TWENTY YEARS OF PATIENT SURVEYS CONFIRM A FASD 4-DIGIT-CODE INTERDISCIPLINARY DIAGNOSIS AFFORDED SUBSTANTIAL ACCESS TO INTERVENTIONS THAT MET PATIENTS' NEEDS

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ABSTRACT

Background

2013 marks the 40th year since the term fetal alcohol syndrome (FAS) was coined at the University of Washington. In 1993, the University of Washington opened the first interdisciplinary FASD diagnostic clinic; expanded to a statewide network of clinics in 1995 (Washington State FAS Diagnostic & Prevention Network (WA FASDPN)), and introduced a new, rigorous diagnostic system, the fetal alcohol spectrum disorder (FASD) 4-Digit Diagnostic Code in 1997. The WA FASDPN mission is FASD primary and secondary prevention. Evidence of successful primary prevention (fewer alcohol-exposed pregnancies and FAS births) was documented in WA in the 1990s. Secondary prevention (reduction of disability among individuals with prenatal alcohol exposure) starts with accurate diagnoses and access to interventions that meet patients' needs.

Objective

Do patients report an FASD diagnostic evaluation affords them access to interventions that meet their needs?

Methods

Twenty years of follow-up surveys from 622 patients (birth through adult) who received an interdisciplinary FASD diagnostic evaluation at the University of Washington FASDPN using the 4-Digit Code were reviewed.

Results

Patients (99%) expressed high satisfaction in the FASD diagnostic process and outcome. Patients reported success accessing (89%) recommended interventions that met their needs (>96%). Patients with Neurobehavioral-Disorder/Alcohol-Exposed and Static-Encephalopathy/Alcohol-Exposed were as successful accessing interventions that met their needs as patients with FAS/Partial-FAS. Families of patients 0-5 years old reported the greatest access and needs met.

Conclusions

Patient surveys confirm an interdisciplinary diagnosis using the 4-Digit Code affords them substantial access to interventions that meet their needs across the spectrum of FASD diagnoses.

Key Words: *Fetal alcohol spectrum disorder (FASD)***,** *Fetal alcohol syndrome (FAS)***,** *FASD 4-Digit Diagnostic Code***,** *Washington State Fetal Alcohol Syndrome Diagnostic & Prevention Network (WA FASDPN) Intervention*

What is FASD?

Fetal Alcohol Syndrome (FAS) is a permanent birth defect syndrome caused by maternal consumption of alcohol during pregnancy. The condition is characterized by prenatal and/or postnatal growth deficiency, a unique cluster of minor facial anomalies, and central nervous system (CNS) abnormalities.[1-3] FAS is the leading known preventable cause of intellectual disabilities in the

Western World.[4] The prevalence of FAS is estimated to be 1 to 3 per 1,000 live births[5] in the general population, 10 to 15 per 1,000 in some higher-risk populations such as children residing in foster care[6,7], and 100 per 1,000 in our statewide fetal alcohol spectrum disorder (FASD) diagnostic clinics (the WA FAS Diagnostic & Prevention Network (WA FASDPN)).[8] Not all individuals damaged by prenatal alcohol exposure have FAS; the majority present with moderate to severe CNS abnormalities without the physical features. This full spectrum of adverse outcomes caused by prenatal alcohol exposure is referred to as Fetal Alcohol Spectrum Disorders (FASD). Diagnoses like FAS, Partial FAS (PFAS), Static Encephalopathy/Alcohol Exposed (SE/AE), and Neurobehavioral Disorder/Alcohol Exposed (ND/AE) fall under the umbrella of FASD.[3] The prevalence of SE/AE and ND/AE is 6-fold greater than the prevalence of FAS/PFAS in the population of individuals receiving FASD diagnostic evaluations at our statewide FASD diagnostic clinics (WA FASDPN) over the past 20 years.

The Role of an FASD Diagnostic Clinic in Primary and Secondary FASD Prevention

The year 2013 marks the 40th year since the term FAS was first coined at the University of Washington.[9] The year 2013 also marks the 20th year of the WA FASDPN diagnostic clinics.[8,10] The mission of the WA FASDPN is primary and secondary prevention of FASD through screening, diagnosis, surveillance, intervention, research, and education. In 1992, we postulated that an FASD diagnostic clinic could and should play a central role in FASD prevention; both primary prevention (reduction in prevalence of alcohol consumption during pregnancy and FASD) and secondary prevention (mitigation of disabilities among individuals with FASD). Empirical evidence now exists confirming and illustrating the central role of an FASD clinic in primary prevention of FASD.[6,11,12,7,13] The focus of the current study is the role of a FASD diagnostic clinic in secondary prevention of FASD. Secondary prevention is a level of health care that focuses on early diagnosis, use of referral services, and rapid initiation of treatment to stop the progress of disease processes or a handicapping disability.[14] In this report, the disease process or handicapping disability is FASD. As stated in the 1996 Institute of Medicine Report[5] on FASD "Children with FAS or ARND have impairments that cannot be normalized, but possibly can be improved with appropriate interventions, and they can possibly be made worse when ignored or misunderstood."

Over the past 20 years interdisciplinary FASD diagnostic clinics have opened worldwide.[2] The FASDPN has trained over 100 interdisciplinary teams in over 16 countries.[15,16] An important public health question that remains largely unanswered is "What is the direct benefit of a FASD diagnostic evaluation?" Does an FASD diagnostic evaluation lead to improved patient outcome? An important component of the FASD diagnostic process is to provide patients with a comprehensive set of intervention recommendations specific to their needs.[17-20] These recommendations are collectively generated by the interdisciplinary diagnostic team at the UW FAS DPN.[17] These recommendations include resources, referrals, and strategies that address presenting clinical concerns in areas such as health, behavior, social welfare, and education. The WA FAS DPN diagnostic teams share these intervention recommendations with caregivers at the end of the 4-hour FASD diagnostic evaluation. These recommendations are included in the patient's FASD Medical Summary Report which is submitted to their medical record. A comprehensive summary of the types and frequencies of recommendations provided to patients across all ages and FASD diagnostic classifications is presented by Jirikowic et al.[17]

Study Objectives

Over the past 20 years 2,550 patients have received an FASD diagnostic evaluation at the WA FASDPN by an interdisciplinary team using the FASD 4-Digit Diagnostic Code.[2,8] At the conclusion of their 4-hour evaluation, 78% received a diagnosis broadly under the umbrella of FASD (FAS (4%), PFAS (6%), SE/AE (24%) or ND/AE (44%)) and all received a comprehensive set of intervention recommendations. All families who attend the University of Washington FASDPN clinic receive a Patient Follow-Up Survey (Figure 1) several months after their diagnostic evaluation.

The objective of this study was to evaluate these patient surveys to answer the following questions:

1. Do families report a high level of satisfaction and confidence in the interdisciplinary FASD diagnostic process and outcome?
2. Do families report obtaining information from the FASDPN clinic they were unable to obtain elsewhere?
3. Did they find the 4-Digit Code method of diagnosis easy to understand?
4. Were families able to find/access the intervention services recommended by the clinic?
5. If they were able to access the interventions, did the interventions meet their needs?
6. Were the responses to the above questions influenced by the patient's age, diagnostic classification, or method of diagnosis (gestalt versus 4-Digit Code)?

METHODS

Interdisciplinary FASD Diagnostic Model

When the University of Washington FASD diagnostic clinic first opened in January 1993, it was the first to propose/implement an interdisciplinary approach to diagnosis[21,22] through a CDC-sponsored FAS prevention project conducted in 1992- 97.[11,12] In 1995, State legislative action (Senate Bill 5688) expanded the single clinic to a statewide network of FASD diagnostic clinics; the WA FASDPN, led by the core clinic at the University of Washington (UW). Because of the complexity and broad array of outcomes observed in individuals with prenatal alcohol exposure, an interdisciplinary team was deemed essential for an accurate and comprehensive diagnosis and intervention plan. Our interdisciplinary FASD diagnostic teams include a medical doctor, psychologist, speech language pathologist, occupational therapist, social worker, and family advocate.[2]

The patient population served by the WA FASDPN has always expressed strong preference for an evaluation that can be completed in one visit. Thus, our FASD diagnostic evaluation is conducted in one 4-hour session. In preparation for the evaluation, the patient's birth, medical, school, psychological, and social service records are collected by the clinic coordinator and pre-reviewed by the lead psychologist or social worker. On the day of the evaluation, the lead psychologist or social worker presents the patient's case history, including the outcomes of any prior medical/psychological assessments, to the team in a 30-minute case conference. While the case-conference is being conducted, the patient's growth is measured and facial photograph is taken for computerized analysis.[23] After the case-conference, the pediatrician and lead psychologist or social worker conduct an interview with the caregiver(s) while the child is assessed over a 2-hour period by the second psychologist, speech-language pathologist, and occupational therapist. The child receives a brief physical examination by the pediatrician at the end of their 2-hour assessment. The caregiver interview and child assessment sessions focus on gathering information that is needed to render an accurate diagnosis and are not already present in the child's records. The battery of assessments administered to each patient (both historically and on the day of the diagnostic evaluation) vary by patient age and area(s) of developmental concern. The team reconvenes for 1 hour to derive the FASD 4-Digit Code and generate an intervention plan. The diagnosis and intervention plan are shared with the family in the final 30 minutes of the evaluation. A single, comprehensive FASD Medical Summary Report documenting the diagnostic outcome, all data used to derive the diagnostic outcome, and intervention recommendations are submitted to the patient's medical record.

Intervention Recommendations

An important component of our FASD diagnostic process is to provide patients with a comprehensive set of intervention recommendations specific to their needs.[17,18,20] These intervention recommendations are collectively generated by the interdisciplinary diagnostic team at the completion of the 4-hour FASD diagnostic evaluation. These recommendations include resources, referrals, and strategies that address presenting clinical concerns in areas such as health, behavior, social welfare, and education. The UW FASDPN has compiled over 200 intervention recommendations in a Microsoft Word template (each assigned a unique key code) that allows for rapid construction of individualized intervention plans by the interdisciplinary team during the course of the 4-hour diagnostic evaluation. These intervention recommendations are shared with caregivers at the end of the 4-hour diagnostic evaluation and are included in the patient's FASD Medical Summary Report that is submitted to their medical record.

A recent study published by members of the UW FASDPN diagnostic team[17] summarized the type and frequency of intervention recommendations provided to patients receiving diagnoses under the spectrum of FASD at the UW FASDPN diagnostic clinic. The focus of the study was to assess how recommendations varied by FASD diagnostic groups and selected sociodemographic characteristics (e.g., age, gender, and caregiver status). In preparation for the study, a coding system was developed to categorize the 200+ intervention recommendations into 12 sub-categories as presented in Table 1 and described more fully by Jirkowic et al.[17] Findings reported by Jirikowic et al[17] indicated that children with FASD, like children with other neurodevelopmental disabilities, have a wide range of complex and specialized needs that span across systems of care. Although FAS has historically been considered among the most severe outcomes of prenatal alcohol exposure, these data show that similar intervention recommendations and needs were seen for children across the full spectrum of diagnoses under the umbrella of FASD.

Starting in 2007, all patients evaluated in the UW FASDPN clinic have had their intervention recommendations coded in accordance with the system described above and entered into the FASDPN clinical/research database described below.

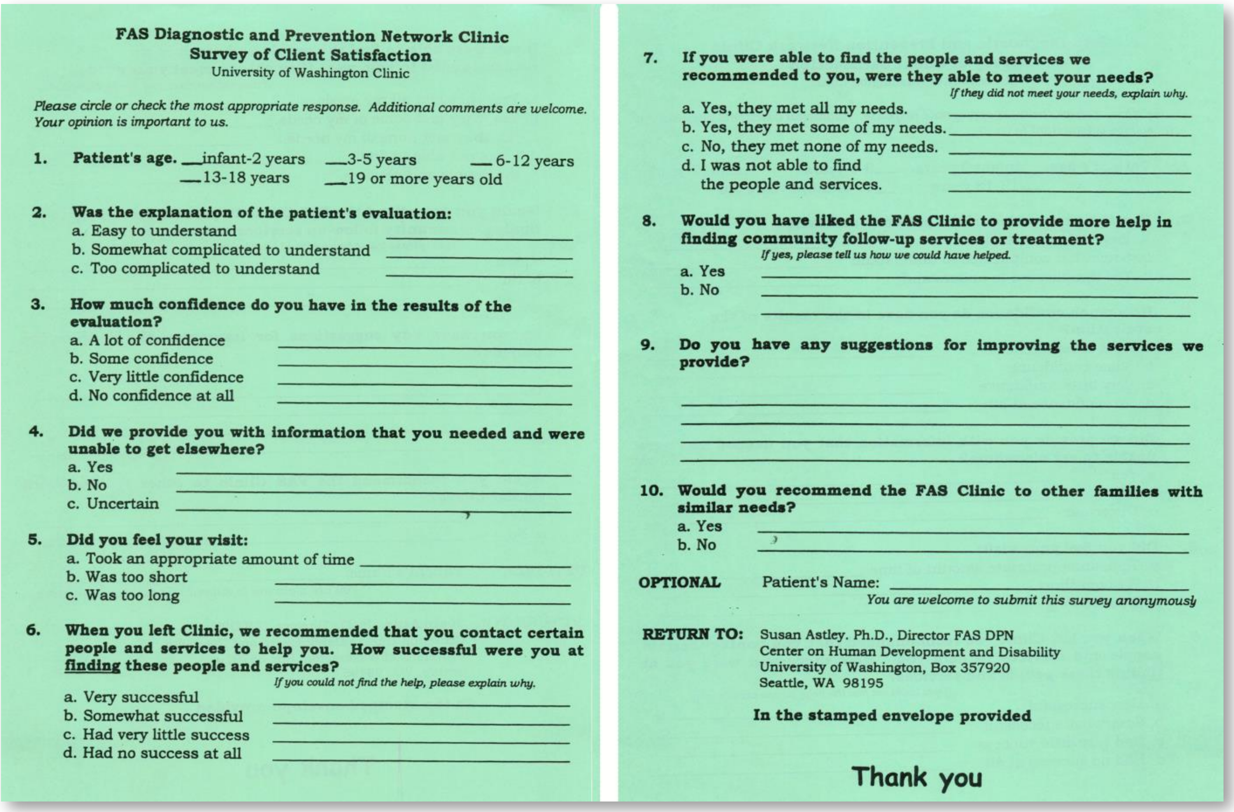
TABLE 1 Intervention recommendation categories and examples[17] (Figure 4)

Category	Examples
Family Support–Resources: Referral/ recommendations for educational materials (e.g., books, Web sites) community support groups, advocacy training, or caregiver education or support.	1. Books, Web-based resources (e.g., attachment, sleep, FASD). 2. Personal/peer support (e.g., National Organization or Fetal Alcohol Syndrome [NOFAS], grandparent support group). 3. Advocacy/education (e.g., parent advocacy group, parent education, community training). 4. Respite/self-care for caregiver.
Medical: Recommendation/referral to medical specialist or current provider for evaluation or follow-up care regarding a specific medical problem or issue.	1. Psychiatric services and/or medication management/consultation. 2. ADHD evaluation 3. Sleep evaluation 4. Vision/hearing evaluation 5. Growth 6. Neurological evaluation/consultation 7. Genetic work up or consultation
Anticipatory Guidance / Prevention: Prevention oriented recommendations based on developmental risk factors for future problems.	1. Substance abuse prevention 2. Learning problems/behavior risks (awareness of potential for school/learning difficulties and/or mental health problems). 3. Reproductive health (e.g., pregnancy and STD prevention).
Social service / Child Welfare: Resources/support for children in out of home placements, including caregiver support and funding resources.	1. Placement advocacy (e.g., stable, safe, structured, supportive home environment; movement towards long-term permanency). 2. Caregiver resources to support appropriate placements and long-term needs (e.g., adoption support, supplemental security income eligibility, family support program).

Developmental Therapy: Referral/recommendation for occupational therapy, physical therapy, speech-language therapy, or specific therapeutic program.	1. Referral to OT 2. Referral to SLP 3. Referral to a social skills group. 4. Referral to another therapeutic program.
Education/Assessment: Referral, advocacy, or support for a specific educational program or service, psycho-educational assessment, or specific skill area that requires educational monitoring.	1. Referral/support for educational service (e.g., special education, life skills training, birth to 3 year program). 2. Monitor a specific area of performance (e.g., fine motor, language). 3. Psychoeducational–neuropsychological assessment to determine special education eligibility, re-examine individual education plan or advocate for continued eligibility.
Community-based Activities: Leisure or recreation recommendations for specific, community-based activities/programs that are prosocial, recreational, extracurricular in nature and include appropriate developmental and social supports.	1. Prosocial extracurricular/play activities (e.g., Boys and Girls Club; community social skills groups). 2. Physical/movement (e.g., noncompetitive sports; therapeutic horseback riding; Special Olympics). 3. Special interest groups (e.g., focused leisure, religious, or cultural activities). 4. Adult mentor (e.g., Big Brother/Big Sister).
Safety Awareness: Recommendations/resources to address home, school, or community safety concerns.	1. Personal ID/safety (e.g., ID bracelet, wallet card). 2. Environmental modification/supervision (e.g., alarms, line-of-sight supervision).
Mental health: Support/referral for mental health services to address individual and/or family needs around behavior, development, or mental health problem.	1. Behavioral consultation or specialist (e.g., behavior management, home-based intervention services). 2. Individual counseling 3. Family counseling 4. Case management
Adult Transition / Future Planning:	1. Vocational 2. Financial 3. Other future plan.
Accommodations: Specific adaptation or modification to environment/routine to be implemented in home, school, or other setting.	1. Behavior/emotional regulation (e.g., supports for group participation, enhancing environmental structure). 2. Communication (e.g., visual schedules, cues for social interaction). 3. Executive function, organization, memory (e.g., memory aids, checklists). 4. Sensory–motor (e.g., headphones, reducing sensory input, keyboarding). 5. Team communication (e.g., communication between home, school, and other providers).
Developmental Therapy: Referral/recommendation for occupational therapy, physical therapy, speech–language therapy, or specific therapeutic program.	1. Referral/recommendation for occupational, physical, or speech language therapy evaluation or treatment. 2. Referral to a therapeutic social skills group.
Other	1. Substance abuse recommendations supporting treatment or recovery (caregiver or patient). 2. FASD re-evaluation

Patient Follow-Up Survey

A 10-question patient follow-up survey (Figure 1) has been sent to all patients evaluated at the University of Washington FASDPN clinic since 1993. The survey is mailed approximately 3 months after the patient's FASD diagnostic evaluation and comes with a stamped, addressed return envelope to maximize participation. The family may elect to submit the survey anonymously, or they can choose to enter the patient's name on the survey. The survey queries the patient's satisfaction with the diagnostic process; their confidence in the outcome; how successful they were at finding and accessing the interventions the diagnostic team recommended; and to what extent the interventions met their needs.



FAS Diagnostic and Prevention Network Clinic
Survey of Client Satisfaction
University of Washington Clinic

Please circle or check the most appropriate response. Additional comments are welcome. Your opinion is important to us.

1. **Patient's age.** __infant-2 years __3-5 years __6-12 years __13-18 years __19 or more years old

2. **Was the explanation of the patient's evaluation:**
   a. Easy to understand __________
   b. Somewhat complicated to understand __________
   c. Too complicated to understand __________

3. **How much confidence do you have in the results of the evaluation?**
   a. A lot of confidence __________
   b. Some confidence __________
   c. Very little confidence __________
   d. No confidence at all __________

4. **Did we provide you with information that you needed and were unable to get elsewhere?**
   a. Yes __________
   b. No __________
   c. Uncertain __________

5. **Did you feel your visit:**
   a. Took an appropriate amount of time __________
   b. Was too short __________
   c. Was too long __________

6. **When you left Clinic, we recommended that you contact certain people and services to help you. How successful were you at <u>finding</u> these people and services?**
   If you could not find the help, please explain why.
   a. Very successful __________
   b. Somewhat successful __________
   c. Had very little success __________
   d. Had no success at all __________

7. **If you were able to find the people and services we recommended to you, were they able to meet your needs?**
   If they did not meet your needs, explain why.
   a. Yes, they met all my needs. __________
   b. Yes, they met some of my needs. __________
   c. No, they met none of my needs. __________
   d. I was not able to find the people and services. __________

8. **Would you have liked the FAS Clinic to provide more help in finding community follow-up services or treatment?**
   If yes, please tell us how we could have helped.
   a. Yes __________
   b. No __________

9. **Do you have any suggestions for improving the services we provide?**

10. **Would you recommend the FAS Clinic to other families with similar needs?**
    a. Yes __________
    b. No __________

OPTIONAL Patient's Name: __________
You are welcome to submit this survey anonymously

RETURN TO: Susan Astley. Ph.D., Director FAS DPN
Center on Human Development and Disability
University of Washington, Box 357920
Seattle, WA 98195

In the stamped envelope provided

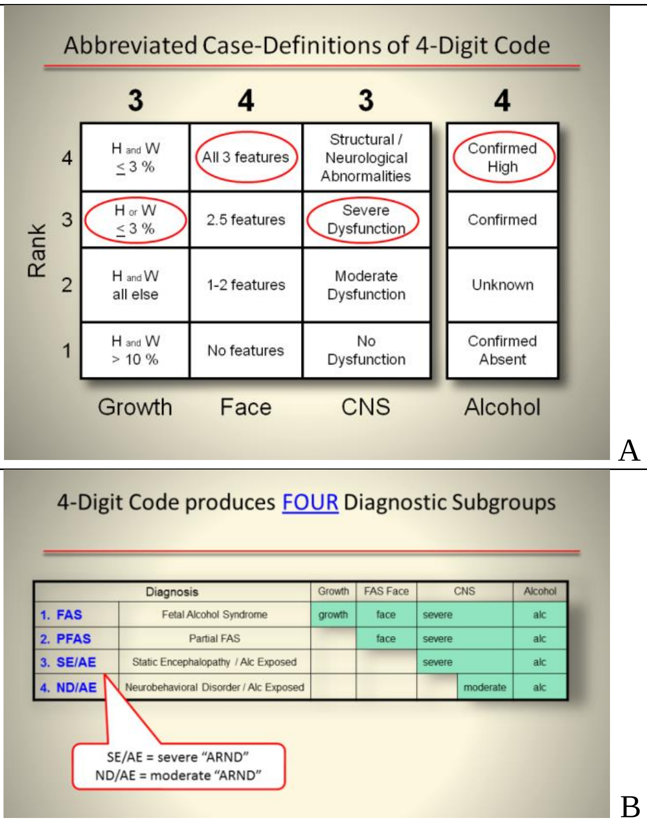
Thank you

FIG. 1 Patient Follow-up Survey mailed to all patients approximately three months after their FASD diagnostic evaluation at the University of Washington FAS Diagnostic & Prevention Network clinic.

FASD Diagnostic Systems Used

When the University of Washington FASD diagnostic clinic first opened in January 1993, the interdisciplinary team used the most current FASD diagnostic guidelines available at that time; the 1989 gestalt diagnostic criteria published by Sokol and Clarren.[24] In 1996, the Institute of Medicine (IOM) published an updated set of FASD diagnostic guidelines[5], but continued to propose a gestalt approach. The gestalt approach to diagnosis presented with many limitations.[2,10,25] The UW FASDPN created the 4-Digit Code in 1997 to overcome these limitations.[26] Thus, from 1993 through 1996, patients experienced an interdisciplinary team using a gestalt[24] approach to diagnosis. Only two FASD diagnostic classifications were rendered back then; FAS and Probable fetal alcohol effects (PFAE). PFAE was equivalent to what the IOM now calls ARND.[5] In 1997, the WA FASDPN interdisciplinary teams started using the FASD 4-Digit Diagnostic Code.[3,25] Diagnostic classifications include FAS, PFAS, SE/AE and ND/AE, as explained more fully below.

In 1997 the FASDPN switched from the gestalt[24] method of diagnosis to the FASD 4-Digit Diagnostic Code.[3,25,26] Briefly, the 4 digits of the FASD 4-Digit Code reflect the magnitude of expression of the 4 key diagnostic features of FASD, in the following order: 1. Growth deficiency, 2. FAS facial phenotype, 3. CNS structural/functional abnormalities, and 4. Prenatal alcohol exposure (Figure 2A). 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. Each Likert rank is specifically case defined. There are a total of 102 4-Digit Codes that fall broadly under the umbrella of FASD (Table 2). These codes cluster under four clinically meaningful FASD diagnostic subcategories: fetal alcohol syndrome (FAS): Diagnostic Categories A and B; Partial FAS (PFAS): Diagnostic Category C; Static Encephalopathy/Alcohol-Exposed (SE/AE): Diagnostic Categories E and F; and Neurobehavioral Disorder/Alcohol-Exposed (ND/AE): Diagnostic Categories G and H (Figure 2B). The attributes of the 4-Digit Code are summarized in Astley.[10]



Abbreviated Case-Definitions of 4-Digit Code

Rank	3	4	3	4
4	H and W ≤ 3 %	All 3 features	Structural / Neurological Abnormalities	Confirmed High
3	H or W ≤ 3 %	2.5 features	Severe Dysfunction	Confirmed
2	H and W all else	1-2 features	Moderate Dysfunction	Unknown
1	H and W > 10 %	No features	No Dysfunction	Confirmed Absent
	Growth	Face	CNS	Alcohol

4-Digit Code produces FOUR Diagnostic Subgroups

Diagnosis		Growth	FAS Face	CNS	Alcohol
1. FAS	Fetal Alcohol Syndrome	growth	face	severe	alc
2. PFAS	Partial FAS		face	severe	alc
3. SE/AE	Static Encephalopathy / Alc Exposed			severe	alc
4. ND/AE	Neurobehavioral Disorder / Alc Exposed			moderate	alc

SE/AE = severe "ARND"
ND/AE = moderate "ARND"

FIG. 2 **A.** Abbreviated case-definitions of the FASD 4-Digit Code.[3] The 4-Digit Code 3434 is one of 12 Codes that fall under the diagnostic category FAS/Alcohol-Exposed (Table 2). **B**. The FASD 4-Digit Code diagnostic system produces four diagnostic subgroups under the umbrella of FASD: FAS, PFAS, SE/AE, and ND/AE.[2 8,10] The 4-Digit Code does not use the term Alcohol Related Neurodevelopmental Disorder (ARND). The terms SE/AE and ND/AE are used in place of the term ARND.

TABLE 2 4-Digit Diagnostic Codes within each FASD Diagnostic Category (2004)[3]

A. FAS / Alcohol Exposed

2433	3433	4433
2434	3434	4434
2443	3443	4443
2444	3444	4444

B. FAS / Alcohol Exposure Unknown

2432	3432	4432
2442	3442	4442

C. Partial FAS /Alcohol Exposed

1333	1433	2333	3333
1334	1434	2334	3334
1343	1443	2343	3343
1344	1444	2344	3344

E. Sentinel Physical Finding(s) / Static Encephalopathy / Alcohol Exposed

3133	3233	4133	4233
3134	3234	4134	4234
3143	3243	4143	4243
3144	3244	4144	4244

F. Static Encephalopathy / Alcohol Exposed

1133	1233	2133	2233
1134	1234	2134	2234
1143	1243	2143	2243
1144	1244	2144	2244

G. Sentinel Physical Finding(s) / Neurobehavioral 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

H. Neurobehavioral Disorder / Alcohol Exposed

1123	1223	2123	2223
1124	1224	2124	2224

WA FASDPN Clinical/Research Database

All data collected by the WA FASDPN clinics since 1993 has been entered into an electronic clinical/research database with patient consent and Human Subjects Review Board approval.[2,10] To date, there are over 2,000 fields of information entered on over 7,000 patients requesting an evaluation and 2,550 patients who have received an evaluation to date. The majority of the data entered into the database comes from the following standardized data forms: 1) the New Patient Information Form; 2) the FASD Diagnostic Form; 3) the FAS Facial Photographic Analysis Software Report; 4) the Medical Summary that includes the Intervention Recommendations; and 5) the Patient Follow-Up

Surveys. These forms are provided in the Diagnostic Guide for FASD[3] and/or are posted on the WA FASDPN website (**www.fasdpn.org**).

Clinical Population and Study Groups

The clinical population from which the study population was drawn is all patients (n = 2, 550) who received an interdisciplinary FASD diagnostic evaluation throughout the 20 year history of the WA FASDPN. The WA FASDPN consists of a core clinic at the University of Washington and 7 Network FASD diagnostic clinics statewide.

Of the 2,550 patients evaluated at the WA FASDPN from 1993 through 2012, 1,545 (61%) were evaluated at the University of Washington clinic. All 1,545 patients evaluated at the University of Washington clinic received patient follow-up surveys 3 months after their FASD diagnostic evaluation. Of the 1,545 patients who received surveys, 622 (40%) completed and returned the surveys. These 622 patients are the focus of this study and were divided into the following study groups to facilitate the analysis/interpretation of their survey outcomes:

The 622 patients who returned patient follow-up surveys were divided into two groups (A & B) based on the FASD diagnostic method used for their evaluation.

A. Gestalt Diagnostic Method (N = 227):
All patients evaluated from 1993 through 1996 were evaluated by the UW interdisciplinary team using a gestalt[24] method of FASD diagnosis.
Twenty-one percent of this group received a gestalt diagnosis of FAS and 60% received a diagnosis of PFAE. Group A was not further divided into the gestalt diagnostic subgroups (like Group B below) because a previous study[25,27] confirmed this gestalt approach to diagnosis led to highly variable and inaccurate diagnostic classifications. Astley[25] confirmed that 75% of the gestalt FAS diagnoses were ruled out when the individual's outcomes are retrofitted to the more rigorous criteria of the 4-Digit Code.

B. FASD 4-Digit Diagnostic Code (N = 395):
All patients evaluated from 1997 through 2012 were evaluated by an interdisciplinary team using the FASD 4-Digit Diagnostic Code.[3,25]
All patients in Group B were further subdivided into six groups based on their 4-Digit Code diagnostic outcomes. Groups B1-4 fall broadly under the umbrella of FASD. The diagnostic features specific to each group were as follows:

1. *Patients in Group B1* had a 4-Digit diagnosis of **FAS or Partial FAS (FAS/PFAS)** (e.g., 4- Digit Diagnostic Categories A,B,C: with Growth Ranks 1-4, Face Ranks 3-4, CNS Ranks 3 and/or 4, Alcohol Ranks 2-4)[3] (Figure 2). Alcohol Rank 2 (unknown exposure) could only be present if the patient had a diagnosis of full FAS because the Rank 4 FAS facial features are so specific to prenatal alcohol exposure.[6,10,28-32] In summary, patients in Group 1 had severe CNS structural and/or functional abnormalities and the full FAS facial phenotype.

2. *Patients in Group B2* had a 4-Digit diagnosis of **Static Encephalopathy / Alcohol-Exposed (SE/AE)** (e.g., 4-Digit Diagnostic Categories E,F: with Growth Ranks 1-4, Face Ranks 1-2, CNS Ranks 3 and/or 4, Alcohol Ranks 3-4).[3] In summary, patients in Group 2 had severe cognitive/behavioral dysfunction, comparable to Group 1, but did not have the FAS facial phenotype.

3. *Patients in Group B3* had a 4-Digit diagnosis of **Neurobehavioral Disorder / Alcohol-Exposed (ND/AE)** (e.g. 4-Digit Diagnostic Categories G, H: with Growth Ranks 1-4, Face Ranks 1-2, CNS Rank 2, Alcohol Ranks 3-4).[3] In summary, patients in Group 3 had prenatal alcohol exposure comparable to Groups 1 and 2, but in comparison to Groups 1 and 2 had moderate cognitive/behavioral dysfunction, and did not have the FAS facial phenotype.

4. *Patients in Group B4* had a 4-Digit diagnosis of Sentinel Physical Findings/Alcohol-Exposed or No Physical Findings or CNS Abnormalities Detected / Alcohol-Exposed **(Normal CNS/AE**) (e.g., 4-Digit Diagnostic

Categories I and J: with Growth Ranks 1-4, Face Ranks 1-4, CNS Rank 1, and Alcohol Ranks 3-4).[3] In summary, patients in Group 4 had prenatal alcohol exposure, no CNS abnormalities, and may or may not have had growth deficiency and/or FAS facial features.

5. *Patients in Group B5* do not qualify for a diagnosis under the umbrella of FASD because their prenatal alcohol exposure is unknown or confirmed absent (**Not FASD**) (e.g., 4-Digit Diagnostic Categories D, K-V).[3] In summary, patients in Group 5 may have growth, facial, and/or CNS outcomes that span the full continuum from normal to abnormal, but in the absence of prenatal alcohol exposure, their outcomes cannot be attributed to prenatal alcohol exposure. Although patients are required to have a confirmed prenatal alcohol exposure to obtain an evaluation in the UW FASDPN clinic, this subset of patients had their exposure status reclassified to unknown (Rank 2) at the time of diagnosis when further information about their exposure status became available.

6. *Patients in Group B6* submitted Patient Follow-up Surveys anonymously, thus their identity and **Diagnostic Classification** are **unknown**. Patients in this group may span the full continuum of diagnostic classifications described for Groups B1-5.

Data Analysis

This study is primarily descriptive in nature. Outcomes are summarized using means, standard deviations, and proportions (valid percentages). Chi-square statistics were used, when appropriate, to compare proportions between two or more groups. Two-tailed p-values were used with a significance level set a $p < 0.05$.

RESULTS

Clinical and Sociodemographic Profile of the WA FASDPN Patient Population

The clinical and sociodemographic profile of all 2,550 patients who received an interdisciplinary FASD diagnostic evaluation at one of the WA State WA FASDPN clinics from 1993 through 2012 is presented in Table 3. This clinical population spans the entire age range (birth to 6 yrs (33%); 6-18 yrs (62%), adults (5%)). The vast majority (76%) were in out-of-home placement at the time of their diagnostic evaluation.

Of the 2,550 WA State FASDPN patients, 1,545 (60.6%) were evaluated at the core University of Washington (UW) FASDPN clinic in Seattle, WA. These are the 1,545 patients who were mailed Follow-up Surveys over the past 20 years and are the focus of this study. This subset of 1,545 patients is highly representative of the entire WA FASDPN population. Their diagnostic profile and age distribution are near identical (within a percentage point) to the diagnostic profile and age distribution of patients evaluated across the entire WA FASDPN presented in Table 3.

TABLE 3 Sociodemograhic profile of 2,550 patients evaluated for FASD over 20 Years (1993-2012) in the WA State FASDPN Clinics

Characteristic	FASD Diagnostic Subgroups*																	
	1. 101 FAS/ 146 PFAS			**2. SE/AE**			**3. ND/AE**			**4. Normal CNS/AE**			**5. Not FASD**			**Total**		
	N = 247 (10%)			**N = 604 (24%)**			**N = 1,117 (44%)**			**N = 197 (8%)**			**N = 385 (15%)**			**N = 2,550**		
Gender: N (valid%)																		
male	124	52.0		380	64.1		642	57.7		86	44.8		201	52.8		1433	56.1	
Race: N (valid%)																		
White	132	55.2		277	46.7		541	48.5		83	42.9		217	57.3		1250	49.6	
Black	30	12.3		34	5.8		86	7.7		17	8.6		12	3.1		178	7.1	
Native Am/Can/Alaskan	8	3.4		67	11.4		98	8.8		12	6.1		21	5.6		207	8.2	
All others (including mixed)	70	29.1		214	36.1		390	35.0		82	42.3		129	33.9		884	35.0	
Age at diagnosis (yr): N (row-column valid%)																		
0 – 2.9	46	15.5	18.7	45	15.1	7.4	104	35.1	9.3	80	27.1	40.7	21	7.2	5.5	297	100	11.6
3 – 5.9	59	10.5	23.9	103	18.2	17.0	285	50.5	25.5	57	10.1	28.7	60	10.7	15.6	564	100	22.1
6 – 12.9	97	8.4	39.2	306	26.4	50.7	518	44.7	46.3	38	3.3	19.2	200	17.2	51.8	1158	100	45.4
13 – 18.9	25	6.0	10.0	119	29.0	19.8	174	42.2	15.6	17	4.0	8.4	77	18.7	19.9	411	100	16.1
19+	20	16.7	8.1	31	25.5	5.1	37	30.4	3.3	6	4.9	3.0	27	22.5	7.1	121	100	4.7
Mean (SD)	8.7	8.1		9.9	5.9		8.7	5.4		6.0	7.0		10.7	7.0		9.1	6.3	
Minimum Maximum	0.3	50.5		0.5	50.8		0.5	37.0		0.2	48.1		0.6	46.2		0.2	50.8	
Caregiver at diagnosis: N (valid%)																		
Birth mother	43	17.6		118	19.6		213	19.7		47	24.7		12	3.2		432	17.4	
Other birth family member	57	23.4		116	19.2		249	23.1		48	25.9		69	18.6		540	21.7	
Adoptive parent	60	24.9		164	27.3		275	25.4		27	14.2		152	41.2		679	27.3	
Foster parent	63	25.9		135	36.8		271	25.0		56	29.1		115	31.0		638	25.6	
Other	20	6.4		70	11.6		74	7.0		12	6.2		22	6.1		199	8.0	

* 1) FAS/PFAS: fetal alcohol syndrome or partial FAS (4-Digit Diagnostic Categories A-C). 2) SE/AE: Static Encephalopathy/Alcohol-Exposed (4-Digit Diagnostic Categories E,F). 3) ND/AE: Neurodevelopmental Disorder/Alcohol-Exposed (4-Digit Diagnostic Categories G,H). 4) Normal CNS/AE; No Central Nervous System abnormalities/Alcohol-Exposed (4-Digit Diagnostic Categories I,J). 5) Not FASD-alcohol exposure unknown or absent (4-Digit Diagnostic Categories D,K-,V)[3].

Patient Follow-Up Surveys

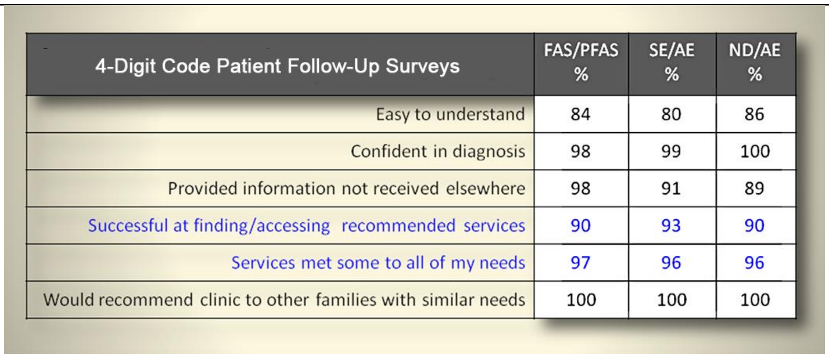
Of the 1,545 Patient Follow-Up Surveys mailed out between 1993 and 2012 to patients evaluated at the UW FASDPN, 622 were completed and returned reflecting a 40% response rate. Although families were given the option to return the survey anonymously, 85% (n=527) chose to identify the name of the patient. This allowed us to connect their responses to the patient's diagnostic outcome. The 622 completed surveys are distributed equally across the 20 years (1993-2012) and reflect a patient population that is near identical to (highly representative of) the FASD diagnostic profile and age distribution of the larger patient populations from which they were pulled (the entire WA FASDPN population (n=2,550), and the subset of 1,545 from the UW FASDPN) (Tables 4 and 5). Of the 622 surveys, 277 (36%) were from patients receiving a gestalt diagnostic evaluation and 395 (64%) were from patients receiving a diagnostic evaluation using the 4-Digit Code.

Family Report of Satisfaction and Confidence

Families (n=395) reported high levels of satisfaction and confidence in the 4-Digit Code administered by the University of Washington interdisciplinary diagnostic team.[26] (Table 4).

Ninety-nine percent would recommend the Clinic to other families with similar needs. Ninety-two percent said they received information they were unable to obtain elsewhere. Eighty-three percent found the explanation of the diagnostic evaluation outcome easy to understand. Ninety-eight percent expressed confidence in the results of the evaluation. Ninety-one percent felt the single 4-hour evaluation was an appropriate length of time for the evaluation.

Measures of satisfaction and confidence were comparably high across all diagnostic sub-classifications (Tables 4, 5, Figure 3), but varied somewhat across age groups (Table 6, 7). The adult patients who returned surveys (18 individuals 19 years of age or older) were less likely to report the explanation of the diagnostic evaluation was easy to understand (53% of adults reported it was easy to understand versus 84% across all younger groups). When adults are evaluated in clinic, the results are shared back directly with the adult patient. In contrast, when children are evaluated, the results are shared with their caregiver(s). Since all 18 adult patients had moderate to severe CNS dysfunction, it is understandable why they might report it was somewhat more difficult to understand the results.



4-Digit Code Patient Follow-Up Surveys	FAS/PFAS %	SE/AE %	ND/AE %
Easy to understand	84	80	86
Confident in diagnosis	98	99	100
Provided information not received elsewhere	98	91	89
Successful at finding/accessing recommended services	90	93	90
Services met some to all of my needs	97	96	96
Would recommend clinic to other families with similar needs	100	100	100

FIG. 3 Patient follow-up surveys (n = 395) confirm families have a very high level of satisfaction and confidence in the 4-Digit Code administered by the University of Washington interdisciplinary diagnostic team. Family's whose child received a diagnosis of SE/AE or ND/AE were as likely to report successfully accessing recommended intervention services that met their needs as family's whose child received a diagnosis of FAS or FAS.

TABLE 4 Summary of 395 Patient Follow-Up Surveys by 4-Digit Code FASD Diagnostic Classification: Satisfaction and Confidence in Diagnostic Evaluation

Questions	Diagnostic Subgroups*																				
	1. 14 FAS/ 29 PFAS			2. SE/AE			3. ND/AE			4. Normal CNS/AE			5. Not FASD			6. Diagnosis Unknown			Total		
	N = 43 (11%)			N = 92 (23%)			N = 132 (33%)			N = 27 (7%)			N = 39 (10%)			N=62 (16%)			N = 395		
	n	valid%		n	valid%		n	%		n	valid%		n	valid%		n	valid%		n	valid%	
1. Patient's age at time of diagnosis		row	col		row	col		row	col		row	col		row	col		row	col		row	col
Birth to 2 years	11	16.9	25.6	8	12.3	8.7	19	29.2	14.5	13	20.0	48.	3	4.6	7.7	11	16.9	20.4	65	100	16.8
3-5 years	9	11.4	20.9	15	19.0	16.3	32	40.5	24.4	7	8.9	25.	6	7.6	15.	10	12.7	18.5	79	100	20.5
6-12 years	16	9.5	37.2	48	28.4	52.2	58	34.3	44.3	4	2.4	14.	20	11.8	51.	23	13.6	42.6	169	100	43.8
13-18 years	4	7.3	9.3	15	27.3	16.3	18	32.7	13.7	1	1.8	3.7	9	16.4	23.	8	14.5	14.8	55	100	14.2
19 or more years	3	16.7	7.0	6	33.3	6.5	4	22.2	3.1	2	11.1	7.4	1	5.6	2.6	2	11.1	3.7	18	100	4.7
Age (yrs)		Mean	SD		Mean	SD		Mean	SD		Mean	SD		Mean	SD		Mean	SD		Mean	SD
		8.6	10.3		10.2	6.1		8.4	5.7		6.8	9.1		9.9	5.8		--	--		8.9	6.9
2. Was the explanation of the evaluation:																					
Easy to understand	36	83.7		71	78.9		113	86.3		25	100.0		30	76.9		43	79.6		318	83.2	
Somewhat complicated	7	16.3		19	21.1		18	13.7		0	.0		9	23.1		11	20.4		64	16.8	
Too complicated to understand	0	0		0	0		0	0		0	0		0	0		0	0		0	0	
3. How much confidence do you have in the evaluation results?																					
A lot of confidence	38	88.4		78	86.7		123	93.2		24	92.3		31	79.5		48	87.3		342	88.8	
Some confidence	4	9.3		9	10.0		9	6.8		2	7.7		6	15.4		7	12.7		37	9.6	
Very little confidence	1	2.3		3	3.3		0	.0		0	.0		2	5.1		0	.0		6	1.6	
4. Did we provide information you needed and were unable to get elsewhere?																					
Yes	42	97.7		84	91.3		115	89.1		24	92.3		35	92.1		52	94.5		352	91.9	
No	0	.0		5	5.4		5	3.9		1	3.8		2	5.3		1	1.8		14	3.7	
Uncertain	1	2.3		3	3.3		9	7.0		1	3.8		1	2.6		2	3.6		17	4.4	
5. Did you feel your visit:																					
Took an appropriate amount of time	38	88.4		80	87.9		118	92.9		22	91.7		38	97.4		47	88.7		343	91.0	
Was too short	4	9.3		9	9.9		6	4.7		0	.0		1	2.6		5	9.4		25	6.6	
Was too long	1	2.3		2	2.2		3	2.4		2	8.3		0	.0		1	1.9		9	2.4	
9. Would you recommend the FAS Clinic to other families with similar needs?																					
Yes	43	100.0		88	100.0		132	100.0		26	100.0		38	97.4		51	98.1		378	99.5	

* 1) FAS/PFAS: fetal alcohol syndrome or partial FAS (4-Digit Diagnostic Categories A-C). 2) SE/AE: Static Encephalopathy/Alcohol-Exposed (4-Digit Diagnostic Categories E,F). 3) ND/AE: Neurodevelopmental Disorder/Alcohol-Exposed (4-Digit Diagnostic Categories G,H). 4) Normal CNS/AE; No Central Nervous System abnormalities/Alcohol-Exposed (4-Digit Diagnostic Categories I,J). 5) Not FASD-alcohol exposure unknown or absent (4-Digit Diagnostic Categories D,K-,V). 6). Diagnosis Unknown (Survey submitted anonymously; patient identity and FASD diagnostic outcome on Survey unknown)[3].

TABLE 5. Summary of 395 Patient Follow-Up Surveys by 4-Digit Code FASD Diagnostic Classification: Access to Interventions and Needs Met

Questions	Diagnostic Subgroups*													
	1. 14 FAS/ 29 PFAS		**2. SE/AE**		**3. ND/AE**		**4. Normal CNS/AE**		**5. Not FASD**		**6. Diagnosis Unknown**		**Total**	
	N = 43 (11%)		**N = 92 (23%)**		**N = 132 (33%)**		**N = 27 (7%)**		**N = 39 (10%)**		**N=62 (16%)**		**N = 395**	
	n	valid%	n	valid%	n	%	n	valid%	n	valid%	n	valid%	n	valid%
6. When you left Clinic, we recommended that you contact certain people and services to help you. How successful were you at finding these people and services?														
Very successful	17	45.9	38	55.1	58	55.2	10	55.6	17	56.7	24	53.3	164	53.9
Somewhat successful	16	43.2	26	37.7	36	34.3	4	22.2	10	33.3	17	37.8	109	35.8
Had very little success	4	10.8	3	4.3	6	5.7	2	11.1	2	6.7	2	4.4	19	6.3
Had no success at all	0	0	2	2.9	5	4.8	2	11.1	1	3.3	2	4.4	12	3.9
7. If you were able to find the people and services we recommended to you, were they able to meet your needs?														
Yes, they met all of my needs	13	44.8	26	53.1	39	51.3	6	42.9	8	40.0	14	42.4	106	48.0
Yes, they met some of my needs	15	51.7	21	42.9	34	44.7	7	50.0	11	55.0	19	57.6	107	48.4
No, they met none of my needs	1	3.4	2	4.1	3	3.9	1	7.1	1	5.0	0	0	8	3.6
8. Would you have liked the FAS Clinic to provide more help in finding community follow-up services or treatment?														
No	19	52.8	45	55.6	67	54.9	12	57.1	19	63.3	31	63.3	193	56.9
Yes	17	47.2	36	44.4	55	45.1	9	42.9	11	36.7	18	36.7	146	43.1

* 1) FAS/PFAS: fetal alcohol syndrome or partial FAS (4-Digit Diagnostic Categories A-C). 2) SE/AE: Static Encephalopathy/Alcohol-Exposed (4-Digit Diagnostic Categories E,F). 3) ND/AE: Neurodevelopmental Disorder/Alcohol-Exposed (4-Digit Diagnostic Categories G,H). 4) Normal CNS/AE; No Central Nervous System abnormalities/Alcohol-Exposed (4-Digit Diagnostic Categories I,J). 5) Not FASD-alcohol exposure unknown or absent (4-Digit Diagnostic Categories D,K-,V). 6). Diagnosis Unknown (Survey submitted anonymously; patient identity and FASD diagnostic outcome on Survey unknown).[3]

TABLE 6 Summary of 386 Patient Follow-Up Surveys by Patient Age at Time of 4-Digit Code FASD Diagnosis: Satisfaction and Confidence in Diagnostic Evaluation

Questions	0-2 Years			3-5 Years			6-12 Years			13-18 Years			19 + years			Total		
	N = 65 (17%)			N = 79 (20%)			N = 169 (44%)			N = 55 (14%)			N = 18 (5%)			N = 386		
Diagnosis*	n	valid%		n	valid%		n	valid%		N	valid%		n	valid%		n	valid%	
		row	col		row	col		row	col		row	col		row	col		row	col
FAS/PFAS	11	25.6	16.9	9	20.9	11.4	16	37.2	9.5	4	9.3	7.3	3	7.0%	16.7	43	100%	11.1%
SE/AE	8	8.7	12.3	15	16.3	19.0	48	52.2	28.4	15	16.3	27.3	6	6.5%	33.3	92	100%	23.8%
ND/AE	19	14.5	29.2	32	24.4	40.5	58	44.3	34.3	18	13.7	32.7	4	3.1%	22.2	131	100%	33.9%
Normal/AE	13	48.1	20.0	7	25.9	8.9	4	14.8	2.4	1	3.7	1.8	2	7.4%	11.1	27	100%	7.0%
Not FASD	3	7.7	4.6	6	15.4	7.6	20	51.3	11.8	9	23.1	16.4	1	2.6%	5.6%	39	100%	10.1%
Diagnosis Unknown	11	20.4	16.9	10	18.5	12.7	23	42.6	13.6	8	14.8	14.5	2	3.7%	11.1	54	100%	14.0%
2. Was the explanation of the evaluation:																		
Easy to understand	52	82.5		68	87.2		138	82.6		49	89.1		9	52.9		316	83.2	
Somewhat complicated	11	17.5		10	12.8		29	17.4		6	10.9		8	47.1		64	16.8	
Too complicated to understand	0	0		0	0		0	0		0	0		0	0		0	0	
3. How much confidence do you have in the evaluation results?																		
A lot of confidence	60	93.8		69	87.3		150	89.3		46	83.6		15	88.2		340	88.8	
Some confidence	3	4.7		10	12.7		14	8.3		9	16.4		1	5.9		37	9.7	
Very little confidence	1	1.6		0	0		4	2.4		0	0		1	5.9		6	1.6	
4. Did we provide information you needed and were unable to get elsewhere?																		
Yes	62	96.9		71	91.0		153	91.6		50	90.9		14	82.4		350	91.9	
No	0	0		3	3.8		7	4.2		3	5.5		1	5.9		14	3.7	
Uncertain	2	3.1		4	5.1		7	4.2		2	3.6		2	11.8		17	4.5	
5. Did you feel your visit:																		
Took an appropriate amount of time	58	93.5		70	94.6		147	88.0		51	92.7		16	88.9		342	91.0	
Was too short	2	3.2		3	4.1		16	9.6		3	5.5		1	5.6		25	6.6	
Was too long	2	3.2		1	1.4		4	2.4		1	1.8		1	5.6		9	2.4	
9. Would you recommend the FAS Clinic to other families with similar needs?																		
Yes	63	100		77	98.7		166	100		53	100		17	94.4		376	99.5	

*FAS/PFAS: fetal alcohol syndrome or partial FAS (4-Digit Diagnostic Categories A-C). SE/AE: Static Encephalopathy/Alcohol-Exposed (4-Digit Diagnostic Categories E,F). ND/AE: Neurodevelopmental Disorder/Alcohol-Exposed (4-Digit Diagnostic Categories G,H). Normal CNS/AE; No Central Nervous System abnormalities/Alcohol-Exposed (4-Digit Diagnostic Categories I,J). Not FASD-alcohol exposure unknown or absent (4-Digit Diagnostic Categories D,K-,V). Diagnosis Unknown (Survey submitted anonymously; patient identity and FASD diagnostic outcome on Survey unknown)[3].

TABLE 7 Summary of 386 Patient Follow-Up Surveys by Patient Age at Time of 4-Digit Code FASD Diagnosis: Access to Interventions and Needs Met

Questions	**0-2 Years**		**3-5 Years**		**6-12 Years**		**13-18 Years**		**19 + years**		**Total**	
	N = 65 (17%)		**N = 79 (20%)**		**N = 169 (44%)**		**N = 55 (14%)**		**N = 18 (5%)**		**N = 386**	
	n	valid%	n	valid%	n	valid%	n	valid%	n	valid%	n	valid%
6. When you left Clinic, we recommended that you contact certain people and services to help you. How successful were you at finding these people and services?												
Very successful	30	60.0	32	52.5	74	54.4	20	47.6	7	50.0	163	53.8
Somewhat successful	15	30.0	24	39.3	46	33.8	17	40.5	3	21.4	105	34.7
Had very little success	3	6.0	1	1.6	13	9.6	4	9.5	2	14.3	23	7.6
Had no success at all	2	4.0	4	6.6	3	2.2	1	2.4	2	14.3	12	4.0
7. If you were able to find the people and services we recommended to you, were they able to meet your needs?												
Yes, they met all of my needs	25	62.5	24	58.5	44	45.8	9	26.5	3	33.3	105	47.7
Yes, they met some of my needs	14	35.0	16	39.0	51	53.1	22	64.7	4	44.4	107	48.6
No, they met none of my needs	1	2.5	1	2.4	1	1.0	3	8.8	2	22. 2	8	3.6
8. Would you have liked the FAS Clinic to provide more help in finding community follow-up services or treatment?												
No	37	64.9	41	57.7	79	52.7	29	64.4	6	42.9	192	57.0
Yes	20	35.1	30	42.3	71	47.3	16	35.6	8	57.1	145	43.0

Family Report of Access to Interventions and Needs Met by Interventions

Family's whose child received a 4-Digit Code diagnosis of SE/AE or ND/AE were as likely to report successfully accessing recommended interventions and having their needs met by the interventions as family's whose child received a diagnosis of FAS or PFAS (Table 5, Figure 3). Overall, 89% of families reported being somewhat to very successful in finding/accessing the recommended intervention services and 96% of those who found the services reported the services met some to all of their needs (Table 5). Access to interventions and having one's needs met by the interventions did not differ by diagnosis, but did differ by age (Table 7). Families of patients over 18 years of age reported less success finding and accessing recommended services and were less likely to report the interventions met their needs. A family's desire to receive more help from the Clinic to find services increased with increasing patient age.

Gestalt versus 4-Digit Code Method of Diagnosis

Among the 622 patients who returned their follow-up surveys, 227 (35%) were from patients who were diagnosed between 1993-1996 with the gestalt method of diagnosis and 395 (64%) were diagnosed between 1997 and 2012 with the 4-Digit Diagnostic Code. The survey outcomes for these two groups of patients are presented in Tables 8 and 9. Patients receiving a gestalt diagnostic evaluation were significantly less likely to report: 1) confidence in the outcome; 2) success in finding/accessing recommended intervention services, and 3) having their needs met by the services they accessed. The patient population evaluated from 1993-96, when the gestalt[24] method of diagnosis was in use, was slightly older than the patient population evaluated from 1997-2012, when the 4-Digit Code[3] method of diagnosis was used.

TABLE 8 Summary of 622 Patient Follow-Up Surveys by Gestalt[24] versus 4-Digit Code Diagnostic Methods: Satisfaction and Confidence in Interdisciplinary Diagnostic Evaluation

	Diagnostic System								
Questions	**Gestalt**			**4-Digit Code**			**Total**		
	N =227 (36%)			**N = 395 (64%)**			**N = 622**		
	n	valid%		n	valid%		n	valid%	
1. Patient's age at time of diagnosis*		row	col		row	col		row	col
Birth to 2 years	19	22.6	8.4	65	77.4	16.8	84	100	13.7
3-5 years	54	40.6	23.8	79	59.4	20.5	133	100	21.7
6-12 years	79	31.9	34.8	169	68.1	43.8	248	100	40.5
13-18 years	55	50.0	24.2	55	50.0	14.2	110	100	17.9
19 or more years	20	52.6	8.8	18	47.4	4.7	38	100	6.2
2. Was the explanation of the evaluation:									
Easy to understand	189	84.4		318	83.2		507	83.7	
Somewhat complicated	34	15.2		64	16.8		98	16.2	
Too complicated to understand	1	0.4		0	0		1	0.2	
3. How much confidence do you have in the evaluation results?**									
A lot of confidence	166	74.1		342	88.8		508	83.4	
Some confidence	54	24.1		37	9.6		91	14.9	
Very little confidence	4	1.8		6	1.6		10	1.6	
4. Did we provide information you needed and were unable to get elsewhere?***									
Yes	192	90.1		352	91.9		544	91.3	
No	19	8.9		14	3.7		33	5.5	
Uncertain	2	.9		17	4.4		19	3.2	
5. Did you feel your visit:									
Took an appropriate amount of time	193	86.9		343	91.0		536	89.5	
Was too short	11	5.0		25	6.6		36	6.0	
Was too long	18	8.1		9	2.4		27	4.5	
9. Would you recommend the FAS Clinic to other families with similar needs?									
Yes	220	98.2		378	99.5		598	99.0	

* Chi-square 24.2, 4df, p=0.000. **Chi-square 23.67, 2df, p=0.000. *** Chi-square 12.2, 2df, p=0.002.

TABLE 9 Summary of 622 Patient Follow-Up Surveys by Gestalt[24] vs 4-Digit Code Diagnostic Methods: Access to Interventions and Needs Met

Questions	Diagnostic System*					
	Gestalt		4-Digit Code		Total	
	N =227 (36%)		N = 395 (64%)		N = 622	
	n	valid%	n	valid%	n	valid%
6. When you left Clinic, we recommended that you contact certain people and services to help you. How successful were you at finding these people and services?						
Very successful*	75	44.4	164	53.9	239	50.5
Somewhat successful	66	39.1	105	34.5	171	36.2
Had very little success	10	5.9	23	7.6	33	7.0
Had no success at all	18	10.7	12	3.9	30	6.3
7. If you were able to find the people and services we recommended to you, were they able to meet your needs?						
Yes, they met all of my needs**	47	36.2	106	48.0	153	43.6
Yes, they met some of my needs	69	53.1	107	48.4	176	50.1
No, they met none of my needs	14	10.8	8	3.6	22	6.3
8. Would you have liked the FAS Clinic to provide more help in finding community follow-up services or treatment?						
No	92	50.8	193	56.9	285	54.8
Yes	89	49.2	146	43.1	235	45.2

* Chi-square 10.7, 3df, p=0.013. ** Chi-square 9.6, 2df, p=0.008.

Profile of Intervention Recommendations by Age Group among Patients Diagnosed with the 4-Digit Code

Intervention recommendation profiles by age group are presented for two subsets of patients evaluated at the UW FASDPN clinic using the 4-Digit Code. Figure 4A illustrates the intervention profile for a representative sample of 170 of the 364 patients who had their interventions coded since 2007, when coding of interventions commenced at the UW FASDPN clinic. Figure 4B illustrates the intervention profile for the subset of 61 patients who returned Patient Follow-up Surveys. Both groups of patients have FASD diagnostic profiles that are comparable to (representative of) the larger population of all 395 patients diagnosed with the 4-Digit Code from which they were drawn. The diagnostic profile for the 170 patients in Figure 4A is: FAS/PFAS 15.2%, SE/AE 13.6%, ND/AE 53.0%, Normal CNS/AE 7.6%, Unknown 10.6%. The diagnostic profile for the 61 patients in Figure 4B is: FASPFAS 13.1%, SEAE 14.8, ndae 52.5, normAE 8.2%, Unknown 11.5%. These intervention profiles help put the Patient Follow-Up Surveys in perspective. When the patients were queried regarding their success at finding, accessing, and having their needs met by the interventions we recommended, the types of interventions they were pursuing are presented in Figure 4.

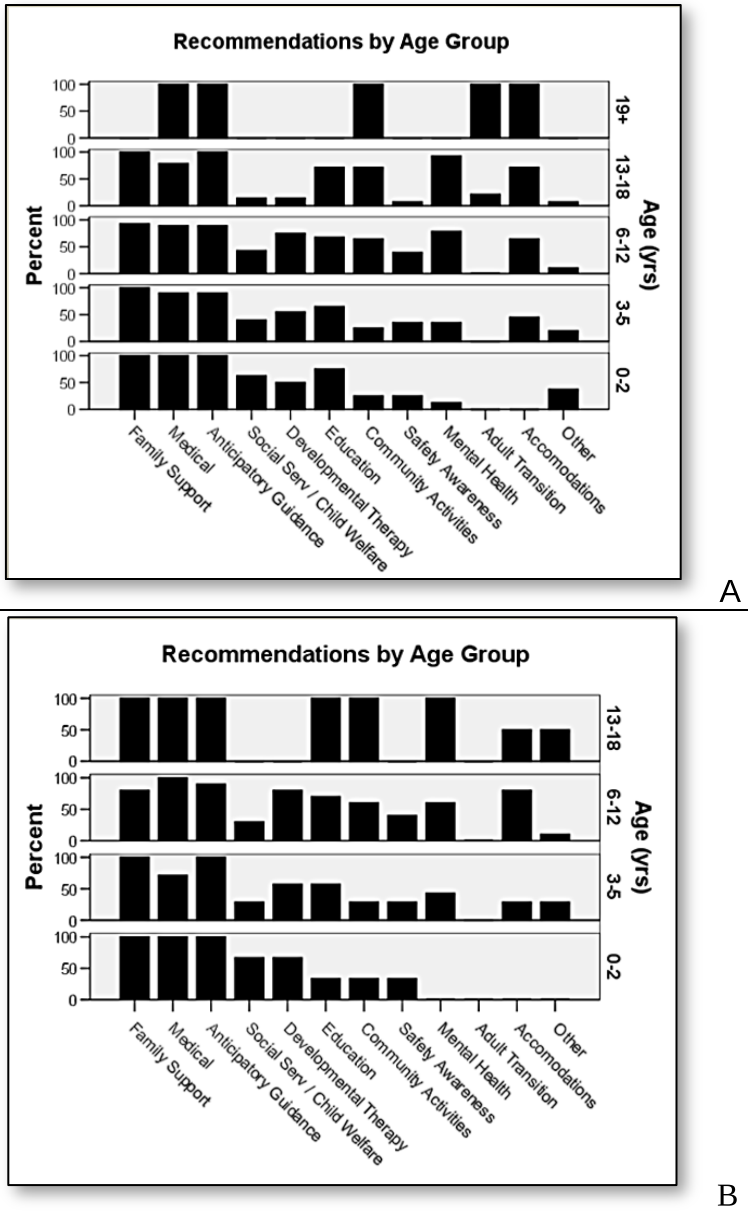


FIG. 4 Intevention recommendation profiles for two groups of patients who received FASD diagnostic evaluations at the Univeristy of Washington FASDPN clinic from 2007 to 2012 using the 4-Digit Code are presented. The bars represent the proportion of patients receiving each type of intervention by age group at the time of their diagnostic evaluation. **A**) Profile of intervention recommendations provided to a representative sample of 170 of the 364 patients evaluted from 2007 through 2012. **B**) Intervention profile for the 61 patients, from among the group of 170, who returned Patient Follow-up Surveys. The larger sample in Figure 4A demonstrates the profile among the subset of 61 who returned Patient Surveys is reflective of the larger population from which they were sampled. The twelve intervention subclassifications[17] are described in Table 1.

DISCUSSION

Patient follow-up surveys over 20 years illustrated the value of an interdisciplinary FASD diagnostic evaluation from an important perspective; the patient's perspective. Families (98%) expressed confidence in the interdisciplinary approach to diagnosis using the FASD 4-Digit Code with essentially all (99.5%) reporting they would recommend the diagnostic service to other families. The vast majority of families (89%) reported they were somewhat to very successful in finding/accessing the recommended intervention services and 96% of those who accessed the services reported the services met some to all of their needs. Patient reports that the recommended interventions "met some to all of their needs" is powerful qualitative evidence of intervention effectiveness and compliments the growing empirical, quantitative evidence-base on FASD intervention effectiveness.[33,34] It is important to clarify that patient outcomes over time were not directly measured in this study. When families/patients reported the interventions met some to all of their needs, the surveys did not document which specific needs were met. The intervention recommendations for each patient spanned the full continuum from services that directly addressed the patient's disabilities to services that provided caregivers with advocacy training, education, resources, even respite care (Table 1). Thus, when families report their needs were met, this is certainly a positive outcome and reflects just one of many ways to assess intervention effectiveness, but does not replace the need for more direct, empirical assessments of improved patient outcome.

The results of this study document a FASD diagnostic evaluation helped break down some of the treatment barriers and unmet needs often reported by caregivers.[35-38] Families report that these unmet needs are one of the primary reasons they are seeking an evaluation in our clinic. They typically report having received evaluations and services from a large array of providers prior to attending our clinic. Nevertheless, 92% report we provided them with information they were unable to obtain elsewhere despite the fact the clinic is located in a large metropolitan area (Seattle) with many genetic, neurodevelopmental, and psychological evaluation services available. This single 4-hour interdisciplinary evaluation appears to provide more information and access to services than the multitude of uncoordinated services the families reported accessing prior to coming to our clinic. The potential cost savings of this more efficient and more effective interdisciplinary approach to meeting these family's complex needs is enormous and will be the focus of a separate report.

Patients with Neurobehavioral Disorder/Alcohol-Exposed (ND/AE) and Static Encephalopathy/Alcohol-Exposed (SE/AE) were as successful accessing interventions that met their needs as patients with FAS or PFAS. This is in contrast to the oft stated belief that a patient will not qualify for services if the diagnosis is not FAS, PFAS or at least given a name that implies alcohol is the causal agent (e.g., Alcohol-Related Neurodevelopmental Disorder (ARND)). The FASD 4-Digit Code does not use the term Alcohol-Related Neurodevelopmental Disorder because one cannot confirm an individual's neurodevelopmental disorder is related to their prenatal alcohol exposure in the absence of the FAS facial phenotype. This study demonstrated that the diagnostic labels SE/AE and ND/AE were as effective as FAS and PFAS in providing access to intervention services. This is encouraging since individuals should qualify for services based on their disability, not on what caused their disability.

Several factors likely contributed to our patients' success in finding and accessing the recommended interventions. Access to services requires more than a diagnostic label. The diagnostic labels FAS, PFAS, SE/AE and ND/AE reveal the magnitude of disability, but do not reveal the individual's specific pattern of disability. No two individuals on the spectrum of FASD necessarily present with the same pattern of disability[8,39], and their unique pattern of disability manifests differently over their lifetime. For this reason, the most important component of the FASD interdisciplinary diagnostic evaluation is a current, comprehensive developmental /neuropsychological assessment. The outcomes of this assessment not only help derive the diagnostic classification, but provide the core information that ultimately drives the intervention plan and qualifies an individual for services.

For a patient to derive the greatest benefit from their FASD diagnostic evaluation, they need an interdisciplinary team that can: 1) render an accurate diagnosis under the umbrella of FASD; 2) generate a comprehensive intervention plan tailored to their specific needs and circumstances; and 3) present all of this in a comprehensive medical summary report that effectively informs and educates the family and their community service providers. Over the last 20 years, the UW FASDPN interdisciplinary team has gained considerable expertise and experience in meeting the needs of this patient population. Most of the clinicians have served on the team for more than 10 years, with several having served the entire 20 years. Two factors that have contributed tremendously to the team's ability to work efficiently and effectively include: 1) their creation of an up-to-date, comprehensive list of over 200 intervention recommendations key-coded into an Intervention Plan template and 2) their creation of the FASD Medical Summary Report template. Both Microsoft Word templates are available to clinicians at no cost through the WA FASDPN. The Intervention Plan template allows the team to construct a detailed, customized list of interventions that not only meet the patient's needs, but are known to be available in the patient's community, and are likely to be financially accessible to the patient. The intervention plan spans the full continuum of patient and caregiver needs from medical, educational, placement, social service, even caregiver respite.[17] The intervention plan is printed and handed to the family at the conclusion of their 4-hour appointment. The FASD Medical Summary Report is a single, comprehensive, interdisciplinary report composed by the interdisciplinary team members. During the 4-hour appointment, team members sit at one of several computer stations, log into their report template and compose a brief report summarizing which assessments they administered, the outcomes of the assessments, and their interpretation of the outcomes. Each of these electronic reports is collected at the end of the 4-hour evaluation and inserted into the FASD Medical Summary Report template by the clinic coordinator. The FASD Medical Summary Report is complete within one hour following the 4-hour evaluation. The Intervention Plan is merged with the Medical Summary report and submitted to the patient's medical record and mailed to the patient's legal guardian within one week of their diagnostic evaluation.

The FASD Medical Summary Report is designed to both educate and inform the patient and their care providers. The content and format of this report is vital to a patient's success in accessing intervention services. A medical summary that conveys a rigorous diagnostic process and includes the assessment outcomes that ultimately drove the intervention recommendations will go far to earn the respect of the professional community. Our FASD Medical Summary Report: 1) outlines the interdisciplinary process used to derive the diagnosis, 2) describes how the 4-Digit Code measures the magnitude of impairment across the four components that characterize FASD (growth deficiency, FAS facial phenotype, CNS abnormalities, and prenatal alcohol exposure), 3) presents the patient's outcomes in each of these four areas, 4) provides a diagnostic classification with brief description, and 5) concludes with a comprehensive intervention plan. In the words of one caregiver of a 10 year old who received a diagnosis of SE/AE "*I cannot say enough good things about your services. A proper diagnosis has resulted in: change of school placement, OT/PT services provided by the school district, a referral to mental health in hopes of finding a therapist w/background in neurodevelopmental problems and patient's psychiatrist reducing his medications*".

Families of patients who were birth to 5 years of age at the time of diagnosis reported the greatest access to recommended interventions that met their needs. The WA FASDPN clinics have been accurately and effectively diagnosing individuals across the entire age span for 20 years. The youngest and oldest patients to date were 2 days old and 53 years old, respectively. One third of the WA FASDPN patient population is birth to

5.9 years of age at the time of diagnosis.[8] Their outcomes span the full continuum of FASD diagnoses. Of the 760 patients (birth to 5.9 years of age) with confirmed prenatal alcohol exposures evaluated in the first 20 years, 13% were diagnosed with FAS/PFAS; 19% with SE/AE, 51% with ND/AE; and 18% with No CNS Abnormalities/AE. Not only is an accurate FASD diagnostic evaluation possible in this young age group, but according to this study, highly beneficial. This is the age group with the greatest access to services and the greatest potential to benefit from the services.[18] This is also the age group that can lead to the most successful primary prevention efforts by reaching out to their birth mothers early in their reproductive history to prevent alcohol exposure in subsequent births.[11,12] Adult patients (19 years of age or older) reported less success (71%) finding and accessing recommended interventions relative to younger age groups (90%). Adults were also less likely (77%) to report the services met their needs compared to the younger age groups (98%). Reports of less access to and benefit from intervention services are reflective of the paucity of services available to adults with disabilities. The primary reason adult patients report seeking an FASD evaluation is the hope that the outcome will qualify them for Supplemental Security Income (SSI) or developmental disabilities assistance. Qualification for these forms of assistance in WA State is based in large part on FSIQ and adaptive behavior performance more than 2 standard deviations below the mean. Most of the adults receiving a diagnosis under the umbrella of FASD, including full FAS, do not present with FSIQs below 70. We are working with our State policy makers to address this issue.

CONCLUSION

Patient surveys over 20 years confirm an interdisciplinary diagnosis using the FASD 4-Digit Diagnostic Code provides substantial access to interventions that meet patients' needs across the full spectrum of FASD diagnoses. This is powerful evidence of the value of an FASD diagnostic evaluation.

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