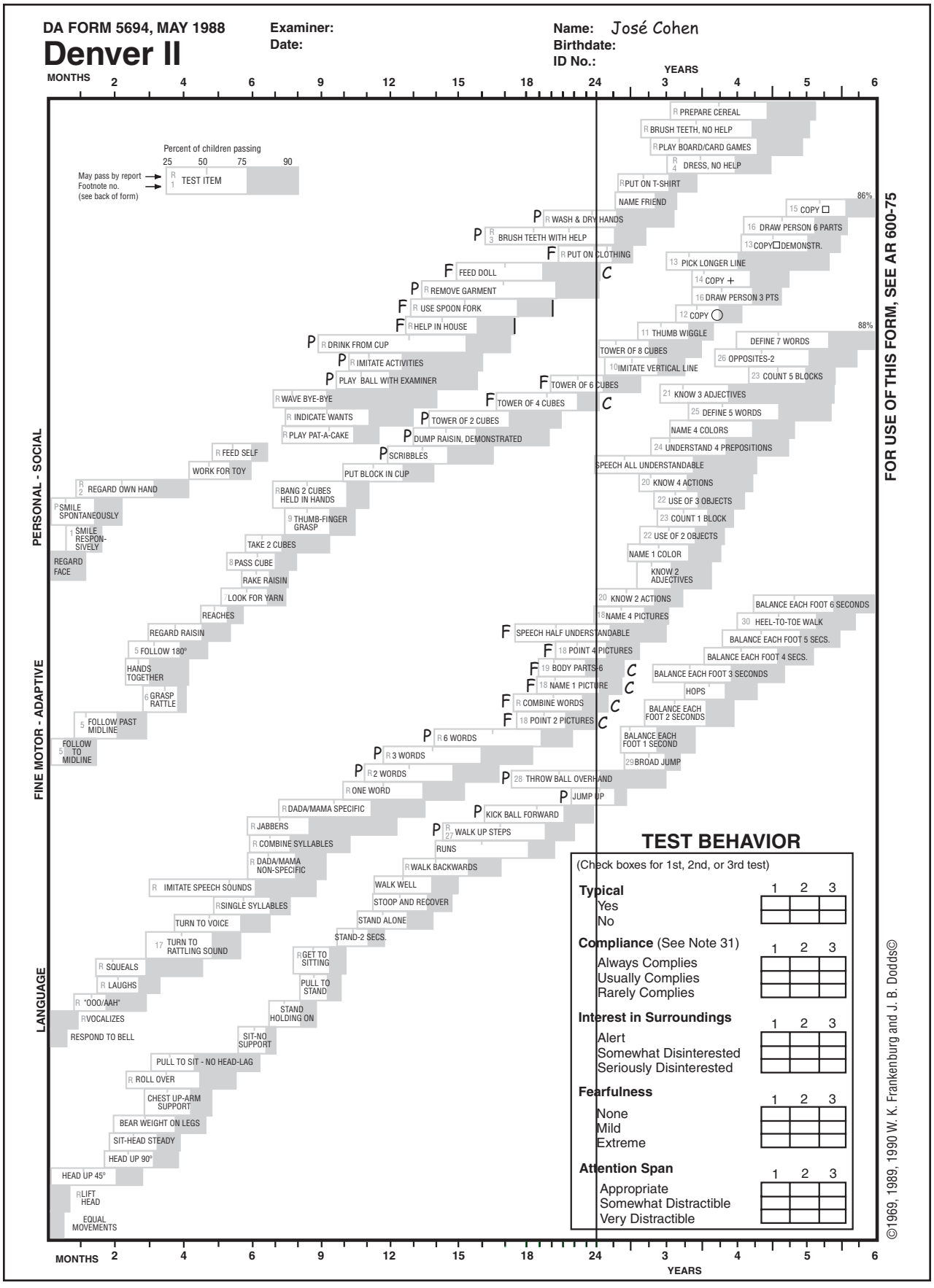
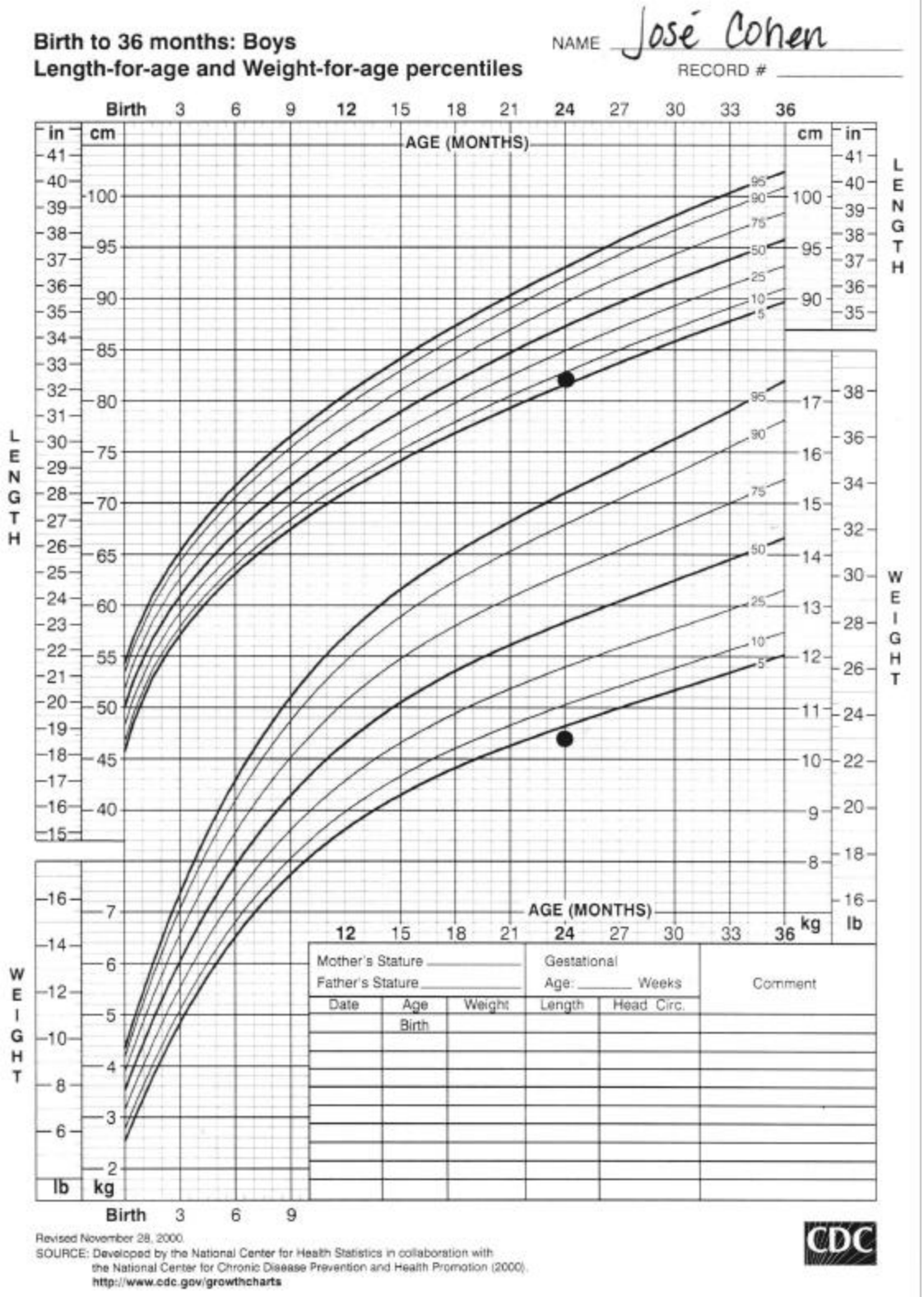
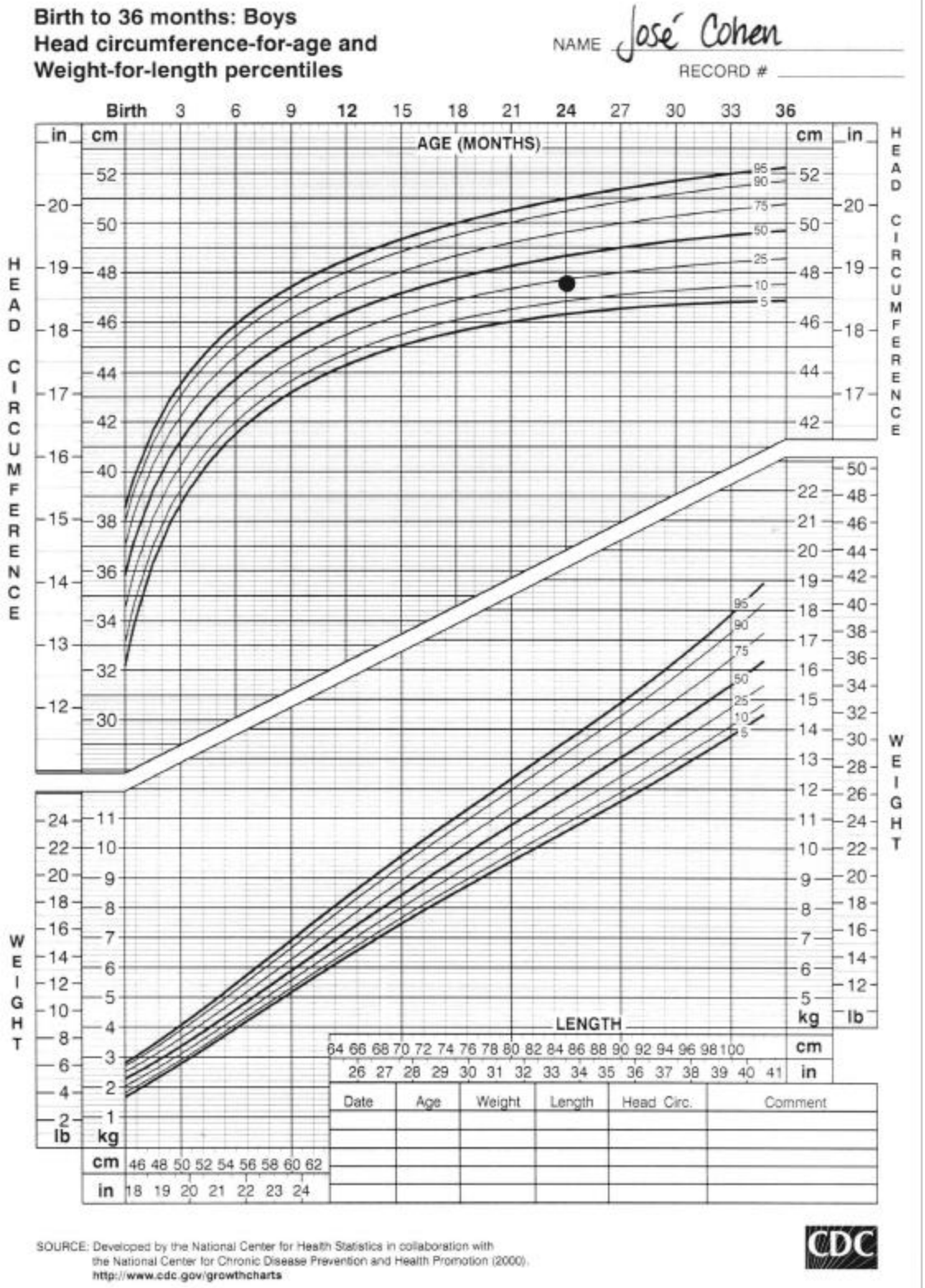
José's New Family
Handout #1: Denver II



Jose's New Family
Handout #2: Jose's Growth Chart



Jose's New Family
Handout #3: Head Circumference Chart



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Suggested Readings (Annotated):

Barnett ED, Miller LC. International adoption: The pediatrician's role. *Contemporary Pediatrics* 1996;13(8):29-46. This article describes the step-by-step procedure of adopting a child internationally and how the pediatrician can guide a couple through this complicated, often confusing process. It gives recommendations for physicians on what to expect and explains the special considerations in approaching the medical assessment and evaluation of these children.

American Academy of Pediatrics Committee on Early Childhood, Adoption, and Dependent Care. Initial medical evaluation of an adopted child. *Pediatrics* 1991;88(3):642-644. This article addresses the initial medical evaluation of adoptive children who may have acute and long-term medical, psychological, and developmental problems because of their genetic, emotional, cultural, psychosocial, and/or medical backgrounds.

Resources for Families:

National Organizations:

National Adoption Information Clearinghouse 5640 Nicholson Lane, Suite 300 Rockville, MD 20852 (301) 231-6512	National Adoption Center 1500 Walnut Street, Ste. 701 Philadelphia, PA 10102 800-TOADOPT, (215) 735-9988

Books:

Alexander-Roberts C. *The Essential Adoption Handbook*. Dallas, TX: Taylor Publishing Company; 1993.
Bascon BB, McKelvey CA. *The Complete Guide to Foreign Adoption*. London: Pocket Books; 1997.

Educational Resources on the World Wide Web:

National Adoption Information Clearinghouse
http://www.calib.com/naic/online.htm

American Academy of Child and Adolescent Psychiatry—Facts for Families. This site provides access to the AACAP's award winning "Facts for Families" pamphlet series on various developmental topics. "The Adopted Child" information sheet is #15.
http://www.aacap.org/publications/factsfam/index.htm