Diagnostic Guide for
Fetal Alcohol Spectrum Disorders

The 4-Digit Diagnostic Code™

FASD 4-Digit Code

Rank	Growth	Face	Brain	Prenatal Alcohol	Other Prenatal Risks	Other Postnatal Risks
	3	**4**	**3**	**4**	3	3
4	severe	all 3 features	abnormal structure/neurology	high	high	high
3	moderate	2.5 features	severe dysfunction	some	some	some
2	mild	1-2 features	moderate dysfunction	unknown	unknown	unknown
1	normal	no features	normal function	none	none	none

FASD Umbrella

3 Diagnoses under the FASD Umbrella		Growth	FAS Face	Brain		Alcohol
1. FAS	Fetal Alcohol Syndrome	growth	face	severe		exposed
2. SE/AE	Static Encephalopathy / Alc-Exposed			severe		exposed
3. ND/AE	Neurodevelopmental Disorder / Alc-Exposed				moderate	exposed

4th Edition
v.1.01
2024

FAS Diagnostic and Prevention Network
University of Washington
Seattle Washington

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We recommend this document be printed in color.

Diagnostic Guide for Fetal Alcohol Spectrum Disorders: The 4-Digit Diagnostic Code

Fourth Edition
Version 1.01
2024

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Free copies of this Guide can be downloaded from our website:

https://depts.washington.edu/fasdpn/pdfs/Guide2024.pdf

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I would like to acknowledge the University of Washington FAS Diagnostic & Prevention Network (FASDPN) clinical team members over the past 30 years who have used this Guide weekly and have helped hone the material on an ongoing basis: Special thanks is also extended to our patients and their families who have contributed a wealth of knowledge and information to the ongoing development of this Guide.

Preface

What's New in this 4th Edition, 2024?

The 1st, 2nd and 3rd editions of the Diagnostic Guide were printed in 1997, 1999, and 2004 respectively (Astley and Clarren, 1997, 1999, 2000; Astley 2004). It is now 2024 and a few key updates are warranted for this 4th Edition. These updates are based on our use of the 4-Digit Code for the past 30 years on over 3,000 patients, advancements in medical research, and feedback from over 1,500 clinicians worldwide trained to use the 4-Digit Diagnostic Code. We will continue to make modifications that enhance accuracy, improve clarity, and increase ease of use. We hope you will find this comprehensive approach to the diagnosis of individuals with prenatal alcohol exposure helpful and broadly applicable.

Since the 3rd edition was released in 2004, twenty years of published research has continued to validate the performance of the 2004 guidelines. Selected publications are presented below.

1. Astley SJ, Clarren SK. **(2000)**
   Diagnosing the full spectrum of fetal alcohol exposed individuals: Introducing the 4-Digit Diagnostic Code.

2. Astley SJ. **(2004a)**
   Fetal alcohol syndrome prevention in Washington State: Evidence of success. Video presentation by Susan (Astley) Hemingway in Poland, 2020.

3. Astley SJ, Aylward E, Olson HC, Kerns K, Brooks A, Coggins T, Davies J, Dorn S, Gendler B, Jirikowic T, Kraegel P, Maravilla K, Richards T. **(2009)**
   Magnetic resonance imaging outcomes from a comprehensive magnetic resonance study of children with fetal alcohol spectrum disorders.

4. Astley SJ. **(2011)**
   Canadian palpebral fissure length growth charts reflect a good fit for two school and FASD clinic-based U.S. populations.

5. Astley SJ **(2013**)
   Validation of the fetal alcohol spectrum disorder (FASD) 4-Digit Diagnostic Code.

6. Astley SJ. **(2014)**
   Twenty years of patient surveys confirm a FASD 4-Digit-Code interdisciplinary diagnosis afforded substantial access to interventions that met patients' needs.

7. Astley SJ. **(2015)**
   Palpebral fissure length measurement: Accuracy of the FAS Facial Photographic Analysis Software and Inaccuracy of the Ruler. Pictorial examples comparing the software to the gold standard measure obtained by a sliding digital caliper.

8. Astley SJ, Bledsoe JM, Davies JK. **(2016)**
   The essential role of growth deficiency in the diagnosis of fetal alcohol spectrum disorder.

9. (Astley) Hemingway SJ, Bledsoe JM, Brooks A, Davies JK, Jirikowic T, Olson EM, Thorne JC. **(2019)**
Comparison of the 4-Digit Code, Canadian 2015, Australian 2016 and Hoyme 2016 fetal alcohol spectrum disorder diagnostic guidelines. Link to video for Figure 2C.

10. Kesmodel US, Nygaard SS, Mortensen EL, Bertrand J, Denny C, Glidewell A, (Astley) Hemingway SJ **(2019)**
Are Low-to-Moderate Average Alcohol Consumption and Isolated Episodes of Binge Drinking in Early Pregnancy Associated with Facial Features Related to Fetal Alcohol Syndrome in 5-Year-Old Children?

11. (Astley) Hemingway SJ, Bledsoe JM, Davies JK, Brooks A, Jirikowic T, Olson EM, Thorne JC. **(2019)**
Twin study confirms virtually identical prenatal alcohol exposures can lead to markedly different fetal alcohol spectrum disorder outcomes - fetal genetics influences fetal vulnerability.

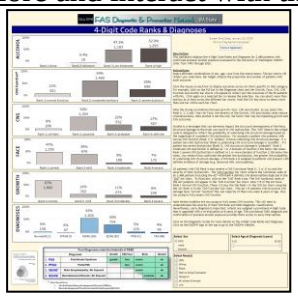
12. (Astley) Hemingway SJ **(2020)**
High facial specificity and positive predictive value are required to diagnose fetal alcohol syndrome when prenatal alcohol exposure is unknown.

13. (Astley) Hemingway SJ, Davies JK, Jirikowic T, Olson EM. **(2020)**
What proportion of the brain structural and functional abnormalities observed among children with fetal alcohol spectrum disorder is explained by their prenatal alcohol exposure and their other prenatal and postnatal risks?

14. (Astley) Hemingway SJ, Baldwin M, Pierce-Bulger M. **(2023)**
Washington and Alaska statewide FASD diagnostic clinical networks: Comparison of three decades of 4-Digit Code diagnostic outcomes and prenatal alcohol exposure histories.

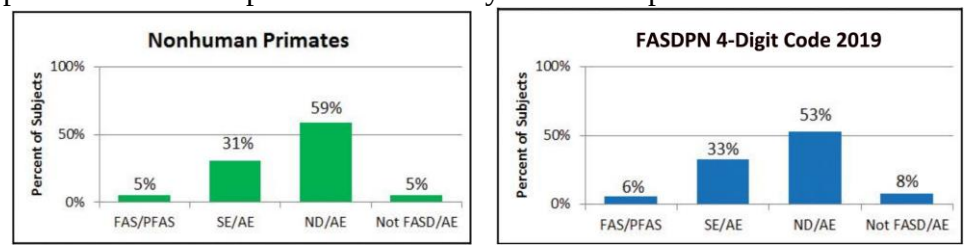
15. Pruner M, Jirikowic T, Baylor C, Hemingway SJA. **(2024)**
Developmental, sensory and behavioral outcomes among infants and toddlers with prenatal alcohol exposure.

16. (Astley) Hemingway SJ. **(1993-2024)**
FASDPN web-based interactive Tableau dashboards allow Users to explore and interact with the FASDPN data. The clinical/research database contains over 2,000 fields of information collected on over 3,000 individuals (newborn to adult) with prenatal alcohol exposure evaluated in the Washington State FASDPN clinics from 1993 through the present. All individuals received an FASD diagnostic evaluation by an interdisciplinary team using the FASD 4-Digit Diagnostic Code.



Research to date continues to confirm:

- **FASD is a spectrum of outcomes, not just severe outcomes** (Astley et al., 2019). The 4-Digit Code is currently the only FASD diagnostic system that includes "moderate" dysfunction (Neurodevelopmental Disorder / Alcohol Exposed (ND/AE)) as well as severe dysfunction (Static Encephalopathy / Alcohol Exposed (SE/AE)) under the umbrella of FASD. Nonhuman primate research confirms that moderate dysfunction (ND/AE) is the most prevalent outcome caused by prenatal alcohol exposure (Clarren et al., 1992). When using the 4-Digit Code, the prevalence of diagnostic outcomes observed in the University of Washington (UW) FASDPN diagnostic clinic matches the prevalence observed in a nonhuman primate model of FASD where prenatal alcohol exposure was the only risk factor present.



- **FASDs are disorders caused by the full continuum of prenatal alcohol exposure (PAE), not just higher exposures.** The higher the exposure the greater the risk, but lower exposures are not risk free (Kesmodel et al., 2019; Astley, 2013). Requiring a threshold level of PAE implies reported levels of PAE are reliably accurate. They are not. When thresholds of exposure are required for diagnosis, over half of individuals with confirmed PAE and severe brain abnormalities do not receive a diagnosis of FASD because details regarding quantity, frequency and timing of exposure are not available. Over half of individuals with the most severe outcome (FAS) have reportedly low to moderate PAE ((Astley) Hemingway, et al., 2019; Petryk et al., 2019). It is also important to note that the teratogenic impact of PAE is not just dependent on the quantity, frequency and timing of exposure. Our twin study confirmed fetal genetics influences fetal vulnerability to PAE ((Astley) Hemingway et al., 2019a). When twin pairs with virtually identical PAE were genetically identical (monozygotic), their FASD diagnoses were identical. When twin pairs with virtually identical PAE were genetically different (dizygotic), close to half (44%) presented with discordant FASD diagnoses. The same level of prenatal alcohol exposure that posed a lower risk for one twin, posed a high risk for the other twin.

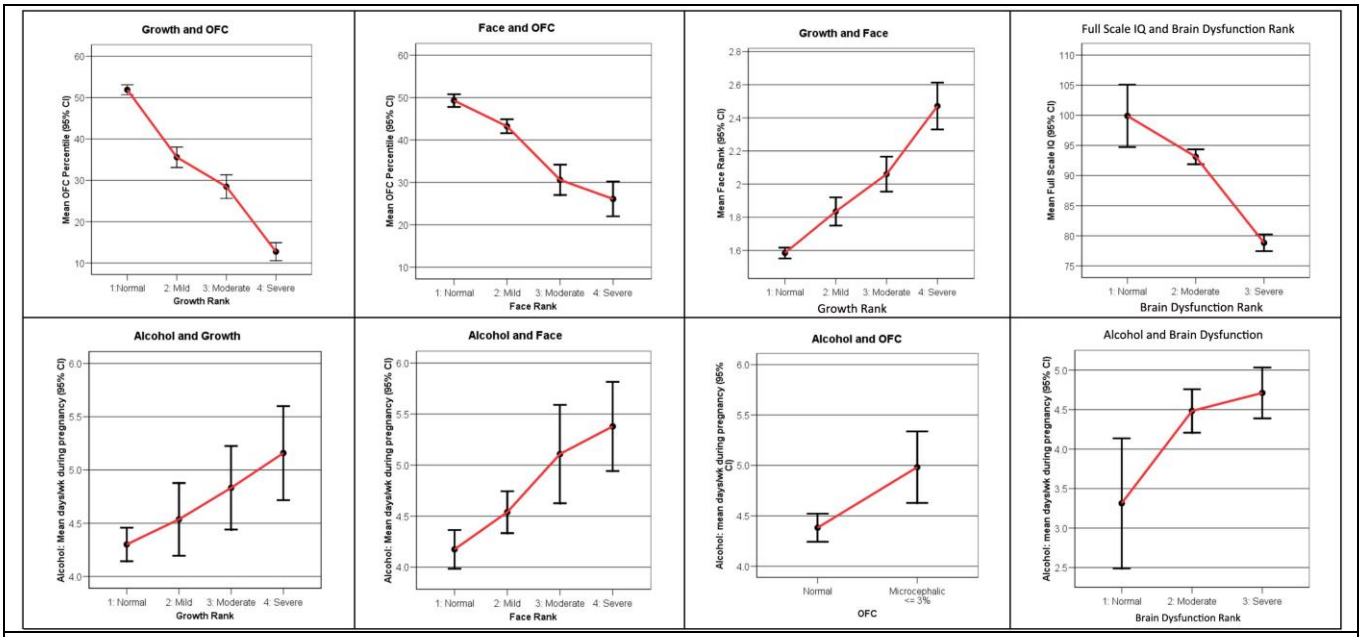
- **FASD is present at birth and can/should be diagnosed at birth to maximize intervention effectiveness** (Pruner et al., 2024; Astley et al., 2019; Astley et al., 2024). Fifteen percent of the patients diagnosed with FASD at the FASDPN over the past 30 years were birth to 3 years of age. Their diagnoses spanned the full continuum of FASD.

- **Growth deficiency (GD) is an essential diagnostic criterion for FASD** (Astley et al., 2016). Based on our empirical study of GD and FASD, GD was significantly correlated with prenatal alcohol exposure. Among individuals with PAE, GD was as prevalent as the other core diagnostic features (facial and brain abnormalities). GD occurred across the full spectrum of FASD diagnoses and increased in prevalence with increasing severity of diagnosis. The most prevalent form of GD was postnatal short stature. GD was as highly correlated with, and predictive of, severe brain dysfunction as the FAS facial phenotype. Individuals with GD had a

two to three-fold increased risk for severe brain dysfunction. Sixty percent of patients with severe GD had severe brain dysfunction. GD accurately predicted which infants had severe brain dysfunction that would not be detectable until later in childhood.

- **The Rank 4 FAS facial phenotype, as defined by the FASD 4-Digit Code, is the only facial phenotype** (Astley et al., 2019) **identified to date that provides sufficient positive predictive value (PPV) and specificity to prenatal alcohol exposure (100%) to allow the facial phenotype to be used as confirmation of prenatal alcohol exposure in a diagnostic setting when a written or verbal documentation of prenatal alcohol exposure is not available** (Astley, et al., 2020). The Rank 4 FAS facial phenotype can also be used to confirm an individual's prenatal alcohol exposure adversely impacted their fetal development. If the facial phenotype of FAS can only be caused by prenatal alcohol exposure, the following two conditions should hold true: 1) All individuals with the FAS facial phenotype have prenatal alcohol exposure (100% PPV); and 2) No individual with a confirmed absence of prenatal alcohol exposure will have the FAS facial phenotype (100% specificity). FASDPN data to date documents the Rank 4 FAS facial phenotype meets these two conditions.

- **FASD is defined by growth deficiency, FAS facial features and brain abnormalities caused by prenatal alcohol exposure (PAE).** If PAE causes FASD, one would expect: 1) strong intercorrelations between the growth, face and brain outcomes among individuals with PAE and 2) strong correlations between each of these three outcomes and prenatal alcohol exposure. This is exactly what is observed when using the 4-Digit Code. The plots below clearly demonstrate growth, face, brain and PAE all present along clinically meaningful continuums; the features are not simply present or absent. (Astley, 2013). The plots also demonstrate that growth, face and brain abnormalities are not only strongly intercorrelated with one another but also increase in severity with increasing PAE. This is powerful evidence supporting a causal association between PAE and these three outcomes.



Significant intercorrelations between growth, face, brain and prenatal alcohol exposure among 3,000 individuals with prenatal alcohol exposure diagnosed with FASD using the FASD 4-Digit Code.

Based on our published studies to date, we recommend the following updates when using this 4th edition of the guidelines (2024):

A. **Updated normal growth charts in electronic format are now widely available on the internet**. We recommend clinicians use the most current electronic charts for height, weight and head circumference that best match the age, sex, race/ethnicity, and country of origin of each patient (See Section III B.2). In our Seattle WA FASDPN clinic, we currently use the CDC, WHO and Rollins et al (2010) growth charts for OFC, weight and height and adjust for mid-parental height (Himes et al., 1985), when both parents' heights are available.

B. **We recommend using the free FAS Facial Photographic Analysis Software (2016, v2.1) distributed by the FASDPN to obtain the most accurate measures of the facial features** (Astley, 2015). The Facial Software incorporates an adjustment factor that is confirmed to accurately measure a palpebral fissure length from a 2-dimensional digital photo within 0.2 mm of the gold standard of measure (a sliding digital caliper). We do not recommend using a handheld ruler to measure PFLs. Numerous studies have confirmed the inaccuracy of the ruler method. We use the Iosub African American PFL charts (Iosub et al., 1985) for individuals that are full or half African American and the Stromland Scandinavian PFL charts for all other races (Stromland. et al., 1999). These charts come with our FAS Facial software and are available in our free excel PFL Z-score calculator. The Hall (1989) Caucasian PFL charts for birth to 16 years are no longer used and should not be used (Astley, 2011; Clarren et al., 2010).

C. **The University of Washington Lip-Philtrum Guides are the only guides that can be validly used to measure the lip and philtrum in accordance with the FASD 4-Digit Code** (Astley et al., 2019). Other Lip/Philtrum Guides may look similar, but are case-defined very differently (e.g., the Rank 4 thin upper lip on the North American Lip/Philtrum Guide (Hoyme et al., 2016) is equivalent to the Rank 2 moderately thick upper lip on the University of Washington Caucasian Lip-Philtrum Guide (Astley et al., 2019). The Seattle FASDPN clinic uses Lip-Philtrum Guide 1 for Caucasians and all races with thinner lips like Caucasians. Lip Philtrum Guide 2 is used for African Americans and all races with thicker lips like African Americans (e.g., Aboriginal Australians).

D. **The 4-Digit Code provides a classification scheme for the full spectrum of FASD and prenatal alcohol exposure that can be used in both the research and clinical arenas**. There are 246 different 4-Digit Codes that range from 1111 (normal development with confirmed absence of prenatal alcohol exposure) to 4444 (full FAS with high prenatal alcohol exposure). These 246 codes can be grouped into 19 different diagnostic categories. Only 108 of the 246 codes fall under the umbrella of FASD. These 108 codes are grouped into 6 distinct FASD diagnostic categories that differentiate individuals with different combinations of growth deficiency, FAS facial features, brain abnormalities and prenatal alcohol exposures. The clinical arena is best served by the smallest number of clinically distinct diagnostic categories that reflect the full spectrum of outcome and exposure. It is for this reason the FASDPN further collapses the 6 Diagnostic Categories for FASD into 3 clinically meaningful subgroups (FAS, SE/AE and ND/AE). FAS includes Diagnostic Category A (see Section IV). SE/AE includes Diagnostic Categories B and C. ND/AE includes Diagnostic Categories D, E and 4 codes in J. The research arena benefits most from a numeric approach to classification (the 4 digits) because the codes

can be used independent of clinical diagnostic nomenclature, can be sorted into any number of subgroups that best meet the study group requirements for the research question at hand and can be used as a universal method for describing FASD study group(s) enrolled across studies. Numeric codes expressed on ordinal scales (e.g., FAS facial phenotype absent, mild, moderate, severe) also provide greater statistical power to identify clinically meaningful correlations between outcomes and exposures than nominal categories expressed on dichotomous scales (e.g., FAS facial phenotype present/absent). Both the clinical and research arenas benefit from a FASD diagnostic system of classification (4-digit numeric codes) that is expressed in the universal language of numbers and portrays, at a glance, the magnitude of expression of each feature (e.g., 4-Digit Code 2334 reflects mild growth deficiency, moderate expression of the FAS facial phenotype, severe brain dysfunction and high prenatal alcohol exposure). Perhaps most importantly, as the clinical arena continues to strive for consensus on how to define and name the clinical subgroups under the umbrella of FASD, the 4-Digit Codes can be collapsed into any number of diagnostic categories The codes can be used independent of the clinical diagnostic names (FAS, SE/AE, ND/AE, ARND, ND-PAE, ARBD) one may apply to the subgroupings of the codes.

E. **The diagnostic term *Neurobehavioral Disorder / Alcohol Exposed* (ND/AE) has been replaced with the term *Neurodevelopmental Disorder / Alcohol Exposed (*ND/AE).** Neurodevelopmental disorders are defined as a group of conditions with onset in the developmental period, inducing deficits that produce impairments of functioning (Morris-Rosendahl & Crocq, 2020). This term is a better fit for the criteria used to define this 4-Digit Code diagnostic category; criteria that remain unchanged in this 4th edition.

F. **Diagnostic Categories A, B and C have been collapsed into a single Category A labeled FAS.** In the 3rd edition (Astley, 2004), Categories A, B and C distinguished *FAS/Alcohol exposed*, *FAS/Alcohol exposure unknown*, and *Partial FAS/Alcohol exposed*, respectively. These three categories have been collapsed into a single Category A labeled FAS for the following reasons. The 4-Digit Codes clearly reflect the various combinations of growth deficiency, FAS facial features, brain abnormalities and prenatal alcohol exposure that meet criteria for FAS. The 4-Digit Code no longer uses the term *Partial FAS* because too often the term was misinterpreted as a milder form of FAS (e.g. had less severe brain dysfunction), potentially jeopardizing an individual's opportunity to qualify for intervention services/supports. The only features that were partially expressed in *Partial FAS* were the growth and/or facial features, not the brain damage. The level of brain damage in Partial FAS was as severe as that required for *FAS*.

G. **Diagnostic Category D: FAS Phenocopy has been removed.** The 4 codes under this category (3431, 3441, 4431, 4441) have been moved to Category N: *Sentinel physical finding(s) / static encephalopathy / no alcohol exposure*. The name applied to Category N is more informative and avoids any potential chart lore confusion that *FAS Phenocopy* is FAS. The growth, face and brain ranks for these 4 codes meet criteria for FAS, but the confirmed absence of prenatal alcohol exposure rules out FAS. These 4-Digit Code outcomes could occur in an individual with growth deficiency and brain dysfunction whose familial facial phenotype happens to match that of FAS. Phenocopies such as these are expected to be rare and to date have never been observed in the FASDPN clinic.

H. **Two 4-Digit Codes (1432 and 1442) were moved from the 2004 Diagnostic Category: *K [sentinel physical finding(s) / static encephalopathy / alcohol exposure unknown*] to the new 2024 Category *A [Fetal alcohol syndrome*].** Since their sentinel physical finding was the Rank 4 FAS facial phenotype and the Rank 4 face provides confirmation of prenatal alcohol exposure when written or verbal evidence of alcohol exposure is unknown (Alcohol Rank 2); these two codes are more appropriately placed in Category A. Among over 4,500 patients evaluated in the FASD diagnostic clinics in AK and WA State (Astley et al, 2024) over 20 and 30 years respectively, only 4 individuals received a diagnosis of 1442. None received a diagnosis of 1432.

I. **Throughout this Guide, weblinks have been inserted** to provide clinicians with easy access to literature citations, diagnostic tools and forms, and training opportunities.

J. Finally, **all diagnostic forms in this Guide are posted on the FASDPN website and have been updated** to reflect this 4th edition of the Guide. The Online Course has also been updated. Those who have already completed the Online Course need not take it again.

FASD 4-Digit Code

Rank	**3** Growth	**4** Face	**3** Brain	**4** Prenatal Alcohol	3 Other Prenatal Risks	3 Other Postnatal Risks
4	severe	all 3 features	abnormal structure/neurology	high	high	high
3	moderate	2.5 features	severe dysfunction	some	some	some
2	mild	1-2 features	moderate dysfunction	unknown	unknown	unknown
1	normal	no features	normal function	none	none	none

FASD Umbrella

3 Diagnoses under the FASD Umbrella		Growth	FAS Face	Brain		Alcohol
1. FAS	Fetal Alcohol Syndrome	growth	face	severe		exposed
2. SE/AE	Static Encephalopathy / Alc-Exposed			severe		exposed
3. ND/AE	Neurodevelopmental Disorder / Alc-Exposed				moderate	exposed

I. Introduction

A. What is Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Spectrum Disorders (FASD)

FAS is a permanent birth defect syndrome caused by maternal consumption of alcohol during pregnancy. The definition of the FAS has changed little since the 1970's when the condition was first described and refined at the University of Washington in Seattle WA (Jones and Smith, 1973; Rosett, 1980; Clarren and Smith, 1978; Sokol and Clarren, 1989; Stratton *et al*., 1996). The condition has been broadly characterized by prenatal and/or postnatal growth deficiency, a unique cluster of minor facial anomalies, and brain structural, neurological and/or functional abnormalities. Prenatal alcohol is a leading known cause of intellectual/developmental disabilities in the Western World (Abel & Sokol, 1987) and is preventable. The prevalence of FAS is estimated to be 1 to 3 per 1,000 live births (Stratton et al., 1996) in the general population, but has been documented to be as high as 10 to 15 per 1,000 in some high-risk populations like foster care (Astley et al., 2002).

The physical, cognitive, and behavioral deficits observed among individuals with prenatal alcohol exposure are not dichotomous, that is either normal or clearly abnormal. Rather, the outcomes, and the prenatal alcohol exposure, all range along separate continua from normal to clearly abnormal and distinctive. This full range of outcomes observed among individuals with prenatal alcohol exposure has come to be called Fetal Alcohol Spectrum Disorders (FASD). FASD is a spectrum of disorders **caused** by prenatal alcohol exposure. FAS is the most severe diagnosis under the umbrella of FASD.

Although reference to the harmful effects of prenatal alcohol exposure on infant outcome date back to biblical times, it was not until 1968 when the first reference was published in the medical literature by Lemoine and colleagues from France (Lemoine et al., 1968). Ulleland and colleagues from the United States published similar research findings in 1970 and 1972 (Ulleland et al., 1970; Ulleland, 1972). In 1973, Jones and Smith coined the term FAS (Jones & Smith, 1973) to describe a subset of alcohol-exposed children, obtained from Dr. Ulleland's study and their own clinical records, who shared a common pattern of malformation (Jones et al., 1973).

B. The Diagnostic Challenge

Individuals with prenatal alcohol exposure present with a wide range of outcomes, most of which are not specific to (caused only by) prenatal alcohol exposure and often manifest differently across the lifespan. Professionals from multiple disciplines (medicine, psychology, speech-language pathology, occupational therapy, etc.) are needed to accurately assess and interpret the broad array of outcomes that define the diagnoses. The pattern and severity of outcome is dependent in part on the timing, frequency, and quantity of alcohol exposure (which is rarely known with any level of accuracy) and the fetus' genetic vulnerability to prenatal alcohol exposure (Astley et al., 2019a). The pattern and severity of outcome is also dependent on the other prenatal and postnatal risk factors that are prevalent among individuals with prenatal alcohol exposure (Astley, 2020; Astley et al., 2020).

In the absence of accurate, precise, and unbiased methods for measuring and recording the severity of exposures and outcomes in individual patients, diagnoses have varied widely from clinic to clinic

(Aase, 1994; Astley & Clarren 2000; Chavez et al., 1988; Stratton et al., 1996). From a clinical perspective, diagnostic misclassification leads to inappropriate patient care, increased risk for secondary disabilities (Streissguth & Kanton, 1997) and missed opportunities for primary prevention. From a public health perspective, diagnostic misclassification leads to inaccurate estimates of incidence and prevalence (Stratton et al., 1996). Inaccurate estimates thwart efforts to allocate sufficient social, educational, and health care services to this high-risk population, and preclude accurate assessment of primary prevention intervention efforts. From a clinical research perspective, diagnostic misclassification reduces the power to identify clinically meaningful contrasts between FAS and control groups (Astley & Clarren, 2001). Non-standardized diagnostic methods prevent valid comparisons between studies.

The 4-Digit Diagnostic Code was first released in 1997 (Astley & Clarren, 1997) to address the following limitations in the conventional gestalt approach to diagnosing individuals with prenatal alcohol exposure.

1. *There have been no standardized operational definitions for FAS or for any of the other diagnoses that fall under the umbrella of FASD. Rather, there have been diagnostic guidelines that physicians have been encouraged to follow, but the guidelines have not been sufficiently specific to assure diagnostic accuracy or precision.*

   For example, according to the diagnostic guidelines published by Sokol and Clarren (1989), which were a minor modification of the 1980 definition of FAS by the Fetal Alcohol Study Group of the Research Society for Alcoholism (Rosett, 1980), which, in turn, were derived from the work of Clarren and Smith (1978): "The diagnosis of FAS can only be made when the patient has signs of abnormality in each of the three categories: 1) Prenatal and/or postnatal growth retardation [weight and/or length below the 10th percentile when corrected for gestational age], 2) central nervous system involvement (including neurological abnormality, developmental delay, behavioral dysfunction or deficit, intellectual impairment, and/or structural abnormalities, such as microcephaly [head circumference below the 3rd percentile or brain malformations found on imaging studies or autopsy] and 3) a characteristic face, currently qualitatively described as including short palpebral fissures, an elongated midface, a long and flattened philtrum, thin upper lip, and flattened maxilla."

   The 1996 guidelines for the diagnosis of FAS proposed by the Institute of Medicine (Stratton et al., 1996) took a similar approach. The diagnosis of FAS can be made when the patient presents with: "1) Evidence of growth retardation, as in at least one of the following: a) low birth weight for gestational age; b) decelerating weight over time not due to nutrition; or c) disproportional low weight to height; 2) Evidence of a characteristic pattern of facial anomalies that includes features such as short palpebral fissures and abnormalities in the premaxillary zone (e.g., flat upper lip, flattened philtrum, and flat midface); and 3) Evidence of brain neurodevelopmental abnormalities, as in at least one of the following: a) decreased cranial size at birth; b) structural brain abnormalities (e.g., microcephaly, partial or complete agenesis of the corpus callosum, cerebellar hypoplasia);c) neurological hard or soft signs (as age appropriate), such as impaired fine motor skills, neurosensory hearing loss, poor tandem gait, poor eye-hand coordination."

   Although these descriptions do provide guidance, they are not sufficiently specific to assure diagnostic accuracy and precision. They reflect a more "gestalt" approach to diagnosis. The guidelines for brain abnormalities do not address how many areas of deficit must be present, how

severe the deficits must be, or what level of documentation must exist to substantiate the presence of the deficit. The guidelines for the facial phenotype are equally nonspecific. How many facial features must be present, how severe must the features be, and what scale of measurement should be used to judge the severity? One need only read the clinical literature or review medical records, birth certificates, birth defect registries or ICD-9 codes to see how variably these criteria are interpreted, applied and reported (CDC, 1995, 1995a; Cordero et al., 1994; Ernhart et al., 1995; Stratton et al., 1996).

2. *There has been a lack of objective, quantitative scales to measure and report the magnitude of expression of key diagnostic features.*

   For example, although a thin upper lip and smooth philtrum are key diagnostic features (Astley & Clarren, 1996; Clarren & Smith, 1978; Jones & Smith, 1973; Smith, 1979; Stratton et al., 1996), prior to 1997, quantitative measurement scales were never used to measure thinness or smoothness, and guidelines had never been established for how thin or smooth the features must be. Objective quantitative scales not only improve accuracy and precision, but also establish a common numeric language for communicating outcomes in medical records and in the medical literature.

3. *The term fetal alcohol effects (FAE) was broadly used and poorly defined.*

   The term 'suspected fetal alcohol effects' was first introduced into the medical literature in 1978 and was defined as 'less complete partial expressions' of FAS in individuals with prenatal alcohol exposure (Clarren & Smith, 1978). Based on this definition, an individual whose mother drank a few glasses of wine intermittently throughout pregnancy and presented with attention deficit hyperactivity disorder would meet the criteria for FAE. So would an individual whose mother drank a fifth of vodka daily throughout pregnancy and presented with microcephaly, severe intellectual disability, growth deficiency and no facial anomalies. The broad use of this term and the reluctance to abandon it points to the clear need to develop diagnostic terms for individuals with prenatal alcohol exposure who present with physical anomalies and/or cognitive/behavioral disabilities, but do not meet the criteria for FAS. New diagnostic terms that more finely differentiate the variable exposures and outcomes of individual patients, without implying alcohol as the sole causal agent, were needed.

4. *Clinical terms like FAE* (Aase et al., 1995), *alcohol-related birth defects (ARBD) (Stratton et al., 1996,) alcohol-related neurodevelopmental disorder (ARND) (Stratton et al., 1996, Hoyme et al.,2016) and FASD without the Face (Cook et al., 2015) imply a causal link between alcohol exposure and outcome in an individual that, to date, cannot be medically confirmed. As far back as 1995, leading dysmorphologists in the field of FAS diagnosis formally requested that the term FAE no longer be used for this reason (Aase et al., 1995; Sokol & Clarren, 1989).*

   With the exception of the Rank 4 full facial phenotype of FAS, no other physical anomalies or cognitive/behavioral disabilities observed in an individual with prenatal alcohol exposure are necessarily specific to (caused only by) their prenatal alcohol exposure (Stratton et al., 1996). Features such as microcephaly, neurological abnormalities, attention deficit, intellectual disability, and growth deficiency frequently occur in individuals with prenatal alcohol exposure, and frequently occur in individuals with no prenatal alcohol exposure. The diagnostic terms

ARBD, ARND (Hoyme et al., 2016) and FASD without Sentinel Facial Features (Cook et al., 2015) introduce the same limitation as does FAE, namely, implying alcohol exposure caused the birth defect or neurodevelopmental disorder in an individual patient. The 4-Digit Code avoids this problem by using a nomenclature that reports the patient was *exposed* to prenatal alcohol rather than reporting the patient's outcomes are *alcohol effects* or *alcohol-related outcomes*. The 4-Digit Code also requires that all other adverse prenatal and postnatal risks be documented and ranked for they too serve as important risk factors that must be taken into consideration when deriving a diagnosis and intervention plan.

5. *Too often diagnoses depicting FASD are reported in the medical records and medical literature with no documentation of the method used to derive the diagnosis and little or no documentation of the data used to support the diagnosis.*

   Failure to report this information can limit the patient's ability to qualify for and receive appropriate intervention services from subsequent health care, social service, and educational providers. For example, simply reporting that an individual has FAS does little to convey the individual's strengths and disabilities. Some individuals with FAS have low IQs, some have normal IQs, some have attention deficits, some do not, some have challenges with memory, while others have language deficits. From a public health perspective, failure to report these data also prevents surveillance efforts from accurately tracking the prevalence of FASD diagnoses in the population. Suportine data are needed to validate the diagnoses. Accurate surveillance is vital for setting public health policy and assessing the effectiveness of primary prevention efforts. The 4-Digit Code requires data be collected not just to corroborate the diagnosis, but to derive the diagnosis. The 4-Digit Code provides a comprehensive FASD Diagnostic Form for recording all supportive data and provides a numeric classification scheme that is readily incorporated into clinical, research, and surveillance databases.

C. Meeting the Diagnostic Challenge

Each of the above limitations has been largely overcome with the development of the "*4-Digit Diagnostic Code*". The four digits reflect the magnitude of expression of four key diagnostic features of FASD in the following order: (1) growth deficiency, (2) the FAS facial phenotype, (3) brain abnormalities, and (4) prenatal alcohol exposure. The magnitude of expression of each feature is ranked independently on a 4-point Likert scale with 1 reflecting complete absence of the FAS feature and 4 reflecting a strong "classic" presence of the FAS feature. Thus, the 4-Digit Code 4444 reflects the most severe expression of FAS (significant growth deficiency, all three FAS facial features, structural/neurological evidence of brain damage, and confirmed prenatal exposure to alcohol). At the opposite end of the scale is the 4-Digit Code 1111 reflecting normal growth, none of the three FAS facial features, no evidence of brain abnormalities, and confirmed absence of prenatal alcohol exposure. Every combination of 4-Digit Code has been observed among individuals with prenatal alcohol exposure evaluated in the WA State FAS Diagnostic & Prevention Network.

This diagnostic method was developed through the combined expertise of the University of Washington FAS Diagnostic and Prevention Network (FASDPN) interdisciplinary clinical teams (Clarren & Astley, 1997; Clarren et al., 2000) and the comprehensive records of over 3,000 patients (newborn to adult) with prenatal alcohol exposure diagnosed over 30 years at the FASDPN clinics.

D. Benefits of the 4-Digit Diagnostic Code

The 4-Digit Diagnostic Code:

1. Greatly increases diagnostic precision and accuracy through use of objective, quantitative measurement scales, image analysis software, and specific case definitions.

2. Diagnoses the full spectrum of outcomes (FASD) observed in individuals across all ages and all levels of prenatal alcohol exposure.

3. Offers an intuitively logical 4-digit numeric approach to reporting outcomes and exposure that clearly and objectively reflect the magnitude of growth deficiency, FAS facial phenotype, brain abnormality and prenatal alcohol exposure.

4. Documents the presence of prenatal alcohol exposure without implying a causal role.

5. Documents all other prenatal and postnatal adverse exposures and events that can also adversely impact outcome.

6. Most importantly, as the clinical and research fields of FASD strives to achieve consensus on diagnostic criteria and nomenclature worldwide, these 4-Digit Codes are expressed in the universal language of numbers and can be grouped and regrouped into any number of diagnostic categories under the umbrella of FASD and assigned any number of diagnostic names that best meet the widely varying medical systems of care worldwide (Appendix 1).

7. Can be taught to a wide array of health care and social service providers, thus greatly expanding the availability of diagnostic services. (Appendix 1)

The 4-Digit Code currently serves as the cornerstone of a fully integrated and highly successful screening, diagnostic, prevention and surveillance program in Washington State (Astley et al., 2002; Astley, 2004a, 2024; Hemingway (Astley) et al., 2024).

While this document might at first appear complex, clinicians that have used it find this diagnostic approach logical and easy to use, facilitating the proper description and classification of patients presenting along the full spectrum of adverse outcomes and prenatal alcohol exposures.

E. Other Syndromes

The methods of diagnosing FAS arise from the larger fields of teratology and dysmorphology (clinical genetics). It is essential to remember that many birth defect syndromes share *isolated* features, but each is differentiated by a unique *constellation* of features. A few examples of conditions that share some, but not all, of the features of FAS include fetal hydantoin syndrome, maternal PKU fetal effects, and fetal valproate syndrome. It is important to note that alcohol is a teratogen that can adversely impact the development of all fetuses, including fetuses with other syndromes. It is not appropriate to rule-out all other syndromes before rendering a diagnosis of FAS/D. And when rendering a diagnosis of FASD, alternate or co-existing syndromic, medical or psychiatric conditions should be considered at all times.

II. FASD Diagnostic Form

The FASD Diagnostic Form guides the interdisciplinary clinical team in the collection, recording, and interpretation of all key information used to derive accurate and precise diagnoses across the full spectrum of outcomes. All forms presented in this Diagnostic Guide are also available free in electronic format on the FASDPN website. Comprehensive assessments lead to accurate diagnoses and informed intervention plans. Although space has been provided to record a full complement of data, we are not implying all these assessments must be conducted to derive a diagnosis. It is the responsibility of the clinical team to select the most appropriate assessment battery for each patient.

The form also serves as a centralized data repository for efficient generation of the final medical report and is designed to facilitate data entry into a database.

Where is the Information for the Diagnostic Form Obtained?

The information recorded in the FASD Diagnostic Form is obtained from four primary sources:

1. The New Patient Information Form, completed by the caregivers prior to the diagnostic evaluation (Appendix 2), serves as a clinical intake form.

2. Medical/psychological/educational assessments conducted prior to the diagnostic evaluation.

3. Assessments administered by the clinical team at the time of the diagnostic evaluation.

4. The caregiver/patient interview conducted at the time of the diagnostic evaluation

When is the Form Completed and by Who?

Diagnosis of fetal alcohol spectrum disorders by an interdisciplinary team of professionals (medical doctor, psychologist, speech-language pathologist, occupation therapist) will result in the most accurate assessment and interpretation of the broad array of outcomes (growth deficiency, facial anomalies, and structural/neurological/functional brain abnormalities) that define the diagnoses. The FASD Diagnostic Form is completed by the clinical team before and during the patient's clinic visit. Typically, the physician completes the sections pertaining to growth, structural and neurological measures of the brain, facial features and other physical findings. The occupational therapist, psychologist, speech language pathologist, complete the sections pertaining to psychometric measures of brain function. All team members participate in the derivation of the 4-Digit Code and intervention plan.

FASD 4-Digit Code Diagnostic Short Form

A 1-page FASD 4-Digit Code Short Form is available free in electronic format for clinics that choose to record only the data needed to support the patient's 4-Digit Code.

FASD 4-Digit Code Diagnostic Form

Medical #		Clinic		Clinic Date	
Patient's Name	First	MI	Last	Age (y)	Birth date

Person accompanying patient	Name:	Relation:
Relationship(s) to patient	Name:	Relation:

Patient's Race(s)	
Patient's sex at birth:	
Patient's gender identity	
Form completed by:	
Diagnosis made by:	
Diagnosis	

4-Digit Diagnostic Code Grid

(See instructions in Diagnostic Guide for FASD)

FASD 4-Digit Code

Rank	Growth	Face	Brain	Prenatal Alcohol	Other Prenatal Risks	Other Postnatal Risks
4	severe	all 3 features	abnormal structure/neurology	high	high	high
3	moderate	2.5 features	severe dysfunction	some	some	some
2	mild	1-2 features	moderate dysfunction	unknown	unknown	unknown
1	normal	no features	normal function	none	none	none

GROWTH

Prenatal Growth

	Gestational Age	Birth Length			Birth Weight		
Date	(wks)	(cm)	(inches)	(percentile)	(gm)	(lbs/oz)	(percentile)

Postnatal Growth

		Height					Weight		
Date	Age (yrs/months)	(cm)	(inches)	Unadjusted (percentile)	Mid-birthparent Adjustment (cm)	Parent-Adjusted (percentile)	(kg)	(lbs)	(percentile)

Birth Parent's Heights

Birth Mother Height		Birth Father Height		Mid-Parent Height
cm	inches	cm	inches	cm

ABC-Score for Growth Deficiency

See instructions in the "Diagnostic Guide for FASD" for deriving the ABC-score for growth and translating it into a 4-Digit Diagnostic Code

	Circle the ABC Scores for: Height	Weight
≤ 3rd percentile = **C**	C	C
>3rd and ≤ 10th percentile = **B**	B	B
> 10th percentile = **A**	A	A

This ABC Score reflects the patient's growth between _____ years and _____ years of age.

FACIAL FEATURES (and other physical findings)

CURRENT PHENOTYPE Age _____ years Date _____/_____/_____

Direct Measures by Hand

	mm	z-score	Normal Chart Used
Left PFL			
Right PFL			
Mean PFL			
Inner Canthal Distance			

	5-Point Rank	UW Lip-Philtrum Guide Used
Philtrum		
Upper Lip		

2D Photograph or 3D Image

Frontal digital photo filename	Internal measure of scale (dot on forehead)		
	True dot size	Units (mm, cm, inches)	Dot size in photo, pixels

	Length in photo (pixels)	mm	z-score	Normal Chart Used
Left PFL				
Right PFL				
Mean PFL				
Inner Canthal Distance				

Photo filename		5-Point Rank	UW Lip-Philtrum Guide	
	Philtrum			Upper Lip Circularity
	Upper Lip			

PAST PHENOTYPE Age _____ years Date _____/_____/_____

Source of Information	Internal measure of scale (dot on forehead)		
	True dot size	Units (mm, cm, inches)	Dot size in photo (pixels)
Photo:			
Text Record:			

	Length in photo (pixel)	mm	z-score	Normal Chart Used
Left PFL				
Right PFL				
Mean PFL				
Inner Canthal Distance				

Photo filename		5-Point Rank	UW Lip-Philtrum Guide	
	Philtrum			Upper Lip Circularity
	Upper Lip			

FACIAL ABC-SCORE

See instructions in the "Diagnostic Guide for FASD" for deriving the ABC Score and 4-Digit Code

5-Point Likert Rank for Philtrum & Lip	Z-score for Palpebral Fissure Length	*Circle the ABC Scores for:* Palpebral Fissure	Philtrum	Upper Lip
4 or 5	≤ -2 SD	C	C	C
3	>-2 SD and ≤ -1 SD	B	B	B
1 or 2	> -1 SD	A	A	A
Source of Data for each Facial Feature ➜				

OTHER PHYSICAL FINDINGS / ANOMALIES / SYNDROMES / MEDICAL CONDITIONS

BRAIN

Severity Score: Severity of Delay/Impairment (Displayed along left margin)
Circle: **0** = Unknown, Not Assessed **1** = Within Normal Limits **2** = Mild to Moderate **3** = Severe

Severity **STRUCTURAL**

0 1 2 3 OFC

cm	smallest %tile	date	cm	%tile	date	cm	%tile	date

0 1 2 3 Structural anomalies seen on brain imaging: _____

0 1 2 3 Other: _____

NEUROLOGICAL

0 1 2 3 Seizures: type: _____ meds. _____ Date of onset _____

0 1 2 3 Other neurological signs (vision, hearing, tics, tremors): _____

_____

FUNCTIONAL/Standardized Measures *Document most recent, valid test scores.*

0 1 2 3 **Cognition** (e.g., WISC, WAIS, DAS, TONI, Stanford-Binet, etc.)

0 1 2 3 **Processing Speed** (e.g., WISC, etc.)

Other Test/Subtest Names	*Score*	*Type of Score*	*Date*	*Other Test/Subtest Names*	*Score*	*Type of Score*	*Date*

0 1 2 3 **Academic Achievement** (e.g., WIAT, Woodcock Johnson, WRAT, Keymath, etc.)

Test/Subtest Name	*Score*	*Type of Score*	*Date*	*Test/Subtest Name*	*Score*	*Type of Score*	*Date*

0 1 2 3 **Adaptive Behavior / Social Skills** (e.g., VABS, BASC, ABAS, etc.)

Test/Subtest Name	*Score*	*Type of Score*	*Date*	*Test/Subtest Name*	*Score*	*Type of Score*	*Date*

BRAIN (Continued)

Severity Score: Severity of Delay/Impairment (Displayed along left margin)
Circle: **0** = Unknown, Not Assessed **1** = Within Normal Limits **2** = Mild to Moderate **3** = Severe

Severity

0 1 2 3 **Executive Function** (e.g., D-KEFS, Rey Complex Figure Test, WCST, NEPSY, etc.)

Test/Subtest Name	*Score*	*Type of Score*	*Date*	*Test/Subtest Name*	*Score*	*Type of Score*	*Date*

0 1 2 3 **Memory** (CVLT, WRAML, Rey Complex Figure Test, etc)

Test/Subtest Name	*Score*	*Type of Score*	*Date*	*Test/Subtest Name*	*Score*	*Type of Score*	*Date*

0 1 2 3 **Motor** (e.g., PDMS, QNST, VMI, Brunuinks-Oseretsky Scales of Motor Dev, etc.)

0 1 2 3 **Sensory** (e.g., SSP, AASP, etc.)

Test/Subtest Name	*Score*	*Type of Score*	*Date*	*Test/Subtest Name*	*Score*	*Type of Score*	*Date*

0 1 2 3 **Language** (e.g., TOLD, PLS, CELF, TOWL etc.)

0 1 2 3 **Social Communication** (e.g., SCQ etc.)

0 1 2 3 **Speech Articulation** (Arizona, etc.)

Test/Subtest Name	*Score*	*Type of Score*	*Date*	*Test/Subtest Name*	*Score*	*Type of Score*	*Date*

BRAIN (Continued)

Severity Score: Severity of Delay/Impairment (Displayed along left margin)
Circle: **0** = Unknown, Not Assessed **1** = Within Normal Limits **2** = Mild to Moderate **3** = Severe

Severity

0 1 2 3 **Mental Health/Psychiatric Conditions:** (e.g., ADHD, ODD, Maj. Depression, ASD, etc)

Disorder	*Date Diagnosed*	*Disorder*	*Date Diagnosed*	*Disorder*	*Date Diagnosed*

Medication. √ if Currently Taking	*Response (+, -, none)*	*Medication. √ if Currently Taking*	*Response (+, -, none)*	*Medication. √ if Currently Taking*	*Response (+, -, none)*

0 1 2 3 **Behavior/Attention/Activity Level** (e.g., CBCL, Conners Rating Scale, NICHQ, BASC, CSHQ, etc.)

Test/Subtest Name	*Score*	*Type of Score*	*Date*	*Test/Subtest Name*	*Score*	*Type of Score*	*Date*

0 1 2 3 **Development** (e.g., Bayley Scales of Infant Dev., Battelle Dev. Invent., Miller Assessment of Preschoolers, etc.)

Test/Subtest Name	*Score*	*Type of Score*	*Date*	*Test/Subtest Name*	*Score*	*Type of Score*	*Date*

BRAIN (Continued)

FUNCTIONAL / Non-Standardized Observational Measures

Severity Score: Severity of Delay/Impairment (Displayed along left margin)
Circle: **0** = Unknown, Not Assessed, Too Young **1** = Within Normal Limits **2** = Mild to Moderate **3** = Severe

Severity

Caregiver Interview

Planning / Temporal Skills

0 1 2 3 Needs considerable help organizing daily tasks_____
0 1 2 3 Can not organize time _____
0 1 2 3 Does not understand concept of time_____
0 1 2 3 Difficulty in carrying out multi-step tasks _____
0 1 2 3 Other _____

Behavioral Regulation/ Sensory Motor Integration

0 1 2 3 Poor management of anger / tantrums _____
0 1 2 3 Mood swings _____
0 1 2 3 Impulsive _____
0 1 2 3 Compulsive _____
0 1 2 3 Perseverative _____
0 1 2 3 Inattentive _____
0 1 2 3 Inappropriately [high or low] activity level _____
0 1 2 3 Lying/stealing _____
0 1 2 3 Unusual [high or low] reactivity to [sound touch light] _____
0 1 2 3 Other _____

Abstract Thinking / Judgment

0 1 2 3 Poor judgment _____
0 1 2 3 Cannot be left alone _____
0 1 2 3 Concrete, unable to think abstractly_____
0 1 2 3 Other _____

Memory / Learning / Information Processing

0 1 2 3 Poor memory, inconsistent retrieval of learned information _____
0 1 2 3 Slow to learn new skills _____
0 1 2 3 Does not seem to learn from past experiences _____
0 1 2 3 Problems recognizing consequences of actions _____
0 1 2 3 Problems with information processing speed and accuracy_____
0 1 2 3 Other _____

Spatial Skills and Spatial Memory

0 1 2 3 Gets lost easily, has difficulty navigating from point A to point B _____
0 1 2 3 Other _____

Social Skills and Adaptive Behavior

0 1 2 3 Behaves at a level notably younger than chronological age_____
0 1 2 3 Poor social/adaptive skills _____
0 1 2 3 Other _____

Motor/Oral Motor Control

0 1 2 3 Poor/delayed motor skills_____
0 1 2 3 Poor balance_____
0 1 2 3 Other _____

BRAIN (Continued)

FUNCTIONAL DOMAINS

Examples include, but are not limited to Memory, Cognition, Language, Executive Function, Motor, and Attention.

Severity Score: Severity of Delay/Impairment (Displayed along left margin)
Circle: **0** = Unknown, Not Assessed **1** = Within Normal Limits **2** = Mild to Moderate **3** = Severe

Severity		
0 1 2 3	Name of Domain	
	Supportive Evidence	
0 1 2 3	Name of Domain	
	Supportive Evidence	
0 1 2 3	Name of Domain	
	Supportive Evidence	
0 1 2 3	Name of Domain	
	Supportive Evidence	
0 1 2 3	Name of Domain	
	Supportive Evidence	
0 1 2 3	Name of Domain	
	Supportive Evidence	
0 1 2 3	Name of Domain	
	Supportive Evidence	
0 1 2 3	Name of Domain	
	Supportive Evidence	
0 1 2 3	Name of Domain	
	Supportive Evidence	
0 1 2 3	Name of Domain	
	Supportive Evidence	
0 1 2 3	Name of Domain	
	Supportive Evidence	
0 1 2 3	Name of Domain	
	Supportive Evidence	
0 1 2 3	Name of Domain	
	Supportive Evidence	

See the "Diagnostic Guide for FASD" for instructions on deriving the 4-Digit Diagnostic Code for Brain

MATERNAL ALCOHOL USE

Alcohol Consumption of the Birth Mother

Before Pregnancy	**average number of drinks** per drinking occasion:					
	maximum number of drinks per occasion:					
	average number of **drinking days per week**:					
	Type(s) of alcohol	wine	beer	liquor	unknown	Other (specify)

During Pregnancy	**average number of drinks** per drinking occasion:					
	maximum number of drinks per occasion:					
	average number of **drinking days per week**:					
	Type(s) of alcohol	wine	beer	liquor	unknown	Other (specify)

Trimester(s) in which alcohol was consumed	1st	2nd	3rd	unknown	none
Was the birth mother ever reported to have a **problem** with alcohol?	yes	suspected	no	unknown	
Was the birth mother ever **diagnosed** with alcoholism?	yes	suspected	no	unknown	
Did the birth mother ever **receive treatment** for alcohol addiction?	yes	suspected	no	unknown	
Was alcohol use during this pregnancy **positively confirmed** through verbal or written documentation?	yes	no			
If yes, **source** of verbal or written confirmation:					
Reported use of alcohol during this pregnancy is:	Reliable	Somewhat reliable		Unk. reliability	
Was the Rank 4 FAS facial phenotype used as a proxy measure of prenatal alcohol exposure?	yes	no			
Other information about alcohol use **during this pregnancy**					

4-DIGIT RANK for Alcohol Exposure

4-Digit Diagnostic Rank	Prenatal Alcohol Exposure Category	Description
4	High Risk	● Alcohol use during pregnancy is CONFIRMED. *and* ● Reported exposure pattern is consistent with the medical literature placing the fetus at "high risk" (generally high peak blood alcohol concentrations delivered at least weekly in early pregnancy, reports of intoxication, binge-drinking).
3	Some Risk	● Alcohol use during pregnancy is CONFIRMED. *and* ● Level of alcohol use is reported to be less than in Rank (4) or the level is unknown.
2	Unknown Risk	● Alcohol use during pregnancy is UNKNOWN (cannot be confirmed or ruled-out).
1	No Risk	● Alcohol use during pregnancy is CONFIRMED to be completely ABSENT from conception to birth.

Circle the 4-Digit Diagnostic Rank in the table above that best reflects the patient's Prenatal Alcohol Exposure

OTHER PRENATAL AND POSTNATAL RISK FACTORS

PRENATAL RISKS:

No known risk	Unknown risk	Some risk	High risk
1	2	3	4

See the "Diagnostic Guide for FASD" for instructions on deriving the rank for Other Prenatal Risks.

Prenatal:

1. Parity ____, Gravity ____ of this birth. Birth order if child is the result of a multiple birth pregnancy: _____ of _____
2. Prenatal care: ____ Yes, (If yes, when did it start?_____), ___ No, ___ Unknown
3. Complications (specify) _____

Genetics

1. Biological parents learning difficulties

   Mother ___ Yes ____ Suspected __ No __ Unknown. **Father** ___ Yes ____ Suspected ____ No ____ Unknown
2. Other conditions of heritability (ADHD, mental health, syndromes, etc.) that may be relevant to this case. *(specify)*

   _____

Prenatal Exposure to Other Substances (e.g., medications, tobacco, illicit drugs, other teratogens, etc.)

POSTNATAL RISKS:

No known risk	Unknown risk	Some risk	High risk
1	2	3	4

See the "Diagnostic Guide for FASD" for instructions on deriving the rank for Postnatal Risks.

Perinatal Difficulties (prematurity, extended stay in birth hospital, etc.): _____

_____

Medical Conditions: _____

_____

Postnatal Adversity (ACES, TESI, etc):

1. Number of out-of-home placements _____ Age at first out-of-home placement _____ Age at last placement _____
2. Please report the age range for all adversities experienced by the patient. If age is unknown, enter Yes, No Suspected or Unknown in each box.

Adversity	age range	Adversity	age range	Adversity	age range
sexual abuse		orphanage/group care		serious medical issue	
physical abuse		abandonment		substance abuse (patient)	
emotional abuse		homelessness		patient incarceration	
domestic violence		poverty		patient suicide attempt	
physical neglect		food insecurity		natural disaster	
emotional neglect		bullying		war, terrorism	
medical neglect		school violence		List others below	
family death		community violence			
family incarceration		discrimination			
parent separated/divorced		serious accident			
family mental health		home fire			
parent substance abuse		animal attack			

Additional details that may be relevant:

FASD 4-Digit Diagnostic Code – Short Form 2024

In lieu of using the 9-page comprehensive Diagnostic Form presented above, this 1-page Short Form documents all pertinent information needed to derive/support the patient's 4-Digit Code. An electronic version of the form is available on the FASDPN website.

FASD 4-Digit Diagnostic Code – Short Form (2024)

*(Astley) Hemingway SJ, Diagnostic Guide for FASD: The 4-Digit Code, 4th ed. 2024

Patient Name		Birth date	
Sex/Gender		Clinic Date	
Race		Age (yrs)	
Clinic Name		Medical #	

NAME OF DIAGNOSIS

FASD 4-DIGIT DIAGNOSTIC CODE

Rank	Growth	Face	Brain	Prenatal Alcohol	Other Prenatal Risks	Other Postnatal Risks
4	severe	all 3 features	abnormal structure/neurology	high	high	high
3	moderate	2.5 features	severe dysfunction	some	some	some
2	mild	1-2 features	moderate dysfunction	unknown	unknown	unknown
1	normal	no features	normal function	none	none	none

DATA BELOW WAS USED TO DERIVE / SUPPORT 4-DIGIT CODE

GROWTH

Date	Height measure	Height percentile	Weight measure	Weight percentile

GROWTH TABLES (Circle ABC Scores to Derive Rank)

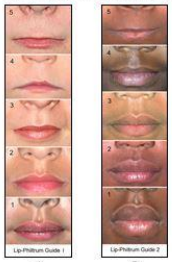
Percentile Range	ABC-Scores for: Height	Weight
≤ 3rd	C	C
> 3rd and ≤ 10th	B	B
> 10th	A	A

4-Digit Diagnostic Rank	Growth Deficiency Category	Height-Weight ABC-Score Combinations
4	Severe	CC
3	Moderate	CB, BC, CA, AC
2	Mild	BA, BB, AB
1	None	AA

FACE

Date		
Right PFL: mm / Z-score		
Left PFL: mm / Z-score		
mean PFL: mm / Z-score		
Philtrum Rank		
Lip Rank		
Lip Circularity		

Circle Guide(s) Used



1 2

FACE TABLES (Circle ABC-Scores to Derive Rank)

5-Point Rank for Philtrum or Lip	Z-scores for Palpebral Fissure Length (PFL)	ABC-Scores for: Palpebral Fissure	Philtrum	Upper Lip
4 or 5	≤ - 2 SD	C	C	C
3	> -2 SD and ≤ -1 SD	B	B	B
1 or 2	> -1 SD	A	A	A

4-Digit Diagnostic Rank	Level of Expression of FAS Facial Features	Palpebral Fissure – Philtrum – Lip ABC-Score Combinations
4	Severe	CCC
3	Moderate	CCB, CBC, BCC
2	Mild	CCA, CAC, CBB, CBA, CAB, CAA BCB, BCA, BBC, BAC ACC, ACB, ACA, ABC, AAC
1	None	BBB, BBA, BAB, BAA ABB, ABA, AAB, AAA

CNS

Rank 4 *Check 1 or more*	microcephaly	abnormal structural brain image	seizure disorder	No evidence	
	Other (specify):				
Rank 2 or 3 *Evidence of Dysfunction*		Domain / Test / Subtest Name		Score (units)	Date
	1				
	2				
	3				

PRENATAL ALCOHOL

	Trimester(s):		Ave. drinking days/week:	Ave. drinks / per occasion:	
Other (Specify):					

Other Prenatal and Postnatal Exposures / Events

Risk Rank: (None = 1, Unknown = 2, Some = 3, High = 4)	Prenatal Rank:		Postnatal Rank:	

FASD-4digit-shortform-032024.docx © (Astley) Hemingway-University of Washington, Seattle, WA Page 1 of 1

III. Instructions for Deriving the 4-Digit Code

A. The 4-Digit Diagnostic Code

What are the 4 Digits?

The four digits reflect the magnitude of expression of the four key diagnostic features of FASD in the following order: (1) growth deficiency, (2) the FAS facial phenotype, (3) brain abnormalities, and (4) prenatal alcohol exposure. Individuals with prenatal alcohol exposure often present with a myriad of other prenatal and postnatal risks that could also adversely impact growth and development. These too are documented. The 4-Digit Diagnostic Code is generated at the completion of the diagnostic evaluation using information recorded on the FASD Diagnostic Form. The code is derived following the directions in Section III. B.

FASD 4-Digit Code

Rank	**3** Growth	**4** Face	**3** Brain	**4** Prenatal Alcohol	3 Other Prenatal Risks	3 Other Postnatal Risks
4	severe	all 3 features	abnormal structure/neurology	high	high	high
3	moderate	2.5 features	severe dysfunction	some	some	some
2	mild	1-2 features	moderate dysfunction	unknown	unknown	unknown
1	normal	no features	normal function	none	none	none

FASD Umbrella

3 Diagnoses under the FASD Umbrella		Growth	FAS Face	Brain		Alcohol
1. FAS	Fetal Alcohol Syndrome	growth	face	severe		exposed
2. SE/AE	Static Encephalopathy / Alc-Exposed			severe		exposed
3. ND/AE	Neurodevelopmental Disorder / Alc-Exposed				moderate	exposed

Example above: If an individual presented with moderate growth deficiency, all 3 FAS facial features, severe brain dysfunction and high prenatal alcohol exposure, they would receive a 4-Digit Code 3434. Code 3434 is one of 40 codes that meet criteria for FAS (see Section V). FAS is one of three diagnoses under the umbrella of FASD. Other prenatal and postnatal risks are also ranked.

How are the 4 Digits Ranked?

The magnitude of expression of each feature is ranked independently on a 4-point Likert scale with 1 reflecting complete absence of the FASD feature and 4 reflecting a strong "classic" presence of the

FASD feature. The other prenatal and postnatal risks are also ranked on 4-point Likert scales. Specific criteria for each Rank are presented in Section III.B.

How Many 4-Digit Codes and Clinical Diagnostic Categories are There?

There are 256 possible 4-Digit Diagnostic Codes ranging from 1111 to 4444. The 256 codes and their corresponding clinical names are listed in numerical order in Section VI. Each 4-Digit Diagnostic Code falls into one of 19 unique Clinical Diagnostic Categories (labeled A through S) (see Sections IV and V). Only 108 of the 256 codes fall broadly under the umbrella of FASD in accordance with the FASD 4-Digit Code. These 108 codes are collapsed into 6 FASD diagnostic categories as portrayed in red font in Sections IV and V. These 6 FASD diagnostic categories are further collapsed into three clinically meaningful diagnostic categories under the umbrella of FASD: FAS, Static Encephalopathy/Alcohol-Exposed, and Neurodevelopmental Disorder/Alcohol-Exposed.

How Many of the Diagnostic Categories Fall Under the Umbrella of FASD?

Only 6 of the 19 diagnostic categories (A-E and J) fall broadly under the umbrella of FASD. These are highlighted in red font in Sections IV, V and VI). For example, 25% of the 4-Digit Codes end in 1 (Alcohol Rank 1, confirmed absence of prenatal alcohol exposure). An individual with confirmed absence of prenatal alcohol exposure cannot have FASD. Why keep 4-Digit Codes ending in 1 in this Diagnostic Guide? Codes ending in 1 help portray that the growth deficiency and brain abnormalities observed among individuals with prenatal alcohol exposure are also observed in individuals with confirmed absence of prenatal alcohol exposure. Presenting all combinations of 4-Digit Codes in this FASD diagnostic system also presents a valuable numeric method for classifying control or comparison groups in research studies designed to compare individuals with FASD to individuals with confirmed absence of prenatal alcohol exposure with and without adverse outcomes.

How are the Names of the Clinical Diagnostic Categories Constructed?

The following terms are used in varying combinations to name the 19 Diagnostic Categories. They include:

- **Sentinel Physical findings:**
  The term "S*entinel Physical Findings*" is used in this diagnostic system when the patient presents with growth deficiency at the Rank 3 or 4 level and/or presents with the FAS facial phenotype at the Rank 3 or 4 level. The term *"sentinel"* refers to the physical findings that are diagnostic indicators of FASD. These include a unique cluster of minor facial anomalies (short palpebral fissures, thin upper lip, and a smooth philtrum) and growth deficiency. Other physical findings (major or minor anomalies) may be detected instead of or in addition to these sentinel findings that may suggest alternate or additional conditions. There are places on the Diagnostic Form to record and interpret other physical findings.

- **Neurodevelopmental Disorder:**
  The term *"Neurodevelopmental Disorder"* is used to label the Diagnostic Category when the patient presents with functional impairments (cognitive, motor, language, etc) at the Brain Rank 2 level and no evidence of structural, neurological or functional abnormalities at the Brain Rank 3 or Rank 4 levels.

- **Static Encephalopathy:**
  The term *"encephalopathy"* refers to "any significant abnormal condition of the structure or function of brain tissues" (Anderson, 2002). The term *"static"* means that the abnormality in the brain is unchanging; neither progressing nor regressing. The term *"Static Encephalopathy"* is used in this diagnostic system when the patient presents with significant structural, neurological, and/or functional abnormalities that strongly support the presence of underlying brain damage at the Rank 3 and/or Rank 4 levels. The term does not define or suggest any specific pattern of structural, neurological, or functional abnormality.

Fetal Alcohol Syndrome

The term FAS is used to refer to patients who present with one of 40 4-Digit Diagnostic Code combinations reflecting growth deficiency; the FAS facial phenotype; significant structural, neurological, and/or functional brain abnormalities; and prenatal alcohol exposure confirmed by verbal or written record or the presence of the Rank 4 FAS facial phenotype (Astley & Clarren, 2001; (Astley) Hemingway, 2020). These 40 Codes are presented in Section V.

- **Alcohol (Exposed, Not Exposed, Exposure Unknown):**
  The last digit of the 4-Digit Code reflects prenatal alcohol exposure as determined through written or verbal documentation. The terms (Exposed) and (Not Exposed) are used when written or verbal documentation exists that confirms the presence or absence of exposure. If the presence or absence of exposure cannot be confirmed through written or verbal documentation, the term (Exposure Unknown) is applied. If exposure is ranked unknown, the Rank 4 FAS facial phenotype can serve as a proxy for confirmation of prenatal alcohol exposure. Alcohol exposure is reported independently of outcome(s) and does not imply that a causal association exists between the exposure and the outcome(s).

The names assigned to the 19 Diagnostic Categories (A-S) are listed in Sections IV and V. These names are constructed from the terms above and reflect the patient's clinical outcome and prenatal alcohol exposure. Five of the Diagnostic Categories A-E fall broadly under the umbrella of FASD as do 4 additional 4-Digit Codes in Category J that present with the Rank 4 FAS facial phenotype. Diagnostic Categories F and G reflect patients with confirmed prenatal alcohol exposure, who only present with growth and/or facial anomalies or no adverse outcomes whatsoever (normal growth, facial and brain outcomes). The 4-Digit Code does not consider these two diagnostic outcomes to be under the umbrella of FASD. The remaining 12 categories (H through S) reflect patients with unknown prenatal alcohol exposure or confirmed absence of prenatal alcohol exposure. These 12 categories present with the full spectrum of physical and functional abnormalities from normal to severe, but with a confirmed absence of prenatal alcohol exposure or the Rank 4 FAS facial phenotype do not fall under the umbrella of FASD.

Ultimately, establishing terms that are both clinically accurate, broadly applicable, and facilitate access to services remains a challenge. One of the greatest strengths of the 4-Digit Code is the assignment of a numeric 4-Digit Code to each patient that clearly captures the full spectrum of outcomes and exposure in the universal language of numbers. The 4-Digit Codes are independent of any proposed system for how to cluster them into diagnostic categories and what names to apply to each category.

How are the Names of the Clinical Diagnostic Categories Constructed?

- **Growth** deficiency and facial features are physical features. When either feature receives a Rank 3 or 4, *Sentinel physical finding(s)* is placed at the beginning of the name.
- When brain receives a Rank 3 or 4, the term *Static Encephalopathy* is included in the name. When **brain** receives only a Rank 2, the term *Neurodevelopmental Disorder* is included in the name.
- When **alcohol** exposure receives a Rank 3 or 4, *alcohol exposed* is placed at the end of the name. When alcohol exposure receives a Rank 2, *alcohol exposure unknown* is placed at the end of the name. When alcohol exposure receives a Rank 1, no *alcohol exposure* is placed at the end of the name.
- When the criteria for FAS are met, the term FAS is used in place of the more generic terms. For example, the term *FAS* would be used for the 4-Digit Code 3443 rather than *Sentinel physical finding(s) / static encephalopathy / alcohol exposed.*

FASD 4-Digit Code

	3	2	4 (2)	3		
Rank 4	severe	all 3 features	abnormal structure/neurology	high	high	high
3	moderate	2.5 features	severe dysfunction	some	some	some
2	mild	1-2 features	moderate dysfunction	unknown	unknown	unknown
1	normal	no features	normal function	none	none	none
	Growth	**Face**	**Brain**	**Prenatal Alcohol**	**Other Prenatal Risks**	**Other Postnatal Risks**

KEY

Growth and/or Face	Brain	Alcohol
Sentinel physical finding(s)	Static encephalopathy	Alcohol exposed
	Neurodevelopmental disorder	Alcohol exposure unknown

In the example above, the 4-Digit Code 3243 would receive the clinical name ***Sentinel physical findings / static encephalopathy / alcohol exposed.*** Note brain received both Rank 4 (for microcephaly) and Rank 2 (for moderate dysfunction). The higher brain Rank is used to derive the 4-Digit Code (3243). If brain receives a Rank 4, it is advised that both brain codes be reported as follows 324(2)3 conveying both the structural and functional status of the patient's brain. In another example, a code of 1222 would receive the clinical name *Neurodevelopmental disorder / alcohol exposure unknown*.

How to Explain the Diagnosis to the Patient

Generic summaries of each of the 19 Clinical Diagnostic Categories are presented in Section VII. These summaries can be used as the first page of the patient's final Medical Summary Note. Subsequent pages in the Medical Summary should document the findings and recommendations specific to the patient. We recommend the growth, face, brain, and exposure data, used to generate the 4-Digit Code, be reported in the Medical Summary to provide essential information for subsequent medical professionals and facilitate records-based public health surveillance efforts.

When sharing the diagnosis with caregivers, we have found that the following graphic provides a simple, clear way to present the results. Families receive a copy of this graphic at the end of the diagnostic appointment along with a comprehensive medical summary (see Section VII). We introduce FASD and the 4-Digit Code to the families as follows:

FASD is characterized by growth deficiency, minor facial anomalies, brain structural and/or functional impairment and prenatal alcohol exposure.

Each component is ranked on a 4-point scale. The higher the rank, the more severe the outcome or exposure.

Together, these ranks produce 4-Digit Codes that range from 1111 to 4444. A code of 1111 reflects an individual with normal growth, none of the FAS facial features, normal brain function and confirmed absence of prenatal alcohol exposure. A code of 4444 reflects an individual with the most severe presentation of FAS (severe growth deficiency, all 3 facial features of FAS, structural and/or neurological brain abnormalities and a confirmed high prenatal alcohol exposure

The 4-Digit Codes are grouped into three clinical diagnoses under the umbrella of FASD that reflect the full spectrum of FASD from moderate to severe. In the example presented, the 4-Digit Code 3434 is one of 40 codes that meet criteria for FAS.

As another example, Code 1134 reflects a person with normal growth, none of the 3 facial features of FAS, severe brain dysfunction and a high prenatal alcohol exposure. The Code 1134 meets criteria for SE/AE.

Other prenatal and postnatal risks may also be present and impact growth and development. These are also ranked on 4-point scales.

FASD 4-Digit Code

Rank	**3** Growth	**4** Face	**3** Brain	**4** Prenatal Alcohol	3 Other Prenatal Risks	3 Other Postnatal Risks
4	severe	all 3 features	abnormal structure/neurology	high	high	high
3	moderate	2.5 features	severe dysfunction	some	some	some
2	mild	1-2 features	moderate dysfunction	unknown	unknown	unknown
1	normal	no features	normal function	none	none	none

FASD Umbrella

3 Diagnoses under the FASD Umbrella		Growth	FAS Face	Brain		Alcohol
1. FAS	Fetal Alcohol Syndrome	growth	face	severe		exposed
2. SE/AE	Static Encephalopathy / Alc-Exposed			severe		exposed
3. ND/AE	Neurodevelopmental Disorder / Alc-Exposed				moderate	exposed

III. Instructions for Deriving the 4-Digit Code

B.1. Ranking Growth

What Type of Growth Deficiency Are We Looking For?

Growth deficiency plays an essential role in the diagnosis of FASD (Astley et al., 2016). Growth deficiency among individuals with prenatal alcohol exposure is highly correlated with and predictive of brain dysfunction. Growth deficiency can serve as a valuable marker for identifying infants with prenatal alcohol exposure at high risk for brain dysfunction that will typically not manifest until later in childhood.

We are looking for growth deficiency characteristic of a teratogenic insult, not characteristic of postnatal environmental factors such as nutritional deprivation or chronic or acute illness. We want to answer the question *'What is the patient's growth potential after controlling for parental height and postnatal environmental influences?'* Growth deficiency of teratogenic origin is likely to present as a relatively consistent impairment over a period of time (i.e., the patient's growth follows the normal curve, but is below genetic expectation for family background). In contrast, growth deficiency due to postnatal environmental influences (e.g., illness, nutritional deprivation, etc.) is likely to present as periodic fluctuations in the curve.

The method described below allows one to rank a patient's overall growth pattern on a single 4-point Likert scale with 1 equal to 'normal' and 4 equal to "significantly deficient". Not all patients will have complete growth curves available, therefore, a guide is provided below for prioritizing the ranking of the patient's growth over a lifetime.

How to Measure and Rank Growth: The 1st Digit of the 4-Digit Diagnostic Code

A. The height percentile should be adjusted for age and sex. Because there is a significant genetic component in attained stature, adjustment for mid-parent stature is also recommended when both parents' heights are known. Himes et. al., (1985) provide charts for mid-parent adjustment of recumbent length (birth to 3 years) and stature (3 to 18 years) of US children relative to National Center for Health Statistics growth charts.

B. The weight percentile should be adjusted for age and sex. Weight is not adjusted for height.

   Clinicians are encouraged to use the most current electronic growth charts that best match the age, sex, race/ethnicity and country of origin of each patient.

C. For ranking purposes, the growth record is separated into two parts:
   1. Prenatal growth (birth measures)
   2. Postnatal growth (all measures collected after birth)

   Select the part of the growth record with the greatest deficiency in the height percentile.

   If the prenatal height percentile is lower than all postnatal height percentiles, proceed to section D for instructions on how to rank prenatal growth.

If any of the postnatal height percentiles are lower than the prenatal height percentile, select the point or consecutive points in the growth record that reflect the lowest height percentiles that cannot be attributed to postnatal environmental influences such as nutritional deprivation or chronic illness. If the height deficiency is reflected in a series of points in the growth record, as opposed to a single point, rank the level of deficiency based on the percentile range where the majority of the points fall. Proceed to section D for instructions.

D. Rank the level of deficiency of the height and weight percentiles, for the part of the growth record with <u>greatest deficiency in the height percentile</u> by circling A, B, or C in the ABC-Score table at the bottom of page 1 of the FASD Diagnostic Form. Tables 1 and 2 below are also printed on the electronic images of the Lip-Philtrum Guides. This ABC-Score table is duplicated below as Table 1. The height and weight percentiles selected for ranking should be matched sets. For example, if the height at 10 years of age is selected for ranking, the corresponding weight percentile at 10 years of age should also be selected for ranking. One does <u>not</u> rank the height at one age and the weight at another age to generate an ABC-Score.

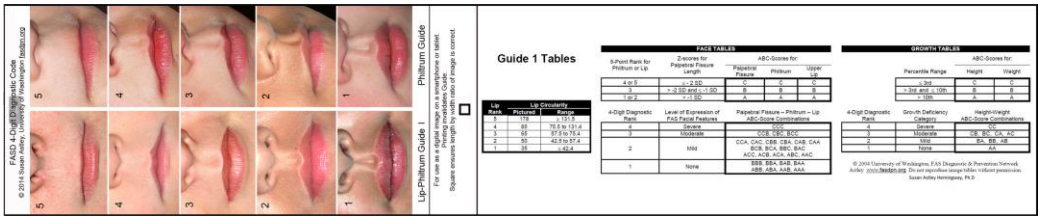


Table 1: Deriving the ABC-Score for Growth

	Circle the ABC-Scores for:	
Percentile Range	Height	Weight
≤ 3rd	C	C
>3rd and ≤ 10th	B	B
>10th	A	A

E. Next, refer to Table 2 to determine the *4-Digit Diagnostic Rank* of the Height-Weight ABC-Score recorded in Table 1. Transfer the resulting 4-Digit Diagnostic Rank for growth to the 4-Digit Diagnostic Code Grid at the top of page 1 of the FASD Diagnostic Form (Section II).

Table 2: Converting the Growth ABC-Score to a 4-Digit Diagnostic Rank for Growth

4-Digit Diagnostic Rank	Growth Deficiency Category	Height-Weight ABC-Score Combinations
4	Severe	CC
3	Moderate	CB, BC, CA, AC
2	Mild	BA, BB, AB
1	None	AA

Normal Growth Charts

Height, Weight, OFC:
Clinicians are encouraged to use the most current electronic charts for height, weight and head circumference that best match the age, sex, race/ethnicity, and country of origin of each patient. In our Seattle WA FASDPN clinic, we currently use the CDC, WHO and Rollins et al (2010) growth charts for OFC,, weight and height and adjust for mid-parental height (Himes et al., 1985) when both parents' heights are available.

Facial Measures:
We recommend using the free FAS Facial Photographic Analysis Software (Astley, 2016) distributed by the FASDPN to obtain the most accurate measures of the facial features (Astley, 2015). The Facial Software incorporates an adjustment factor that is confirmed to accurately measure a palpebral fissure length from a 2-dimensional digital photo within 0.2 mm of the gold standard of measure (a sliding digital caliper). We do not recommend using a handheld ruler to measure PFLs. Numerous studies have confirmed the inaccuracy of the ruler method (Astley, 2015). The FASDPN currently uses the Iosub African American PFL charts (Iosub et al., 85) for individuals that are full or half African American and the Stromland Scandinavian PFL charts for all other races (Stromland et al., 1999). These charts come with our FAS Facial software and are available in our free excel PFL Z-score calculator. The Hall Caucasian PFL charts (1989) are no longer in use (Clarren et al., 2010).

Example for Scoring Growth Deficiency

Patient's Growth Record:

	Age (years)	Height Percentile	Weight Percentile
birth	0.0	8 %	1 %
	1.5	14 %	16 %
	5.0	12 %	15 %
	7.0	12 %	15 %
	15.5	15 %	15 %

Assume in this case the clinical records rule-out any adverse environmental influence on the postnatal measures and mid-parental height is unknown.

Ranking:

- Priority would be placed on ranking the birth length and weight because the birth length percentile is lower than all postnatal height percentiles recorded.
- Birth length (8 %) would receive an **ABC-Score = B** (> 3rd and ≤ 10th percentile) (Table 1).
- Birth weight (1 %) would receive an **ABC-Score = C** (≤ 3rd percentile) (Table 1).
- The Height-Weight ABC-Score combination would be **BC** (Table 1).

Table 1: Deriving the ABC Score for Growth

	Circle the ABC-Scores for:	
Percentile Range	Height	Weight
≤ 3rd	C	**C**
>3rd and ≤ 10th	**B**	B
>10th	A	A

- The Height-Weight ABC-Score of **BC** reflects **Moderate** growth deficiency (Table 2)
- **Moderate** growth deficiency would receive a **Rank 3** in the 4-Digit Diagnostic Code (Table 2).

Table 2: Converting the Growth ABC-Score to a 4-Digit Diagnostic Rank for Growth

4-Digit Diagnostic Rank	Growth Deficiency Category	Height-Weight ABC-Score Combinations
4	Severe	CC
3	**Moderate**	CB, **BC**, CA, AC
2	Mild	BA, BB, AB
1	None	AA

- **Rank 3** would be transferred to the 4-Digit Diagnostic Code Grid on page 1 of the FASD Diagnostic Form (as duplicated below).

Result:

FASD 4-Digit Code

3

Rank	Growth	Face	Brain	Prenatal Alcohol	Other Prenatal Risks	Other Postnatal Risks
4	severe	all 3 features	abnormal structure/neurology	high	high	high
3	moderate	2.5 features	severe dysfunction	some	some	some
2	mild	1-2 features	moderate dysfunction	unknown	unknown	unknown
1	normal	no features	normal function	none	none	none

III. Instructions for Deriving the 4-Digit Code

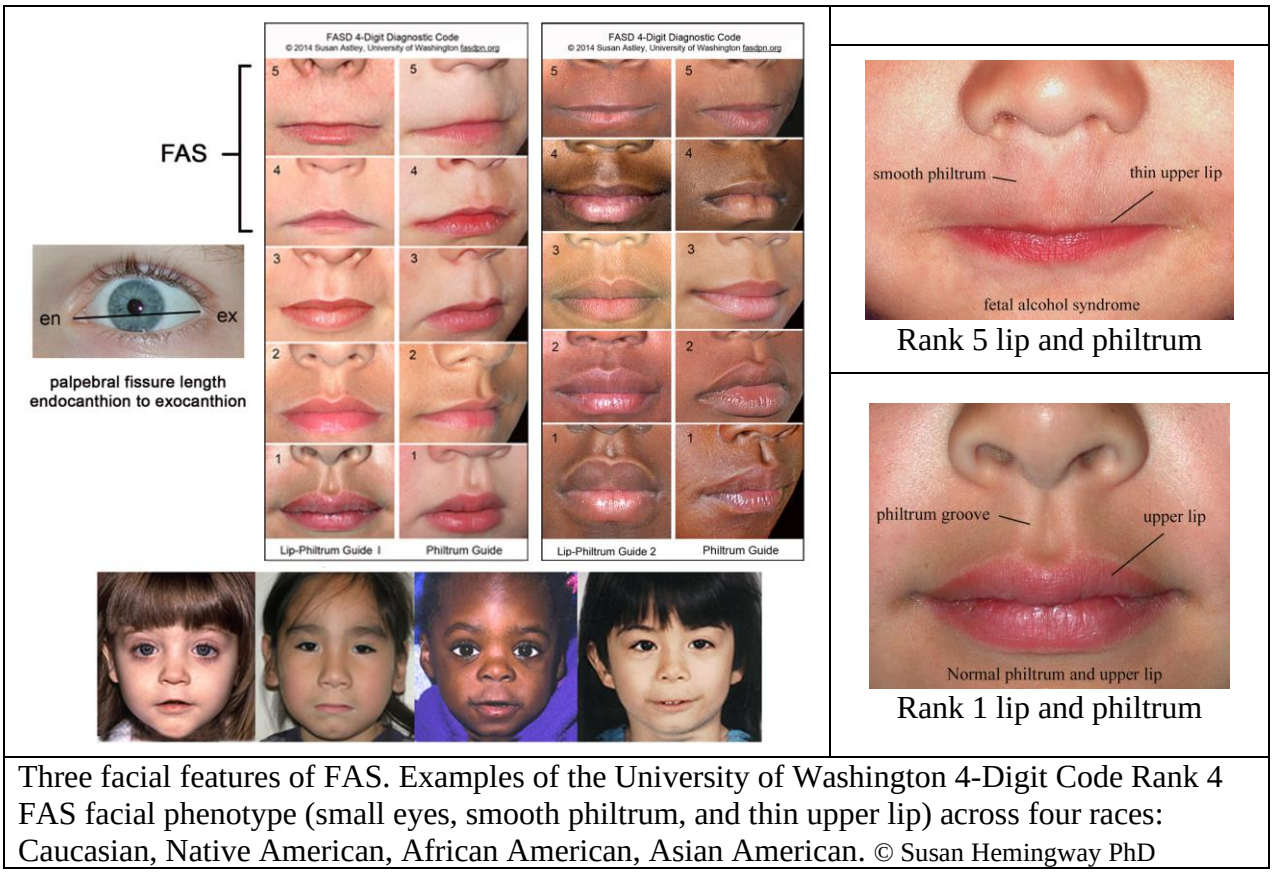
B.2. Ranking the Facial Phenotype

The FAS Facial Phenotype

The face of FAS is defined by the 4-Digit Code as the simultaneous expression of three facial features:

1. Short palpebral fissure lengths (2 or more standard deviations below the mean)
2. Smooth philtrum (Rank 4 or 5 on the University of Washington Lip-Philtrum Guides).
3. Thin upper lip (Rank 4 or 5 on the University of Washington Lip-Philtrum Guides).

If facial measures are available at different ages, the age when the expression of the FAS facial phenotype is most severe (highest Face Rank) should be used.



Three facial features of FAS. Examples of the University of Washington 4-Digit Code Rank 4 FAS facial phenotype (small eyes, smooth philtrum, and thin upper lip) across four races: Caucasian, Native American, African American, Asian American. © Susan Hemingway PhD

David Smith, M.D., who coined the term FAS in 1973, identified these features as the *key* diagnostic facial features in 1979 (Smith, 1979). A series of empirical studies conducted over the next 30 years confirmed: 1) The 4-Digit-Code Rank 4 FAS facial phenotype is the only facial phenotype that provides sufficient positive predictive value (PPV) and specificity (100%) to prenatal alcohol exposure (PAE) to allow the facial phenotype to serve as confirmation of alcohol exposure in a diagnostic setting when PAE is unknown. Even minimal relaxation of the phenotype (e.g., Face Rank 3) results in PPV (35%) and specificity (88.7%) values too low to use as confirmation of PAE. (Astley

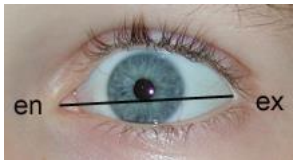
& Clarren, 1996, 2000, 2001; Astley-Hemingway et al., 2020). The clinical validity of these features has been confirmed through population-based screening and surveillance studies (Astley et al., 2002; Astley, 2004a) and empirical studies documenting remarkably strong correlations between these midline facial anomalies and decreased volume of the frontal lobe (Astley et al., 2009). The FAS facial phenotype presents on a clinically meaningful continuum. As the FAS facial phenotype increases in severity of expression from Rank 1 to Rank 4, the prevalence and severity brain damage/dysfunction, growth deficiency and prenatal alcohol exposure increase significantly (Astley et al., 2013).

How to Measure and Rank the Face: The 2nd Digit of the 4-Digit Diagnostic Code

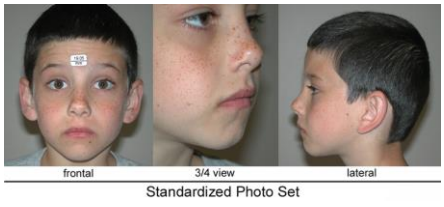
There are two methods for measuring the 3 facial features of FAS: 1) direct measurement and 2) computerized analysis of a 2-dimensional digital facial photograph using the FAS Facial Photographic Analysis Software developed by the University of Washington FASDPN. The latter is confirmed more accurate (Astley & Clarren, 2001; Astley, 2015). A video demonstration of the software is available online. The FAS Facial Photographic Analysis Software 2016 v2.1 is available free from the FASDPN website. Animations demonstrating proper measurement technique are also available.

A. Palpebral Fissure Length (PFL)

Direct Measurement: The PFL is the distance from the endocanthion (en) to the exocanthion (ex). The PFLs can be measured to the nearest mm with a clear plastic, 15-cm ruler, held as close as possible to the eye without touching the eye or eyelashes. The patient is asked to open their eyes fully to allow accurate identification of the endocanthion and exocanthion landmarks (Astley & Clarren, 1996; Farkas, 1994). Numerous published studies have confirmed the inaccuracy of measuring PFLs with a ruler (Astley, 2015). Although sliding digital calipers are the most accurate method of measurement, use of calipers is too dangerous. The FASDPN recommends all facial features, including the PFLs be measured using the free FAS Facial Photographic Analysis Software 2016 v2.1.



Digital Photographic Measurement: Three standardized 2-dimensional digital photos of the face are taken with a ¾ inch machine-cut paper sticker placed between the eyebrows to serve as an internal measure of scale (e.g., a ruler in the photo) (Astley, 2015). Write the size of the sticker on the sticker. The camera is held 4 feet from the face to avoid lens distortion.



Standardized Photo Set

The digital images are analyzed using the FAS Facial Photographic Analysis Software (Astley, 2016). View a video demonstration of the software. The PFL is measured by clicking the mouse curser on the endocanthion and exocanthion landmarks of the right and left eyes. The length of each palpebral fissure and its z-score (number of standard deviations above or below the norm) are computed automatically based on formulas and normal charts embedded in the software. More detailed instructions are provided with the software.

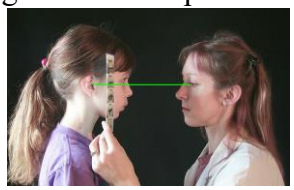
Ranking the PFL*:* The PFL is ranked according to its z-score (or how many standard deviations above or below the mean it is on a normal PFL growth chart) using the Face Tables on the backside of the Lip-Philtrum Guides (Figure 2). If the eyes are substantially different in size, (more than 2

mm different) rank the larger PFL. If the eyes are comparable in size, rank the mean of the right and left PFL. The FASDPN currently uses the Iosub African American PFL charts (Iosub, 1985) for individuals that are full or half African American and the Stromland Scandinavian PFL charts for all other races (Stromland, 1999). These charts come with the FAS Facial software and are available in our free Excel PFL Z-score calculator posted online. The Hall Caucasian PFL charts for birth to 16 years (1989) are no longer used and should not be used (Clarren et al., 2010).

B. Upper Lip Thinness and Philtrum Smoothness

Direct Measurement: Upper lip thinness (the red or vermilion portion of the upper lip) and philtrum smoothness are measured independent of one another using the 5-point pictorial Likert scale presented on the University of Washington Lip-Philtrum Guides (see Figure 2 below). Guide 1 is used for Caucasians and any race or racial mix with lips similar in thickness to Caucasians. Guide 2 is used for African Americans and any race or racial mix with lips similar in thickness to African Americans (e.g., aboriginal Australians). Which Guide was selected should be reported in the medical summary. The physician holds the Lip-Philtrum Guide next to the patient's face and identifies the picture that best matches the patient's upper lip and identifies the picture that best matches the patient's philtrum.

When measuring the upper lip thinness, the physician's eyes need to be aligned with the patient's Frankfort horizontal plane. The Frankfort horizontal plane is defined by a line (green line) that passes through the patient's external auditory canal and the lowest border of the bony orbital rim (orbitale). The physician's eyes (or camera lens) should be directly in line with this plane. If the physician stood above this plane looking down on the patient, the patient's upper lip could appear thinner than it truly is. View this animation demonstrating how to align yourself in the patient's Frankfort horizontal plane.

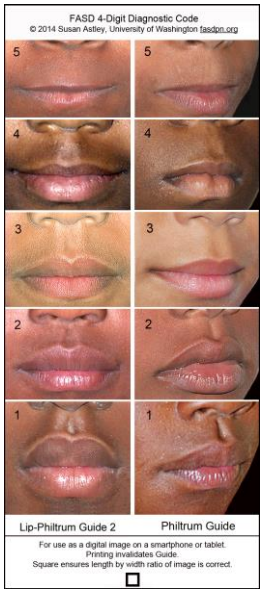


Lips must be *gently closed with no smile* to accurately measure philtrum smoothness and upper lip thinness (Astley et al., 1999). This is the same child with and without a smile. A smile makes the philtrum appear smoother and the upper lip thinner than they truly are. Note that without a smile, the lip and philtrum would both receive a correct Rank 2 on the Caucasian Lip-Philtrum Guide 1. With a smile, the lip and philtrum would both receive an *incorrect* Rank 5.

Digital Photographic Measurement: Lip thinness is measured from the frontal photograph using the FAS Facial Photographic Analysis Software. The red (e.g. vermilion) portion of the upper lip in the frontal photograph is outlined with the mouse to compute circularity (perimeter^2/area). The thinner the upper lip, the bigger the circularity.

Pictured is an example of the upper lip outlined to compute circularity. The circularity of this lip is 44.2, which is equivalent to Rank 2 on Lip-Philtrum Guide 1. Each Rank on the Lip-Philtrum Guide is defined by a range of circularities (See the Face Tables printed with the Lip-Philtrum Guide 1 in Figure 2 below). The software automatically ranks lip thinness using the circularity measure. The philtrum is measured by selecting the ¾ view picture on the University of Washington Lip-Philtrum Guide that best matches the patient's philtrum. More detailed instructions are provided in the software Instruction Manual.

A



B

Guide 1 Tables

Lip Rank	Lip Circularity Pictured	Lip Circularity Range
5	178	≥ 131.5
4	85	75.5 to 131.4
3	65	57.5 to 75.4
2	50	42.5 to 57.4
1	35	≤ 42.4

FACE TABLES

5-Point Rank for Philtrum or Lip	Z-scores for Palpebral Fissure Length	ABC-Scores for: Palpebral Fissure	Philtrum	Upper Lip
4 or 5	≤ - 2 SD	C	C	C
3	> -2 SD and ≤ -1 SD	B	B	B
1 or 2	> -1 SD	A	A	A

4-Digit Diagnostic Rank	Level of Expression of FAS Facial Features	Palpebral Fissure – Philtrum – Lip ABC-Score Combinations
4	Severe	CCC
3	Moderate	CCB, CBC, BCC
2	Mild	CCA, CAC, CBB, CBA, CAB, CAA BCB, BCA, BBC, BAC ACC, ACB, ACA, ABC, AAC
1	None	BBB, BBA, BAB, BAA ABB, ABA, AAB, AAA

GROWTH TABLES

Percentile Range	ABC-Scores for: Height	Weight
≤ 3rd	C	C
> 3rd and ≤ 10th	B	B
> 10th	A	A

4-Digit Diagnostic Rank	Growth Deficiency Category	Height-Weight ABC-Score Combinations
4	Severe	CC
3	Moderate	CB, BC, CA, AC
2	Mild	BA, BB, AB
1	None	AA

Guide 2 Tables

Lip Rank	Lip Circularity Pictured	Lip Circularity Range
5	80	≥ 62.1
4	57	52.1 to 62.0
3	39	30.1 to 52.0
2	29	27.5 to 30.0
1	25	≤ 27.4

FACE TABLES

5-Point Rank for Philtrum or Lip	Z-scores for Palpebral Fissure Length	ABC-Scores for: Palpebral Fissure	Philtrum	Upper Lip
4 or 5	≤ - 2 SD	C	C	C
3	> -2 SD and ≤ -1 SD	B	B	B
1 or 2	> -1 SD	A	A	A

4-Digit Diagnostic Rank	Level of Expression of FAS Facial Features	Palpebral Fissure – Philtrum – Lip ABC-Score Combinations
4	Severe	CCC
3	Moderate	CCB, CBC, BCC
2	Mild	CCA, CAC, CBB, CBA, CAB, CAA BCB, BCA, BBC, BAC ACC, ACB, ACA, ABC, AAC
1	None	BBB, BBA, BAB, BAA ABB, ABA, AAB, AAA

GROWTH TABLES

Percentile Range	ABC-Scores for: Height	Weight
≤ 3rd	C	C
> 3rd and ≤ 10th	B	B
> 10th	A	A

4-Digit Diagnostic Rank	Growth Deficiency Category	Height-Weight ABC-Score Combinations
4	Severe	CC
3	Moderate	CB, BC, CA, AC
2	Mild	BA, BB, AB
1	None	AA

Figure 2. University of Washington Lip-Philtrum Guides 1 (A) and 2 (B) are used to rank upper lip thinness and philtrum smoothness. The philtrum is the vertical groove between the nose and upper lip. The guides reflect the full range of lip thickness and philtrum depth with Rank 3 representing the population mean. Ranks 4 and 5 reflect the thin lip and smooth philtrum that characterize the FAS facial phenotype. Guide 1 is used for Caucasians and any race or racial mix with lips indigenously similar in thickness to Caucasians. Guide 2 is used for African Americans and any race or racial mix with lips indigenously similar in thickness to African Americans. Free digital images of these Guides and Tables for loading on a cell phone are available from astley@uw.edu. Circularity is perimeter^2/area and is measured using the FAS Facial Photographic Analysis Software (Astley, 2016). © Susan (Astley) Hemingway PhD.

C. Deriving the Facial ABC-Score

Rank the mean palpebral fissure length, philtrum smoothness, and upper lip thinness by circling A, B, or C in each column in the ABC-Score printed on the backside of the Lip-Philtrum Guide (Figure 2). This table is duplicated below as Table 1. The three facial features must be measured at the same age. In other words, one would NOT rank the philtrum at 10 years of age and the PFL and lip at 15 years of age. If facial measures are available at more than one age, rank the age when the expression of the FAS facial phenotype is most severe (has the highest Face Rank).

Table 1: Deriving the ABC-Score for Facial Phenotype

5-Point Likert Rank for Philtrum & Lip	Z-score* for Palpebral Fissure Length	Circle the ABC-Scores for: Palpebral Fissure	Philtrum	Upper Lip
4 or 5	≤ -2 SD	C	C	C
3	>-2 SD and ≤ -1 SD	B	B	B
1 or 2	> -1 SD	A	A	A

* Z-Score = (patient's mean PFL - mean PFL for a normal population) / (standard deviation of the mean PFL for a normal population)

Use the FAS Facial Photographic Analysis Software or the PFL Z-score Calculator to compute the z-score.

The z-score reflects how many standard deviations above or below the mean the patient's PFL is.

D. Deriving the 4-Digit Rank for Face: The 2nd Digit in the 4-Digit Code

Next, refer to Table 2 to determine the *4-Digit Diagnostic Rank* based on the ABC-Score derived from Table 1. Transfer the resulting 4-Digit Diagnostic Rank for face to the 4-Digit Diagnostic Code Grid on page 1 of the FASD Diagnostic Form (Section 11).

Table 2: Converting the Facial ABC-Score to a 4-Digit Diagnostic Rank for Face

4-Digit Diagnostic Rank	Level of Expression of FAS Facial Features	Palpebral Fissure - Philtrum - Lip ABC-Score Combinations
4	Severe	CCC
3	Moderate	CCB, CBC, BCC
2	Mild	CCA, CAC, CBB, CBA, CAB, CAA BCB, BCA, BBC, BAC ACC, ACB, ACA, ABC, AAC
1	None	BBB, BBA, BAB, BAA ABB, ABA, AAB, AAA

Example: Ranking the Facial Phenotype

Patient Facial Measures at 10 Years of Age (male, Caucasian):

- **Mean PFL = 24.5 mm**: Left PFL = 24.6 mm. Right PFL = 24.4 mm.

  Mean PFL Z-score = -2.16 using Stromland's PFL growth charts for Caucasian males (Stromland, 1999).

  - Note: a normal PFL for a 10-year-old male using Stromland's PFL chart =27.43 mm.
  - Use the FAS Facial Photographic Analysis Software or the PFL Z-score Calculator to compute the Z-score.

- Philtrum smoothness received a **Rank 5** on the Caucasian Lip-Philtrum Guide (Figure 2).

- The circularity of the upper lip was 65.5. Thus, upper lip thinness received a **Rank 3** on the Caucasian Lip-Philtrum Guide (Figure 2 above). The circularity range for Rank 3 is 57.5 to 74.9.

Ranking

- The mean PFL z-score of -2.16 receives an **ABC-Score = C** (≤ -2 SD) (Table 3).

- The Rank 5 philtrum receives an **ABC-Score = C** (Table 3).

- The Rank 3 upper lip receives an **ABC-Score = B** (Table 3).

- The ABC-Score combination for Palpebral Fissure - Philtrum - Lip is **CCB** (Table 3).

Table 3: Deriving the ABC-Score for Facial Phenotype

5-Point Likert Rank for Philtrum & Lip	Z-score for Palpebral Fissure Length	Circle the ABC-Scores for: Palpebral Fissure	Philtrum	Upper Lip
4 or 5	≤ -2 SD	**C**	**C**	C
3	>-2 SD and ≤ -1 SD	B	B	**B**
1 or 2	> -1 SD	A	A	A

- The Facial ABC-Score of **CCB** reflects a **Moderate** level of expression of the FAS facial phenotype (Table 4).
- A **Moderate** expression of the FAS facial phenotype would receive a **Rank 3** in the 4-Digit Diagnostic (Table 4).

Table 4: Converting the Facial ABC-Score to a 4-Digit Diagnostic Rank

4-Digit Diagnostic Rank	Level of Expression of FAS Facial Features	Palpebral Fissure - Philtrum - Lip ABC-Score Combinations
4	Severe	CCC
3	**Moderate**	**CCB**, CBC, BCC
2	Mild	CCA, CAC, CBB, CBA, CAB, CAA, BCB, BCA, BBC, BAC ACC, ACB, ACA, ABC, AAC
1	None	BBB, BBA, BAB, BAA ABB, ABA, AAB, AAA

- **Rank 3** would be transferred to the 4-Digit Diagnostic Code Grid on page 1 of the FASD Diagnostic Form (as duplicated below).

Result:

FASD 4-Digit Code

3

Rank	Growth	Face	Brain	Prenatal Alcohol	Other Prenatal Risks	Other Postnatal Risks
4	severe	all 3 features	abnormal structure/neurology	high	high	high
3	moderate	2.5 features	severe dysfunction	some	some	some
2	mild	1-2 features	moderate dysfunction	unknown	unknown	unknown
1	normal	no features	normal function	none	none	none

The FAS Facial Photographic Analysis Software produces a 1-page summary report for entry into the patient's medical record. Below is an example of an individual with none of the FAS facial features.

FAS Facial Photographic Analysis Report

IDENTIFICATION

Name: John (First) T (Middle) Doe (Last)
Subject I.D.: None
Source of Photo: Clinic
Gender: Male
Race: Caucasian/Caucasian
Birth Date: 1/1/1990

PHOTO ASSESSMENT

Normal PFL Chart: Scandinavian (Stromland '99) Lip-Philtrum Guide: Caucasian
Normal ICD Chart: Caucasian (Hall '89)

	Frontal	¾ View	Lateral
File Name	Demo Frontal	Demo 3/4	Demo Lateral
Date of Photo	6/22/1998	6/22/1998	6/22/1998
Age (yrs) in photo	8.47	8.47	8.47
Date of Photo Assessment	6/22/1998	6/22/1998	6/22/1998
Photo Assessor	Astley	Astley	Astley

Length of Real Internal Measure of Scale(sticker) placed on forehead (mm): 19.05
Length of Internal Measure of Scale in Frontal Photo (pixels): 155.2

Left Palpebral Fissure Length:	In photo (pixels) 208.5	True Length (mm) 28.2	Z-score 1.04
Right Palpebral Fissure Length:	In photo (pixels) 205.5	True Length (mm) 27.7	Z-score 0.67
Mean Palpebral Fissure Length:	In photo (pixels) 207.0	True Length (mm) 28.0	Z-score 0.86
Inner Canthal Distance (ICD):	In photo (pixels) 200.0	True Distance (mm) 24.5	Z-score -2.22

Flat Philtrum (5-point rank): In Frontal Photo 3 In ¾ Photo 3
Thin Upper Lip: Circularity (perimeter²/area) 44.2 5-Point rank (Circ) 2 5-Point rank (Scale) 2

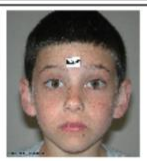
clown eyebrows ☐ ptosis ☐ strabismus ☐ epicanthal folds ■
flat midface ☐ protruding ears ☐ flat nasal bridge ☐ hypertelorism ☐

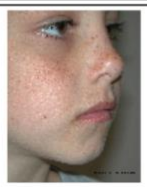
Other anomalies present: hypotelorism

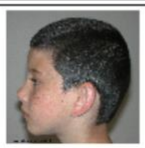
Comments:
Other syndromes present: None reported

PHOTO QUALITY

	Frontal	¾ View	Lateral
Side showing		Right	Left
Head rotation (5-point rank/degrees) to subject's Right (+) or Left (-)	0°	0	0
Head tilt (5-point rank) toward subject's Right (+) or Left (-) shoulder			0
Head tip (degrees) Up (+) or Down (-) from Frankfort Horizontal Plane	0°		
Exposure (3-point rank)	1 (good)	1 (good)	1 (good)
Focus (3-point rank)	1 (good)	1 (good)	1 (good)
Facial Expression (3-point rank)	1 (Relaxed)	1 (Relaxed)	1 (Relaxed)
Reliability of ABC-Score for palpebral fissure length (5-point rank)	1 (very good)		
Reliability of ABC-Score for philtrum (5-point rank)	1 (very good)	1 (very good)	
Reliability of ABC-Score for upper lip (5-point rank)	1 (very good)		


Demo Frontal


Demo 3/4


Demo Lateral

OUTCOME

	PFL	Philtrum	Lip
ABC-Score	A	B	A
Data Used	mean	3/4 view	circularity

4-Digit Diagnostic Code for Face: 1: FAS features absent

III. Instructions for Deriving the 4-Digit Code

B.3. Ranking the Brain

Alcohol's Impact on the Developing Brain

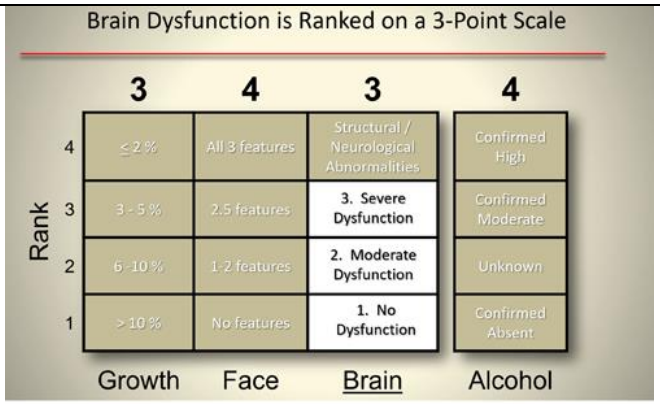
Alcohol is a teratogen that can alter the developing brain in a variety of ways from gross structural anomalies to subtle alterations in neurochemical levels (Stratton et al., 1996; West, 1986). Alterations in brain structure and/or chemistry can lead to altered brain function. Our ability to detect structural, neurological, and functional brain abnormalities is dependent on the sensitivity of today's measurement tools, which will continue to improve over time. Not all structural or neurological abnormalities result in *measurable* dysfunction and not all functional abnormalities are due to underlying brain damage. Some functional abnormalities result from adverse postnatal environmental factors and are transient in nature if the environment is improved.

How to Rank Brain: The 3rd Digit of the 4-Digit Diagnostic Code

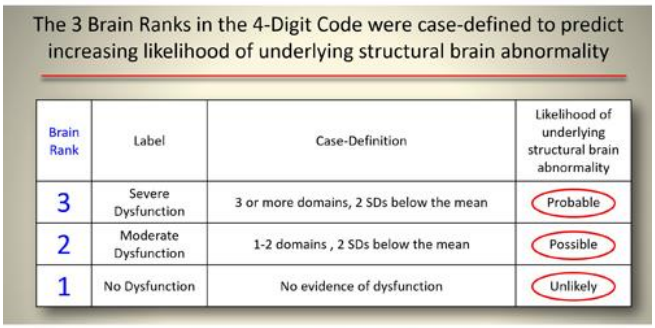
The 4-point Likert Scale for Brain documents: 1) that individuals with prenatal alcohol exposure can present with structural, neurological and/or functional brain abnormalities and 2) that these brain abnormalities occur along a continuum of severity.

An important point to keep in mind is that the Brain scale performs as two scales in one. In its first use, the full scale (from 1 to 4) documents increasing "probability" of underlying brain damage based on structural, neurological, and/or functional evidence. *The higher the Rank from 1 to 4, the stronger the evidence or higher the probability that there is underlying brain damage (Figure 3)* (Astley, 2013, Astley et al., 2009). In its second use, the scale (from 1 to 3) also documents increasing severity of brain dysfunction. *The higher the Rank from 1 to 3, the more severe and global the dysfunction.*

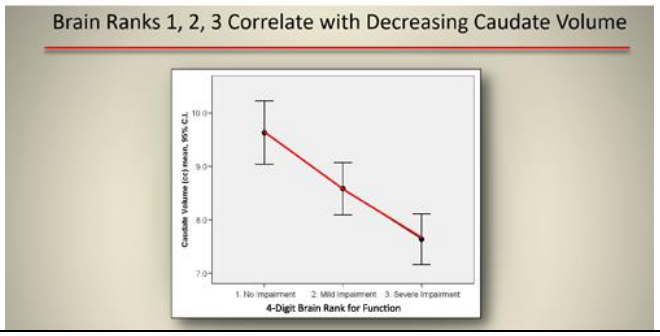
The descriptive labels assigned to Ranks 1 through 4 reflect the increasing probability that underlying brain damage exists. Rank 4 is labeled "definite" because structural/neurological abnormalities are definitive evidence of brain damage. Ranks 1, 2, and 3 are labeled "unlikely", "possible", and "probable" evidence of brain damage, respectively, because measures of dysfunction are not definitive evidence of underlying brain damage, but the probability of underlying brain damage increases with increasing severity of dysfunction. Data from the University of Washington FASDPN show this to be true. Among the first 1,500 patients diagnosed, those presenting with Rank 2 or Rank 3 level dysfunction had a 5.8-fold and 10.8-fold increased risk of having structural/neurological brain damage, respectively, relative to patients with no evidence of dysfunction (Rank 1). This correlation between brain function and structure was also confirmed in our FASD MRI study. The more severe the Brain Rank for function, the smaller the volume of the frontal lobe (Fig 12 from (Astley, 2013; Astley et al., 2009) below. As stated in the Institute of Medicine report (Stratton et al., 1996) "FAS can be characterized by behavioral or cognitive problems that are thought to result from *organic brain damage*, are not easily related to genetic background or environmental influences and may be resistant to improvement with traditionally effective intervention techniques".



A



B



C

Figure 12 from (Astley, 2013). A) The 4-Digit Code ranks brain dysfunction on a 3-point scale (none, moderate, severe). B) The 3 Brain Ranks were case-defined to predict increasing likelihood of underlying structural brain abnormality. C) MRI confirmed this to be true (Astley et al., 2009). The more severe the brain dysfunction (Rank 1, 2, 3), the smaller the caudate volume (significant linear trend F=13.5; p<.001; Duncan range test confirms each brain group is significantly distinct from the others).

All patients receive a Rank 1, 2 or 3 to document their level of brain dysfunction. Patients who present with significant structural and/or neurological evidence of brain damage will also receive a Rank 4. Thus, all patients with structural/neurological evidence of brain damage will have two Brain Ranks, one documenting their structural/neurological damage (Rank 4) and one documenting their level of dysfunction (Rank 1, 2 or 3). More specifically, they will receive either: (a) Brain Ranks 4 and 3 (structural/neurological damage with Rank 3 level dysfunction); (b) Brain Ranks 4 and 2 (structural/neurological damage with Rank 2 level dysfunction); or (c) Brain Ranks 4 and 1 (structural/neurological damage with no current evidence of dysfunction). When two Brain Ranks are applicable, the 4-Digit Code and Diagnostic Category are based on the *highest* Brain rank received, for it reflects the highest level of certainty there is underlying Brain damage. Both Brain

ranks should be circled in the Brain Column of the Diagnostic Grid and both numbers would be inserted in the Diagnostic Code with the lower Rank placed in parentheses 4(3). (See 4-Digit Diagnostic Code grid below). The Diagnostic Category would be based on the highest Rank in the Brain column.

FASD 4-Digit Code

4 (3)

Rank	Growth	Face	Brain	Prenatal Alcohol	Other Prenatal Risks	Other Postnatal Risks
4	severe	all 3 features	abnormal structure/neurology	high	high	high
3	moderate	2.5 features	severe dysfunction	some	some	some
2	mild	1-2 features	moderate dysfunction	unknown	unknown	unknown
1	normal	no features	normal function	none	none	none

Definitions of Brain Ranks 1 through 4.

Brain Rank 4: (Structural/Neurological Abnormalities) "Static Encephalopathy" "Definite" Evidence of Brain Damage.

Rank 4 Description: This rank is selected when the evidence for brain damage is defined through a traditional medical approach. It is our impression that "brain damage" or "static encephalopathy" is readily diagnosed by physicians when 'significant' structural abnormalities of the brain are detected or when neurological findings of presumed prenatal origin are found.

Structural evidence of brain damage may include, but is not limited to:

1. Microcephaly, defined as an occipital frontal circumference (OFC) 2 or more standard deviations below the mean. Head circumference 2 or more standard deviations below the mean has long been associated with functional impairment in the literature (Dolk, 1991; Pryor & Thelander, 1968). Among 999 patients with prenatal alcohol exposure evaluated at the FASDPN, those with microcephaly have IQs that on average are 10 points lower than those with normal head circumferences.

2. Significant brain abnormalities of presumed prenatal origin observable through imaging techniques. Abnormalities may include, but are not limited to hydrocephaly, heterotopias, and change in shape and/or size of brain regions. These abnormalities should be determined by appropriately trained medical professionals.

Neurological evidence of brain damage may include, but is not limited:

1. Seizures not due to a postnatal insult or other postnatal events.

2. Other hard neurological signs of presumed prenatal origin (e.g. cerebral palsy, tick disorders).
3. Hearing loss. Among children evaluated at the FASDPN, neurosensory hearing loss was 16-fold more prevalent among children with FAS (40%) than among children with other FASDs (2.4%) (McLaughlin et al., 2019), for whom the prevalence of hearing loss was similar to that estimated for the general U.S. adolescent population (2.3%) (Lin, et al., 2011)

***Rank 4 Criteria*:** At least one "significant" structural or neurological finding is required for a classification of Brain Rank 4 (Table 5). A significant finding is one that is 2 or more standard deviations below the mean if measured on a standardized scale or deemed "clinically significant" when assessed by an appropriate trained professional like a clinical radiologist or neurologist.

Documenting the Evidence that Supports a Rank 4 Classification: Structural and neurological findings are recorded under the STRUCTURAL and NEUROLOGICAL headings of the Brain section (page 3) of the FASD Diagnostic Form. A 'Severity Score' is provided along the left margin of the Form to allow the clinical team to rank the severity of all structural and neurological findings. Only structural and/or neurological findings that receive a Severity Score = 3 (Significant) can contribute toward a Brain Rank 4 classification. For example, a seizure disorder not due to a postnatal insult would receive a Severity Score = 3. Often this type of seizure would warrant medical treatment. A seizure that occurred just once during a high fever would receive a Severity Score = 2. Absence of any seizure-like activity would receive a Severity Score = 1. An OFC $\leq$ -2 SDs ($\leq 3^{rd}$ percentile) would receive a Severity Score = 3. An OFC > 3^{rd} percentile and $\leq 10^{th}$ percentile would receive a Severity Score = 2. An OFC > 10^{th} percentile would receive a Severity Score = 1. This Severity Score allows one to rapidly scan the FASD Diagnostic Form and identify significant findings that support a Rank 4 classification.

Brain Rank 3: (Severe Dysfunction) "Static Encephalopathy"
"Probable" Evidence of Brain Damage.

Rank 3 Description: Brain Rank 3 is assigned when a patient presents with severe brain dysfunction. These patients typically have challenges across multiple domains of function that may include, but are not limited to, executive function, memory, cognition, processing speed, academic achievement, language, motor, sensory, attention or activity level.

Rank 3 Criteria: Brain Rank 3 is assigned when there is evidence of "severe" impairment in 3 or more domains of brain function. "Sever" impairment is defined as performance 2 or more standard deviations below the mean (or its equivalent) on standardized, validated neuropsychological assessment tools (e.g., WISC, WIAT, CELF, D-KEFS, NEPSY, CVLT, VMI, etc.) administered and interpreted by qualified professionals (e.g., psychologists, occupational therapists, speech-language pathologists, etc). Developmental instruments, such as the Bayley Scales of Infant Development would typically not be used as a source of psychometric data to support a classification of severe brain dysfunction because developmental delay is not always predictive of underlying brain damage/dysfunction. The one exception to this rule would be developmental scores that reflect global developmental delay.

Documenting the Evidence that Supports a Rank 3 Classification*:* The clinical team records which functional domains are impaired and which tests/scores support their decisions on the Functional Domains page (page 7) of the FASD Diagnostic Form. Evidence to support a Rank 3 classification must come from standardized psychometric tests administered by professionals. The outcomes of these psychometric tests are recorded on pages 3-5 of the FASD Diagnostic Form. A 'Severity Score' is provided along the left margin of the Functional Domains page (page 7) to allow the clinical team to rank the severity of delay/impairment for each assessed domain. A functional domain must receive a Severity Score = 3 (Severe) to contribute toward a Brain Rank 3 classification. The Severity Score is described more fully below.

Brain Rank 2 (Moderate Delay/Dysfunction). "Neurodevelopmental Disorder (or Delay)" "Possible" Evidence of Brain Damage.

Rank 2 Description: This Rank should be given to two groups of patients, all of whom should have histories of behavioral, cognitive, and/or developmental problems.

One group includes infants/toddlers/young children (generally under 7 years of age) who are not developmentally mature enough to engage in assessments of higher order functions such as executive function, memory, higher order language skills. If a child is under 7-8 years of age at the time of assessment, they should be reassessed at 9 years of age when their brains are sufficiently mature to engage in assessment of higher order functions. *Note the term "neurodevelopmental disorder" is assigned to brain Rank 2. When this Rank is being assigned to infants/toddlers based primarily on developmental data, the clinical team may decide to replace the term "neurodevelopmental disorder" with "neurodevelopmental delay".*

The other group of patients is those whose testing did not reveal 3 domains of function 2 or more standard deviations below the mean required for a Rank 3 classification, but moderate to less severe impairments were identified nonetheless, preventing them from being classified Brain Rank 1 (normal function).

***Rank 2 Criteria*:** Rank 2 reflects a range of delay and/or dysfunction that suggests the possibility of underlying brain damage. At the mild end of the Rank 2 range are those who present with developmental delay that, by clinical judgment, precludes a Rank 1 classification and warrants intervention. At the severe end of the Rank 2 range are those who present with 1 or 2 domains of function 2 or more standard deviations below the mean, with multiple domains 1.5 standard deviations below the mean (Table 5). A Rank 2, by definition, is assigned to all who fall between Ranks 1 and 3. Evidence to support a Rank 2 classification can come from standardized psychometric tests, observational data, and/or caregiver interview. Deficiencies (or definite differences from normative expectations) recorded in the FUNCTIONAL section (pages 3-7) of the FASD Diagnostic Form serve to support a Rank 2 classification.

Documenting the Evidence that Supports a Rank 2 Classification: The clinical team records which functional domains are delayed or impaired and which tests/scores support their decisions on the Functional Domains page (page 7) of the FASD Diagnostic Form. Evidence to support a Rank 2 classification can come from standardized psychometric tests, observational data, and/or caregiver interview. These data are recorded on pages 3-6 of the FASD Diagnostic Form. A

'Severity Score' is provided along the left margin of the Functional Domains page (page 7) to allow the clinical team to rank the severity of delay or impairment for each assessed domain. Typically a patient that meets the criteria for Rank 2 will have at least one domain with a Severity Score = 2 (mild to moderate delay or impairment), but less than three domains with a Severity Score = 3 (severe impairment). The Severity Score is described more fully below.

Brain Rank 1 (No Current Evidence of Delay/Dysfunction)
"No" Current Evidence of Brain Damage.

A Rank 1 classification is assigned when no functional or developmental problems are discerned that are likely to reflect brain damage and no intervention recommendations are warranted. Evidence to support a Rank 1 can come from standardized psychometric tests, observational data, and/or caregiver interview. While this classification is typically quite rare in an FASD Diagnostic Clinic, it might help to think of this outcome in the context of a well-child assessment conducted in a general pediatric clinic where most children would be classified as Rank 1. On the other hand, if patients under 3 years of age with prenatal alcohol exposure present with normal development (Brain Rank 1) it would be important to conduct a re-evaluation later in childhood when they are old enough to engage in more sophisticated assessments of brain function. The neurodevelopmental impairments caused by prenatal alcohol exposure often do not fully manifest until later in childhood (Pruner et al., 2024). Infants/toddlers with prenatal alcohol exposure at greatest risk of severe brain dysfunction that will not manifest until later in childhood are those presenting with any of the sentinel physical features of FASD (growth deficiency, FAS facial features or microcephaly) (Astley et al., 2016).

Completing the Brain Section of the FASD Diagnostic Form

The Brain section appears on pages 3 through 7 of the FASD Diagnostic Form. These pages serve as a place to record pertinent structural, neurological, neuropsychological, and caregiver interview data available on the patient. Although space has been provided to record a full complement of assessments, we are not implying that all these assessments must be conducted to derive a diagnosis. It is the responsibility of the clinical team to select the most appropriate assessment battery for an individual patient. Recording data for the structural, neurological, and neuropsychological sections is self-explanatory. The Caregiver Interview section, however, warrants further explanation.

An important aspect of the FASD evaluation is an in-depth interview of the caregivers of the patient. This interview takes approximately one hour and is conducted by a qualified member(s) of the clinical team. At the University of Washington FASDPN clinic, this interview is conducted by the medical doctor while the patient is being formally assessed by the other clinical team members. As in any diagnostic situation, once records are reviewed and there is a preliminary case formulation, the diagnostic interview will address several questions, such as: What are the problems that led to the diagnostic referral? What do the caregivers hope to gain from the assessment? What are the caregivers' views of the patient's overall strengths and weaknesses? What is the child's social and medical history pertinent to this diagnostic evaluation? In an FASD diagnostic evaluation, we have found it very useful to also methodically ask questions that review age-appropriate functional abilities in areas that, according to the literature, are commonly problematic for alcohol-exposed individuals. These areas (planning/temporal skills, behavioral regulation/sensory motor integration,

abstract thinking/judgment, memory/learning/information processing, spatial skills/spatial memory, social skills/adaptive behavior, and motor/oral motor control) are presented on the FASD Diagnostic Form (page 6). Routinely inquiring about the patient's capabilities in these areas serves several purposes. First, the caregivers' answers to these questions give insight into their interpretation of the patient's behaviors and about their general relationship with the patient. Second, it is often helpful to compare this subjective assessment to the psychometric profile. This can reveal information about the pattern of neurodevelopmental difficulties that standardized testing may miss or provide evidence that is supportive of test results. The data recorded on page 6 of the Diagnostic Form are non-standardized observational measures. A summary of the first 1,400 caregiver interviews at the FASDPN clinic documented caregivers perceptions of their child's strengths and challenges were remarkably concordant with their child's neuropsychological test outcomes and FASD diagnostic classification (Astley, 2013; see Fig. 19).

Severity Score [0, 1, 2, 3]

Along the left margin of each Brain page is a Severity Score. This Severity Score serves two purposes. 1) It allows one to rapidly scan the left margin of the Brain pages to see what structural, neurological, and functional areas are most impacted. 2) The Severity Scores in the Structural/Neurological Sections and the Functional Domains page also serve to document what evidence was present to meet the criteria for Brain Ranks 2, 3, and 4, as described above. For example, at least one area in the Structural or Neurological Sections should have a Severity Score = 3 to meet criteria for a Brain Rank 4. At least three domains on the Functional Domains page should a Severity Score = 3 to meet criteria for a Brain Rank 3.

The clinical team ranks the level of impairment/abnormality as follows:

0	Unknown, Not Assessed
1	Within Normal Limits
2	Mild to Moderate
3	Severe

For outcomes measured on standardized scales, in general, outcomes two or more standard deviations below the norm would be judged severe, whereas outcomes between one and two standard deviations below the norm could be judged mild to moderate.

A comprehensive assessment will identify domains of strength, as well as domains with mild to severe impairment. Documenting the outcomes of all assessed domains, not just those with severe impairment, is important for treatment planning.

Primary Sources of Information Used and Generated by the Interdisciplinary Team to Derive the Brain Rank.

1. **Previous medical, school, psychological and mental health assessments**.

   Prior to the diagnostic evaluation, consent is obtained from the legal guardian to obtain the results of prior school, psychological and/or medical assessments that will be pertinent to the diagnostic evaluation. These assessments typically include:

   A. Medical records (growth, neurological evaluations, brain imaging, other medical conditions).
   B. School records (IEP, school psychological and/or achievement assessments).
   C. Psychological Records (neuropsychological assessments).
   D. Mental Health Records (mental health assessments, diagnoses, medications).

   These records are reviewed and discussed by the interdisciplinary team prior to the diagnostic evaluation.

2. **Caregiver interview conducted at the time of the diagnostic evaluation**.

   As described above, a semi-structured interview (page 6 of the *FASD Diagnostic Form*) is conducted with the caregiver(s) to document their concerns, impressions and experiences with the patient.

3. **Psychometric assessments conducted at the time of, or in preparation for, the diagnostic evaluation.**

   The primary goal in the diagnostic evaluation is to document/verify the presence of brain abnormalities. The battery of assessments administered by the interdisciplinary team will most likely differ for each patient. Assessments will be selected based on the patient's age and area(s) of perceived deficit. Many patients will have already had some level of prior assessment conducted by other educational and health care providers. Thus, assessments conducted by the interdisciplinary diagnostic team will be selected to compliment, not duplicate what has already been done. The FASDPN Psychometric and Behavior Observations Training Guide (Olson et al., 2005) provides a brief overview of psychometric assessments typically used to assess patients of all ages seen in the FASDPN clinics. Clarren et al., 2000 provides a description of a typical FASD interdisciplinary diagnostic evaluation at the University of Washington FASDPN clinic. The following published research reports document the neuropsychological, behavioral, sensory, sleep disorder, and psychiatric outcomes of individuals across the spectrum of FASD (Astley, 2010; Astley et al., 2009a; Chen et al., 2012; Franklin et al., 2008; Jirikowic et al., 2008; Jirikowic et al., 2008a; Jirikowic et al., 2013; Olson et al., 2007).

Table 5: Criteria for Brain Ranks 1 through 4

4-Digit Diagnostic Brain Rank*	Probability of underlying Brain Damage	Confirmatory Findings
4	Definite **Structural and/or Neurological Abnormalities** *Static Encephalopathy*	● Microcephaly: OFC 2 or more SDs below the norm. *and / or* ● Significant abnormalities in brain structure of presumed prenatal origin. *and / or* ● Evidence of abnormal neurological findings (e.g. seizures, tick disorders, etc.) likely to be of prenatal origin.
3	Probable **Severe Dysfunction** *Static Encephalopathy*	● Severe impairment (2 or more SDs below the mean) in 3 or more domains of brain function such as, but not limited to: cognition, achievement, memory, executive function, motor, sensory, language, attention, activity level, neurological 'soft' signs.
2	Possible **Moderate Dysfunction** *Neurodevelopmental Disorder*	● Evidence of delay or dysfunction that do not permit a Rank 1 classification, but also do not permit a Rank 3 classification.
1	Unlikely **No Dysfunction**	● No current evidence of delay or dysfunction likely to reflect brain damage.

* Transfer the resulting 4-Digit Diagnostic Rank for Brain to the 4-Digit Diagnostic Code Grid on page 1 of the FASD Diagnostic Form (Section II).

FASD 4-Digit Code

Rank	Growth	Face	Brain (3)	Prenatal Alcohol	Other Prenatal Risks	Other Postnatal Risks
4	severe	all 3 features	abnormal structure/neurology	high	high	high
3	moderate	2.5 features	severe dysfunction	some	some	some
2	mild	1-2 features	moderate dysfunction	unknown	unknown	unknown
1	normal	no features	normal function	none	none	none

III. Instructions for Deriving the 4-Digit Code

B.4. Ranking Prenatal Alcohol Exposure

Method for Ranking Alcohol: The 4th Digit of the 4-Digit Diagnostic Code

Alcohol exposure is ranked according to the quantity, timing, frequency, and certainty of exposure during pregnancy (Table 6). The case-definitions for the four Ranks address two important issues: 1) that exposure information in a clinical setting can be of limited availability or of unknown accuracy (Astley, 2013; Astley et al, 2019) and 2) and a clear consensus is not available concerning the amount of alcohol that can actually be toxic to each individual fetus (Stratton et al., 1996; (Astley)Hemingway et al., 2019a).

The case-definitions for prenatal alcohol exposure differentiate four clinically meaningful groups: Rank 4: confirmed exposure to high levels of alcohol; Rank 3: confirmed exposure, but the level is less than Rank 4 or the level is unknown; Rank 2: unknown exposure (neither confirmed absent nor confirmed present); and Rank 1: confirmed absence of exposure from conception to birth. These exposure Ranks are based on verbal or written records. High exposure is defined generally to be a blood alcohol concentration of greater than 100 mg/dL (a level that typically can be reached by a 55-kg woman consuming six to eight beers) weekly, early in pregnancy. In the absence of a clear consensus on the amount of alcohol that can actually be toxic to the fetus, this general definition should only serve as a guide, not a threshold.

One example of a 'Rank 4' exposure is the birth mother reported drinking to the point of intoxication weekly throughout pregnancy. Two examples of 'Rank 3' exposures include: 1) birth mother was observed to be drinking during pregnancy, but the amount is unknown, 2) birth mother reported drinking a single glass of wine weekly, but stopped drinking as soon as she learned she was pregnant at 2 months. Two examples of when alcohol exposure is ultimately unknown and thus coded as Rank 2 include: 1) the child is adopted and the birth records are closed, and 2) the birth mother is known to have a problem with drinking, but there are no records or direct observation of her drinking during the index pregnancy. A Rank 1 classification (confirmed absence of drinking from conception to birth) may not be as common as one would hope in the general population. Most women of reproductive age consume some level of alcohol and not all pregnancies are planned.

The Rank 4 FAS facial phenotype as defined by the 4-Digit Code can be used to confirm prenatal alcohol exposure when a written or verbal history of prenatal alcohol exposure is unknown (Alcohol Rank 2). The 4-Digit Code Rank 4 FAS facial phenotype is the only facial phenotype, to date, that provides sufficient positive predictive value (PPV) and specificity (100%) to prenatal alcohol exposure to allow the facial phenotype to serve as confirmation of alcohol exposure in a diagnostic setting when a verbal or written record of prenatal alcohol exposure is unavailable. Even minimal relaxation of the phenotype (e.g., Face Rank 3) results in PPV (35%) and specificity (88.7%) values too low to use as confirmation of prenatal alcohol exposure. (Astley & Clarren, 1996, 2000, 2001; (Astley)Hemingway et al., 2020). If the facial phenotype of FAS can only be caused by prenatal alcohol exposure, the following two conditions should hold true: 1) All individuals with the FAS facial phenotype have prenatal alcohol exposure (100% PPV); and 2) No individual with a confirmed absence of prenatal alcohol exposure will have the FAS facial phenotype (100% specificity). Data to date documents the Rank 4 FAS facial phenotype meets these two conditions ((Astley)Hemingway et al.,

2020). The Rank 4 FAS facial phenotype can also be used to confirm an individual's prenatal alcohol exposure adversely impacted their fetal development.

Table 6: Criteria for Prenatal Alcohol Exposure Ranks 1 through 4

4-Digit Diagnostic Rank	Prenatal Alcohol Exposure Category	Description of Alcohol Use During Pregnancy
4	High Risk	● Alcohol use during pregnancy is CONFIRMED. *and* ● Reported exposure pattern is consistent with the medical literature placing the fetus at "high risk" (generally high peak blood alcohol concentrations delivered at least weekly in early pregnancy, reports of intoxication, binge drinking).
3	Some Risk	● Alcohol use during pregnancy is CONFIRMED. *and* ● Level of alcohol use is reported to be less than Rank (4) or level is unknown.
2	Unknown Risk	● Alcohol use during pregnancy is UNKNOWN (neither confirmed absent nor confirmed present).
1	No Risk	● Alcohol use during pregnancy is CONFIRMED ABSENT from conception to birth.

Transfer the resulting 4-Digit Diagnostic Rank for Alcohol Exposure to the 4-Digit Diagnostic Code Grid on page 1 of the FASD Diagnostic Form (Section II).

FASD 4-Digit Code

4

Rank	Growth	Face	Brain	Prenatal Alcohol	Other Prenatal Risks	Other Postnatal Risks
4	severe	all 3 features	abnormal structure/neurology	high	high	high
3	moderate	2.5 features	severe dysfunction	some	some	some
2	mild	1-2 features	moderate dysfunction	unknown	unknown	unknown
1	normal	no features	normal function	none	none	none

III. Instructions for Deriving the 4-Digit

B.5. Ranking Other Pre- and Postnatal Risk Factors

The Importance of Documenting Other Risk Factors

A comprehensive diagnostic process must take into consideration all other adverse prenatal and postnatal adverse exposures and experiences, not just prenatal alcohol exposure. Many of the outcomes observed in individuals with prenatal alcohol exposure are not specific to (caused only by) prenatal alcohol exposure. A variety of other prenatal (poor prenatal care, pregnancy complications, familial genetics, and exposure to other potentially teratogenic agents, etc.), and/or postnatal (physical/sexual abuse, neglect, disrupted placement histories, trauma, head injuries, chronic substance abuse by the patient, etc.) risk factors could also contribute to the adverse outcomes presented by the patient. In the FASDPN clinical population, other prenatal and postnatal risk factors were 3 to 7-fold more prevalent than in the general population (Astley Hemingway et al., 2020).

The 4-Digit Diagnostic method requires the clinical team to record all pertinent prenatal and postnatal risk factors on the standardized FASD Diagnostic Form, rank their severity of risk on 4-point Likert scales, report them in the medical summary, and take them into consideration when deriving a diagnosis and intervention plan.

It is important to note that the presence of other risk factors does not reduce the teratogenic potential of alcohol. When multiple risk factors are present, including prenatal alcohol exposure, each risk factor has the potential of being fully responsible, partially responsible, or not responsible at all for any one particular outcome. Together these risk factors can have additive or multiplicative adverse impacts on development.

While there is currently no medical means to determine which risk factor is responsible for which outcome in an individual patient, group statistics can begin to shed light on this issue. A recent study addressed the question "*What proportion of brain structural and functional abnormalities observed among children with FASD is explained by their prenatal alcohol exposure and their other prenatal and postnatal risks*? (Astley Hemingway et al., 2020). The study revealed prenatal alcohol exposure was the dominant risk factor explaining the largest proportion of variance (52%) in regional brain size (total brain, frontal lobe, caudate, hippocampus and corpus callosum) and brain function (intellect, achievement, memory, language, executive-function, motor, adaptation, behavior-attention and mental health symptoms). Other prenatal and postnatal risk factors were 3 to 7-fold more prevalent among these children with FASD than documented in the general population. Individually, each risk factor explained a statistically significant, but smaller proportion of variance (5-15%) in brain outcome compared to prenatal alcohol exposure. In combination, the proportion of variance explained by the presence of multiple prenatal and postnatal risks rivaled that of prenatal alcohol exposure.

A. Other Prenatal Risk Factors: Rank Definitions

Prenatal exposures and experiences are recorded and assigned a Rank on page 9 of the Diagnostic Form. The definitions below are intended to provide guidance for ranking. The circumstances surrounding each patient case will be unique. Selecting a rank will require clinical judgement.

Rank 4: High Risk

This Rank is reserved for alternate genetic conditions (e.g., Fragile X, velocardiofacial syndrome, down syndrome, etc.) or exposure to known teratogens (e.g., dilantin, valproic acid, etc.) that have been clearly shown to produce physical abnormalities.

Rank 3: Some Risk

This category is used for potential genetic conditions, exposures or prenatal conditions that have been associated with physical or neurodevelopmental problems in a less well-established way, when compared to those falling in Prenatal Rank 4. Examples of conditions that would be placed in this category could include poor prenatal care; patients whose parents have attention deficit disorders, significant learning disabilities or learning problems thought to be due to a non-specific (and non-teratogenic) source; prenatal exposure to non-teratogenic drugs like marijuana; and cigarette smoking during pregnancy.

Rank 2: Unknown Risk

This category is used when the details of the family background and gestation are unknown – generally in the circumstance of a closed adoption.

Rank 1: No Known Risk

On occasion, the genetic, teratogenic, and prenatal histories are well documented and no factors can be identified that would explain the abnormalities found in the patient.

B. Postnatal Risk Factors: Rank Definitions

Postnatal risks are recorded and assigned a Rank on page 9 of the Diagnostic Form.

There is a growing body of literature on the prevalence and impact of traumatic childhood experiences among individuals with prenatal alcohol exposure (Price et al., 2017; (Astley) Hemingway SJA et al., 2020; Lebel et al., 2019: Rockhold et al., 2023). Documenting postnatal adverse experiences can be achieved retrospectively from historical records and/or prospectively from administration of parent-report questionnaires like the Adverse Childhood Experiences (ACES) (Felitti et al., 1998) or the Traumatic Events Screening Inventory (TESI) (Ghosh-Ippen et al., 2002).

Childhood adversity has been conceptualized variously as linking specific experiences with outcomes, cumulative risk (e.g. ACE score), dimensional approaches (threat / deprivation / unpredictability frameworks), and "topological" models which consider features like chronicity, intensity, and developmental timing of adversity along with child aspects like stress response phenotypes and environmental factors such as predictability and caregiver responses (Ellis et al., 2022; Rockhold et al., 2023; Gabard-Durnam & McLaughlin, 2020; Smith & Polak, 2021).

Until there is more empirical support for one of these approaches, we rely upon clinical judgement to rank the magnitude of risk posed by the adverse postnatal experiences and the likelihood that postnatal events contributed to growth and developmental differences. The definitions provided below are meant to provide guidance. Consider factors like severity, chronicity, number of risk factors, timing (e.g. developmentally sensitive period of the first 2-3 years or recency), child's perceptions of the events, and buffering by caregivers (resilience/resources or lack thereof) when evaluating the degree of adversity and how likely the postnatal environment is to have influenced the patient's outcomes.

Rank 4: High Risk

This Rank is used to note postnatal circumstances that have been shown to have a significant adverse effect on development in most instances. Examples include, but are not limited to, physical and/or sexual abuse, multiple disrupted placements with clear impact on the child, severe neglect (based on clinical judgment or apparent impacts such as failure to thrive), serious head injury, or medical conditions which lead to brain impacts (e.g., hypoxic/ischemic encephalopathy, kernicterus, severe malnutrition). Perinatal/prematurity factors like extremely low birth weight (ELBW), extremely premature (< 28 weeks), and intracranial hemorrhage grade 3-4 can be captured here as well). Other postnatal experiences that could contribute to a high-risk Rank 4 classification are presented on page 9 of the Diagnostic Form (page 16 of this Diagnostic Guide).

Rank 3: Some Risk

This Rank is used to note conditions akin to those in Rank 4, but the circumstances are judged less severe and so less likely to be a definite factor in the patient's present condition. Obviously, clinical judgment is needed in judging the magnitude of postnatal problems and interpreting this information into a Rank 3 or 4 placement.

Rank 2: Unknown Risk

This Rank is used when historical information is missing. This is sometimes the case with adopted children or those in foster care. Adult patients may, at times, be unable to reconstruct their own early histories.

Rank 1: No Known Risk

This Rank is used when a well-documented history confirms an absence of adverse postnatal exposures/events.

Transfer the resulting 4-Digit Diagnostic Ranks for Prenatal and Postnatal Risks to the 4-Digit Diagnostic Code Grid on page 1 of the FASD Diagnostic Form in Section II.

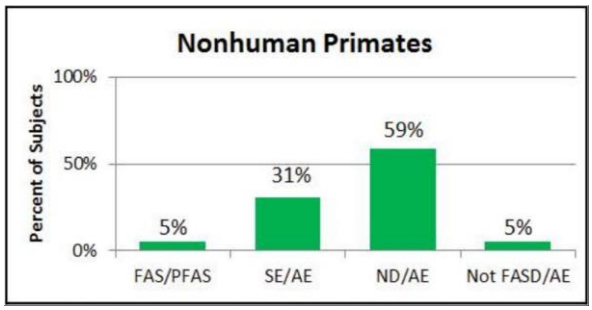
FASD 4-Digit Code

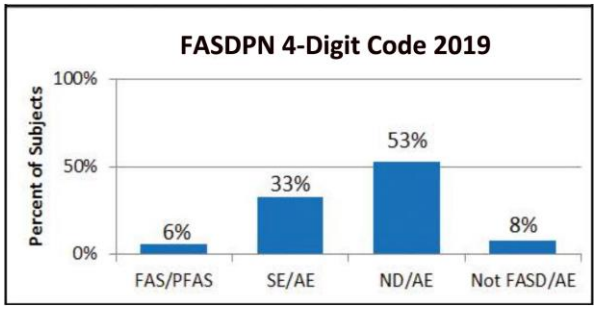
Rank	Growth	Face	Brain	Prenatal Alcohol	Other Prenatal Risks (3)	Other Postnatal Risks (4)
4	severe	all 3 features	abnormal structure/neurology	high	high	high
3	moderate	2.5 features	severe dysfunction	some	some	some
2	mild	1-2 features	moderate dysfunction	unknown	unknown	unknown
1	normal	no features	normal function	none	none	none

IV. Diagnostic Categories

Generic descriptions for each of the 19 Diagnostic Categories are presented on the following pages listed alphabetically from A through S. A complete list of the 19 categories is presented in Section IV. Note only 6 of the Diagnostic Categories (A-E and 4 codes in J highlighted in red) fall "broadly" under the umbrella of FASD in accordance with the 4-Digit Code. What do we mean by "broadly" under the umbrella of FASD?

Fetal Alcohol Spectrum Disorders are, by definition, adverse outcomes *caused* by prenatal alcohol exposure. When we label a diagnosis FAS, we are stating explicitly that alcohol caused the syndrome. *How do we know an individual's prenatal alcohol exposure caused their FAS?* FAS is characterized by growth deficiency, brain abnormalities and the FAS facial phenotype. Although a myriad of prenatal and postnatal risk factors including PAE can cause adverse growth and brain outcomes, only prenatal alcohol exposure can cause the FAS facial phenotype. But the diagnoses SE/AE and ND/AE do not require the FAS facial phenotype. *Do all individuals with SE/AE and ND/AE have FASD?* Not necessarily. Only the subset of individuals whose growth and/or brain impairments were caused (in whole or in part) by their prenatal alcohol exposure. Which subset of individuals is that? We currently have no way of knowing. Individuals with SE and ND caused by their alcohol exposure have FASD. Individuals with SE/AE and ND/AE that was not caused by their alcohol exposure do not have FASD. *What proportion of individuals with SE/AE or ND/AE have FASD?* Research to date would suggest it is likely the majority. Although the prevalence of other prenatal and postnatal risk factors is 3- to 7-fold higher in the FASDPN clinic population than in the general population, a recent study ((Astley) Hemingway et al., 2020) found among these children with prenatal alcohol exposure and other risk factors, alcohol was the dominant risk factor explaining the largest proportion (50%) of variance in regional brain size and brain function. Individually, each of the other risk factors explained a smaller proportion of the variance, but in combination explained an additional 20-30% of the variance. *What would the prevalence of FAS, SE/AE and ND/AE look like if alcohol was the only risk factor?* The 4-Digit Code was applied to a nonhuman primate model of FASD where the only risk factor was PAE ((Astley) Hemingway et al., 2019). The prevalence of the FAS, SE/AE and ND/AE caused by alcohol looked near identical to the prevalence of FASD diagnostic outcomes observed among 3,000 patients with prenatal alcohol exposure evaluated in the FASDPN over 30 years.





The 256 Diagnostic Codes can be logically grouped into 19 Diagnostic Categories.

Only the 5 Categories in red font (A-E) and 4 codes in Category J with the Rank 4 facial phenotype are considered to be broadly under the umbrella of FASD in accordance with the 4-Digit Code.

Category	Name
A	Fetal alcohol syndrome
B	Sentinel physical finding(s) / static encephalopathy / alcohol exposed
C	Static encephalopathy / alcohol exposed
D	Sentinel physical finding(s) / neurodevelopmental disorder / alcohol exposed
E	Neurodevelopmental disorder / alcohol exposed
F	Sentinel physical finding(s) / alcohol exposed
G	No sentinel physical findings or brain abnormalities detected / alcohol exposed
H	Sentinel physical finding(s) / static encephalopathy / alcohol exposure unknown
I	Static encephalopathy / alcohol exposure unknown
J	Sentinel physical finding(s) / neurodevelopmental disorder / alcohol exposure unknown)
K	Neurodevelopmental disorder / alcohol exposure unknown
L	Sentinel physical finding(s) / alcohol exposure unknown
M	No sentinel physical findings or brain abnormalities detected / alcohol exposure unknown
N	Sentinel physical finding(s) / static encephalopathy / no alcohol exposure
O	Static encephalopathy / no alcohol exposure
P	Sentinel physical finding(s) / neurodevelopmental disorder / no alcohol exposure
Q	Neurodevelopmental disorder / no alcohol exposure
R	Sentinel physical finding(s) / no alcohol exposure
S	No sentinel physical findings or brain abnormalities detected / no alcohol exposure

V. 4-Digit Diagnostic Codes Within each Diagnostic Category

Only the 4-Digit Codes in red font are considered to be broadly under the umbrella of FASD in accordance with the 4-Digit Code.

Category	Diagnostic Name and Codes
A	Fetal alcohol syndrome
	1333 1433 2333 2433 3333 3433 4333 4433
	1334 1434 2334 2434 3334 3434 4334 4434
	1343 1443 2343 2443 3343 3443 4343 4443
	1344 1444 2344 2444 3344 3444 4344 4444
	1432 2432 3432 4432 1442 2442 3442 4442
B	Sentinel physical finding(s) / static encephalopathy / alcohol exposed
	3133 3233 4133 4233
	3134 3234 4134 4234
	3143 3243 4143 4243
	3144 3244 4144 4244
C	Static encephalopathy / alcohol exposed
	1133 1233 2133 2233
	1134 1234 2134 2234
	1143 1243 2143 2243
	1144 1244 2144 2244
D	Sentinel physical finding(s) / neurodevelopmental disorder / alcohol exposed
	1323 2323 3123 3323 4123 4323
	1324 2324 3124 3324 4124 4324
	1423 2423 3223 3423 4223 4423
	1424 2424 3224 3424 4224 4424
E	Neurodevelopmental disorder / alcohol exposed
	1123 1223 2123 2223
	1124 1224 2124 2224

Category	Diagnostic Name and Codes (4-Digit Codes under the umbrella of FASD in red font)

F Sentinel physical finding(s) / alcohol exposed

1313	2313	3113	3313	4113	4313
1314	2314	3114	3314	4114	4314
1413	2413	3213	3413	4213	4413
1414	2414	3214	3414	4214	4414

G No physical findings or brain abnormalities detected / alcohol exposed

1113	1213	2113	2213
1114	1214	2114	2214

H Sentinel physical finding(s) / static encephalopathy / alcohol exposure unknown

1332	2332	3132	3232	3332	4132	4232	4332
1342	2342	3142	3242	3342	4142	4242	4342

I Static encephalopathy / alcohol exposure unknown

1132	1232	2132	2232
1142	1242	2142	2242

J Sentinel physical finding(s) / neurodevelopmental disorder / alcohol exposure unknown

1322	2322	3122	3322	4122	4322
1422	2422	3222	3422	4222	4422

K Neurodevelopmental disorder / alcohol exposure unknown

1122	1222	2122	2222

L Sentinel physical finding(s) / alcohol exposure unknown

1312	2312	3112	3312	4112	4312
1412	2412	3212	3412	4212	4412

M No physical findings or brain abnormalities detected / alcohol exposure unknown

1112	2112	1212	2212

Category	Diagnostic Name and Codes
N	Sentinel physical finding(s) / static encephalopathy / no alcohol exposure 1331 2331 3131 3331 4131 4331 1341 2341 3141 3341 4141 4341 1431 2431 3231 3431 4231 4431 1441 2441 3241 3441 4241 4441
O	Static encephalopathy / no alcohol exposure 1131 1231 2131 2231 1141 1241 2141 2241
P	Sentinel physical finding(s) / neurodevelopmental disorder / no alcohol exposure 1321 2321 3121 3321 4121 4321 1421 2421 3221 3421 4221 4421
Q	Neurodevelopmental disorder / no alcohol exposure 1121 2121 2221 1221
R	Sentinel physical finding(s) / no alcohol exposure 1311 2311 3111 3311 4111 4311 1411 2411 3211 3411 4211 4411
S	No physical findings or brain abnormalities detected / no alcohol exposure 1111 2111 1211 2211

VI. 4-Digit Diagnostic Codes Sorted Numerically

Code	Category	Diagnostic Name (4-Digit Codes under the umbrella of FASD in red font)
1111	S	No sentinel physical findings or brain abnormalities detected / no alcohol exposure
1112	M	No sentinel physical findings or brain abnormalities detected / alcohol exposure unknown
1113	G	No sentinel physical findings or brain abnormalities detected / alcohol exposure
1114	G	No sentinel physical findings or brain abnormalities detected / alcohol exposure
1121	Q	Neurodevelopmental disorder / no alcohol exposure
1122	K	Neurodevelopmental disorder / alcohol exposure unknown
1123	E	Neurodevelopmental disorder / alcohol exposed
1124	E	Neurodevelopmental disorder / alcohol exposed
1131	O	Static encephalopathy / no alcohol exposure
1132	I	Static encephalopathy / alcohol exposure unknown
1133	C	Static encephalopathy / alcohol exposed
1134	C	Static encephalopathy / alcohol exposed
1141	O	Static encephalopathy / no alcohol exposure
1142	I	Static encephalopathy / alcohol exposure unknown
1143	C	Static encephalopathy / alcohol exposed
1144	C	Static encephalopathy / alcohol exposed
1211	S	No sentinel physical findings or brain abnormalities detected / no alcohol exposure
1212	M	No sentinel physical findings or brain abnormalities detected / alcohol exposure unknown
1213	G	No sentinel physical findings or brain abnormalities detected / alcohol exposure
1214	G	No sentinel physical findings or brain abnormalities detected / alcohol exposure
1221	Q	Neurodevelopmental disorder / no alcohol exposure
1222	K	Neurodevelopmental disorder / alcohol exposure unknown
1223	E	Neurodevelopmental disorder / alcohol exposed
1224	E	Neurodevelopmental disorder / alcohol exposed
1231	O	Static encephalopathy / no alcohol exposure
1232	I	Static encephalopathy / alcohol exposure unknown
1233	C	Static encephalopathy / alcohol exposed
1234	C	Static encephalopathy / alcohol exposed
1241	O	Static encephalopathy / no alcohol exposure
1242	I	Static encephalopathy / alcohol exposure unknown
1243	C	Static encephalopathy / alcohol exposed
1244	C	Static encephalopathy / alcohol exposed
1311	R	Sentinel physical finding(s) / no alcohol exposure
1312	L	Sentinel physical finding(s) / alcohol exposure unknown
1313	F	Sentinel physical finding(s) / alcohol exposed
1314	F	Sentinel physical finding(s) / alcohol exposed
1321	P	Sentinel physical finding(s) / neurodevelopmental disorder / no alcohol exposure
1322	J	Sentinel physical finding(s) / neurodevelopmental disorder / alcohol exposure unknown
1323	D	Sentinel physical finding(s) / neurodevelopmental disorder / alcohol exposed

Code	Category	Diagnostic Name (4-Digit Codes under the umbrella of FASD in red font)
1324	D	Sentinel physical finding(s) / neurodevelopmental disorder / alcohol exposed
1331	N	Sentinel physical finding(s) / static encephalopathy / no alcohol exposure
1332	H	Sentinel physical finding(s) / static encephalopathy / alcohol exposure unknown
1333	A	FAS
1334	A	FAS
1341	N	Sentinel physical finding(s) / static encephalopathy / no alcohol exposure
1342	H	Sentinel physical finding(s) / static encephalopathy / alcohol exposure unknown
1343	A	FAS
1344	A	FAS
1411	R	Sentinel physical finding(s) / no alcohol exposure
1412	L	Sentinel physical finding(s) / alcohol exposure unknown
1413	F	Sentinel physical finding(s) / alcohol exposed
1414	F	Sentinel physical finding(s) / alcohol exposed
1421	P	Sentinel physical finding(s) / neurodevelopmental disorder / no alcohol exposure
1422	J	Sentinel physical finding(s) / neurodevelopmental disorder / alcohol exposure unknown
1423	D	Sentinel physical finding(s) / neurodevelopmental disorder / alcohol exposed
1424	D	Sentinel physical finding(s) / neurodevelopmental disorder / alcohol exposed
1431	N	Sentinel physical finding(s) / static encephalopathy / no alcohol exposure
1432	A	FAS
1433	A	FAS
1434	A	FAS
1441	N	Sentinel physical finding(s) / static encephalopathy / no alcohol exposure
1442	A	FAS
1443	A	FAS
1444	A	FAS
2111	S	No sentinel physical findings or brain abnormalities detected / no alcohol exposure
2112	M	No sentinel physical findings or brain abnormalities detected / alcohol exposure unknown
2113	G	No sentinel physical findings or brain abnormalities detected / alcohol exposure
2114	G	No sentinel physical findings or brain abnormalities detected / alcohol exposure
2121	Q	Neurodevelopmental disorder / no alcohol exposure
2122	K	Neurodevelopmental disorder / alcohol exposure unknown
2123	E	Neurodevelopmental disorder / alcohol exposed
2124	E	Neurodevelopmental disorder / alcohol exposed
2131	O	Static encephalopathy / no alcohol exposure
2132	I	Static encephalopathy / alcohol exposure unknown
2133	C	Static encephalopathy / alcohol exposed
2134	C	Static encephalopathy / alcohol exposed
2141	O	Static encephalopathy / no alcohol exposure
2142	I	Static encephalopathy / alcohol exposure unknown
2143	C	Static encephalopathy / alcohol exposed
2144	C	Static encephalopathy / alcohol exposed)
2211	S	No sentinel physical findings or brain abnormalities detected / no alcohol exposure
2212	M	No sentinel physical findings or brain abnormalities detected / alcohol exposure unknown
2213	G	No sentinel physical findings or brain abnormalities detected / alcohol exposure

Code	Category	Diagnostic Name (4-Digit Codes under the umbrella of FASD in red font)
2214	G	No sentinel physical findings or brain abnormalities detected / alcohol exposure
2221	Q	Neurodevelopmental disorder / no alcohol exposure
2222	K	Neurodevelopmental disorder / alcohol exposure unknown
2223	E	Neurodevelopmental disorder / alcohol exposed
2224	E	Neurodevelopmental disorder / alcohol exposed
2231	O	Static encephalopathy / no alcohol exposure
2232	I	Static encephalopathy / alcohol exposure unknown
2233	C	Static encephalopathy / alcohol exposed
2234	C	Static encephalopathy / alcohol exposed
2241	O	Static encephalopathy / no alcohol exposure
2242	I	Static encephalopathy / alcohol exposure unknown
2243	C	Static encephalopathy / alcohol exposed
2244	C	Static encephalopathy / alcohol exposed
2311	R	Sentinel physical finding(s) / no alcohol exposure
2312	L	Sentinel physical finding(s) / alcohol exposure unknown
2313	F	Sentinel physical finding(s) / alcohol exposed
2314	F	Sentinel physical finding(s) / alcohol exposed
2321	P	Sentinel physical finding(s) / neurodevelopmental disorder / no alcohol exposure
2322	J	Sentinel physical finding(s) / neurodevelopmental disorder / alcohol exposure unknown
2323	D	Sentinel physical finding(s) / neurodevelopmental disorder / alcohol exposed
2324	D	Sentinel physical finding(s) / neurodevelopmental disorder / alcohol exposed
2331	N	Sentinel physical finding(s) / static encephalopathy / no alcohol exposure
2332	H	Sentinel physical finding(s) / static encephalopathy / alcohol exposure unknown
2333	A	FAS
2334	A	FAS
2341	N	Sentinel physical finding(s) / static encephalopathy / no alcohol exposure
2342	H	Sentinel physical finding(s) / static encephalopathy / alcohol exposure unknown
2343	A	FAS
2344	A	FAS
2411	R	Sentinel physical finding(s) / no alcohol exposure
2412	L	Sentinel physical finding(s) / alcohol exposure unknown
2413	F	Sentinel physical finding(s) / alcohol exposed
2414	F	Sentinel physical finding(s) / alcohol exposed
2421	P	Sentinel physical finding(s) / neurodevelopmental disorder / no alcohol exposure
2422	J	Sentinel physical finding(s) / neurodevelopmental disorder / alcohol exposure unknown
2423	D	Sentinel physical finding(s) / neurodevelopmental disorder / alcohol exposed
2424	D	Sentinel physical finding(s) / neurodevelopmental disorder / alcohol exposed
2431	N	Sentinel physical finding(s) / static encephalopathy / no alcohol exposure
2432	A	FAS
2433	A	FAS
2434	A	FAS
2441	N	Sentinel physical finding(s) / static encephalopathy / no alcohol exposure
2442	A	FAS
2443	A	FAS
2444	A	FAS

Code	Category	Diagnostic Name (4-Digit Codes under the umbrella of FASD in red font)
3111	R	Sentinel physical finding(s) / no alcohol exposure
3112	L	Sentinel physical finding(s) / alcohol exposure unknown
3113	F	Sentinel physical finding(s) / alcohol exposed
3114	F	Sentinel physical finding(s) / alcohol exposed
3121	P	Sentinel physical finding(s) / neurodevelopmental disorder / no alcohol exposure
3122	J	Sentinel physical finding(s) / neurodevelopmental disorder / alcohol exposure unknown
3123	D	Sentinel physical finding(s) / neurodevelopmental disorder / alcohol exposed
3124	D	Sentinel physical finding(s) / neurodevelopmental disorder / alcohol exposed
3131	N	Sentinel physical finding(s) / static encephalopathy / no alcohol exposure
3132	H	Sentinel physical finding(s) / static encephalopathy / alcohol exposure unknown
3133	B	Sentinel physical finding(s) / static encephalopathy / alcohol exposed
3134	B	Sentinel physical finding(s) / static encephalopathy / alcohol exposed
3141	N	Sentinel physical finding(s) / static encephalopathy / no alcohol exposure
3142	H	Sentinel physical finding(s) / static encephalopathy / alcohol exposure unknown
3143	B	Sentinel physical finding(s) / static encephalopathy / alcohol exposed
3144	B	Sentinel physical finding(s) / static encephalopathy / alcohol exposed
3211	R	Sentinel physical finding(s) / no alcohol exposure
3212	L	Sentinel physical finding(s) / alcohol exposure unknown
3213	F	Sentinel physical finding(s) / alcohol exposed
3214	F	Sentinel physical finding(s) / alcohol exposed)
3221	P	Sentinel physical finding(s) / neurodevelopmental disorder / no alcohol exposure
3222	J	Sentinel physical finding(s) / neurodevelopmental disorder / alcohol exposure unknown
3223	D	Sentinel physical finding(s) / neurodevelopmental disorder / alcohol exposed
3224	D	Sentinel physical finding(s) / neurodevelopmental disorder / alcohol exposed
3231	N	Sentinel physical finding(s) / static encephalopathy / no alcohol exposure
3232	H	Sentinel physical finding(s) / static encephalopathy / alcohol exposure unknown
3233	B	Sentinel physical finding(s) / static encephalopathy / alcohol exposed
3234	B	Sentinel physical finding(s) / static encephalopathy / alcohol exposed
3241	N	Sentinel physical finding(s) / static encephalopathy / no alcohol exposure
3242	H	Sentinel physical finding(s) / static encephalopathy / alcohol exposure unknown
3243	B	Sentinel physical finding(s) / static encephalopathy / alcohol exposed
3244	B	Sentinel physical finding(s) / static encephalopathy / alcohol exposed
3311	R	Sentinel physical finding(s) / no alcohol exposure
3312	L	Sentinel physical finding(s) / alcohol exposure unknown
3313	F	Sentinel physical finding(s) / alcohol exposed
3314	F	Sentinel physical finding(s) / alcohol exposed
3321	P	Sentinel physical finding(s) / neurodevelopmental disorder / no alcohol exposure
3322	J	Sentinel physical finding(s) / neurodevelopmental disorder / alcohol exposure unknown
3323	D	Sentinel physical finding(s) / neurodevelopmental disorder / alcohol exposed
3324	D	Sentinel physical finding(s) / neurodevelopmental disorder / alcohol exposed
3331	N	Sentinel physical finding(s) / static encephalopathy / no alcohol exposure
3332	H	Sentinel physical finding(s) / static encephalopathy / alcohol exposure unknown
3333	A	FAS
3334	A	FAS

Code	Category	Diagnostic Name (4-Digit Codes under the umbrella of FASD in red font)
3341	N	Sentinel physical finding(s) / static encephalopathy / no alcohol exposure
3342	H	Sentinel physical finding(s) / static encephalopathy / alcohol exposure unknown
3343	A	FAS
3344	A	FAS
3411	R	Sentinel physical finding(s) / no alcohol exposure
3412	L	Sentinel physical finding(s) / alcohol exposure unknown
3413	F	Sentinel physical finding(s) / alcohol exposed
3414	F	Sentinel physical finding(s) / alcohol exposed
3421	P	Sentinel physical finding(s) / neurodevelopmental disorder / no alcohol exposure
3422	J	Sentinel physical finding(s) / neurodevelopmental disorder / alcohol exposure unknown
3423	D	Sentinel physical finding(s) / neurodevelopmental disorder / alcohol exposed
3424	D	Sentinel physical finding(s) / neurodevelopmental disorder / alcohol exposed
3431	N	Sentinel physical finding(s) / static encephalopathy / no alcohol exposure
3432	A	FAS
3433	A	FAS
3434	A	FAS
3441	N	Sentinel physical finding(s) / static encephalopathy / no alcohol exposure
3442	A	FAS
3443	A	FAS
3444	A	FAS
4111	R	Sentinel physical finding(s) / no alcohol exposure
4112	L	Sentinel physical finding(s) / alcohol exposure unknown
4113	F	Sentinel physical finding(s) / alcohol exposed
4114	F	Sentinel physical finding(s) / alcohol exposed
4121	P	Sentinel physical finding(s) / neurodevelopmental disorder / no alcohol exposure
4122	J	Sentinel physical finding(s) / neurodevelopmental disorder / alcohol exposure unknown
4123	D	Sentinel physical finding(s) / neurodevelopmental disorder / alcohol exposed
4124	D	Sentinel physical finding(s) / neurodevelopmental disorder / alcohol exposed
4131	N	Sentinel physical finding(s) / static encephalopathy / no alcohol exposure
4132	H	Sentinel physical finding(s) / static encephalopathy / alcohol exposure unknown
4133	B	Sentinel physical finding(s) / static encephalopathy / alcohol exposed
4134	B	Sentinel physical finding(s) / static encephalopathy / alcohol exposed
4141	N	Sentinel physical finding(s) / static encephalopathy / no alcohol exposure
4142	H	Sentinel physical finding(s) / static encephalopathy / alcohol exposure unknown
4143	B	Sentinel physical finding(s) / static encephalopathy / alcohol exposed
4144	B	Sentinel physical finding(s) / static encephalopathy / alcohol exposed
4211	R	Sentinel physical finding(s) / no alcohol exposure
4212	L	Sentinel physical finding(s) / alcohol exposure unknown
4213	F	Sentinel physical finding(s) / alcohol exposed
4214	F	Sentinel physical finding(s) / alcohol exposed
4221	P	Sentinel physical finding(s) / neurodevelopmental disorder / no alcohol exposure
4222	J	Sentinel physical finding(s) / neurodevelopmental disorder / alcohol exposure unknown
4223	D	Sentinel physical finding(s) / neurodevelopmental disorder / alcohol exposed
4224	D	Sentinel physical finding(s) / neurodevelopmental disorder / alcohol exposed

Code	Category	Diagnostic Name (4-Digit Codes under the umbrella of FASD in red font)
4231	N	Sentinel physical finding(s) / static encephalopathy / no alcohol exposure
4232	H	Sentinel physical finding(s) / static encephalopathy / alcohol exposure unknown
4233	B	Sentinel physical finding(s) / static encephalopathy / alcohol exposed
4234	B	Sentinel physical finding(s) / static encephalopathy / alcohol exposed
4241	N	Sentinel physical finding(s) / static encephalopathy / no alcohol exposure
4242	H	Sentinel physical finding(s) / static encephalopathy / alcohol exposure unknown
4243	B	Sentinel physical finding(s) / static encephalopathy / alcohol exposed
4244	B	Sentinel physical finding(s) / static encephalopathy / alcohol exposed
4311	R	Sentinel physical finding(s) / no alcohol exposure
4312	L	Sentinel physical finding(s) / alcohol exposure unknown
4313	F	Sentinel physical finding(s) / alcohol exposed
4314	F	Sentinel physical finding(s) / alcohol exposed
4321	P	Sentinel physical finding(s) / neurodevelopmental disorder / no alcohol exposure
4322	J	Sentinel physical finding(s) / neurodevelopmental disorder / alcohol exposure unknown
4323	D	Sentinel physical finding(s) / neurodevelopmental disorder / alcohol exposed
4324	D	Sentinel physical finding(s) / neurodevelopmental disorder / alcohol exposed
4331	N	Sentinel physical finding(s) / static encephalopathy / no alcohol exposure
4332	H	Sentinel physical finding(s) / static encephalopathy / alcohol exposure unknown
4333	A	FAS
4334	A	FAS
4341	N	Sentinel physical finding(s) / static encephalopathy / no alcohol exposure
4342	H	Sentinel physical finding(s) / static encephalopathy / alcohol exposure unknown
4343	A	FAS
4344	A	FAS
4411	R	Sentinel physical finding(s) / no alcohol exposure
4412	L	Sentinel physical finding(s) / alcohol exposure unknown
4413	F	Sentinel physical finding(s) / alcohol exposed
4414	F	Sentinel physical finding(s) / alcohol exposed
4421	P	Sentinel physical finding(s) / neurodevelopmental disorder / no alcohol exposure
4422	J	Sentinel physical finding(s) / neurodevelopmental disorder / alcohol exposure unknown
4423	D	Sentinel physical finding(s) / neurodevelopmental disorder / alcohol exposed
4424	D	Sentinel physical finding(s) / neurodevelopmental disorder / alcohol exposed
4431	N	Sentinel physical finding(s) / static encephalopathy / no alcohol exposure
4432	A	FAS
4433	A	FAS
4434	A	FAS
4441	N	Sentinel physical finding(s) / static encephalopathy / no alcohol exposure
4442	A	FAS
4443	A	FAS
4444	A	FAS

VII. Medical Summary Report & Generic Summaries for Diagnostic Categories

The FASDPN clinic generates a single comprehensive Medical Summary Report composed jointly by the interdisciplinary team.

An example of the format and content of our report is presented below for a fictitious patient. An electronic template of our Medical Summary Report is available free (contact Susan Astley Hemingway Ph.D. (astley@uw.edu)).

<Clinic Name>
Medical Summary Report Clinic Date: mm/dd/yyyy

Diagnosis	**Fetal Alcohol Syndrome**

Fetal alcohol syndrome (FAS) is defined by evidence of growth deficiency, a specific set of subtle facial anomalies, and evidence of significant brain damage/dysfunction that occur in individuals exposed to alcohol during gestation. On the attached pages are the specific findings in this patient's case that confirm they meet criteria for FAS.

Although this patient meets criteria for FAS, this does not mean that alcohol exposure during pregnancy is the only cause of the patient's current challenges. Other factors could also be contributing to the present issues such as the patient's genetic background, other potential exposures or problems during gestation, and various experiences since birth. Such factors may partly explain why there is so much variability in the kinds of specific challenges that patients with FAS have.

Individuals with FAS have significant brain damage/dysfunction and should be viewed as individuals with disabilities. This FAS diagnosis has implications for educational planning, societal expectations, and health. On the attached sheets you will find a list of specific concerns that have been identified that need attention.

_____

<Name>, MD
<Name of Clinic>

Diagnosis: Fetal Alcohol Syndrome (4-Digit Code 4433)

FASD 4-Digit Code

Rank	Growth	Face	Brain	Prenatal Alcohol	Other Prenatal Risks	Other Postnatal Risks
	4	**4**	**3**	**3**	3	3
4	severe	all 3 features	abnormal structure/neurology	high	high	high
3	moderate	2.5 features	severe dysfunction	some	some	some
2	mild	1-2 features	moderate dysfunction	unknown	unknown	unknown
1	normal	no features	normal function	none	none	none

Overview of Evaluation Procedure:

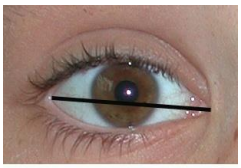
<Name> (10.2 of age) was accompanied today (mm/dd/yyyy) in clinic by his adoptive parents. A 4-hour interdisciplinary diagnostic evaluation using the 4-Digit Diagnostic Code[1] was conducted by the Fetal Alcohol Syndrome Diagnostic & Prevention Network (FASDPN) interdisciplinary clinical team composed of a pediatrician (<Name>, MD), an occupational therapist (<Name>, PhD, OTR/L), speech/language pathologist (<Name>, PhD, CCC-SLP), psychologist (<Name>, PhD), social worker (<Name>, MSW), family advocate (<Name>) and clinic director (<Name>, PhD). In the weeks leading up to this clinic appointment, prior school, medical, psychological and social service records were obtained and reviewed by the social worker. In addition, the patient's caregivers completed standardized questionnaires. Upon arrival today, the patient had his height, weight, and OFC measured and a clinical photograph taken of his face. Concurrently, the FASDPN diagnostic team participated in a 30-minute case presentation conducted by the social worker. Upon completion of the case presentation, the team pediatrician and social worker conducted a joint clinical interview with the caregivers. Concurrently, the patient received a 2-hour multi-disciplinary screening conducted by the occupational therapist, speech/language pathologist and psychologist. The team reconvened for 75 minutes and derived a diagnosis and treatment plan. The team shared the diagnosis with the patient's parents in the final 30 minutes of the appointment. The psychologist scheduled a 30-minute telephone conference with the caregivers for the following week to discuss the intervention recommendations.

1. S.J (Astley) Hemingway. Diagnostic Guide for Fetal Alcohol Spectrum Disorders: The 4-Digit Diagnostic Code. 4th Edition, Seattle WA: University of Washington Publication Services, 2024.

Growth:

Individuals with FASD are often growth deficient either pre- or postnatally. Two key indices for growth are height and weight percentiles adjusted for age. <Patient's name> presents with severe growth deficiency (Growth ABC-Score = CC; Growth Rank 4) based on his postnatal measurements. After a birth ending in the 38th week of gestation, <Patient's name> was 44.8 cm in length (7th percentile) and weighed 2,879 g (20th percentile). His current height and weight are 130.2 cm (3rd percentile after adjustment for midparental height) and 23.7 kg (3rd percentile).

Face:



palpebral fissure length

The face of fetal alcohol syndrome is characterized by the presence of all three of the following features: small eyes (as measured by palpebral fissure length), a thin upper lip and a smooth philtrum (the vertical groove between the nose and the upper lip). The palpebral fissures must be two or more standard deviations below the norm and the thin upper lip and smooth philtrum must be a Rank 4 or 5 on the Lip-Philtrum Guide. Based on the 4-Digit Code, if all three of these features are present, the Face is assigned a Rank 4. Moderate and mild expressions of these FAS facial features receive Face Ranks of 3 and 2 respectively. If none of these three facial features are present, the face receives a Rank 1.

<Patient's name> palpebral fissure lengths were significantly small (22.4 mm, estimated to be 3.75 SDs below the mean on the Stromland PFL growth charts) for his age and race (Caucasian). <Patient's name> has a very smooth philtrum (Rank 5) and a moderately thin upper lip (Lip Circularity = 79.5; Rank 4) based on the use of UW Lip-Philtrum Guide 1. Based on these facial measures, <Patient's name> receives a Facial ABC-Score of CCC (or 4-Digit Face Rank 4). <Patient's name> presents with the full expression of the FAS facial phenotype. <Patient's name> also presented with hypertelorism (inner canthal distance 35.1 mm, estimated to be 2.01 SDs above the mean on the Hall inner canthal distance growth charts). In addition, <Patient's name> presented with epicanthal folds. See FAS Facial Photographic Analysis Software photo report below.

FAS Facial Photographic Analysis Report

IDENTIFICATION

	First	Middle	Last
Name	Name	Name	Name

Subject I.D.:
Source of Photo: Clinic Name
Gender: Male
Race: Caucasian / Caucasian
Birth Date: mm/dd/yyyy

PHOTO ASSESSMENT

Normal PFL Chart: Scandinavian (Stromland '99) Lip-Philtrum Guide: Caucasian
Normal ICD Chart: Caucasian (Hall '89)

	Frontal	¾ View	Lateral
File Name	frontal.jpg	oblique.jpg	lateral.jpg
Date of Photo	mm/dd/yyyy	mm/dd/yyyy	mm/dd/yyyy
Age (yrs) in photo	10.2	10.2	10.2
Date of Photo Assessment	mm/dd/yyyy	mm/dd/yyyy	mm/dd/yyyy
Photo Assessor	name	name	name

Length of Real Internal Measure of Scale(sticker) placed on forehead (mm): 19.05
Length of Internal Measure of Scale in Frontal Photo (pixels): 122.5

Left Palpebral Fissure Length:	In photo (pixels) 129.0	True Length (mm) 22.1	Z-score -3.97
Right Palpebral Fissure Length:	In photo (pixels) 132.5	True Length (mm) 22.7	Z-score -3.52
Mean Palpebral Fissure Length:	In photo (pixels) 130.8	True Length (mm) 22.4	Z-score -3.75
Inner Canthal Distance (ICD):	In photo (pixels) 226.0	True Distance (mm) 35.1	Z-score 2.01

Flat Philtrum (5-point rank): In Frontal Photo 5 In ¾ Photo 5
Thin Upper Lip: Circularity (perimeter²/area) 79.5 5-Point rank (Circ) 4 5-Point rank (Scale) 4

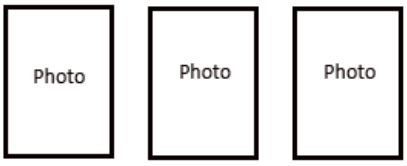
clown eyebrows ☐ ptosis ☐ strabismus ☐ epicanthal folds ■
flat midface ☐ protruding ears ☐ flat nasal bridge ☐ hypertelorism ■

Other anomalies present: None reported

Comments:
Other syndromes present: None reported

PHOTO QUALITY

	Frontal	¾ View	Lateral
Side showing		Right	Left
Head rotation (5-point rank/degrees) to subject's Right (+) or Left (-)	1°	0	0
Head tilt (5-point rank) toward subject's Right (+) or Left (-) shoulder			0
Head tip (degrees) Up (+) or Down (-) from Frankfort Horizontal Plane	1°		
Exposure (3-point rank)	1 (good)	1 (good)	1 (good)
Focus (3-point rank)	1 (good)	1 (good)	1 (good)
Facial Expression (3-point rank)	1 (Relaxed)	1 (Relaxed)	1 (Relaxed)
Reliability of ABC-Score for palpebral fissure length (5-point rank)	1 (very good)		
Reliability of ABC-Score for philtrum (5-point rank)	1 (very good)	1 (very good)	
Reliability of ABC-Score for upper lip (5-point rank)	1 (very good)		



Frontal.jpg oblique.jpg lateral.jpg

OUTCOME

	PFL	Philtrum	Lip
ABC-Score	C	C	C
Data Used	mean	3/4 View	circularity

4-Digit Diagnostic Code for Face: 4: FAS features severe

University of Washington FAS DPN FAS Facial Photographic Analysis Software

Brain: Brain damage may be evidenced by abnormal brain structure (such as microcephaly or abnormal structure identified through brain imaging), abnormal neurological signs of presumed prenatal origin (such as seizures, tics or spasticity) and/or significant brain dysfunction as measured by standardized psychometric assessments. Based on the 4-Digit Diagnostic Code, a Brain Rank 4 is assigned when structural and/or neurological evidence of impairment is present, a Brain Rank 3 is assigned when there is evidence of significant brain dysfunction, a Brain Rank 2 is assigned when there is some evidence of brain dysfunction or delayed development, but not at the level of a Rank 3 and a Brain Rank 1 is assigned when there is no functional evidence of impairment.

Based on the information available to us to date, <Patient's name> met the criteria for a Brain Rank 3. This information is described more fully below.

Structurally, <Patient's name> head circumference has always been in the normal range. At birth his OFC was 32.7 cm (37th percentile for 38 weeks gestation) and is currently 51 cm (20th percentile). <Patient's name> has had his brain imaged. A cranial ultrasound in <year> was reported normal. Neurologically, <Patient's name> does not have a reported history of seizures or other neurologic problems.

Brain or central nervous system function was assessed both prior to and during this clinic visit.

Psychometric assessments administered today in clinic include the following:

Psychological Screen:
- *California Verbal Learning Test- Children's Version (CVLT-C)*
- *Child Behavior Checklist for Ages 6-18 (CBCL/6-18)*
- *Children's Sleep Habits Questionnaire (CSHQ)*
- *Delis-Kaplan Executive Function System (D-KEFS)*

Motor/Sensory/Developmental Screen:
- *Developmental Test of Visual Motor Integration, 6th Edition (VMI-6)*
- *Quick Neurological Screening Test-3R (QNST-3R)*
- *Short Sensory Profile (SSP)*

Language Screen:
- *Children's Communication Checklist-2 (CCC-2)*
- *Clinical Evaluation of Language Fundamentals - 4th Edition (CELF-4)*

Previous Testing:

Records from the following previous assessments were also available for our review and consideration:
- *KTEA-3, <year>*
- *ABAS-3, <year>*
- *BASC-3, <year>*
- *BOT-2, <year>*
- WISC-5, <year>

Previous records document <Patient's name> has a diagnosis of ADHD.

The standardized testing and clinical observations carried out in this FASD diagnostic clinic are conducted solely for the purposes of diagnosing alcohol-related disabilities and making related recommendations and referrals. This is not a comprehensive assessment of skills. To more completely understand <Patient's name>'s unique cognitive and behavioral profile, additional comprehensive psychological, neuropsychological, occupational therapy and speech assessments carried out by qualified professionals may be necessary.

The test outcomes presented in this report use a variety of scoring systems. Unless otherwise indicated, Standard scores are based on a scale in which the mean is 100 and the standard deviation is 15. This means that most individuals attain a Standard score between 85 and 115 (the "average" range). Scores that are 2 or more standard deviations below the mean are considered significantly below the mean. Thus, Standard scores at or below 70 are considered to be significantly below the mean. T-scores are based on a scale in which the mean is 50 and the standard deviation is 10. An average T-score falls between 40 and 60. A T-score at or below 30 is significantly below the mean. Some subtests use Scaled scores, in which the mean is 10 and the standard deviation is 3. An average Scaled score falls between 7 and 13. A Scaled score at or below 4 is significantly below the mean. Percentile ranks indicate where the individual's score falls relative to his age peers. Average scores fall between the 25th to the 75th percentile (the 50th percentile is in the middle of the average range and corresponds to a Standard score of 100). Scores below the 3rd percentile are significantly below the average range.

Psychological Screen conducted in clinic today at chronological age 10.2 years:

It was a pleasure working with <Patient's name> today. <Patient's name> was cooperative and engaged throughout the assessment. He shared his sense of humor and was talkative. <Patient's name> used emphatic gestures, established eye contact with the examiner, and engaged in reciprocal interactions. He remained at the table throughout the assessment although he fidgeted in his chair and required movement at times. He also responded impulsively and was inattentive to details on occasion. Despite these behaviors, he put forth appropriate effort and completed every task. Snack breaks and encouragement were helpful in supporting <Patient's name>'s performance. The results reported here are believed to be a valid indicator of <Patient's name>'s current functioning in the areas assessed. Therefore, these results are considered valid estimates of his thinking and reasoning ability.

The *California Verbal Learning Test - Children's Version (CVLT-C)* is a measure of multiple components of verbal learning and memory. Strategies and processes involved in learning and recalling verbal material are also assessed. On this test, <Patient's name> received the following scores:

CVLT-C		
Task	**Level of Recall**	
List A: Total Trials	T-Score	31
List A: Short Delay Free Recall	z-score	-2
List A: Short Delay Cued Recall	z-score	-1.5
List A: Long Delay Free Recall	z-score	-1.5
List A: Long Delay Cued Recall	z-score	-1.5
List B: Free Recall	z-score	-1

CVLT-C			
Learning Characteristics	*z-score*	**Recall Errors/Recognition Measures**	*z-score*
Semantic Cluster Ratio	0	Perseverations	-0.5
Serial Cluster Ratio	-0.5	Free-recall Intrusions	1
Learning Slope	-3	Cued-recall Intrusions	2
Percent Recall Consistency	-2	Discriminability	1

<Patient's name> demonstrated significant difficulty with verbal learning and memory. Rather than increasing the number of words he recalled from a list across five repeated trials, he recalled fewer than expected resulting in a *T*-score of 31, which is in the very low range compared to his same-aged peers. He also had difficulty recalling the list after a short delay with distraction and when cued to recall items within a specific category. During these memory tasks, he tended to add words that were within the categories but were not within the initial list. This performance indicates that <Patient's name> may be overwhelmed by too much information and unable to sustain attention. Additionally, he confabulates to appear and feel more competent or to please others, which may be interpreted by others as lying. Despite the difficulty of this task, <Patient's name> persisted without complaint and put forth good effort.

Delis-Kaplan Executive Function System (D-KEFS) consists of 9 independent tests designed to measure quantitative and qualitative aspects of executive functions.

The *D-KEFS Color-Word Interference Test* typically measures inhibition and cognitive flexibility. This subtest is comprised of four conditions. The first two conditions measure speed and accuracy of naming colors and reading color names written in black ink. The third condition evaluates the ability to inhibit the name-reading response to perform the less-automatic skill of naming the color of ink, while the fourth condition examines the ability to both inhibit and switch between two sets of rules. On this measure, <Patient's name> received the following scores:

D-KEFS Color-Word Interference	
Primary Measures	**Scaled Score**
Color Naming	7
Word Reading	8
Inhibition	8
Inhibition/Switching	10
Combined Naming + Reading	7
Primary Contrast Measures	**Scaled Score**
Inhibition vs. Color Naming	10
Inhibition/Switching vs. Combined Naming + Reading	11
Inhibition/Switching vs. Inhibition	12
Error Measures	**Scaled Score**
Inhibition Condition	3
Inhibition/Switching Condition	1

<Patient's name> was able to complete each of these tasks as quickly as expected for his age; however, he sacrificed accuracy for speed and made several errors. At times, he caught his errors and self-corrected, yet for several, he was unaware that he made a mistake. The number of errors significantly exceeded expectations compared to his same-aged peers indicating impulsive responding, poor cognitive flexibility, and difficulty with self-monitoring yet age-appropriate processing speed.

The *D-KEFS Trail Making Test* is a well-known drawing test that assesses planning, organization, sequencing, motor speed, and flexible thinking skills. This task is made up of five conditions. Four of the conditions are used to isolate the four skills necessary to perform the fifth task (which measures the ability to switch sets). On this measure, <Patient's name> received the following scores:

D-KEFS Trail Making	
Primary Measures	**Completion Times Scaled Score**
Visual Scanning	12
Number Sequencing	13
Letter Sequencing	3
Number-Letter Switching	3
Motor Speed	10
Combined Number + Letter Sequencing	8
Contrast Measures	**Contrast Scaled Score**
Switching vs. Visual Scanning	2
Switching vs. Number Sequencing	2
Switching vs. Letter Sequencing	0
Switching vs. Combined Number + Letter Sequencing	5
Switching vs. Motor Speed	3
Error Analysis	**Scaled Score**
All Error Types for Number-Letter Switching	3

<Patient's name> was able to scan an array of letters and numbers, sequence numbers, and connect dots on paper with a pencil as quickly as others his age. When sequencing letters, <Patient's name> needed help remembering that H came after G rather than J and he spent quite a bit of extra time searching for the letter J and incorrectly rehearsing the alphabet. Had the examiner not assisted <Patient's name> by giving him the correct letter, he would not have completed this task. Even with the help, his score is in the very low range. On the switching task, however, <Patient's name> remembered the correct order of the alphabet yet made a significant number of errors and took extra time reviewing and rehearsing the number and letter sequences. This performance is consistent with Color-Word Interference and indicates that <Patient's name> has difficulty with impulsive responding, cognitive flexibility, and self-monitoring.

The *Child Behavior Checklist for Ages 6-18 (CBCL/6-18)* is a caregiver checklist reporting on children's social competence and behavior problems. This questionnaire presents: (1) a list of behavior problems which are rated by the parent for frequency of occurrence (high scores reflect

deficits); and (2) a series of questions about social activities and school performance to provide information on the child's degree of participation in these activities and at school, and the quality of the child's performance (low scores reflect deficits). The patient's caregiver completed this checklist on mm/dd/yyyy. The caregiver's responses yielded the following scores:

CBCL/6-18			
Index/Scale	**T-Score**	**Behavior Problem Scales**	**T-Score**
Total Competence	**30-C**	Anxious/Depressed	66-B
Activities	52	Withdrawn/Depressed	68-B
Social	28-C	Somatic Complaints	72-C
School	24-C	Social Problems	70-C
Total Behavior Problems	**73-C**	Thought Problems	71-C
Internalizing	71-C	Attention Problems	92-C
Externalizing	65-C	Rule-Breaking Behavior	67-B
		Aggressive Behavior	64

B= scores are in the Borderline Range, C=scores are in the Clinical Range

The caregiver's ratings indicated that they perceive significantly elevated Externalizing and Internalizing Behaviors. The caregiver endorsed items indicating that <Patient's name> has Clinical levels of inattention, impulsivity, and social problems. Rule-breaking behaviors, such as lying, and thought problems, such as hording items and getting stuck on specific characters were reported. The caregiver also noted that <Patient's name> has a tendency to be moody and argumentative. Several ratings were consistent with <Patient's name>'s medical problems and diagnoses of attention deficit hyperactivity disorder and anxiety. Additionally, the caregiver reported concerns with school performance and academic learning in all areas. <Patient's name> currently has an Individualized Education Plan (IEP) at school. <Patient's name> was reported to get along with others and has friends. He engages in some age-appropriate activities such as soccer, basketball, and running. He also enjoys playing video games and drawing. Positively, the caregiver described <Patient's name> as loving towards friends, family, and pets. He cares greatly about people around him and is sympathetic when they are sad. He loves entertaining people and joking around.

The *Children's Sleep Habits Questionnaire (CSHQ; Owens 2000.)* Sleep disorders in children are often under-diagnosed. In children with Fetal Alcohol Spectrum Disorders, objective data on the presence of increased sleep disorders are emerging. Therefore, <Patient's name>'s caregiver was administered the CSHQ, which is a validated screening tool for identifying school-aged children with a possible sleep disorder. The CSHQ focuses on sleep disorders common to this age group in three domains: Dyssomnias, Parasomnias, and Sleep-Disordered Breathing. <Patient's name> scored 35 out of a possible 99 points. A score of 39 or higher reflects a potential sleep problem. Based on the CSHQ and parent interview, a referral to a sleep specialist is not indicated.

Motor/Sensory/Developmental Screen at chronological age 10.2 years:

The *Short Sensory Profile* measures a caregiver's report of behaviors related to sensory processing and integration abilities. The Short Sensory Profile is a standardized questionnaire of sensory processing abilities in children ages 3 to 10 years. The scores in each category are classified as Typical Performance, Probable Difference or Definite Difference. Probable or Definite Differences may suggest sensory processing and integration difficulties that are affecting behavior and daily life. On this test, <Patient's name> received the following scores:

SSP	
Test/Subtest	**Outcome**
Total Test	definite difference
Tactile Sensitivity	typical performance
Taste/Smell Sensitivity	probable difference
Movement Sensitivity	typical performance
Under-responsive/Seeks Sensation	definite difference
Auditory Filtering	definite difference
Low Energy/Weak	definite difference
Visual/Auditory Sensitivity	probable difference

Per caregiver report, it was endorsed that <Patient's name> has strengths in the areas of tactile sensitivity and movement sensitivity and challenges in the areas of taste/smell sensitivity, under-responsive/seeks sensation, auditory filtering, low energy/weak, and visual/auditory sensitivity. Results suggest that processing sensory information is challenging for <Patient's name>, and this may account for some of the behaviors that caregivers identified as concerning (e.g., difficulty staying on task, trouble listening to directions, avoidance of self-care tasks).

The *Developmental Test of Visual Motor Integration, 6th Edition (VMI-6)* measures eye-hand coordination copying various geometric forms of increasing complexity. Results on the VMI suggest that <Patient's name>'s visual motor skills are at the 2nd percentile range (standard score 70), placing his performance significantly below the average range when compared to same age peers.

VMI	
Test	Standard Score
VMI	70
Visual Perception	110
Motor Coordination	73

<Patient's name> received a standard score of 110 for visual perception (75th percentile), placing his performance in the average range. <Patient's name> received a standard score of 73 for motor coordination (4th percentile), placing his performance in the below average range. He would benefit from handwriting support and accommodations (e.g. learning to keyboard).

The *Quick Neurological Screening Test-3R (QNST-3R)* is a screening tool that measures neurological soft signs in ages 5 years of age through adulthood. It consists of items adapted from neurologic and neuropsychological examinations that sample fine and gross motor coordination, balance and vestibular function, visual and auditory perceptual skills, motor planning and sequencing, and spatial organization. Items on the QNST-3 reflect measures of neurological maturation or integrity. Deficient performance on several of these measures may be suggestive of an underlying developmental or neurological basis for learning or behavioral problems. Scores fall into one of three categories 1) Normal indicates performance at or above the 25th percentile; 2) Moderate Discrepancy indicates performance in the 6th through 25 percentile and 3) Severe Discrepancy indicates performance in the 5th percentile or lower. On this measure, <Patient's name> received an overall raw score of 58, which falls into the Severe Discrepancy category for a child his age.

<Patient's name> was cooperative and worked hard throughout the screening today. When asked to write a sentence, <Patient's name> remembered the sentence and demonstrated good spacing, but he struggled with letter sizing, line use, mixing upper- and lower-case letters, and overall legibility. <Patient's name> held the pencil in his right hand using an efficient tripod grasp. Although he has a good pencil grasp, <Patient's name> fatigued quickly during paper and pencil tasks. He would benefit from handwriting support and accommodations (e.g. learning to keyboard).

<Patient's name> was able to match shapes and skip for thirty feet, but he had difficulty with visual tracking, remembering and repeating patterns, and spatial awareness. Activities that required visual-motor integration (e.g. copying shapes), fine motor coordination (e.g. mazes), motor planning, strength/endurance, bilateral coordination, static balance (e.g. standing on one foot) and dynamic balance (e.g. walking on a line backwards) were also very challenging for him. He benefited from structure, sensory supports (e.g. a quiet room, movement breaks), and a reward system (e.g. verbal praise). <Patient's name> is a sensitive, creative, and engaging boy who was a pleasure to work with!

Language Screen at chronological age 10.2 years:

<Patient's name> came to clinic without previous speech-language testing. Results from today's assessment indicate age-appropriate language development at this time. Results are based on standardized testing, caregiver report, and structured clinical observations. Details presented below.

The *Children's Communication Checklist-2 (CCC-2)* is a parent-report checklist that assists in identifying communication problems. <Patient's name>'s caregiver completed this checklist and he received the following scores:

CCC-2			
Scale	**Scaled Score**	**Composite**	**Percentile**
Speech	5		5
Syntax	10		50
Semantics	3		1
Coherence	4		2
Initiation	7		16
Scripted Language	3		1
Context	7		16
Nonverbal Communication	6		9
Social relations	5		5
Interests	6		9
General Communication Composite	45	**74**	4
Social Interaction Difference Index (SIDI)	**2:** This score is in the expected range		

Results of this caregiver questionnaire indicate concerns for <Patient's name>'s overall success as a communicator with a General Communication Composite score of 74, where most children receive scores between 85 and 115 and lower scores indicate more concern. His pattern of performance indicates the most concern for vocabulary (semantics), coherence/organization of communication, and reliance on scripted language. Strengths include grammar (syntax), initiation, and use of context.

The *Clinical Evaluation of Language Fundamentals - 4th Edition (CELF-4)* examines an individual's grasp of the relationships among semantics, syntax/morphology, and pragmatics (form, content, and use) and the interrelated domains of receptive and expressive language. On this test, <Patient's name> received the following scores:

CELF-4	
Scaled Scores: scores between 7 and 13 are expected	
Formulated Sentences	12
Word Classes-Total	9
Word Classes-Receptive	9
Word Classes-Expressive	9

Results indicate age-appropriate development of grammar and vocabulary at this time.

Structured observations during today's assessment indicated that <Patient's name> uses an age-appropriate range of vocabulary in grammatical sentences to meet an expected range of communicative functions. He engages in reciprocal conversations, responds to and asks questions, shares personal experiences and opinions, clarifies messages, requests, uses humor, comments, explains, and uses language to problem solve. He provides his listener with background information to support understanding, organizes his information appropriately, and uses idioms appropriately to sustain engagement and convey his attitude/opinion.

Taken together these results indicate that language and discourse skills are a strength that <Patient's name> can use to support his access to strategies supporting other areas that may be more challenging for him.

Despite age-appropriate language development at this time, <Patient's name>'s prenatal alcohol exposure and early medical history are a risk for difficulty with later-developing, more complex aspects of language. Progress in this and all academic areas should be closely monitored so that appropriate support can be put in place.

Summary of Psychometric Assessments of Brain Function:

<Patient's name> came to clinic today with previous neurodevelopmental testing indicating moderate concerns for written expression, mathematics, adaptive skills, and motor development. There are moderate concerns for behavior, social skills, sleep, and adaptive skills. There are previous diagnoses including attention-deficit/hyperactivity disorder and attachment disorder. He has an individualized education program supporting academics, adaptive skills, and behavior.

Today's assessment indicated significant impairment (i.e., performance two or more standard deviations below the mean on standardized testing) in sensory-motor development (e.g., visual-motor integration, visual tracking, spatial awareness, motor planning, static and dynamic balance), in verbal memory/learning, executive functioning (performance monitoring, cognitive flexibility, inhibition). Definite differences in sensory processing were documented (sensory seeking, low-energy week, auditory attention).

Caregiver Interview:

We had the pleasure of interviews with <Patient's name>'s caregivers. His caregivers expressed concerns about <Patient's name>'s growth deficiency and noted that he is very smart but inattentive. He is eating better, sleeping well, and socially successful. Parents report <Patient's name> does well with lists and routines but struggles with multistep instructions. <Patient's name> is inattentive and can be quite impulsive, especially in answering questions before the question is finished and figuring out if he knows the answer. He rapidly cycles through activities but gets bored easily. It takes <Patient's name> longer to learn new academic skills and games, and he has inconsistent retrieval of learned information. He frequently has word recall and word mix-up challenges. Socially, <Patient's name> is very social and makes friends easily from age 5 to 15; he does misinterpret social scenarios at times. His motor abilities have been impacted by lower stamina, strength, and speed. <Patient's name> has so many strengths, including his inventive game characters, having excellent humor, and being social and kind.

Alcohol Exposure:
<Patient's name>'s biological mother confirmed she drank alcohol during this pregnancy, although the exact quantities, frequency, and timing of alcohol use during pregnancy were not reported. Confirmed exposure, but of unknown quantity or frequency, meets the 4-Digit Diagnostic criteria for an Alcohol Rank 3.

Co-Morbidities
When assessing the potential impact of prenatal alcohol exposure on an individual, it is important to document all other significant prenatal and postnatal exposures and events, for they too serve as potential risk factors for cognitive/behavioral dysfunction. Prenatal risk factors may include, but are not limited to poor prenatal care, genetic conditions that may run in the family and other potential teratogenic exposures. Postnatal risk factors may include but are not limited to perinatal difficulties, adverse home environments, multiple home placements, neglect, abuse and other events that could explain brain dysfunction like head injuries or a patient's own chronic substance abuse. While it is not possible with today's medical technology to determine which risk factor(s) may be responsible for each adverse outcome, it remains important to document all exposures and events and take them into consideration when deriving a diagnosis and intervention plan.

Potential risk factors reported to the clinic to date include:

Prenatal Rank 3:
- No prenatal care.
- Tobacco use during pregnancy

Postnatal Rank 3:
- Some neglect birth to 3 years of age.
- One out of home placement at 3 years of age.

The next section of the Medical Summary Report is the Intervention Recommendations. The intervention section starts on a new page so it can be shared with schools while maintaining the medical confidentiality of the information in the first section of the report. These recommendations cover a wide range of needs: medical, education, mental health, family support, community-based programs and activities, and anticipatory guidance (Jirikowic et al., 2010). The intervention recommendations below are reflective of what is generally available in Washington State in the 2020s. Availability of services will vary considerably by community and region worldwide.

<u>Diagnosis</u>: Fetal Alcohol Syndrome

Intervention Recommendations

Based on records review and assessments, observations and caregiver interviews completed today by the FASDPN interdisciplinary team, the following recommendations are offered:

A. Medical

Please note that recommendations that involve medical issues should be shared with <Patient's name>'s primary care physician before initiating any action.

A. <Patient's name> has been receiving excellent general and specialty medical care. Continue regular medical & dental checkups, specialty follow up, and periodic hearing/vision screenings.

B. <Patient's name> has unusually short palpebral fissure lengths (eye openings). If not already performed, he would benefit from a comprehensive ophthalmology evaluation that includes visualization of retina and optic nerve, as we might expect associated ophthalmological findings such as refractive errors, strabismus and fundus abnormalities.

C. <Patient's name>'s ADHD is having an impact on his performance. It could be worth another trial of ADHD medication. Stimulant medications could impact his growth but might be cautiously used, or you could try non-stimulant long-acting alpha-agonists.

B. Education

- <Patient's name> will continue to benefit from an individualized education program (IEP) to support his challenges with learning as a student with other health impairment. He will continue to benefit from support in adaptive, behavior, mathematics, reading, and written language skills. We would recommend that an occupational therapist be a part of his team to support fine motor skills (handwriting) and sensory processing needs. <Patient's name>'s impairments in sensory-motor development represent an important barrier to his access to age-appropriate curriculum and educational activities.

    - Sensory accommodations are recommended. Examples are a "wiggle pad" or a weighted lap pillow to be used during the school day or in homework sessions.
    - Modifications of the classroom environment may be useful, such as a "quiet office" space to assist in focusing at school, headphones, or the use of techniques such as keyboarding. Recess is an important chance for movement, which should *never* be eliminated as a classroom discipline strategy or to complete assignments. Scheduled "down time" in a quieter, calmer space can help. The occupational therapist (OT) at school or in a private practice should be able to consult on environmental modifications and sensory accommodations.
    - A good resource for educators is the book: *Building Sensory Friendly Classrooms* by Rebecca Moyes

- If not already in place, we also recommend that the accommodations from which <Patient's name> benefits be formalized in a written plan (so that accommodations will be available now and in future educational and workplace settings). Accommodations that are important for <Patient's name> include:
  - Preferential seating and a safe place to retreat when <Patient's name> needs to self-regulate.
  - Allow extra time for testing (up to 1.5X extra) and extra time on math and writing assignments.
  - Allow testing to occur in smaller settings with reduced distractions.
  - Reduce volume of workload so that <Patient's name> does not have to work longer than peers and thus miss opportunities for other extracurricular opportunities.
  - Allow extra time for processing (for example, when answering a question in class, wait longer for <Patient's name> to formulate an answer).
  - Have instructions presented in visual form (written) rather than just verbally stated.
  - After a period of learning/ instruction, provide a break so that <Patient's name> can be ready for new learning.
  - Identify a "trusted-adult" mentor that <Patient's name> can go to for help managing stress/anxiety.
  - Time-ins (with the teacher or trusted adult) versus time-out.

- Additional resources for children with prenatal alcohol exposure:
  - *Teaching Students with Fetal Alcohol Spectrum Disorder* https://depts.washington.edu/fasdpn/pdfs/teaching-students-with-fasd-2004.pdf
  - *Fetal Alcohol Spectrum Disorders Education Strategies* https://depts.washington.edu/fasdpn/pdfs/FASD%20Educational%20Strategies%20Handbook.pdf

C. Mental Health

- Continued counseling to support the development of emotion/behavior regulation and coping strategies is recommended. Cognitive Behavioral Therapy (CBT) is an evidence-based therapeutic intervention that has been shown to be an effective therapeutic modality with many individuals <Patient's name>'s age. Additionally, there is scientific data to support "mindfulness approaches" to emotion regulation, stress management, and improving life function. There are books that can teach people how to use mindfulness in daily life, such as *The Mindfulness Solution: Everyday Practices for Everyday Problems*, by Ronald Siegel and *The Yes Brain: How to Cultivate Courage, Curiosity, and Resilience in Your Child*, by Daniel Siegel and Tina Bryson.

  - <Patient's name> has experienced intrusive comments about his medical issues from peers. One aspect of therapy that would be helpful is role-playing responses to such comments and questions.
  - Continue to closely monitor <Patient's name>'s mental health as he develops so that appropriate support can be put in place if the need arises.

D. Family Support

- Here are several parenting resources for FASD:
  - FASD Parenting Toolkit (https://adai.uw.edu/fasdtoolkit/parents.htm) is available from the University of Washington
  - The CDC has a number of FASD resources – https://www.cdc.gov/ncbddd/fasd/families.html
  - Making Sense of Fetal Alcohol Spectrum Disorder (FASD) –
  - https://www.nhsaaa.net/media/5702/fasd-info-for-parents-carers-online.pdf is an excellent resource
  - Proof Alliance (https://www.proofalliance.org) has a nice 3-page handout on Parenting Children with FASD – https://adoptmed.org/s/Parenting-children-with-FASD.pdf
  - FASD United (https://fasdunited.org/index.php/tools-for-parents-and-caregivers/) has many tools and resources for parents
  - We also like Parenting Children with Affected by FAS: A Guide for Daily Living – https://adoptmed.org/s/daily_guide_for_living.pdf
- Because of the high maintenance and complexity of raising children who are prenatally exposed to alcohol, a resource such as The National Organization on Fetal Alcohol Syndrome Washington State (NOFAS Washington) is recommended. They provide programs such as FASt Friends (a caregiver and community provider support network), family summer camps, social skills and friendship groups, and online support. www.nofaswa.org..

E. Community-based Programs and Activities

- Continue to seek opportunities to participate in extracurricular activities in supervised and structured settings. This can provide positive social experiences, mentorship, and enjoyable and successful free time activities. Possibilities include therapeutic horseback riding, Boys and Girls Club, martial arts, Outdoors-for-All, swimming lessons, choir, gymnastics, and dance.
  - Information can be obtained at https://outdoorsforall.org
- A blended Special Olympics program (http://specialolympicswashington.org) could be a lovely way to work on <Patient's name>'s physical skills and help regulate his emotions.
- Martial arts provide many benefits that can include improvements in sensory-motor, emotional self-regulation, peer interaction, and self-confidence. Kung Fu Northwest is one local option. https://www.marysvillemartialarts.com/
- Consider involvement in music and theater activities. These activities could provide <Patient's name> with social connections and be an avenue for him to explore vocational and recreational interests that can continue throughout his life.

F. Anticipatory Guidance

- <Patient's name>'s genetic history and prenatal exposures place him at high risk for developing challenges with drug and alcohol abuse and dependence. We recommend that developmentally appropriate prevention education begin very early and be repeated regularly and often. This type of education is important for children, and will remain important through elementary, middle school, and high school. The social lessons learned about alcohol at home are an important component of this education process.

- We strongly encourage all caregivers to pursue avenues of self-care, including respite care opportunities, to ensure they may continue parenting as effectively as possible.

It was a pleasure seeing <Patient's name> in clinic today.
If you have any questions, please call our clinic <phone number>.

_____

<Name>, MD
<Name of Clinic>

Generic First Page of Medical Summary Report

Note the first page of the Medical Summary Report above has a generic description of the diagnosis. The generic descriptions of all 19 Diagnostic Categories (A-S) are presented below. Simply copy and paste the generic description below that matches the patient's diagnosis into page 1 of the patient's Medical Summary Report. The text may require minor alterations or additions to conform to the specifics of an individual case. Diagnoses in red font are broadly under the umbrella of FASD.

A.
Diagnosis: Fetal Alcohol Syndrome

Fetal alcohol syndrome (FAS) is defined by evidence of growth deficiency, a specific set of subtle facial anomalies, and evidence of significant brain damage/dysfunction that occur in individuals exposed to alcohol during gestation. On the attached pages are the specific findings in this patient's case that confirm they meet criteria for FAS.

Although this patient meets criteria for FAS, this does not mean that alcohol exposure during pregnancy is the only cause of the patient's current challenges. Other factors could be contributing to the present issues such as the patient's genetic background, other potential exposures or problems during gestation, and various experiences since birth. Such factors may partly explain why there is so much variability in the kinds of specific challenges that patients with FAS have.

Individuals with FAS have significant brain damage/dysfunction and should be viewed as individuals with disabilities. This FAS diagnosis has implications for educational planning, societal expectations, and health. On the attached sheets you will find a list of specific concerns that have been identified that need attention.

B.
Diagnosis: Sentinel physical finding(s) / static encephalopathy / alcohol exposed

Fetal alcohol syndrome (FAS) is defined by evidence of growth deficiency, a specific set of facial characteristics, and evidence of brain damage/dysfunction in individuals exposed to alcohol during gestation. Not all individuals exposed to alcohol during gestation have FAS.

In this patient's case, some but not all the characteristic growth and facial features associated with FAS were present and there was evidence of significant brain damage and/or dysfunction as you will see noted on the attached pages. There was also a confirmed history of exposure to alcohol during gestation. These outcomes meet the criteria for *Sentinel physical finding(s) / static encephalopathy / alcohol exposed*. The patient's brain abnormalities may include structural, neurological and/or functional problems. The diagnosis of *Sentinel physical finding(s) / static encephalopathy* in the presence of alcohol exposure does not mean that alcohol is the only cause of the problem. Other factors could be contributing to the present issues such as the patient's genetic background, other potential exposures or problems during gestation, and various experiences since birth. These kinds of differences may partly explain why there is so much variability in the kinds of specific challenges that patients with static encephalopathy and alcohol exposure have.

Individuals with *Static encephalopathy* have significant brain damage/dysfunction and should be viewed as individuals with disabilities. The diagnosis of *Static encephalopathy* has implications for educational planning, societal expectations, and health. On the attached sheets you will find a list of specific problems that have been identified that need attention.

C.
Diagnosis: Static encephalopathy / alcohol exposed

Fetal Alcohol Syndrome (FAS) is defined by evidence of growth deficiency, a specific set of subtle facial anomalies, and evidence of brain damage/dysfunction occurring in patients exposed to alcohol during gestation. Not all individuals exposed to alcohol during gestation have FAS.

In this patient's case, no growth deficiency or characteristic set of facial features were found, but there was evidence of significant brain damage/dysfunction as you will see noted on the attached pages. There was also a confirmed history of exposure to alcohol during gestation. These outcomes meet the criteria for S*tatic encephalopathy / alcohol exposed*. The patient's brain abnormalities may include structural, neurological and/or functional problems. The diagnosis of *Static encephalopathy* in the presence of prenatal alcohol exposure does not mean that alcohol is the only cause of the problem. Other factors could be contributing to the present issues such as the patient's genetic background, other potential exposures or problems during gestation, and various experiences since birth. These kinds of differences may partly explain why there is so much variability in the kinds of specific challenges that patients with static encephalopathy and alcohol exposure have.

Individuals with *Static encephalopathy* have significant brain damage/dysfunction and should be viewed as individuals with disabilities. The diagnosis of S*tatic encephalopathy* has implications for educational planning, societal expectations, and health. On the attached sheets you will find a list of specific problems that have been identified that need attention.

D.
Diagnosis: Sentinel physical finding(s) / neurodevelopmental disorder / alcohol exposed

Fetal Alcohol Syndrome (FAS) is defined by evidence of growth deficiency, a specific set of subtle facial anomalies, and evidence of significant brain damage/dysfunction occurring in patients exposed to alcohol during gestation. Not all individuals exposed to alcohol during gestation have FAS.

In this patient's case, some or all the characteristic growth and facial features associated with FAS were present and there was evidence of brain dysfunction as you will see noted on the attached pages. There was also a confirmed history of exposure to alcohol during gestation. These outcomes meet the criteria for *Sentinel physical finding(s) / neurodevelopmental disorder / alcohol exposed*. The diagnosis of *Sentinel physical finding(s) / neurodevelopmental disorder* in the presence of alcohol exposure does not mean that alcohol is the only cause of the problem. Other factors could be contributing to the present issues such as the patient's genetic background, other potential exposures or problems during gestation, and various experiences since birth. These kinds

of differences may partly explain why there is so much variability in the kinds of specific challenges that patients with neurodevelopmental disorder and alcohol exposure have.

<Include the following paragraph if the patient is under 8 years of age at the time of diagnosis.>

The patient is still quite young and remains at risk for additional learning and developmental challenges because of prenatal alcohol exposure. It is important to note that the majority of children who have cognitive or other developmental challenges caused by prenatal alcohol exposure do not exhibit these challenges fully until school-age. All those working with and caring for the patient are advised to keep monitoring closely. This team would very much like to see the patient in clinic again to update assessment of brain functioning and overall diagnosis when the patient is old enough to allow for a broader range and depth of assessment. We invite the patient to return to our clinic after their 9th birthday. In the meantime, development should be closely monitored.

Individuals with *Neurodevelopmental Disorder* have brain damage/dysfunction and should be viewed as individuals with disabilities. This diagnosis of *Neurodevelopmental disorder* has implications for educational planning, societal expectations, and health. On the attached sheets you will find a list of specific problems that have been identified that need attention.

E.
Diagnosis: Neurodevelopmental disorder / alcohol exposed

Fetal alcohol syndrome (FAS) is defined by evidence of growth deficiency, a specific set of facial characteristics, and evidence of significant brain damage/dysfunction in individuals exposed to alcohol during gestation. Not all individuals exposed to alcohol during gestation have FAS.

In this patient's case, no growth deficiency or characteristic set of facial features were found, but there was evidence of brain dysfunction as you will see noted on the attached pages. There was also a confirmed history of exposure to alcohol during gestation. These outcomes meet the criteria for *Neurodevelopmental disorder / alcohol exposed*. The diagnosis of *Neurodevelopmental disorder* in the presence of prenatal alcohol exposure does not mean that alcohol is the only cause of the problem. Other factors could be contributing to the present issues such as the patient's genetic background, other potential exposures or problems during gestation, and various experiences since birth. These kinds of differences may partly explain why there is so much variability in the kinds of specific challenges that patients with neurodevelopmental disorder and alcohol exposure have.

<Include the following paragraph if the patient is under 8 years of age at the time of diagnosis.>

The patients is still quite young and remains at risk for additional learning and developmental challenges because of prenatal alcohol exposure. It is important to note that the majority of children who have cognitive or other developmental challenges caused by prenatal alcohol exposure do not exhibit these challenges fully until school-age. All those working with and caring for the patient are advised to keep monitoring closely. This team would very much like to see the patient in clinic again to update assessment of brain functioning and overall diagnosis when the patient is old enough to allow for a broader range and depth of assessment. We invite the patient to return to our clinic after their 9th birthday. In the meantime, development should be closely monitored.

Individuals with *Neurodevelopmental Disorder* have brain damage/dysfunction and should be viewed as individuals with disabilities. This diagnosis of *Neurodevelopmental disorder* has implications for educational planning, societal expectations, and health. On the attached sheet you will find a list of specific problems that have been identified that need attention.

F.
Diagnosis: Sentinel physical finding(s) / alcohol exposed

Fetal Alcohol Syndrome (FAS) is defined by evidence of growth deficiency, a specific set of subtle facial anomalies, and evidence of significant brain damage/dysfunction occurring in patients exposed to alcohol during gestation. Not all individuals exposed to alcohol during gestation have FAS.

Some individuals present with growth deficiency and/or the characteristic facial features, but do not have evidence of brain damage or dysfunction. We refer to this condition as *Sentinel physical finding(s) / Alcohol exposed.* We do not consider this diagnosis under the umbrella of FASD. On the attached sheets are the specific findings in this patient's case.

<Include the following paragraph if the patient is under 8 years of age at the time of diagnosis.>

The patient is still quite young and remains at risk for additional learning and developmental challenges because of prenatal alcohol exposure. It is important to note that the majority of children who have cognitive or other developmental challenges caused by prenatal alcohol exposure do not exhibit these challenges fully until school-age. All those working with and caring for the patient are advised to keep monitoring closely. This team would very much like to see the patient in clinic again to update assessment of brain functioning and overall diagnosis when the patient is old enough to allow for a broader range and depth of assessment. We invite the patient to return to our clinic after their 9th birthday. In the meantime, development should be closely monitored.

G.
Diagnosis No sentinel physical findings or brain abnormalities detected / alcohol exposed

Fetal Alcohol Syndrome (FAS) is defined by evidence of growth deficiency, a specific set of subtle facial anomalies, and evidence of significant brain damage/dysfunction occurring in patients exposed to alcohol during gestation. Not all individuals exposed to alcohol during gestation have FAS.

In this patient's case, we conclude they were exposed to alcohol during gestation, but no physical findings or brain abnormalities were detected at this time, as you will see noted on the attached pages. No alcohol-related diagnoses are offered at this time.

<Include the following paragraph if the patient is under 8 years of age at the time of diagnosis.>

The patient is still quite young and remains at risk for additional learning and developmental challenges because of prenatal alcohol exposure. It is important to note that the majority of children who have cognitive or other developmental challenges caused by prenatal alcohol exposure do not exhibit these challenges fully until school-age. All those working with and caring for the patient are advised to keep

monitoring closely. This team would very much like to see the patient in clinic again to update assessment of brain functioning and overall diagnosis when the patient is old enough to allow for a broader range and depth of assessment. We invite the patient to return to our clinic after their 9th birthday. In the meantime, development should be closely monitored.

H.
Diagnosis Sentinel physical finding(s) / static encephalopathy / alcohol exposure unknown

Fetal alcohol syndrome (FAS) is defined by evidence of growth deficiency, a specific set of facial characteristics, and evidence of significant brain damage/dysfunction in individuals exposed to alcohol during gestation. Not all individuals exposed to alcohol during gestation have FAS.

In this patient's case, some but not all of the characteristic growth and/or facial features associated with FAS were present, and there was evidence of significant brain damage/dysfunction as you will see noted on the attached pages. In this situation, we use the term *Sentinel physical finding(s) /Static encephalopathy/ alcohol exposure unknown* to describe the patient's condition. Although it is unknown whether this patient was exposed to alcohol during gestation, other factors could also be contributing to the patient's current cognitive/behavioral problems such as the patient's genetic background, other potential exposures or problems during pregnancy, and various experiences since birth. These kinds of differences may partly explain why there is so much variability in the kinds of specific difficulties that patients with brain abnormalities have.

The diagnosis made today is based on the information available at the time of this assessment. In the event a confirmed history of alcohol exposure is obtained, then a re-evaluation would be appropriate. Alternately other birth defect syndromes or conditions not related to alcohol exposure may also need reconsideration.

Individuals with *static encephalopathy* have evidence of significant brain damage/dysfunction and should be viewed as a person with a disability. The diagnosis of *static encephalopathy* has implications for educational planning, societal expectations, and health. On the attached sheet you will find a list of specific problems that have been identified that need attention.

I.
Diagnosis: Static encephalopathy / alcohol exposure unknown

Fetal Alcohol Syndrome (FAS) is defined by evidence of growth deficiency, a specific set of subtle facial anomalies, and evidence of significant brain damage/dysfunction occurring in patients exposed to alcohol during gestation. Not all individuals exposed to alcohol during gestation have FAS.

In this patient's case, no growth deficiency or characteristic set of facial features were found, but there was evidence of significant brain damage/dysfunction as you will see noted on the attached pages. In this situation, we use the term *Static encephalopathy / alcohol exposure unknown* to describe the patient's condition. Although it is unknown whether this patient was exposed to alcohol during gestation, other factors could be contributing to the patient's current cognitive/behavioral problems such as the patient's genetic background, other potential exposures or problems during pregnancy, and various experiences since birth.

The diagnosis made today is based on the information available at the time of this assessment. In the event a confirmed history of alcohol exposure is obtained then a re-evaluation would be appropriate. Alternately other birth defect syndromes or conditions not related to alcohol exposure may also need reconsideration.

Individuals with *Static encephalopathy* have evidence of significant brain damage/dysfunction and should be viewed as individuals with disabilities. The diagnosis of *Static encephalopathy* has implications for educational planning, societal expectations, and health. On the attached pages you will find a list of specific problems that have been identified that need attention.

J.
Diagnosis: Sentinel physical finding(s) / neurodevelopmental disorder / alcohol exposure unknown

Fetal Alcohol Syndrome (FAS) is defined by evidence of growth deficiency, a specific set of subtle facial anomalies, and evidence of significant brain damage/dysfunction occurring in patients exposed to alcohol during gestation. Not all individuals exposed to alcohol during gestation have FAS.

In this patient's case, some or all the characteristic growth and facial features associated with FAS were present and there was evidence of brain dysfunction as you will see noted on the attached pages. These outcomes meet the criteria for *Sentinel physical finding(s) / neurodevelopmental disorder / alcohol exposure unknown*. Although it is unknown whether this patient was exposed to alcohol during gestation, other factors could be contributing to the patient's current cognitive/behavioral problems such as the patient's genetic background, other potential exposures or problems during pregnancy, and various experiences since birth.

The diagnosis made today is based on the information available at the time of this assessment. In the event a confirmed history of alcohol exposure is obtained then a re-evaluation would be appropriate. Alternately other birth defect syndromes or conditions not related to alcohol exposure may also need reconsideration.

Individuals with *Neurodevelopmental disorder* have evidence of brain dysfunction and should be viewed as individuals with disabilities. The diagnosis of *Neurodevelopmental disorder* has implications for educational planning, societal expectations, and health. On the attached pages you will find a list of specific problems that have been identified that need attention.

K.
Diagnosis: Neurodevelopmental disorder / alcohol exposure unknown

Fetal alcohol syndrome (FAS) is defined by evidence of growth deficiency, a specific set of facial characteristics, and evidence of significant brain damage/dysfunction in individuals exposed to alcohol during gestation. Not all individuals exposed to alcohol during gestation have FAS.

In this patient's case, none of the characteristic growth and facial features associated with FAS were present and there was evidence of brain dysfunction as you will see noted on the attached pages. These outcomes meet the criteria for Neurodevelopmental *disorder / alcohol exposure*

unknown. Although it is unknown whether this patient was exposed to alcohol during gestation, other factors could be contributing to the patient's current cognitive/behavioral problems such as the patient's genetic background, other potential exposures or problems during pregnancy, and various experiences since birth.

The diagnosis made today is based on the information available at the time of this assessment. In the event a confirmed history of alcohol exposure is obtained a re-evaluation would be appropriate. Alternately other birth defect syndromes or conditions not related to alcohol exposure may also need reconsideration.

Individuals with *neurodevelopmental disorder* have evidence of brain dysfunction and should be viewed as individuals with disabilities. This diagnosis of *neurodevelopmental disorder* has implications for educational planning, societal expectations, and health. On the attached sheets you will find a list of specific problems that have been identified that need attention.

L.
Diagnosis: Sentinel physical finding(s) / alcohol exposure unknown

Fetal Alcohol Syndrome (FAS) is defined by evidence of growth deficiency, a specific set of subtle facial anomalies, and evidence of significant brain damage/dysfunction occurring in patients exposed to alcohol during gestation. Not all individuals exposed to alcohol during gestation have FAS.

In this patient's case, some or all the characteristic growth and facial features associated with FAS were present but there was no evidence of brain abnormalities as noted on the attached pages. These outcomes meet the criteria for *Sentinel physical finding(s) / alcohol exposure unknown*. Although it is unknown whether this patient was exposed to alcohol during gestation, other factors could be contributing to the patient's current cognitive/behavioral problems such as the patient's genetic background, other potential exposures or problems during pregnancy, and various experiences since birth.

The diagnosis made today is based on the information available at the time of this assessment. In the event a confirmed history of alcohol exposure is obtained, a re-evaluation would be appropriate. Alternately other birth defect syndromes or conditions not related to alcohol exposure may need consideration.

M.
Diagnosis: No sentinel physical finding(s) or brain abnormalities detected / alcohol exposure unknown

In this current assessment, it is unknown whether or not this patient was exposed to alcohol during gestation. Furthermore, no characteristic physical findings or brain abnormalities were detected in our examination.

No alcohol-related diagnoses are offered at this time. In the event a confirmed history of alcohol exposure is obtained, a re-evaluation would be appropriate.

N.
Diagnosis Sentinel physical finding(s) / static encephalopathy / no alcohol exposure

Fetal alcohol syndrome (FAS) is defined by evidence of growth deficiency, a specific set of facial characteristics, and evidence of brain damage/dysfunction in individuals exposed to alcohol during gestation. Not all individuals exposed to alcohol during gestation have FAS.

In this patient's case, some but not all the characteristic growth and facial features associated with FAS were present and there was evidence of significant brain damage and/or dysfunction as you will see noted on the attached pages. Since prenatal alcohol exposure was confirmed absent, the full spectrum of FASD is ruled out. These outcomes meet the criteria for *Sentinel physical finding(s) / static encephalopathy / no alcohol exposure*. The diagnosis of *Sentinel physical finding(s) / static encephalopathy* in the confirmed absence of prenatal alcohol exposure suggests other factors could be contributing to the present issues such as the patient's genetic background, other potential exposures or problems during gestation, and various experiences since birth. The physical findings may suggest that other syndrome diagnoses be considered.

Individuals with *static encephalopathy* have significant brain damage/dysfunction and should be viewed as individuals with disabilities. The diagnosis of *static encephalopathy* has implications for educational planning, societal expectations, and health. On the attached sheets you will find a list of specific problems that have been identified that need attention.

O.
Diagnosis: Static encephalopathy / no alcohol exposure

Fetal Alcohol Syndrome (FAS) is defined by evidence of growth deficiency, a specific set of subtle facial anomalies, and evidence of significant brain damage/dysfunction occurring in patients exposed to alcohol during gestation.

In this patient's case, some but not all the characteristic growth and facial features associated with FAS were present and there was evidence of significant brain damage and/or dysfunction as noted on the attached pages. Since prenatal alcohol exposure was confirmed absent, the full spectrum of FASD is ruled out. The outcomes observed in this patient meet the criteria for *Static encephalopathy / no alcohol exposure*. The diagnosis of *Static encephalopathy* in the confirmed absence of prenatal alcohol exposure suggests other factors could be contributing to the present issues such as the patient's genetic background, other potential exposures or problems during gestation, and various experiences since birth.

Individuals with *Static encephalopathy* have significant brain damage/dysfunction and should be viewed as individuals with disabilities. The diagnosis of *Static encephalopathy* has implications for educational planning, societal expectations, and health. On the attached sheets you will find a list of specific problems that have been identified that need attention.

P.
Diagnosis Sentinel physical finding(s) / neurodevelopmental disorder / no alcohol exposure

Fetal alcohol syndrome (FAS) is defined by evidence of growth deficiency, a specific set of facial characteristics, and evidence of brain damage/dysfunction in individuals exposed to alcohol during gestation.

As noted on the attached pages, some but not all the characteristic growth and facial features associated with FAS were present and there was evidence of brain damage/dysfunction. A confirmed absence of prenatal alcohol exposure, however, rules out FASD. These outcomes meet the criteria for *Sentinel physical finding(s) / neurodevelopmental disorder / no alcohol exposure*. A confirmed absence of prenatal alcohol exposure suggests other factors could be contributing to the patient's current cognitive/behavioral problems such as the patient's genetic background, other potential exposures or problems during pregnancy, and various experiences since birth. The observed physical findings may suggest that other syndrome diagnoses be considered.

Individuals with *Neurodevelopmental disorder* have evidence of brain dysfunction and should be viewed as a person with a disability. The diagnosis of *Neurodevelopmental disorder* has implications for educational planning, societal expectations, and health. On the attached sheet you will find a list of specific problems that have been identified that need attention.

Q.
Diagnosis: Neurodevelopmental disorder / no alcohol exposure

Fetal alcohol syndrome (FAS) is defined by evidence of growth deficiency, a specific set of facial characteristics, and evidence of significant brain damage/dysfunction in individuals exposed to alcohol during gestation.

As noted on the attached pages, some but not all of the characteristic growth and facial features associated with FAS were present and there was evidence of brain damage/dysfunction. A confirmed absence of prenatal alcohol exposure, however, rules out FASD. These outcomes meet the criteria for *Neurodevelopmental disorder / no alcohol exposure*. A confirmed absence of prenatal alcohol exposure suggests other factors could be contributing to the patient's current cognitive/behavioral problems such as the patient's genetic background, other potential exposures or problems during pregnancy, and various experiences since birth.

Individuals with *Neurodevelopmental disorder* have evidence of brain dysfunction and should be viewed as a person with a disability. The diagnosis of *Neurodevelopmental disorder* has implications for educational planning, societal expectations, and health. On the attached sheet you will find a list of specific problems that have been identified that need attention.

R.
Diagnosis: Sentinel physical finding(s) / no alcohol exposure

Fetal Alcohol Syndrome (FAS) is defined by evidence of growth deficiency, a specific set of minor facial anomalies, and evidence of significant brain damage/dysfunction occurring in patients exposed to alcohol during gestation.

In this patient's case, some or all the characteristic growth and facial features associated with FAS were present but there was no evidence of brain abnormalities as noted on the attached pages. A confirmed absence of prenatal alcohol exposure rules out FASD. The outcomes observed in this patient meet the criteria for *Sentinel physical finding(s) / no alcohol exposure*. The physical findings might suggest that other syndrome diagnoses be considered.

S.
Diagnosis No physical findings or brain abnormalities detected / no alcohol exposure

In this current assessment, we conclude that this patient was not exposed to alcohol during gestation. Furthermore, no specific cognitive, behavioral, or characteristic physical findings were detected in our examination. The full spectrum of FASD is ruled-out. No diagnoses are offered at this time.

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IX. Appendices

1. FASDPN WEBSITE https://depts.washington.edu/fasdpn/index.htm

The University of Washington FASDPN website provides a comprehensive overview of all clinical, research, and training activities conducted by the FASDPN. Below are links to FASDPN publications, and 4-Digit Code training opportunities, diagnostic forms, Lip-Philtrum Guides and the FAS Facial Photographic Analysis Software. All resources listed below are available free of charge.

A. Publications

Literature published by the FASDPN since 1993.

B. 4-Digit Code TRAINING PROGRAMS AND ONLINE COURSE

i. One-Day Clinical Observational Training Program. This training provides healthcare, social service, and educational professionals with insight into their role in the community for screening, referral, diagnosis, prevention, and intervention of FASD.

ii. Two-Day Interdisciplinary Clinical Training Program. This training program is offered twice a year at the University of Washington. Interdisciplinary clinical teams are taught how to use the 4-Digit Diagnostic Code in an interdisciplinary clinical setting.

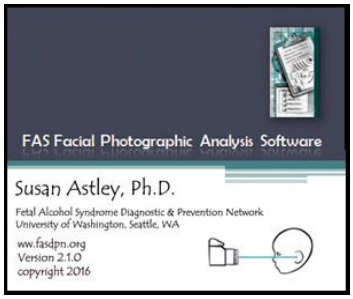
iii. FASD 4-Digit Code Online Course. This accredited course will provide healthcare, educational, and social service professionals with detailed instruction on the use of the 4-Digit Diagnostic Code in an interdisciplinary clinical setting.

A. Diagnostic Forms and Medical Summary Templates.

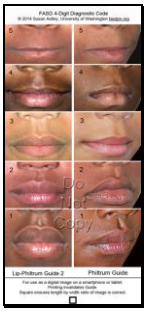
Electronic versions of the 4-Digit Code Diagnostic Forms are available free on the FASDPN website. An electronic template of our Medical Summary Report (see section VII) is available free (contact Susan Astley Hemingway Ph.D (astley@uw.edu)).

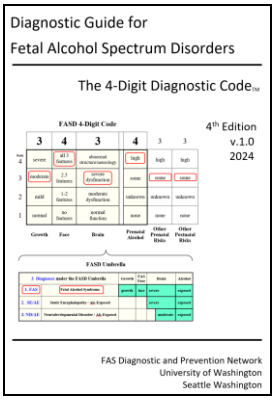
C. DIAGNOSTIC TOOLS AND SOFTWARE

i. FAS Facial Photographic Analysis Software (2016). This software is intended for use by healthcare and research professionals. The software allows one to measure the magnitude of expression of the key facial features of FAS from a 2D digital facial photograph. Video demonstration of the software. A free copy of the software can be obtained by submitting the FASDPN order form.



iii. FASD 4-Digit Diagnostic Guide (2024) and Lip-Philtrum Guides. Free electronic copies of the "*Diagnostic Guide for Fetal Alcohol Spectrum Disorders: The 4-Digit Diagnostic Code, 2024*" and the *Lip-Philtrum Guides* can be ordered from the FASDPN.



2. NEW PATIENT INFORMATION FORM (NPIF) (See form below).

This form is sent to families requesting a diagnostic evaluation at the University of Washington FASDPN clinic. The form allows the family to share with the clinic why they are seeking a diagnostic evaluation, what they hope to gain from the evaluation and what they currently know about the patient's exposure(s) and outcomes. We do not expect the family to be able to respond to all requests for information on the Form. During the intake, the clinical team will also obtain and review (with caregiver consent) all medical, school, and social service records on the patient, in preparation for the evaluation. This New Patient Information form serves as a clinical intake form. Families can download the NPIF from the FASDPN website along with instructions for how to request a FASD diagnostic evaluation. At the Seattle FASDPN clinic, a confirmed prenatal alcohol exposure is the only information required to be evaluated in the clinic. The NPIF is available in electronic fillable form on our website.

New Patient Information Form FASD Clinic

Office Use: Date received ___/___/___ Deadline ___/___/___ ASAP ____ Response Let. ___/___/___ Photo ___ Screen Code _____
G _____ F _____ B _____ A _____ M _____: 1 2 3 4

Patient Identification

Patient's sex at birth _____ Gender identity _____ Race(s) _____

Patient's Name _____ Birth date _____ Age _____
First Middle Last

Patient's Address _____

City _____ County _____ State _____ zip code _____

Patient's Telephone Home ( ) _____ Work ( ) _____

Caretaker Identification

Name of patient's primary caretaker(s)_____

Relationship to patient: ❑ birth, ❑ adoptive, or ❑ foster parent ❑ other (specify _____)

Caretaker's Address

City _____ County _____ State _____ zip code _____

Telephone Home ( ) _____ Work ( ) _____

Name of patient's legal guardian(s) _____

Person Completing the Form

Name of person completing this form _____ Date _____

Relationship to patient: ❑ birth, ❑ adoptive, or ❑ foster parent, ❑ caseworker, ❑ medical care provider

❑ other relationship (specify _____)

Referred by (e.g., who or what organization told you about the clinic?) _____

Who Should Correspondence be Sent To?

Name _____

Relationship to patient: ❑ birth, ❑ adoptive, or ❑ foster parent ❑ other (specify _____)

Address _____

City _____ County _____ State _____ zip code _____

Telephone Home ( ) _____ Work ( ) _____

Please complete this form to the best of your ability. We realize you will not have the answers to all questions. All information requested in this form is important in allowing us to provide you with the most accurate diagnosis and most appropriate referrals for care. Thank you for taking the time to complete it.

Reasons for Evaluation What are the patient's primary problems? Please be specific.

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

What do you hope to gain from the evaluation?

_____

_____

_____

_____

_____

_____

_____

Growth

Birth Measures

1. Birth weight: lbs / oz _____ or gms _____

   Birth length: inches _____ or cm _____

   Birth head circumference: inches _____ or cm _____

   Gestational age *(length of pregnancy)*: weeks _____ or months _____

Please provide additional height, weight and head measures if available*

2. Date _____ Weight: lbs _____ or kg _____

   Age _____ Height: inches _____ or cm _____

   Head Circumference: inches _____ or cm _____

3. Date _____ Weight: lbs _____ or kg _____

   Age _____ Height: inches _____ or cm _____

   Head Circumference: inches _____ or cm _____

4. Date _____ Weight: lbs _____ or kg _____

   Age _____ Height: inches _____ or cm _____

   Head Circumference: inches _____ or cm _____

5. Date _____ Weight: lbs _____ or kg _____

   Age _____ Height: inches _____ or cm _____

   Head Circumference: inches _____ or cm _____

Birth Parents' Heights: Birth Mother: inches _____ or cm _____

Birth Father: inches _____ or cm _____

* This information may be available from the patient's physician or school nurse. If growth charts are available and can be photocopied and attached to this form, you need not fill out this section.

Physical Appearance and Health

1. Photographs of the patient's face are very helpful to us. The best photos are ones where the face fills the photo and the patient is not smiling.

- Are such photographs available? ____ yes ____ no
- Are one or two included with this form? ____ yes ____ no
- Can others be brought to the clinic? ____ yes ____ no

2. Was the patient born with (or later discovered to have) any birth defects (things like cleft lip, congenital heart defects, club foot, etc.)? ____ yes ____ no _____ unknown

If yes, please describe: _____

_____

3. Has this patient ever had:

	yes	no	unknown		yes	no	unknown
Allergies	_____	_____	_____	Chronic illness of the heart	_____	_____	_____
Multiple ear infections	_____	_____	_____	Chronic illness of the kidneys	_____	_____	_____
Chronic sinusitis	_____	_____	_____	Chronic illness of the joints/limbs	_____	_____	_____
Chronic hearing loss	_____	_____	_____	Chronic illness of stomach/bowels	_____	_____	_____
Visual problems	_____	_____	_____				

4. Has this patient ever had:

A. Operations (since birth) ____ yes ____ no ____ unknown

Describe Operation	Surgeon's Name	Patient's Age

B. Any other hospitalizations ____ yes ____ no ____ unknown

Reason for Hospitalization	Hospital/Doctor	Patient's Age

Neurological Issues

1. **Has this patient ever had:**
   Seizures

   ____ yes ____ no ____ suspected ____ unknown

   Type: _____

   Age when seizure(s) started: _____

   Name(s) of medication(s) given? _____

2. **Has this patient ever had a head injury leading to unconsciousness or evaluation by a doctor?**

   ____ yes ____ no ____ unknown

   If yes, please describe _____

3. **Has the patient ever had a CT scan or MRI scan of the brain**

   ____ yes ____ no ____ unknown

   If yes, was it described to be abnormal? ____ yes ____ no ____ unknown

Attention Deficit and Hyperactivity

1. **Has the patient ever been evaluated for attention deficit/hyperactivity disorder (ADD / ADHD)**

   ____ yes ____ no ____ unknown

   If yes:

   When was the evaluation done? Age: _____ Date: _____

   Was the patient diagnosed with ADD or ADHD? ____ yes ____ no ____ unknown

   Was the patient ever treated for ADD or ADHD? ____ yes ____ no ____ unknown

   What medications have been tried?

Drug	**Dose**	**Ages**	**Response**

Mental Health Issues

1. Has the patient ever been evaluated by a psychiatrist, psychologist, or MH counselor?

____ yes ____ no ____ unknown

If yes, please list each psychiatrist, psychologist and/or counselor.

A. Type of professional: _____

Reason for assessment: _____

Type of therapy (i.e., behavioral, individual counseling, group counseling, family counseling, medicine): _____

_____

Age at the time of therapy: _____ Did the therapy help? ____ yes ____ no ____ unknown

If yes, how did it help? _____

_____

_____

B. Type of professional: _____

Reason for assessment: _____

Type of therapy (i.e., behavioral, individual counseling, group counseling, family counseling, medicine): _____

_____

Age at the time of therapy: _____ Did the therapy help? ____ yes ____ no ____ unknown

If yes, how did it help?_____

_____

_____

2. Has the patient ever been evaluated for mood problems (depression, anxiety, etc.) or phobia?

____ yes ____ no ____ unknown

If yes:

When was the evaluation(s) done? Age(s): _____ Date(s): _____

3. What medications have ever been tried and how well did they work?

Drug	Dose	Response	Currently Using?

School Issues

1. List <u>ALL</u> schools the patient has attended and the grades of attendance:

School	**City**	**Grades Attended**	**Received Special Education, Resource Room, Tutoring, etc.** yes	no	unknown
_____	_____	_____	____	_____	_____
_____	_____	_____	____	_____	_____
_____	_____	_____	____	_____	_____
_____	_____	_____	____	_____	_____
_____	_____	_____	____	_____	_____
_____	_____	_____	____	_____	_____
_____	_____	_____	____	_____	_____
_____	_____	_____	____	_____	_____
_____	_____	_____	____	_____	_____
_____	_____	_____	____	_____	_____

2. What <u>learning</u> problems does the patient have?

_____
_____
_____
_____
_____
_____
_____

3. What <u>behavioral</u> problems does the patient have?

_____
_____
_____
_____
_____
_____
_____

Alcohol Exposure

Please fill in this information as completely as possible.
This information is critical to the evaluation of the patient.

Alcohol use by the birth mother

- **Before pregnancy**: Average number of drinks consumed at one time: _____
  Maximum number of drinks consumed at one time: _____
  Average number of days per week (1 to 7) that alcohol was consumed: _____
  Type(s) of alcohol: __wine __beer __liquor __unknown ___other (specify) _____

- **During pregnancy:** Average number of drinks consumed at one time: _____
  Maximum number of drinks consumed at one time: _____
  Average number of days per week (1 to 7) that alcohol was consumed: _____
  Type(s) of alcohol: __wine __beer __liquor __unknown ___other (specify) _____

Which trimester(s) did the mother drink alcohol? ___ 1st ___2nd ___3rd ___unknown

	No	Yes	Unknown
Was the birth mother ever reported to have a problem with alcohol?	____	____	_____
Was the birth mother ever diagnosed with alcoholism?	____	____	_____
Did the birth mother ever receive treatment for alcohol addiction?	____	____	_____

If the above information is unknown, please provide any information that might help describe the mother's level of ALCOHOL USE DURING THIS PREGNANCY _____

_____

_____

What is the source(s) of this information on alcohol use? _____

_____

Did the birth mother use any of the following substances during pregnancy?

Yes	No	Unknown	Type	Please List Specific Substance(s)	Month(s) of Pregnancy
___	___	___	Drugs	_____	_____
___	___	___	Tobacco	_____	_____
___	___	___	Medications	_____	_____
___	___	___	X-rays	_____	_____

Information about the Patient's Biological Parents

Birth mother's name_____ Birth date _____
First *Middle* *Last*

Mother's Race ❑ White ❑ Black ❑ American Indian ❑ Alaskan Native ❑ Hispanic
❑ Asian ❑ unknown ❑ other (specify) _____

Education level attained (last year of school completed) _____ Age at birth of patient ____

Does she have a history of learning problems? _____

When was the last contact with the birth mother? _____

Birth father's name_____ Birth date _____
First *Middle* *Last*

Father's Race ❑ White ❑ Black ❑ American Indian ❑ Alaskan Native ❑ Hispanic
❑ Asian ❑ unknown ❑ other (specify) _____

Education level attained (last year of school completed) _____ Age at birth of patient _____

Does he have a history of learning problems? _____

When was the last contact with the birth father? _____

Medical History of the Biological Family

Has anyone in this patient's biological family ever had any of these conditions? *Check all that apply*.

	Birth Mother	Birth Father
Alcoholism	_____	_____
Birth Defects	_____	_____
Stillbirths	_____	_____
Miscarriages	_____	_____
Intellectual disability	_____	_____
Other developmental disabilities	_____	_____
Learning disorder	_____	_____
Attention deficit	_____	_____
Hyperactivity	_____	_____
Epilepsy	_____	_____
Neurological disease	_____	_____
Tourette syndrome	_____	_____
Depression	_____	_____
Delinquency	_____	_____
Suicide	_____	_____
Mental health issues	_____	_____
Vision problems	_____	_____
Hearing problems	_____	_____
Chronic illnesses	_____	_____
Any specific genetic condition	_____	_____
Other (specify)	_____	_____
Other (specify)	_____	_____
Other (specify)	_____	_____
Other (specify)	_____	_____

Pregnancies of Birth Mother

1. Please list **all** the birth mother's pregnancies including miscarriages, abortions, in the order of their occurrence:

Year	Length of Pregnancy	First name of child if applicable	Live born Child yes	Live born Child no	Normally Developed yes	Normally Developed no	If not normal, please explain *Include FASD diagnosis, if known*
_____	_________	___________________	___	___	___	___	______________________________
_____	_________	___________________	___	___	___	___	______________________________
_____	_________	___________________	___	___	___	___	______________________________
_____	_________	___________________	___	___	___	___	______________________________
_____	_________	___________________	___	___	___	___	______________________________
_____	_________	___________________	___	___	___	___	______________________________
_____	_________	___________________	___	___	___	___	______________________________
_____	_________	___________________	___	___	___	___	______________________________
_____	_________	___________________	___	___	___	___	______________________________
_____	_________	___________________	___	___	___	___	______________________________

Pregnancy, Labor, and Delivery of this Patient

1. **Did the birth mother experience any difficulties during pregnancy?** __ Yes ___ No ___ Unk.
   If yes, please describe: ____
2. **Did the birth mother receive prenatal care?** ___ Yes ___ No ___ Unknown
3. **Were there complications during the labor or delivery?** ___ Yes ___ No ___ Unknown
   If yes, please explain:____
4. **Was the delivery:**_______ Natural ________ By C-section _______ Unknown
   Reason for C-Section, if performed ______________________________________
5. **What was the gravity _____ and parity _____of the birth mother**?
6. **Where was the patient born?** Hospital _____ City, State
7. **How many days did the infant stay in the birth hospital?** ________________________
8. **Did the patient have any of the following problems while still in the birth hospital?**

	Yes	No	Unknown		Yes	No	Unknown
Feeding problems	_____	_____	_____	Infections	______	______	______
Apnea / breathing difficulties	_____	_____	_____	Jaundice	______	______	______
Supplemental oxygen required	_____	_____	_____	Convulsions	______	______	______

List of Professionals Currently Involved in Patient's Care

Primary Physician Name: _____ Phone: _____

Address: _____

Other Physicians Name: _____ Phone: _____

Specialty: _____

Address: _____

Name: _____ Phone: _____

Specialty: _____

Address: _____

Name: _____ Phone: _____

Specialty: _____

Address: _____

Mental Health Consultants *(includes Psychiatrists Psychologists, and Counselors)* Name: _____ Phone: _____

Specialty: _____

Address: _____

Name: _____ Phone: _____

Specialty: _____

Address: _____

School Name: _____ Phone: _____

Address: _____

Contact Person *(teacher, nurse, counselor, etc.)*:

_____

Other Name: _____ Phone: _____

Profession: _____

Address: _____

Home Placements

1. List all home placements the patient has had from birth through today.

Type of placement (i.e., foster, adoptive, etc.)	Duration of placement	Age of patient when placement started

How many years has the patient been in your care? _____

Patient Trauma

Please report the age range for all traumatic events experienced by the patient. If age is unknown, place a check mark in the box if the trauma occurred.

Trauma	age range	Trauma	age range	Trauma	age range
placed out of home		sexual abuse		natural disaster	
abandonment		physical abuse		war, terrorism	
homelessness		emotional abuse		*Other (specify below)*	
food insecurity		physical neglect			
suicide attempt		emotional neglect			
serious medical issue		family death			
school violence		family incarceration			
bullying		family mental health			
serious accident		parental drug abuse			
home fire		parental divorce			
animal attack		domestic violence			

Other Details: _____

_____

What to bring to Clinic

If the patient has had any of the following assessments, please bring them to Clinic on the day of your appointment if you have copies of the results. The Clinic will also make every effort to collect this information with your consent. This information is very important to the patient's diagnostic evaluation.

_____ Facial photographs of the patient from birth to 18 years of age, without a smile.

_____ Medical records which document the problems you have reported above.

_____ School Assessments including:
- Achievement tests
- IQ tests
- Language assessments
- Social Skills assessments
- Behavior assessments

_____ Neuropsychological Assessments

_____ Developmental Assessments (birth to 3 years of age) including:
- Motor Development (fine and gross motor)
- Cognitive Development