Children and Youth With Fetal Alcohol Spectrum Disorders: Summary of Intervention Recommendations After Clinical Diagnosis

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Abstract

Children with fetal alcohol spectrum disorders (FASDs) present with a wide range of developmental disabilities; however, clinical standards of care after a diagnosis are not well established. This retrospective review summarizes the types of intervention recommendations generated by an interdisciplinary FASD diagnostic team for 120 children ages 0.2 to 16.5 years receiving an FASD diagnosis at the University of Washington FAS Diagnostic & Prevention Network Clinic. Intervention recommendations documented in a FASD diagnostic summary report and submitted to each patient's medical record were subject to masked review and content analysis. Intervention recommendations were compared across 3 FASD diagnostic groups and selected demographic variables. The results show the type and frequency of services, supports, and resources recommended to a clinical sample of children with FASD.

Prenatal alcohol exposure has a well-established and wide-ranging teratogenic impact on the central nervous system (CNS), with resultant impairments in learning, development, and adaptive function (Astley et al., 2009a; Riley & McGee, 2005). Fetal alcohol syndrome (FAS), a permanent birth defect characterized by a unique cluster of minor facial anomalies, CNS structural and/or functional abnormalities, and growth deficiency, is one of the more widely recognized outcomes of prenatal alcohol exposure. At 0.2 to 1.5 cases per 1,000 live births, FAS is the leading known preventable cause of developmental and intellectual disability (U.S. Centers for Disease Control and Prevention, 2006). However, FAS represents a relatively small proportion of children affected by prenatal alcohol exposure. The continuum of birth defects and developmental disabilities associated with alcohol exposure, currently referred to under the umbrella term of *fetal alcohol spectrum disorders* (*FASD*), may occur up to eight times as often as FAS among clinical populations of individuals with prenatal alcohol exposure (Astley, 2006). As such, FASD remains a significant public health concern that places substantial social and financial burdens on communities (Lupton, Burd, & Harwood, 2004).

A number of intervention guidelines and treatment strategies have been identified as useful for individuals with FASD and their families (Bertrand et al., 2004; Clarren, 2004; Kalberg & Buckley, 2007). Recently, several important evidence-based interventions also have emerged or are forthcoming (see Bertrand, 2009; Peadon, Rhys-Jones, Bower, & Elliott, 2009, for review). However, evidence-based standards of care for children and families following a diagnosis on the fetal alcohol spectrum remain limited (Olson, Jirikowic, Kartin, & Astley, 2007; Premji, Benzies, Serret, & Hayden, 2006). Moreover, caregivers continue to describe treatment barriers, unmet needs, and high levels of parenting stress (Olson, Oti, Gelo, & Beck 2009; D.M. Ryan, Bonnett, & Gass, 2006; S. Ryan & Ferguson, 2006). Difficulty qualifying for services, poorly coordinated services across systems and providers, gaps in the continuum of care, and a general paucity of specialized interventions for individuals affected by prenatal alcohol exposure are among the specific challenges reported.

Access to appropriate services and supports across all systems of care is a clearly stated need and a high priority among caregivers raising children with FASD and community professionals (Bertrand et al., 2004; Olson et al., 2009; D. M. Ryan et al., 2006; S. Ryan & Ferguson, 2006; Streissguth et al., 2004; Streissguth & O'Malley, 2000). Yet, the full scope of supports, services, and resources most needed by individuals who receive a diagnosis on the fetal alcohol spectrum have not been systematically described among large, clinically referred populations. As such, examining the type and frequency of clinical recommendations received by children and youths following a systematic diagnosis on the fetal alcohol spectrum is one means to better understand the unique needs of this population and to inform program development, research, and policy efforts.

The Washington state Fetal Alcohol Syndrome Diagnostic and Prevention Network (FAS DPN) was established in 1993. The network consists of four Washington-state, community-based clinics linked by the core research and training clinic at the University of Washington. The FAS DPN provides diagnostic evaluations using the FASD 4-Digit Diagnostic Code (Astley, 2004) administered by an interdisciplinary diagnostic team (Clarren, Olson, Clarren, & Astley, 2000). Currently, the FAS DPN clinical database contains more than 2,000 patient records with patient consent and institutional review board approval. With over 2,000 fields of information recorded per patient, the FAS DPN database is one of the largest and most comprehensive repositories of sociodemographic, cognitive–behavioral, and physical information for individuals of all ages and races–ethnicities with prenatal alcohol exposure, their families, and birth parents. Thus, it provides a rich source of information for a statewide clinical population of individuals systematically evaluated for FASDs.

An important component of the diagnostic process is to provide patients with a comprehensive set of intervention and/or follow-up recommendations specific to their needs. These recommendations are collectively generated by the interdisciplinary diagnostic team as part of the clinic visit after the 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. Team members share these intervention recommendations with caregivers during a brief care conference and include the recommendations in the patient's FASD medical summary note that is submitted to the medical record.

A description of these recommendations, which have not been comprehensively analyzed to date, serves to provide insight into the types of interventions that may support the needs of children with FASDs and their caregivers at the time of diagnosis. The primary purposes of this study were to (a) describe the type and frequency of intervention recommendations provided to patients receiving a FASD diagnosis at a FASD diagnostic clinic and (b) determine if recommendations varied by FASD diagnostic groups and selected sociodemographic characteristics (e.g., age, gender, and caregiver status).

Method

Study Design

We completed a retrospective review of patient records from the University of Washington FAS DPN clinical database. The University of Washington Institutional Review Board approved the study.

Diagnostic Method

An interdisciplinary team (pediatrician, 2 psychologists, occupational therapist, speech–language pathologist, family advocate, and social worker) used the FASD 4-Digit Diagnostic Code to derive the FASD diagnoses (Astley, 2004; Astley & Clarren, 2000). Table 1 outlines key phases of the diagnostic process and primary sources of clinical data used to derive the diagnoses (Clarren et al., 2000). Although the FAS DPN database is a clinic-referred sample, the only requirement for obtaining a diagnostic evaluation is confirmed prenatal alcohol exposure of any quantity, frequency, or duration.

The FASD 4-Digit Diagnostic Code is an objective, case-defined diagnostic system. The four digits of the code reflect the magnitude of expression of the four key diagnostic features of FASD in the following order: (a) growth deficiency, (b) FAS facial features, (c) CNS structural–functional abnormality, and (d) 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"

Table 1. Overview of FAS DPN Diagnostic Process and Sources of Clinical Data

Phase	Description
Phase 1	*Clinical intake:* Caregivers complete a comprehensive "New Patient Information Form" prior to the clinic visit to report current concerns and developmental, social and alcohol exposure history. Past medical, educational, psychological, social, and legal records are also obtained.
	Record review: Psychologist reviews all available medical, developmental, and educational records and presents a case summary to the FASD diagnostic team on the day of the diagnostic evaluation.
Phase 2	*Psychometric screening/evaluation*: Diagnostic team members (occupational therapist, psychologist, speech–language pathologist) screen/assess the patient's current neurobehavioral performance (e.g., language and communication, executive function, cognition, sensory–motor skills).
	Physical examination: Physician examines diagnostic parameters of growth and facial dysmorphology (and general health).
	Caregiver(s) interview: Pediatrician and psychologist conduct a 2-hr caregiver interview to query about past and present child behavior, developmental concerns, and the child's current level of function.
Phase 3	*Diagnosis and intervention recommendations*: Diagnostic team reviews and synthesizes data, derives the 4-Digit Code, and generates intervention recommendations.
	Diagnostic summary: Diagnostic team shares the diagnosis and intervention recommendations with caregiver(s) in a brief case conference.
	Diagnostic summary report: Diagnosis, assessment results, and intervention recommendations are integrated into a comprehensive 6–8-page diagnostic summary report and submitted to the patient's medical record.

Note. FAS DPN = Washington state Fetal Alcohol Syndrome Diagnostic and Prevention Network; FASD = fetal alcohol spectrum disorders.

presence of the FAS feature. There are 256 possible 4-Digit Diagnostic Codes, ranging from 1111 to 4444. Each 4-Digit Diagnostic Code falls into 1 of 22 (labeled A–V) unique clinical diagnostic categories. Seven (A–C; E–H) of the 22 diagnostic categories fall broadly under the designation of FASD (A. FAS–alcohol exposed; B. FAS–alcohol exposure unknown; C. partial FAS–alcohol exposed; E and F. static encephalopathy–alcohol exposed; G and H. neurobehavioral disorder–alcohol-exposed). See Astley (2004) for a full description of the 4-Digit Diagnostic Code and diagnostic categories.

Study Population

We applied the following inclusion criteria to the FAS DPN clinical database to establish the study sample: (a) chronological ages, birth through 18.9 years; (b) received a FASD diagnostic evaluation at the core University of Washington FAS DPN clinic between January 2001 and June 2007; (c) received a 4-Digit Diagnostic classification of FAS with confirmed or unknown alcohol exposure, partial FAS–alcohol exposed (pFAS), static encephalopathy–alcohol exposed (SE/AE), or neurobehavioral disorder–alcohol exposed (ND/AE); and (d) signed a consent to allow the use of their clinical data for research purposes. We used records from the core University of Washington FAS DPN clinic because they represented a patient group with clinical recommendations that were procedurally consistent and fully documented in the patients' diagnostic summary reports. Records from 2001 to 2007 contained the most current intervention needs and service availability. Initially, we considered adult patient records for the study but ultimately excluded them because of the relatively small proportion of patients older than 18 years of age seen in the diagnostic clinic.

One hundred ninety patient records met eligibility criteria. From these records, we established three study groups based on 4-Digit Code

INTELLIGENCE AND DEVELOPMENTAL DISABILITIES
Children and youth with FASD

VOLUME 48, NUMBER 5: 330–344 | OCTOBER 2010
T. Jirikowic et al.

diagnostic outcomes. Children in Group 1 had FAS or partial FAS (FAS/pFAS): significant cognitive–behavioral dysfunction with the FAS facial phenotype ($n = 40$). Children in Group 2 had static encephalopathy, alcohol exposed (SE/AE): significant cognitive–behavioral dysfunction broadly comparable with Group 1 but no FAS facial phenotype ($n = 65$). Children in Group 3 had neurobehavioral disorder, alcohol exposed (ND/AE): mild to moderate cognitive–behavioral dysfunction and no FAS facial phenotype ($n = 85$). Previous research has confirmed these three diagnostic subgroups are clinically distinct and span the full continuum of FASD (Astley et al., 2009a).

To balance age, gender, and race–ethnicity across the three FASD study groups, we started with the smallest of the three study groups (FAS/pFAS; $n = 40$) and selected an equal number of records (40 per group) from the eligible SE/AE and ND/AE groups by pair matching on age (within 6 months), gender, and race–ethnicity to each case in the FAS/pFAS group. If multiple records met matching criteria we randomly selected a single record.

Content Analysis

For each patient record reviewed, we examined only the portion of the FASD diagnostic summary report containing the clinical intervention recommendations. We used masked review and content analysis to develop a standard coding scheme for categorizing recommendations (Waltz, Strickland, & Lenz, 2005). The first two authors (T. J. and J. G.), both FASD diagnostic team members for over 13 years, developed the first draft of the coding scheme by reviewing 20 randomly selected, eligible patient recommendation reports (not included in the final study sample). Three additional diagnostic team members from different professional disciplines (e.g., psychology, social work) provided expert review of the clinical relevance, clarity, and completeness of the coding scheme. The first two authors (T. J. and J. G.) revised the coding scheme and assessed interrater reliability on 20 additional eligible patient records (not included in the final sample). After the coding scheme was finalized, the first author (T. J.) used it to code all 120 patient recommendation records (masked to their diagnostic outcome) in the study. Table 2 illustrates the coding scheme with category and subcategory definitions and examples of coded text from the diagnostic summary reports.

Data Analysis

The primary focus of the analysis was to determine if intervention recommendations differed significantly among FASD diagnostic groups, caregiver status, and across age groups. Descriptive statistics (Ms, SDs, and proportions) were used to summarize sociodemographic and cognitive variables, and intervention recommendation categories across study groups. Analyses of variance (ANOVAs) and chi-square tests were used to compare means and proportions, respectively, among the study groups. Significance levels were set at a conventional two-tailed alpha ($\alpha = .05$). Analyses were exploratory, with no adjustment for multiple comparisons, thus p values should be interpreted accordingly.

Results

Sociodemographic Characteristics

The mean age of the total sample was 6.5 years ($SD = 4.1$), with a range of 0.2 to 16.5 years; 53% were male and 60% were Caucasian. Sociodemographic characteristics of this sample were comparable with the entire statewide sample of FAS DPN patients ($N = 1,235$) less than 19 years of age seen since 1993 with similar FASD diagnostic classifications (M age $= 8.0$ years, $SD = 4.1$; 59% male; 49% Caucasian). Sociodemographic and clinical characteristics of the study sample by FASD diagnostic group are presented in Table 3.

At least 56% of children in the sample had confirmed exposure to high levels of alcohol (i.e., 4-Digit Code, Alcohol Scale Rank 4, indicating an exposure pattern consistent with the medical literature placing the fetus at high risk. The remaining 44% of the sample had confirmed exposure, but the actual levels of exposure were low to moderate or unknown (i.e., 4-Digit Code, Alcohol Scale Rank 3; Astley, 2004). Other reported prenatal risk factors included in utero exposure to illicit drugs (70%) and/or tobacco (71%). Eighty-five (71%) children also experienced notable postnatal risk factors. For example, among these 81 children, 55% experienced physical abuse and 31% had been in one or more out-of-home placements. Approximately 30% of the sample had a reported diagnosis of attention deficit disorder with or without hyperactivity. In general, these other risk factors were distributed comparably across the three diagnostic study groups, with one

Table 2. Coding Scheme and Sample Recommendations From Diagnostic Summary Report

Recommendation category and definition	Subcategories	Sample content from diagnostic summary report
1. 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)	Code: 1.1 "Based on observations made in clinic today, this team recommends the use of visual strategies and supports to help James maintain attention and manage his behavior."
2. 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)	Code: 2.1 "James is at high risk for substance abuse later in life, developmentally appropriate substance abuse education that occurs early and often is critical for future prevention.
3. Community-based: 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)	Code: 3.2 "Structured physical activity, such as swimming lessons and/or gymnastics is recommended to help develop balance and gross motor skills."
4. Education/assessment: Referral, advocacy, or support for a specific educational program or service, psychoeducational 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	Code: 4.1 "Sarah's level of adaptive functioning remains quite low. Continued attention to adaptive living skills is strongly recommended. We strongly recommend that Sarah's special education services remain intact as she moves into middle school as we anticipate that this transition will require increased support."

Table 2. Continued

Recommendation category and definition	Subcategories	Sample content from diagnostic summary report
5. *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	Code 5.2 and 5.4 "We recommend continued personal, professional and peer support for parents through organizations such as NOFAS Washington for advocacy and training. We strongly encourage parents to pursue avenues for self-care, including respite care to help them continue parenting as effectively as possible."
6. *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	Code 6.3 "Consultation with a sleep specialist with an overnight sleep study may reveal primary sleep issues impacting late bedtimes, nap refusal and sleep behaviors. Code 6.5 A thorough nutritional assessment to assess failure to thrive is recommended."
7. *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	Code 7.3 "Beth and her family may benefit from counseling. They have done a wonderful job with this complex child but may need support for her behavioral and cognitive issues as she goes through adolescence."
8. *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	Code 8.1 "Language assessment indicates difficulties with unstructured communication, increasing risk for future academic and social problems. An evaluation by an SLP can help determine if reading and writing difficulties have a basis in language impairment."

Table 2. Continued

Recommendation category and definition	Subcategories	Sample content from diagnostic summary report
9. Safety 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)	Codes 9.2 and 9.1 "Because of personal safety issues we recommend that Mary should be in line of sight supervision at all times, in all settings and we recommend that she wear an ID bracelet."
10. 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)	Code 10.1 "Chris would benefit from a stable home environment with structured daily activities. The new foster, and prospective adoptive parents, will need support and education for complex health and behavioral needs.
11. Other	1. Substance abuse recommendations supporting treatment or recovery (caregiver or patient). 2. FASD re-evaluation 3. Other	Code 11.1 "The team highly recommends that Eric's mother continue to access her social and sobriety supports."

Note. FASD = fetal alcohol spectrum disorders; ADHD = attention deficit hyperactivity disorder.

Table 3 Sociodemographic and Cognitive Profiles by Diagnostic Group

Variable	FAS/pFAS (n = 40)	SE/AE (n = 40)	ND/AE (n =40)	Test statistic
Sex: n (%)				
Male	20 (50)	23 (58)	21 (53)	χ^2 = 0.47
Female	20 (50)	17 (42)	19 (47)	
Age (years)				
M (SD)	6.3 (4.2)	6.8 (4.1)	6.4 (4.1)	F = 1.70
Range	0.4–16.5	0.2–15.4	0.4–15.8	
Age (group): n (%)				
0–2 years	8 (20)	9 (23)	8 (20)	χ^2 = 5.90
3–5 years	16 (40)	7 (18)	14 (35)	
6–11 years	11 (28)	18 (45)	13 (33)	
12–17 years	5 (13)	5 (13)	5 (13)	
Race/ethnicity: n (%)				
Caucasian	24 (60)	24 (60)	24 (60)	χ^2 = 0.03[a]
African American	7 (18)	5 (13)	6 (15)	
Native American	4 (10)	6 (15)	7 (18)	
Other	5 (13)	5 (13)	3 (8)	
Primary Caregiver: n (%)				
Biological mother	3 (8)	5 (13)	6 (15)	χ^2 = 2.97
Foster	18 (45)	11 (28)	14 (35)	
Adoptive	9 (23)	13 (33)	9 (23)	
Other relative	10 (25)	11 (28)	11 (28)	
Highest maternal education (reported): n (valid %)	(n = 26)	(n = 28)	(n = 25)	
Some HS	15 (58)	16 (57)	15 (60)	χ^2 = 0.002[b]
HS graduate	8 (31)	9 (32)	8 (32)	
Some college	2 (8)	3 (11)	2 (8)	
College degree	1 (4)	0 (0)	1 (4)	
IQ	(n = 20)	(n = 24)	(n = 21)	
M (SD)	81.0 (16.1)	83.8 (13.1)	96.8 (15.4)	F = 6.64**
Range	60–120	60–103	66–135	

Note. FAS/pFAS = fetal alcohol syndrome/partial fetal alcohol syndrome; SE/AE = static encephalopathy, alcohol-exposed; ND/AE = neurobehavioral disorder, alcohol-exposed; HS = high school.
[a]The groups were collapsed into Caucasian/non-Caucasian to adjust for small samples in some cells. [b]The groups were collapsed into high school graduate or not high school graduate to adjust for small samples in some cells.
*p < .05. **p < .01.

exception. Children with SE/AE (42%) and ND/AE (36%) were significantly more likely to present with other psychiatric diagnosis (e.g., oppositional defiant disorder, reactive attachment disorder) compared with those with FAS/pFAS (13%),

χ^2(2, N = 114) = 8.49, p =.01. The high prevalence of other prenatal and postnatal adverse exposures and events observed in this study sample were comparable with the prevalence observed in the entire FAS DPN clinical sample.
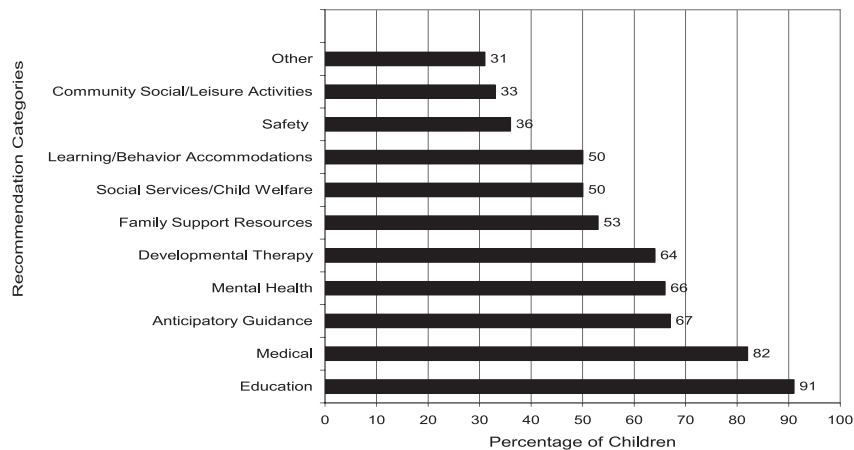
Figure 1 Percentages of children and youths with fetal alcohol spectrum disorders (FASD; $n = 120$) receiving one or more recommendations by category.

Coding Scheme and Interrater Agreement

The final coding scheme (see Table 2) consisted of 11 primary intervention categories each with respective subcategories. Interrater agreement between the first two authors (T. J. and J. G.) on the 11 primary categories exceeded 90%. Intrarater agreement on 11 (10%) records from the final sample was 94%; interrater agreement compared with a masters-level clinical trainee (who was not a diagnostic team member) was 90%.

Primary Intervention Recommendations

The proportion of children with FASD from the entire sample receiving one or more recommendations across each of the 11 primary intervention categories is profiled in Figure 1. The majority of children in this sample received one or more recommendations targeting educational needs. Comprehensive psychoeducational or neuropsychological assessments (50%); special education programs, services, or eligibility (40%); or advocacy to enhance or modify existing educational programs or services (28%) were the most frequent recommendations in the education category. The medical needs of children with FASD in this sample were also high. Medical referrals and recommendations reflected needs for psychiatric care and/or medication management (35%); vision and/or hearing screening (30%); neurological consultation or treatment (22%); attention deficit disorder/attention deficit hyperactivity disorder evaluation or treatment (20%); and growth–small

stature (17%), sleep medicine (14%), or genetic (13%) evaluation or consultation.

Approximately two thirds of children and youth in this sample received mental health, developmental therapy, and/or anticipatory guidance recommendations. Individual counseling (33%), family counseling (20%), or specialized behavior management support (18%) constituted the majority of mental health recommendations. Speech–language assessment or intervention (50%), occupational therapy or physical therapy assessment or intervention (50%), or therapeutic social skills groups (12%) were the most frequent types of developmental therapy services recommended. Substance abuse prevention (51%), prospectively monitoring risks for learning and/or behavioral problems (32%), and attention to reproductive health and safety (e.g., pregnancy prevention; 13%) were the anticipatory guidance recommendations provided most often.

About half of the children and youths received one or more recommendations for family support resources, social service–child welfare support, or learning or behavior accommodations. Caregiver support groups (36%), printed or electronic resources (20%), advocacy training and education (16%), and respite or "self-care" (10%) were the most frequent family resource recommendations. Supportive fiscal resources for caregivers (30%) and advocacy for stable, timely, and appropriate home placements (26%) composed most of the social service or child welfare recommendations. Instructional or behavioral accommodations included

Table 4 Percentages of Children and Youths Receiving One or More Intervention Recommendations by Category Across Diagnostic Groups

Recommendation category	FAS/pFAS ($n = 40$): n (%)	SE/AE ($n = 40$): n (%)	ND/AE ($n = 40$): n (%)
Accommodations[a]	26 (65)	21 (53)	13 (33)
Anticipatory guidance	25 (63)	24 (60)	31 (78)
Community-based program	17 (43)	10 (25)	13 (33)
Education[b, c]	40 (100)	36 (90)	33 (83)
Family support resources	23 (56)	22 (55)	18 (45)
Medical	33 (83)	32 (80)	33 (83)
Mental health	28 (70)	24 (60)	27 (68)
Developmental therapy	26 (60)	25 (63)	26 (65)
Safety	14 (35)	15 (38)	14 (35)
Social services/child welfare	22 (55)	19 (48)	19 (48)
Other[d]	18 (45)	8 (20)	12 (30)

Note: FAS/pFAS = fetal alcohol syndrome/partial fetal alcohol syndrome; SE/AE = static encephalopathy, alcohol-exposed; ND/AE = neurobehavioral disorder, alcohol-exposed
[a]Significant contrast, FAS/pFAS vs. ND/AE: $\chi^2(1, N = 80) = 8.45\ p = .004$. [b]Significant contrast, FAS/pFAS vs. ND/AE: $\chi^2(1, N = 80) = 7.67\ p = .006$. [c]Significant contrast, FAS/pFAS vs. SE/AE: $\chi^2(1, N = 80) = 4.21\ p = .04$. [d]Significant contrast, FAS/pFAS vs. SE/AE: $\chi^2(1, N = 80) = 5.70\ p = .02$.

recommendations for team communication among caregivers and providers (25%) and specific strategies to support learning or behavior in response to executive function (17%), behavior regulation (16%), sensory–motor (14%), or communication (7%) challenges or impairments.

Strategies to enhance personal safety or participate in community-based recreation or leisure activities were important but less frequent recommendations. Procuring personal identification (e.g., ID bracelet; 21%) or enhancing features of the physical (e.g., alarms) or social environment (e.g., line-of-sight supervision; 20%) were among the primary safety interventions made by this team. Referrals to local youth groups, clubs, or programs to facilitate prosocial and/or leisure skill development (23%), physical development (e.g., Special Olympics) (18%), or provide opportunities for adult mentorship (6%) constituted community-based leisure or recreation recommendations.

Primary Intervention Recommendations: Group Contrasts

Table 4 presents the percentages of children receiving one or more primary intervention recommendations by FASD diagnostic group. Intervention recommendations were relatively comparable across the three diagnostic groups, with three exceptions. Children with FAS/pFAS or SE/AE were significantly more likely than children with ND/AE to receive specific instructional or behavioral accommodations. Significantly more children with FAS/pFAS than children with ND/AE received education recommendations. Last, significantly more children with FAS/pFAS than SE/AE received recommendations categorized as *other* ($p < .05$). Recommendations coded as *other* included substance abuse treatment or recovery support for the patient or caregiver, referrals for research studies, or consultation with a diagnostic team member.

Important developmental trends emerged when recommendations were analyzed across four age categories. Figure 2 illustrates recommendations that were significantly different across age groups. A higher proportion of children in the youngest age group (birth–2 years) received recommendations for family support resources, $\chi^2(3, N = 120) = 11.37$, $p = .010$, and social service–child welfare interventions, $\chi^2(1, N = 120) = 20.79$, $p = .000$, compared with children in older age groups. Mental health recommendations and referrals to community-based programs for prosocial recreation or leisure activities, $\chi^2(3, N = 120) = 16.27$, $p =$
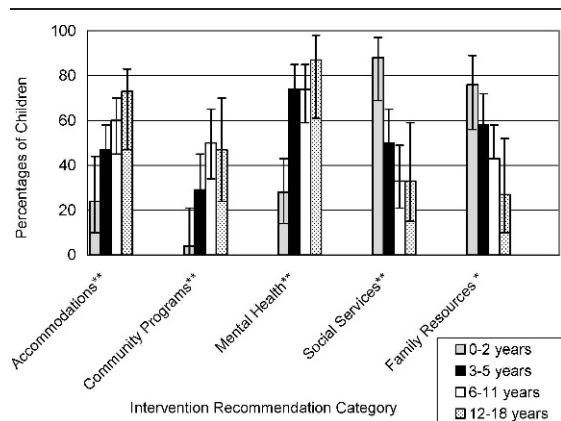
Figure 2 Percentages of children and youth receiving one or more intervention recommendations: significant trends by age group. Error bars indicate 95% confidence interval. *$p \leq .01$. **$p \leq .001$.

.001, were notably higher among children 3 years and older than infants and toddlers (birth–2 years), $\chi^2(3, N = 120) = 11.57$, $p = .009$. Specific behavioral or instructional accommodations also increased with age, with the highest proportion seen among children in the oldest age group (12–18 years), $\chi^2(3, N = 120) = 11.57$, $p = .009$. Figure 3 illustrates recommendations that were comparable across age groups.

Overall, intervention recommendations were relatively consistent across caregiver status (i.e., biological mother, foster parent, adoptive parent, or
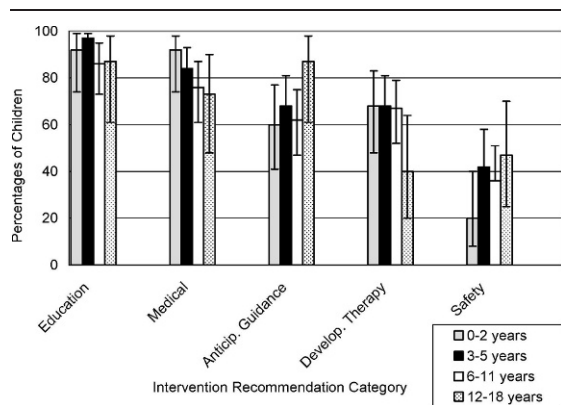

Figure 3 Percentages of children and youth receiving one or more intervention recommendations: nonsignificant trends by age group. Error bars indicate 95% confidence interval.

other) with two exceptions. Children with a foster caregiver were significantly more likely to receive social service–child welfare recommendations than children with adoptive parents, $\chi^2(1, N = 74) = 15.48$, $p = .001$; birth parents, $\chi^2(1, N = 57) = 6.00$, $p = .014$; or other caregivers, $\chi^2(1, N = 75) = 3.83$, $p = .05$. In addition, children in the care of an adoptive parent were significantly more likely to receive recommendations for community-based leisure or prosocial recreational activities than foster caregivers, $\chi^2(1, N = 74) = 4.94$, $p = .03$, although more than half of children living with their birth mothers also received recommendations in this category. The type and frequency of recommendations were generally consistent across gender for the entire sample. One exception was that females were significantly more likely (82%) to receive one or more recommendations categorized as anticipatory guidance than males (53%), $\chi^2(1, N = 120) = 11.32$, $p = .001$.

Discussion

This retrospective analysis sheds light on the type and frequency of supports, services, and referrals recommended by an interdisciplinary diagnostic team for children and youths who received a FASD diagnosis. Findings indicate 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 fetal alcohol spectrum, regardless of diagnosis.

Several important developmental trends also emerged. Though not surprising, this is notable because children with FASD are often diagnosed at different ages, and some disabilities associated with prenatal alcohol exposure may not be evident until school age. Furthermore, a large proportion of children in this sample experienced other prenatal (e.g., exposure to tobacco or illicit drugs) and postnatal (e.g., multiple home placements, abuse, neglect) risks. Although these children received a diagnosis under the umbrella of FASD, prenatal alcohol exposure was clearly not the only risk factor that may have impacted their development and needs at the time of diagnosis. Detailed neuropsychological, behavioral, and mental health profiles

of children from the same clinical population with the same FASD diagnostic classifications (FAS/pFAS, SE/AE, and ND/AE) have been described by Astley et al. (2009b) and provide more perspective on the needs and developmental challenges underlying these clinical recommendations.

The large percentage of children receiving educational recommendations reflects the well-substantiated and elevated risks associated with prenatal alcohol exposure and learning and academic achievement for individuals across the fetal alcohol spectrum (Riley & McGee, 2005; S. Ryan & Ferguson, 2006). Comprehensive developmental or educational assessments were frequently recommended as a means to more thoroughly evaluate neurobehavioral or neurocognitive concerns impacting school performance. Although the amount of neuropsychological and behavioral assessment data available at the time of the diagnostic evaluation is sufficient to render an accurate diagnosis, a child will often benefit from additional neuropsychological–behavioral assessments to guide individualized intervention efforts. Special education programs and services were also noticeably perceived as necessary sources of academic support for many children with FASD, but the need to consider alternative instructional approaches, monitor academic risks, or advocate for specific interventions (e.g., transition support, functional behavior analysis) was evident.

The learning and behavior accommodations we provided these children give additional insight into the neurobehavioral challenges experienced by children with FASD. The types of accommodation strategies recommended were congruent with domains (e.g., communication, executive function, sensory–motor, and behavior regulation) commonly associated with the adverse effects of prenatal alcohol exposure (Astley et al., 2009b, Church & Kaltenbach, 1997; Coggins, Olswang, Olson, & Timler, 2003; Jirikowic, Olson, & Kartin, 2008; Rasmussen, 2005; Riley & McGee, 2005). The scope and variability of the accommodation strategies identified within each neurobehavioral domain also underscore the need for interdisciplinary approaches to diagnosis, assessment, and intervention.

Service providers should be aware of and prepared to consider an array of educational resources, supports, and services for children with FASD. Emerging evidence supports the use of targeted instructional strategies for children with FASD (e.g., for mathematics, safety, and social skills; Kable, Coles, & Taddeo, 2007; O'Connor et al., 2006) as well as behavioral interventions that provide caregiver education, behavioral reframing, and environmental accommodations (Olson et al., 2005). Differentiated instruction, accommodations that enhance external structure and environments (e.g., visual supports), and learning and functional expectations congruent with neurobehavioral abilities appear to be meaningful and important treatment considerations for children with FASD (Clarren, 2004; Kalberg & Buckley, 2007).

Referrals for primary and specialized medical care also constituted a large proportion of the intervention recommendations we made. Several concomitant health, developmental, and psychopathological concerns among this group of children with FASD were revealed. The types of referrals and services that were often advised reflect body structures and functions reported as more vulnerable to the teratogenic impact of prenatal alcohol exposure (e.g., vision, hearing, CNS) as well as the adverse and cumulative impact of other prenatal and postnatal risk factors (Stratton, Howe, & Battaglia, 1996). As such, these findings alert providers to areas of health and development that may benefit from screening, as well as referrals to, and/or treatment by appropriate medical specialists.

A clear need for mental health services, particularly for children older than 3 years of age with an upward trend through adolescence, also emerged. As in other studies of individuals with FASD, mental health or psychiatric conditions were reported across the full range of diagnosis in this sample (Astley et al., 2009b; Streissguth & O'Malley, 2000; Streissguth et al., 2004). Prenatal alcohol exposure has also been considered a risk factor for attachment problems and later psychopathology (O'Connor et al., 2002; O'Connor & Paley, 2006). As such, infant mental health interventions, which have been found useful among other biologically and ecologically vulnerable children (Fisher, Gunnar, Dozier, Bruce, & Pears, 2006) warrant more attention and research among young children with prenatal alcohol exposure and FASD.

Despite a lack of formal infant mental health services, advocacy for important protective factors early in life (Streissguth et al., 2004) were among the social service– or child welfare–related recommendations received by many of the youngest children. As expected, a higher proportion of these

recommendations were received by children in foster care at the time of the diagnostic evaluation, presumably to optimize responsive and stable caregiving environments.

Although parent education and family support resources were a clear priority for caregivers of young children, the frequency of these recommendations did not occur uniformly across older age groups in this sample. This is surprising because education and resources to support and empower caregivers and families are important considerations for parents of children with disabilities across all ages and through different stages of development (Douma, Dekker, & Koot, 2006). One possible explanation is that caregiver education and support are inherent throughout the diagnostic process of this clinic; therefore, the breadth of caregiver support provided was not formally documented for all patients.

Last, diagnosis also serves as an important point of intervention for anticipatory guidance and primary prevention. Although most children and caregivers received some type of anticipatory guidance during their clinic visit, only about half of the children and youth across the entire sample received specific recommendations for substance abuse prevention. As a recognized and critical need with this population, developmentally appropriate substance abuse education that occurs early and often in life has since become a standard recommendation for all patients in this diagnostic clinic.

Findings need to be considered within the context of several study limitations. The recommendations were generated by a diagnostic team within the context of a tertiary care setting. Recommendations were made in the geographic context of a large metropolitan area; therefore, they reflect, in part, the availability of local programs, services, and resources at the time of diagnosis. These factors may limit generalizability of findings. However, this study is the first to describe clinically derived intervention recommendations using a large, representative, clinical sample of children from a Washington-state FASD diagnostic specialty clinic. As such, these results profile and benchmark child and family needs and priorities identified during a FASD diagnostic assessment, a critical point in the continuum of care for individuals affected by prenatal alcohol exposure.

Results from this descriptive study raise several questions regarding the outcomes of these intervention recommendations. Future research should investigate the success with which families access and implement the recommended services, resources, and supports after receiving an alcohol-related evaluation and diagnosis. The perceived short- and long-term value of the intervention recommendations should also be investigated, as developmental needs often change over time. Furthermore, the supports and services needed by adults with FASD remain important to examine, given the lifelong disabilities associated with FASD.

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