

A Child with Fetal Alcohol Syndrome

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Alcohol is a common human teratogen that, when ingested by a pregnant woman, can produce a wide array of fetal complications. The fetus's developing brain seems most sensitive to prenatal alcohol exposure: Alcohol-related brain damage can be quite diffuse, ranging from microcellular, neurochemical aberrations to macroscopic malformations (Stratton, Howe, & Battaglie, 1996). The neurological, cognitive, and behavior problems that arise from prenatal alcohol exposure are protean in their severity and diversity. Other prenatal determinants - for example, genetic factors or teratogenic exposures that lead to specific conditions, such as attention-deficit/hyperactivity disorder (ADHD) or learning disabilities-can further affect the developmental outcome of a child prenatally exposed to alcohol. Aversive experiences after birth and throughout life also can have a profound influence on an individual's performance in these domains. Complexity in etiology and outcome is the rule, not the exception, in working with children who have been exposed to alcohol.

Fetal alcohol syndrome (FAS) does not represent the totality of individuals exposed to alcohol in gestation or the entire group of people with impairments related to prenatal alcohol exposure. Rather, FAS is defined by specific aberrations in growth, facial form, and central nervous system (CNS) functioning (Stratton et al., 1996). FAS is noteworthy because it can be specifically identified as a condition due to gestational alcohol abuse. Thus, it is an important starting point for outreach to women who are at high risk of having other children with disabilities. In addition, this designation assists government systems related to education, social service, and criminal justice in planning for service needs.

The label *FAS* is actually less helpful for individuals who have the disorder themselves as it does not, in and of itself, guide parents or professionals in proceeding with interventions specific to the child. Moreover, the term excludes many individuals with the same degree of developmental delays related to alcohol exposure who do not have the diagnostic markers of FAS. Nevertheless, there are two important reasons to examine whether a child's impairments are related to alcohol teratogenesis, especially to FAS. First, knowing that alcohol exposure occurred during pregnancy helps a clinician understand that if the child has a complex profile of cognitive or behavior difficulties, then alcohol-related damage may be one antecedent in a larger set of etiological factors. Children with FAS or related conditions may generally have some combination of ADHD, learning delays, language processing and usage difficulties, problems in planning and judgment, or increased soft neurological signs. In addition, if the child is school-age or older, "secondary disabilities" may have emerged from experiences of frustration, failures, and lack of acceptance by peers and adults, particularly if the full extent of the child's disability has not been recognized.

Clearly, a team approach to assessment and intervention is necessary for understanding such complex problems. A diagnosis often initiates an important spontaneous intervention by changing the attitude of family members and teachers working with the child, so they can see that the child "can't" rather than "won't" behave in an acceptable manner. Members of the child's community can then understand that the child is disabled and not simply disobedient (Streissguth, Barr, Kogan, & Bookstein, 1996). Second, recognizing that a child has FAS may help prevent prenatal alcohol exposure in the biological mother's future pregnancies. In an assessment of FAS, both the biological mother and her child are the focus of the team's efforts. Women who have children with FAS usually drink regularly and in high volume during pregnancy. Although it is true that women who consume alcohol in the gestation period may be committing "fetal abuse", the case of a woman drinking purposefully during pregnancy to harm her child is rare. It is therapeutic to inform biological mothers of this problem so that they know that the child is receiving appropriate supports and everyone can proceed in a positive manner. Although the process of working with the biological mother can be complex and involves a different group of professionals than those needed to assess the child, it is critical and ethically necessary that these

diagnostic and intervention efforts be linked (Astley, Bailey, Talbot, & Clarren, 1998).

ASSESSMENT FOR DIAGNOSIS OF FETAL ALCOHOL SYNDROME

The features of FAS are not dichotomous (present or absent) but, rather, each feature is on a continuum from clearly within the normal range to clearly the feature of FAS. Without suitable guides and standards, this leads clinicians to variable judgment in final diagnosis. To minimize clinical variability, the diagnosis of FAS or related conditions is made using a sequence of four 4-digit Likert scales (Astley & Clarren, 1997) in the clinics of the Washington State FAS Diagnostic and Prevention Network. Delays in growth, facial morphology, organic brain damage, and teratogenic exposure to alcohol are each evaluated separately. A "1" on any scale means a finding within the normal range. A "4" on any scale represents a finding that corresponds with accepted cases of FAS. A score of "2" or "3" specifically defines intermediate steps between clearly typical and atypical. It is important to note that these scales do not necessarily measure increasing severity; rather, they are scales of greater clinical confidence that the sought FAS characteristic is present. A child with a "4" for brain damage, for example, meets the medical criteria for a structurally altered brain but may be more cognitively or behaviorally within the normal range than a child with a score of "2" in whom the etiological relationship between brain structure and brain function is diagnostically indeterminate. Similarly, a child with a "4" for facial morphology has all of the facial diagnostic features of FAS yet may be somewhat more attractive than child with a score of "2"-who has an unusual face, but not the facial features common to FAS. The final category based on examination of the child is whether he or she has delayed growth. Establishing if a person's height or weight is "blunted", due to prenatal reasons, from its genetic potential is actually the most difficult part of diagnosis. Growth retardation is defined as a "4" when a child's measurements are less than 2 standard deviations (SD) from the mean after height (adjustment for mean parent height) and for weight.

The alcohol exposure scale is judged by whether the dose exposure pattern approaches on that causes fetal damage in animal models and whether the information is documented or speculative. Dose response relationships between maternal alcohol intake and fetal outcomes remain complex and somewhat vague for various reasons. Obtaining accurate information on alcohol intake during pregnancy is difficult because it is almost always recorded in retrospect, with the potential problems of the mother's poor memory or denial. Many maternal and fetal factors also play key roles in determining if any specific dosing pattern is damaging to that individual. In the majority of animal studies in multiple species, it has been necessary to give high dosage exposures, with peak blood alcohol concentrations (BAC) in the 100-200 milligrams per kilogram (mg/kg) range, and to deliver them at least weekly for the first several weeks of pregnancy. Even these high doses are not uniformly teratogenic; they are "high risk". When women report consumption likely to cause drunkenness (an approximate BAC = 100 mg/kg or higher) on a weekly basis, this is considered a "4". Any other pattern of definite exposure is judged a "3" because no dose is guaranteed to be absolutely safe.

The term FAS applies to children who have all "4"s or combinations of at least two "4"s and no more than two "3"s on the four scales. Other scores are converted to words in combinations of the descriptive terms: sentinel physical findings; static encephalopathy or neurobehavior disorder; and alcohol exposed, alcohol unexposed, and alcohol exposure unknown. A full explanation of this approach and its diagnostic terms as well as a method for judging the importance of these comorbidities, are available in the *Diagnostic Guide for Fetal Alcohol Syndrome and Related Conditions* (Astley & Clarren, 1997). The fetal alcohol diagnosis must be considered in the context of other prenatal and postnatal factors that contribute to the unique findings for each individual.

CASE STUDY INVOLVING AN INTERDISCIPLINARY TEAM ASSESSMENT

The FAS clinic team is comprised of individuals who help collect and interpret the data needed for diagnosis, assist in developing a comprehensive intervention plan, or both. Professionals are needed

from the disciplines of medicine, psychology, speech-language pathology, occupational therapy, social work, public health nursing, and family advocacy. It is also helpful to have a staff epidemiologist who can create data forms and databases and direct clinical research efforts based on these data.

The remainder of this chapter presents the composite case of Anna, a child with FAS. This case illustrates the following steps in the diagnostic interdisciplinary team process: 1) preliminary team conference; 2) team assessment, including caregiver interview, physical examination of the child, and assessments of the child by occupational therapy, speech-language pathology, and psychology team members; 3) team deliberation; 4) case discussion and feedback to the parents; 5) additional case discussion and a therapeutic debriefing with the parents; 6) further case discussion and a therapeutic debriefing with the child (when appropriate); and 7) staff debriefing. Beside preserving patient confidentiality, employing a composite case permits discussion of a combination of FAS characteristics that would not necessarily be found in any one case. Exploring the case of a primary school-age child allows a more extended developmental perspective. It also sensitizes the reader to the full scope of difficulties that children with FAS have by the time they reach elementary school, which generally are not clear in preschool. Overall, although Anna is fictitious, she presents the typical challenges in FAS diagnosis, treatment, and family support.

Record Review and Preliminary Team Conference

Anna's adoptive parents initially called the FAS clinic for an appointment. The family had been referred to the clinic by Anna's teacher, who had taken a workshop on FAS, and by her physician. As is frequently the case, Anna's doctor had not previously considered an alcohol-related diagnosis but agreed to the assessment when Anna's parents sought his advice (Clarren & Astley, 1998). The family had been sent an extensive intake form. This form was specifically designed to obtain historical data from the family that would help the clinic team reach a fair and complete conclusion. These data included 1) growth records; 2) childhood photos; 3) medical records of congenital abnormalities; 4) neurological problems and ongoing health issues; 5) previous evaluations of cognition and behavior; 6) reports of response to psychotropic medication; 7) specific documentation of alcohol exposure in pregnancy; 8) exposure to other drugs or additional complications during pregnancy; 9) academic problems or cognitive delays of the biological parents or their families; 10) a general overview of the family's genetic background; 11) reports of multiple placements and issues of caregiver attachment; 12) abuse or neglect; and 13) a general record of problems or difficulties with family, peers, and school. This intake form is available in the *Diagnostic Guide for Fetal Alcohol Syndrome and Related Conditions* (Astley & Clarren, 1997).

At the preliminary team conference, these extensive past records were reviewed, and the following summary was presented to the clinic staff by the physician and psychologist. Anna was 8 years and 1 month old. She was born to married, Caucasian parents when her mother was 28 years of age and her birth father was 35 years old. This was the third live born infant for Anna's birth mother. Her pregnancy was complicated by extensive alcohol use. The birth father reported that he would generally buy one case of beer daily and that when it was available he and his wife would each drink about half of this amount in the evening. This level of drinking persisted through the first half of the pregnancy. During the second half of Anna's gestation, Anna's birth father drank more while her mother drank less, although she still probably ingested about a six-pack daily until delivery. Anna's mother also used marijuana about once a month and smoked half a pack of cigarettes each day. The pregnancy was further complicated by physical abuse of the mother by her husband, although this abuse never led to a medical assessment during the pregnancy. Both biological parents reported that their own fathers, but not their mothers, had been heavy drinkers. Neither biological parent reported significant academic problems, and both had finished high school.

Anna was born at term, and her delivery was described as typical. At birth, she weighed 2.2 kilograms (kg) and her length was 44 centimeters (cm). Anna was always described as small. While in foster care, Anna received a nutritional evaluation and a thyroid screen. Anna grew steadily but more slowly than

typically developing children. One previous foster parent repeatedly asked her physician to hospitalize the infant because she ardently believed that her inability to "fatten the baby up" meant that the baby was ill. Anna had an inguinal hernia that was repaired when she was 9 months old. She had chronic problems with otitis media until she reached age 3, though she never had a documented hearing loss. Despite these problems, she had been in good health overall.

After Anna was born, she lived with her parents for about 6 months, then she was removed from parental custody after the biological mother was several beaten by her husband. In addition, investigators found that the child was living in an unclean apartment without food or appropriate clothing. Six month-old Anna was placed in foster care and moved periodically over the next two and a half years while social service agencies determined that neither parent could control their drinking and regain custody. Anna was then made available for adoption and was retained by her last foster family (mother, father, and a brother 3 years older than Anna) when she was about 3 years of age. The adoption was legalized when Anna was almost 5 years old.

At the time of the clinic visit, Anna's adoptive parents reported that she had shown behavior problems since 30 months of age. Sometimes Anna was very negative and aggressive, especially with family members, while at other times she was cooperative and pleasant. Upon entering preschool, she was reported to be quiet but soon showed qualities similar to those observed at home. In fact, she was so aggressive with her peers that she was unsuccessful in two preschool programs. Her parents said that these behavior problems continued but had grown less frequent and violent since Anna started kindergarten.

Anna was evaluated by a developmental pediatrician at 6 years and 11 months of age, and she was diagnosed with severe ADHD. Anna was placed on methylphenidate but had an unanticipated response with a dramatic increase in irritability. Her parents stopped giving her the medication. Anna's reaction distressed her whole family, and her parents declined to try other medications, but they did attempt to reduce the amount of sugar in her diet with no apparent positive effect. A psychiatric evaluation produced a further diagnosis of oppositional defiant disorder, and Anna was described as "anxious".

At age 7 and midway through first grade, Anna was made a "focus of concern" by her school district because of poor academic progress and increasingly problematic behavior. As part of her school assessment she was evaluated using a standardized test of intelligence, the Wechsler Intelligence Scale for Children-Third Edition (WISC-III; Weschler, 1991). On that test, her verbal IQ score was a standard 68 (below expectations), and her performance IQ score was a standard 90 (within normal limits). A fullscale IQ score was not calculated because of the discrepancy between Anna's verbal and performance scores. Factor scores in the areas of verbal comprehension and freedom from distractibility revealed significant difficulties while Anna's factor score in the area of perceptual organization was in the lowaverage range. On an individually administered academic skills measure, the Woodcock-Johnson Test of Achievement-Revised (Woodcock & Johnson, 1989), Anna received the following scaled scores: Broad Reading (75), Broad Mathematics (71), Broad Written Language (80), and Broad Knowledge (86). Her standard score on the Vineland Adaptive Behavior Scales' (VABS; Sparrow, Balla & Cicchetti, 1984) Adaptive Behavior Composite was 52, and the subdomain scores were Communication (50), Daily Living Skills (45), and Socialization (64). School district recommendations were to provide resource room assistance given her ADHD diagnosis, but no specific educational plan was developed to address her cognitive and academic difficulties.

At the time of the FAS assessment, Anna's adoptive parents were confused and exhausted. They wished to understand how Anna's multiple diagnoses related to each other and how to maximize the effectiveness of her academic and mental health interventions.

Team Assessment

The FAS clinic evaluation included an hour-long interview of Anna's adoptive parents and several assessments of the child (whose chronological age was 8 years and 1 month), which included a physical examination, an occupational/physical therapy assessment for soft neurological signs and fine motor problems, a specialized speech-language evaluation, and a limited amount of additional psychological testing. The goal of conducting these assessments was not necessarily to evaluate the full extent of Anna's development. Rather, it was to gather sufficient information to reach a diagnostic conclusion regarding the diversity and nature of her developmental functioning.

Caregiver Interview

A team physician and psychologist conducted an interview with Anna's adoptive parents. The interviewers guided the session to determine if Anna had the related conditions and functional impairments common in case of FAS. These questions probed the arenas of planning, behavior regulation, abstract thinking and judgment, information processing and verbal memory, spatial skills and memory, social skills and adaptive behavior, sensorimotor integration, and both oral-motor and motor control skills.

Anna's parents seemed appropriately concerned but confused about the many previous assessments of their daughter that had apparent nonoverlapping diagnoses. They commented that they sometimes understood the antecedents of her angry outbursts (but often did not) and that Anna was basically loving and caring. Nevertheless, Anna had never enjoyed being held or hugged for more than a brief period time. Furthermore, her parents said that she had always been very sensitive to loud noise and to rough or scratchy clothing.

Anna's parents noted that their daughter had difficulty organizing spaces; for example, she tended to crowd the letters of her name into one corner of a page and she could not put her toys away in their proper places. Her parents also agreed that their daughter had tremendous difficulty following directions. They reported that she generally failed to remember an instruction if more than a few minutes elapsed between the time the instruction was given and when she was expected to carry it out. Anna also could not successfully follow more than a one-step instruction. She could repeat instructions if she practices saying them many times (e.g., Question: "Anna, what do we do before we eat?"; Answer: "We was our hands"). Yet Anna usually forgot the rule without a direct reminder at the time the instruction was to be implemented. In fact, she did not understand lengths of time (e.g., the difference between an event taking place in a few minutes or one that was a few days away).

In the domain of social skills, Anna's parents described her as isolated with no friends. She seemed to enjoy the company of other children but often tried to direct all activities. This behavior usually led to marginalization by her peer group. When rejected, Anna sometimes played alone, but she usually responded to peer rejection or noncompliance with anger or physical aggression. Anna played well with younger children (ages 3 or 4 years) and was kind to animals.

In physical terms, Anna had trouble going to bed and often awoke in the night, but then she generally tired during the latter part of the day. Her mother commented ruefully that Anna could climb, in-line skate, and do other age-appropriate outdoor activities but did them in a frighteningly reckless and somewhat clumsy way. In general, Anna was described as having problems with self-regulation. Her parents had learned to send their daughter to her room when she was out of control. In time out, Anna quickly calmed down and seemingly forgot the entire event within minutes. Such outbursts could occur daily or even several times per day.

During the interview, Anna's parents confirmed the history of alcohol exposure that had been reported to them by the biological father. Apparently, Anna's biological mother had been in recovery at the time of the adoption and had given the adoptive parents the same facts. Anna's adoptive parents thought her biological mother was still living in the area and was once again drinking. They had not been in contact with her for several years.

Pediatrics

The results of the physical examination conducted by the team physician revealed that Anna's height was 115 cms, her weight was 18k kgs, and her head circumference was 48.5 cms. The three facial features that defines the dysmorphic face of FAS were each carefully assessed. Her palpebral fissures (the horizontal length of the eyelid slit opening) measured 2.3 cms. Her philtrum (the vertical furrows between the nose and border of the red portion or vermilion border of the upper lip) was judged to be "flat" when compared to standard photos of philtrums of variable fullness. Similarly, the vermilion border was judged to be "very thin" using the photographic guide (available in the *Diagnostic Guide for Fetal Alcohol Syndrome and Related Conditions* [Astley & Clarren, 1997]). In addition, Anna had a small jaw and a mild overbite of her new secondary upper incisors. The rest of Anna's physical examination was unremarkable.

Occupational Therapy

Fine and gross motor skills were within normal limits using the Bruininks-Oseretsky Test of Motor Proficiency (Bruininks, 1978). Although Anna's parents had concerns about "clumsiness," that problem was not identified with this tool. The Quick Neurological Screening Test-Revised (QNST-R; Mutti, Sterling, & Spalding, 1978) was also administered. This tool is generally more useful to screen multiple areas of neuromotor integration and soft neurological signs. A normal score is less than 20; an abnormal score is more than 50. Anna's score was 45, in the "suspicious" range. Particularly difficult for Anna were coordinating rapid controlled movements, balance, and tasks involving spatial awareness of her body. These results fit with findings on the Beery-Buktencis Developmental Test of Visual-Motor Integration (VMI; Beery, 1997), signifying that Anna had below-average abilities in figure copying and a very disorganized approach to more complex visual information. A short sensorimotor history questionnaire completed by Anna's adoptive parents revealed sensitivities to tactile and auditory information, echoing descriptions from the caregiver interview. This sort of nonstandardized checklist is used in FAS clinics when there are concerns about sensory processing.

Speech-Language Pathology

Impairments with language, cognition, and social behavior are not unusual for children with FAS and related conditions, and they underlie difficulties in social competence and some aspects of academic performance. Research measures of social communication and social reasoning are used in FAS clinics to tap this common area of concern, and the results these measures produce capture something of the day-to-day problems that parents of children affected by alcohol describe. In addition, age- and developmentally appropriate standardized measures of receptive and expressive language are also employed in clinics to conduct a brief assessment of language development.

Anna's receptive and expressive language skills were broadly within the typical range; she nonetheless showed notable delays in storytelling and mental-state reasoning, two aspects of social communication and social reasoning. Anna was asked to retell a story she had just heard, using a picture book without words as a cue. Anna's narrative was vague and poorly connected; in effect, she described elements in each picture without linking them into a story line. She could not take her listener's perspective into account in communicating the story. Anna understood the facts of the story but could not mentally "step into another person's shoes" when asked questions that required understanding another person's perspective. In these tasks, Anna did not give clear evidence that she understood what other people were thinking. These observations were congruent with reported information from the caregiver interview.

Psychology

As is often the case, the clinic was provided with valid and relatively recent testing by school and community professionals. To supplement these data, Anna was given the core assessment from the NEPSY, a Developmental Neuropsychological Assessment (Korkman, Kirk, & Kemp, 1998), a standardized battery of tasks that provides a developmental neuropsychological assessment for children ages 3-12 years. Anna's scores on the test's Core Domains of Language and Sensorimotor Function were low-average while visuospatial processing was in the borderline range. She scored well below average

on Attention/Executive Function and Memory and Learning. Her scores on individual subtests were uneven and provided considerable insight regarding her problem-solving and learning styles. Of particular interest was Anna's very poor performance on a narrative memory task similar to one given in the speech-language assessment. In this task, which resembles school activities, the child listened to a story read aloud, attempted to tell it on her own, and then answered comprehension questions. Again, Anna's version of the story was vague and sparsely detailed. Even when cued, Anna often could not always remember the information offered in the story. When asked a question she often started to give an answer, then seemed to lose the aim of the task, and finally made unrelated responses that suggested she was guessing just to give an answer. She appeared very anxious during this task, shifting around in her chair, commenting on noises outside the room, and asking whether the testing was almost done.

To provide an estimate of behavioral function, Anna's adoptive mother completed the Child Behavior Checklist for 4- to 18-year olds (CBCL; Achenbach, 1991). Her second grade teacher completed the Teacher's Report Form (TRF; Achenbach, 1991). Parent report on the CBCL revealed overall behavior difficulties, with a Total Behavior Problems T score of 79, which is within the clinically significant range. The realm of internalizing problems was also clinically significant due to an elevated score suggesting anxiety. Externalizing behavior problems were also rated in the significant range, with elevated scores on scales of aggressive and "delinquent" behavior as well as difficulties with thinking, social skills, and attention span. Anna's Total Competence T score was 32, falling below the clinical cutoff, with poor scores on scales of social and school competence. This resonated with the mother's concerns about her daughter's inability to learn right from wrong: Anna sometimes attempted to hurt family members, yet she had a sense of humor and the ability to be loving and caring.

On the TRF, Anna's teacher expressed concern about behaviors in both Internalizing and Externalizing scales. Again, Anna's overall Internalizing problem score was elevated primarily because of her anxious behavior. Her Externalizing behavior problem score was elevated mostly due to her overactive and aggressive behavior. Anna's teacher reported that the child would destroy her own and others' possessions when angered. However, her rating showed that she could occasionally work hard and seem happy. Overall, Anna's teacher's ratings also indicated that her student was having some difficulty behaving appropriately and learning. She noted that Anna did better in small, highly structured environments than in the larger classroom setting. The teacher thought that Anna was very hard on herself, with very high expectations and a tendency to become very upset (even self-abusive) if she did not meet her own expectations.

For many children in the FAS clinic, only brief screening is carried out by the psychologist to supplement available test results from community professionals. For children who are old enough and have sufficient intellectual capability, the child and adult versions of the California Verbal Learning Test (CVLT; Delis, Kramer, Kaplan, & Ober, 1994) and the Rey Complex Figure Test (RCFT; Meyers, Meyers, & Kelly 1995) are highly informative. Used together these tools assess verbal learning and memory, nonverbal memory and visuospatial skills, the child's ability to organize his or her behavior toward a complex end, and his or her behavior when carrying out demanding tasks. Literature on fetal alcohol effects suggests these might be areas of concern for individuals affected by prenatal alcohol ingestion. Findings from the CVLT and RCFT are often supplemented by several informal drawing tasks and a short interview. For children from preschool to late elementary school age, behavior observations are often carried out while the child is receiving the physical examination or other on-site testing and when the child is in an unstructured, highly stimulating environment (e.g., in the waiting room, on an elevator ride, during a walk through the building). Because a formal adaptive behavior assessment is often not part of a child's file, the psychologist will sometimes give the Summary Version of the VABS (Sparrow et al., 1984) prior to the caregiver interview.

Team Deliberation

Anna met the criteria for FAS in that she had been exposed to alcohol and had confirmed growth delays, specific atypical facial features, and evidence of CNS dysfunction. Details for these and other factors are

provided as follows:

Growth

Anna's growth was considered definitely atypical, as her height and weight were both below the 3rd percentile after a height adjustment for mean parental height. Anna's height of 155 cms was at the 2nd percentile. The height of her biological parents averaged 174 cms. Adjusting for mid-parental stature determined that Anna was actually 3 cms smaller than would be predicted from her genetic background. Therefore, her atypical growth pattern was independent of her genetic background.

Dysmorphology

Those with FAS have short palpebral fissures ("short" when more than 2 SD below the mean) and a flat philtrum and thinned vermilion border. The philtrum and lip must each be judged a "4" or "5" on a 5-point rating scale in comparison to a standard set of five photos. Anna's palpebral fissures were measured at 3.5 SD below the mean. Her lip was judged a "5" while her philtrum was given a rating of "4". Her dental malocclusion, although not of relevance to the FAS diagnosis, was a common associated finding. Overall, she had the distinctive facial features that characterize FAS.

Central Nervous System Dysfunction

Evidence for CNS dysfunction can be defined structurally, neurologically, or by examining psychometric evidence. Anna had positive findings in all of these areas. Her head circumference was below the 2nd percentile. By itself, microcephaly is a sufficient finding for FAS diagnostic purposes, but Anna also had an atypical neurological exam, with a QNST score about the usual cutoff and evidence of visual-motor difficulties on the Developmental Test of Visual-Motor Integration. Anna's behavior was characterized by severe ADHD, adaptive behavior problems, clear social-communication impairments, a learning disorder, a significant verbal-performance discrepancy shown in IQ testing, and evidence of memory and attention/executive function problems in neuropsychological assessment. The descriptive diagnostic term *static encephalopathy*, with evidence of diffuse CNS dysfunction, applied to Anna.

Alcohol Exposure History

The history of alcohol exposure in utero was judged to be definite, as it was independently confirmed by both birth parents. Consumption of 6-12 beers or more, on a daily or nearly daily basis, would place a fetus at definite risk for damage due to alcohol exposure.

Comorbidities

There were no additional physical findings, problems in the genetic background, or other teratogenic exposures that suggested an alternate or additional prenatal etiological diagnosis. Based on record review, interview, and behavioral observations, the team was in agreement with the psychiatric diagnoses of oppositional defiant disorder and moderate anxiety. In part, these conditions were hypothesized by the team to be situational, arising from Anna's prolonged frustration from criticism by others as well as herself regarding her poor performance. In other words, these would be secondary disabilities.

Recommendations

After discussion to establish the diagnosis, the team began to develop a tentative list of recommendations to be shared with the family during the case conference. It is useful to divide suggestions into at least four categories: medical, mental health, formal/informal education, and social services. In certain cases, additional categories (e.g., legal, correctional) are needed.

Medical

Anna had a classic presentation of FAS. No further specific medical diagnostic evaluations were necessary in this case. However, this is not always the case. Individuals with prenatal alcohol exposure can have alcohol-related and other conditions or simply alternate conditions. Differential diagnosis often need to consider relatively common genetic conditions like fragile X syndrome or Turner syndrome as

well as obscure dysmorphic syndromes of genetic or alternate teratogenic cause. Any FAS program must always be alert to the possibility of alternate diagnoses involving other syndromes.

Another noteworthy medical issue was that there was a strong history of family alcoholism. Both of Anna's parents and her grandfathers were alcoholics. Thus, there was a chance that Anna carried a genetic propensity for alcoholism independent of her condition of FAS. The team felt that Anna would need clear and regular warnings throughout childhood and adolescence that drinking could cause her to become an alcoholic. Such direct messages help some children withstand peer pressure to begin alcohol use in adolescence.

In addition, Anna was small but had consistently grown parallel to typical parameters. This fact, along with her generally unremarkable physical examination, meant that there was no reason to recommend further medical evaluation of her growth. (Intriguingly, many children with FAS have a robust growth spurt at the time of puberty, moving in the typical range for height at that time.) On this note, it is not surprising that Anna's physician had not considered FAS diagnosis or referral, because Anna's physical health was good and her problems were in areas not usually considered as health care problems.

Mental Health

Anna had clinical evidence of distractibility and inattention and had had an unexpectedly adverse reaction to methylphenidate. At the time of the clinic visit, it remained possible that Anna fit the diagnostic criteria for ADHD within broader diagnosis of FAS. Thus, Anna might still respond to methylphenidate prescribed at a lower dose or to an alternate stimulant medication. It was also possible that her inattention and distractibility were due to anxiety and could be resolved if her anxiety and other problems were addressed, perhaps with an alternative, nonstimulant pharmacological approach as well as situational remediation.

Some families are concerned by the use of medications with children already affected by prenatal alcohol exposure. It was important that Anna's family be reassured of the general safety and potential benefits of medications. Nevertheless, the team felt it better for Anna's overall emotional state to be judged and the adjustments in her educational program and family expectations to be evaluated before further drug trials. Based on the outcome of such monitoring, a psychiatrist might then be better able to prescribe psychotropic medications.

Making those additional changes would be difficult. Anna's parents were already frustrated and fatigued by caring for a child whose behavior problems had escalated while her adaptive function had declined. Anna demonstrated complex cognitive and behavior impairments. Managing the child's behavior and helping her to learn would require expert assistance. The team decided to encourage Anna's parents to work with a counselor in developing appropriate parenting strategies and addressing the stressed inherent in raising a child with FAS. However, it is difficult to find such counselors and to fund this type of ongoing counseling assistance. If the parents did find a counselor, the team felt it would be ideal if that person or Anna's psychiatrist functioned as a service coordinator. The case management goal would be to align home and school behavior programs, with dual foci on eliminating aggressive behaviors and building anger management and socialization skills.

Another possible source of assistance was parent networks. Such support groups are remarkably useful resources for families raising children with FAS. In the 1990s, parents increasingly began joining together to support and educate on another, to advocate for funding and missing services, and to promote societal recognition of and research on FAS and related conditions. The team planned to augment the parents' access to information and self-help advice by providing them with a telephone hotline number for FAS and copies of recent issues of FAS community education newsletters.

Formal/Informal Education

In some states, Anna would qualify for special education under the category of "health impaired" given

either her diagnosis of FAS or of ADHD. She might also qualify as "neurologically impaired" based on microcephaly coupled with atypical neurological findings of fine motor delays and a significant number of soft neurological signs. In addition, Anna could qualify as "learning disabled" because of her psychological evaluation. Anna clearly met the criteria for, and needed, an individualized education program (IEP).

Most school districts have an approach to children with complex needs, such as Anna, that involves special education classes or resource room help for academic work; supplemental speech-language, occupational, and physical therapy services; and inclusion with typically developing peers during certain activities (e.g., recess, lunch, library time). These qualifying children may also be accompanied by a paraeducator for a portion of or the entire school day. This general plan seemed reasonable for Anna, although her pattern of special needs did not completely fit interventions such as those designed for children with mental retardation, learning disabilities, or severe behavior disorders. Therefore, individualized and flexible intervention planning at school was needed. Based on Anna's profile of test results, specific classroom techniques included 1) repeating practice of learning materials; 2) using less abstract materials; 3) limiting the need for Anna to remember spatial information; 4) breaking long instructions, stories, or lessons into smaller parts; 5) encouraging Anna to work slowly and carefully; 6) allowing time during transitions for Anna to become self-motivated and interested in the next activity; 7) analyzing strategies Anna used on her own during learning activities and offering more effective strategies as appropriate; and 8) informing Anna when she was doing well by rewarding effort and not achievement.

The team felt that Anna would benefit from occupational therapy services designed to assist her in better modulating incoming stimuli and to decrease performance anxiety by altering her classroom environment. If occupational therapy services could be provided at school, a private occupation therapist might be a useful addition to Anna's service team. Finally, speech-language consultation was recommended to enhance Anna's social-communication skills.

Furthermore, Anna would benefit from participation in extracurricular activities that she enjoyed and did well. Such activities could help raise her self-esteem and would be less likely to promote performance anxiety. Nevertheless, it was important to emphasize that Anna should only be enrolled in activities supervised by adults accustomed to working with children with special needs.

Social Services

At the time of Anna's adoption, fetal alcohol effects and the possibility of a lifelong disability were not raised with the family. Given the documented history of voluminous alcohol exposure during gestation and the history of growth problems from birth, the team believed that the issue of FAS should have been evaluated at the time of adoption. It would have been reasonable then to offer a subsidized adoption to offset added educational and mental health services that Anna would probably need. The team recommended that this issue be revisited with the appropriate social service agency. Subsidized adoption should include medical coverage, psychiatric benefits for the future if preapproved, and a monthly cost supplement. In addition, because Anna had permanent disabilities, she should qualify for Supplemental Security Income (SSI) coverage. As a child, eligibility is based primarily on functional ability, and the receipt of benefits is dependent on parental income. The issue of SSI funding could be reexamined later when Anna neared adulthood. The Division of Developmental Disabilities was another agency to contact for possible resources or benefits. The agency has strict qualifying criteria, but this option was worth pursuing.

Case Discussion: Feedback to Parents

The case discussion actually occurred in two phases. The first part consisted of elements typically discussed with parents during an assessment feedback session. The second phase, however, was a unique feature of the particular clinic that evaluated Anna.

Part I

Diagnosis and treatment recommendations were shared with Anna's parents in a roundtable forum. Each team member who had tested Anna briefly stated his or her specific findings, gearing discussion of test results to support the recommendations that would be mentioned later. For example, the physician articulated the medical diagnosis of FAS, and then the occupational therapist, the speech-language pathologist, and the psychologist who had tested Anna all stated their findings. The psychologist who interviewed the family then gave the team's recommendations in broad outline. All feedback was provided with careful sensitivity to the parents' emotional state and apparent level of comprehension.

In this large group setting, with all team members and some observers, the parents appeared fairly composed and quietly accepting of the diagnosis and intervention ideas. Nonetheless, their emotional responses were complex. On one hand, Anna's parents seemed pleased and relieved to receive an overall explanation for Anna's primary problems. On the other hand, they were troubled that Anna's complex neurological problems and her reactions to the accompanying difficulties had not previously been made clear. They also felt despair because they believed they had floundered for so long in caring for their daughter. Finally, they mentioned some fleeting anger at Anna's biological mother for causing these problems.

Part II

At this particular clinic, after clients have discussed the situation with the whole team, they have a quiet time when they can talk privately with one person on the team, usually the psychologist involved in the initial interview. This final phase with the caregivers provides a time for parents to catch their breath, express their feelings about the events of the day, and share their reaction to the diagnosis. Thereafter, they can hear and discuss the diagnosis and recommendations again to clarify their understanding and to begin initial planning for interventions based on clinic referrals. This final period honors the caregivers' and child's needs for a limited emotional closure to a stressful experience and for a way to review the many concepts and ideas they have just heard. Families often report how important this final time of consolidation is for them.

Anna's parents had endured an emotionally intense morning. At this second phase of the discussion process, the psychologist asked, "How are you doing? Does Anna's diagnosis make sense to you?" Then she waited and listened. Tears welled up in Anna's mother's eyes; her father let out a deep sigh. Finally, the father said how hard it was to hear that Anna did have FAS. The mother said she thought all along that Anna had FAS; Anna was so like the descriptions she had read. However, she kept wishing she would wake up and Anna would be just like her cousins and the kids next door. But now the mother knew Anna would never be an ordinary little girl, teenager, or adult. For several minutes the parents quietly cried, but they eventually regained their composure. The psychologist expressed her support. Then, Anna's mother asked what the family's next step should be.

The psychologist began to help the parents make sense of the diagnosis and recommendations. The psychologist read the diagnostic information and suggestions aloud to the parents to make sure the wording was clear and sufficiently informative. She clarified the meaning of a diagnosis of FAS. Using schematic drawings and straightforward descriptions the psychologist reviewed the word syndrome and each of the three basic aspects of the fetal alcohol syndrome: growth, facial features, and organic brain damage. She discussed how Anna met the growth criteria, as she had always been small, and her height and weight measurements during the assessment were below the 5th percentile compared to those of her peers. The psychologist explained the importance of small eyes and a thin upper lip and philtrum as physical markers for FAS and briefly described the embryology of these features. She also pointed out that Anna was a very pretty child and these facial characteristics did not stand out or negatively affect her looks. Then the psychologist explained the organic brain damage portion of the syndrome and how Anna demonstrated this characteristic. This was the time when the old and the new test data were analyzed. The parents asked many questions, and time was given to explain to them how Anna's profile of test results related to her learning and behavior problems. In particular, the results of the QNST,

which had indicated an atypical pattern of neurological soft signs and motor weaknesses, and her low scores on adaptive problem solving on the VABS were reviewed because both lent support to the finding that Anna was functioning at the level of a child half her chronological age. Also, her limited linguistic understanding of another's point of view and the discrepancy between her verbal and average nonverbal reasoning were discussed to help the parents understand why Anna seemed well adjusted at one moment and then had such great difficulties and frustrations the next.

Specific telephone numbers were provided, and referrals to three possible counselors/behavioral consultants were made. The parents also signed a mutual exchange of information form so the psychologist could talk to Anna's teacher and school counselor at a future date. In addition, the psychologist provided handouts from the resource box of articles on FAS, copies of the most recent newsletters, and ordering information for books that might be of value to Anna's teachers. The psychologist next asked if the parents thought Anna needed to talk about the diagnosis, and the parents said they did not think she would understand. To Anna, this day of testing was similar to her assessment process at school. In the future, they thought they could explain her diagnosis or they would contact the clinic for assistance. As a rule, feedback is given to an older child, a teenager, or an adult. If the child is briefed, there are several topics that generally should be considered for discussion with the child and the caregivers together. The feelings the child or caregivers may have about the biological mother's role and the frustration of ongoing problems in learning, behavior, and growth need to be recognized. The team should emphasize that they know the child works hard but has difficulties and may have been misunderstood over the years. In addition, the professionals need to clarify that the diagnosis explains why learning and being calm have been hard. Also, the child must be encouraged that he or she can learn and work but may need extra time and assistance. Again, the child also needs to be informed of his or her risk of becoming alcoholic. Finally, definite closure of the team assessment has to be made. This is the time to determine if the child requires follow-up with the clinic. In Anna's case, the psychologist closed the session by expressing her appreciation to the caregivers for their courage, good parenting, and cooperation as well as acknowledging how difficult the process had been. She stated she would be available to telephone Anna's teacher if necessary. Then the psychologist walked to the area where Anna was playing and shook the child's hand, told her what a good job she had done, and thanked her for coming to clinic.

CONCLUSION

The reader may wonder why a school-age child was used as a case example when the primary focus of this book is assessment in the early childhood years. Although younger children are assessed for FAS and related conditions, an older child's case demonstrated the richness and complexity of the accompanying performance problems that are not well described or measured until elementary school. Yet early diagnosis is important. It is likely that proper planning will reduce secondary disabilities and perhaps even improve cognitive performance when a diagnosis is made at the earliest possible time. Furthermore, the younger the child at the time of diagnosis, the more probable it is that the biological mother is still of childbearing age and would ingest alcohol during future pregnancies.

Unfortunately, the diagnosis of FAS cannot always be established conclusively in young children; even if the diagnosis is established in the preschool years, it is rarely clear what specific cognitive and behavior problems will follow. After all, the diagnosis of FAS relies on independent evidence of growth delays, a cluster of specific atypical facial features, organic brain damage, and a history of prenatal exposure to alcohol. The physical findings of poor growth and facial alteration and the history of alcohol exposure can all be fairly assessed in preschoolers, but detecting subtle levels of brain damage is much more problematic. If the child has microcephaly, hard neurological signs, or has had a brain image that discloses structural aberrations, this component of the diagnosis can be confirmed. If these observations are typical, alcohol-related brain damage could still be present at a microscopic level that can only be detected with late 20th century clinical techniques through a battery of psychometric testing. Reliable and valid testing of this type is not available for very young children. Furthermore, even if the diagnosis

can be established through physical observations, the child's functional problems could be wide ranging and only well understood through formal assessments done over several subsequent years. As of 2000, there is no solid evidence that the facial characteristics and growth delays in children with FAS predict that there will be definite brain impairments or any specific level of delay. These findings cannot be used as proxy measures for brain performance itself. For infants, toddlers, and preschoolers, a sensorimotor history questionnaire, developmental screening (e.g., the Bayley Infant Neurodevelopmental Screener [Aylward, 1995] or the Miller Assessment for Preschoolers [MAP; Miller, 1988]), and observation of parent-child interactions are often carried out by the FAS clinic occupational therapist and psychologist working together. Although these assessments are useful, they can rarely predict the types of processing difficulties that are at the heart of the ongoing FAS disability. Anna was noted to have had problems with anger and socialization in preschool although the cause was not understood at that time. Actually, many children who are later found to have significant cognitive and behavior problems seemed, to both their parents and teachers, to be developing typically before the age of 4 or 5 years.

As of 2000, the approach to the problem of FAS diagnosis in young children is twofold. First, the most complete assessment possible is conducted along the lines discussed in this chapter. Then the interdisciplinary team assesses the risk factors of each client (i.e., the biological mother and the child). If the mother drank substantially during this child's gestation and is still drinking and of childbearing age, she needs direction toward appropriate interventions to prevent subsequent adverse birth outcomes. She also needs support in rearing her child if she has custody. The child is considered at risk as well, based on the exposure history itself. Whether the child meets criteria for FAS, a related condition, or is found to be typically developing at the time of assessment, he or she needs appropriately stimulating home and preschool experiences and reassessments in the age period from kindergarten to second grade. As of 2000, few specific preschool programs have been specifically developed for children with FAS and related conditions (see Olson & Burgess, 1997). The need for more such programs is imperative for improving the quality of these children's lives.

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