

Specialized Neurodevelopmental Assessment and Consultation Service: An Innovative Clinic Model for Children with Prenatal Alcohol Exposure Based at an Autism Center

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Abstract

Background: While global prevalence of conditions on the fetal alcohol spectrum is surprisingly high, there is insufficient diagnostic capacity so children can be missed or misdiagnosed. This study described an innovative clinic model for screening prenatal alcohol exposure (PAE), assessing children using the DSM-5 diagnostic category for conditions on the fetal alcohol spectrum, and providing consultation.

Methods: A retrospective review of 40 child patients with PAE examined feasibility of the clinic model.

Results: Overall, the SNACS Clinic served families across a wide demographic range raising preschool and school-aged children with diverse neurodevelopmental and behavioral presentations. Study findings informed ongoing quality improvement of the clinic model, and identified provider and hospital-wide training needs.

Conclusions: Findings indicate this clinic is feasible as a method for increasing diagnostic capacity, improving patient services, and potentially preventing misdiagnosis or missed diagnosis of children with PAE. Results can inform best practices for FASD-informed care.

Background

The estimated prevalence of fetal alcohol spectrum disorders (FASD) in the United States ranges from 1%, conservatively, to 5% using active case ascertainment methods (1). The global prevalence of FASD among children and youth in the general population, using less sensitive ascertainment methods, is estimated to be 7.7 per 1000 population (2). The surprisingly high prevalence of FASD has galvanized public health discussion about prevention, targeted screening and, especially, improved diagnostic and treatment services.

Children and youth with conditions in the category of FASD have wide-ranging deficits in neurodevelopment and behavior. As they grow older, they often show significant life challenges (3). Diagnosis of these children and youth has typically been accomplished through “gold standard” team evaluations generating a diagnosis within interdisciplinary FASD clinics that have slowly been created over the past two decades. Yet there are still a very limited number of these FASD specialty clinics, and many countries lack targeted services for children who present with prenatal alcohol exposure (PAE). Given the high prevalence and global reach of this public health problem, there is clearly insufficient diagnostic capacity. As a result, many children with PAE and evidence of neurodevelopmental deficits, who would meet criteria for a condition in the category of FASD, have limited or no access to appropriate diagnostic services. Because PAE affects many domains of neurodevelopmental and behavioral functioning, it is likely that children with PAE present in a wide range of settings. This may include clinics focused on other neurodevelopmental disorders [e.g., autism spectrum disorder (ASD)], or at child development and outpatient mental health centers. In these settings, where provider knowledge of the teratogenic effects of PAE may not be available, the highly variable and often unusual

neurodevelopmental concerns of these alcohol-exposed children and youth may go unrecognized or misdiagnosed.

To augment diagnostic capacity and improve patient care, one strategy is to create an innovative and feasible specialty mental health-oriented clinic that can be based in community settings with an accessible diagnostic approach where these children and youth are likely to present. While not a replacement for an interdisciplinary FASD diagnostic team, a specialty mental health clinic can accurately and sensitively: (1) screen for the presence of PAE and other risk factors; and (2) identify children and youth affected by PAE using mental health (DSM-5) diagnostic criteria. This type of clinic could also provide short-term FASD-informed consultation, referrals, and time limited treatment using a scientifically validated program. If needed, families could then be referred for a “gold standard” interdisciplinary team diagnosis [e.g.,see (4)] already armed with recommendations and psychoeducation to support them during the often long waiting periods required to obtain a team evaluation [see (5) for barriers relayed by parents of children with FASD and providers]. The availability of a feasible, flexible clinic model that can be deployed in appropriate mental health settings may reduce the serious, possible “missed diagnosis or misdiagnosis” that can occur with the many individuals who are affected by PAE (6).

To this end, an innovative clinic model for screening PAE and diagnosing conditions in the category of FASD was developed, piloted, and subjected to continuous quality improvement (QI) over several years. Termed the “Specialized Neurodevelopmental Assessment and Consultation Service” (referred to as the “SNACS Clinic”), this model was created based on precedents from the field of FASD diagnosis and treatment, along with standards of excellence for mental health care and services for neurodevelopmental disorders. Its short-term assessment and consultation format has similarities to therapeutic assessment models found to be effective for infants and children with developmental and behavioral problems (7,8). In this pilot project, the SNACS Clinic was carefully embedded in a hospital-based Autism Center, given that autism spectrum disorder (ASD) specialty centers are one location where children impacted by PAE may be misreferred.

While the SNACS Clinic is flexible enough to be embedded into other mental health and child development settings, an Autism Center was a prime location to pilot this model. Case reports and a few small longitudinal studies suggest there is an overlap between FASD symptoms and those of ASD, and this may increase misreferrals of alcohol-affected youth to Autism Centers (9–14). Highlights of the limited FASD-ASD comparison literature reveal similar social deficits, including socially inappropriate behavior and challenges with peer relations, unusual sensory responses, and rigidity among both those with FASD and ASD. However, individuals with an FASD are characterized as more often showing indiscriminate friendliness and a higher degree of social initiation than those with ASD (10). Therefore, it is vital to have a viable clinical mechanism to differentiate children with a diagnosable FASD from those with ASD or other mental health and neurodevelopmental conditions so these youth can be provided with FASD-informed care and appropriate interventions.

The SNACS Clinic was designed with two patient care objectives: (1) to accurately identify and diagnose children (2 to 16 years) who meet criteria for PAE using the proposed DSM-5 “neurobehavioral disorder associated with prenatal alcohol exposure” (ND-PAE) mental health diagnostic criteria (15), and other mental health diagnoses as appropriate; and (2) to meet the complex needs of children with PAE and their families by providing caregivers with service delivery based on a scientifically validated family-focused treatment for this population (i.e., Families Moving Forward (FMF) Program) (16,17). As the SNACS Clinic evolved, two additional patient care objectives emerged: (3) to serve patients and providers by providing consultation or diagnostic clarification on questions regarding the differential between ASD vs. ND-PAE; and (4) to provide provider consultation about the implications of PAE for treatment recommendations. The SNACS Clinic also offers education and training about this clinical population to graduate students and post-graduate fellows in psychology and related fields, given that limited provider knowledge about this set of neurodevelopmental disabilities is the most significant barrier to care for individuals with FASD and their families (5).

The current paper describes the innovative SNACS Clinic model of FASD-informed short-term assessment and consultation, including QI efforts, and presents clinic feasibility data. To the authors’ knowledge, this is the first paper to describe this type of clinic. Findings describe a flexible clinic model for possible replication to improve diagnosis and FASD-informed treatment when an interdisciplinary team evaluation is not available or readily accessible.

DSM-5 Definition: Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (ND-PAE)

ND-PAE was introduced into the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) in 2013 as a proposed “condition for further study.” It was also given as a designated specifier in Chapter 1 on Neurodevelopmental Disorders under “Other Specified Neurodevelopmental Disorder” (315.8; ICD-10 code F88) (15). ND-PAE was proposed as a diagnosis because there was no specific mental health diagnosis that adequately documented the full cognitive, behavioral regulation, adaptive functioning, and mental health impact of prenatal alcohol exposure. Olson has provided guidelines for the clinical use of ND-PAE (18), Hagan et al. offers a careful overview of ND-PAE (19), and Kable et al. reviews the considerable amount of research supporting recognition of this condition (20). ND-PAE is currently undergoing empirical validation, with initial studies supporting good internal validity and inter-rater reliability (21,22).

In the current definition, ND-PAE requires confirmed PAE, at least at a “more than minimal” level (i.e., exposure to more than “light drinking” during pregnancy) – and evidence of significant impairment in three domains: neurocognitive (one symptom required), self-regulation (one symptom required), and adaptive function (two symptoms required, one of which must be a communication deficit or impairment in social communication and interaction). DSM-5 defines light drinking during pregnancy as 1-13 drinks per month with no more than two of these drinks consumed on any one drinking occasion. In ND-PAE, disorder onset must occur in childhood, with the disturbance causing clinically significant distress or impairment in social, academic, occupation, or another important area of functioning, and must not be

better explained by the direct physiological effects associated with postnatal use of a substance, a general medical condition, another known teratogen, a genetic condition, or environmental neglect.

The ND-PAE diagnostic classification is complementary to, but different from, the evolving range of current diagnostic guidelines for FASD developed for research and also used clinically (e.g., Emory FAS Clinic, The 4-Digit Diagnostic Code, Centers for Disease Control and Prevention and Fetal Alcohol Syndrome Task Force Guidelines for Diagnosis, Canadian Guidelines revised Institute of Medicine diagnostic criteria, Australian Guidelines, Scottish Guidelines, German Guidelines Version 2013, and ICD-10 Coding Guidelines). Referring to conditions across the fetal alcohol spectrum, these systems include diagnostic terms such as “fetal alcohol syndrome” (FAS), “partial FAS,” “alcohol-related neurodevelopmental disorder” (ARND), or other diagnostic terms such as “static encephalopathy, alcohol-exposed” or “neurobehavioral disorder, alcohol-exposed.” Policy discussion to reach general expert consensus on diagnostic guidelines and needed programmatic research is currently underway. For now, using ND-PAE diagnostic criteria from the DSM-5, mental health providers can describe the effects of PAE in terms of symptoms among individuals who may or may not have accepted physical signs (e.g., growth impairment, facial dysmorphology). The diagnosis of ND-PAE can be rendered alone, or more specifically noted as “without dysmorphia” or “with dysmorphia” (when physical signs are present). The diagnosis of ND-PAE can be accompanied by diagnosis of other co-occurring mental health conditions.

PAE can affect central nervous system (CNS) development in many ways, and at any point during gestation, resulting in a wide variety of neurobehavioral outcomes which are being defined by accumulating research (3). Because exposed individuals can have very different outcomes, experts have found it is useful to identify the profile of neurobehavioral effects arising from PAE unique to each child or youth, which can lead to “primary” learning and behavioral deficits. In the context of individual risk and protective influences, these deficits can result in “secondary” conditions (i.e., difficulties in lifestyle and daily function) (23,24). Neurobehavioral effects need not be accompanied by sentinel physical signs, such as growth impairment or dysmorphic features. In fact, in studies by Astley (2010) and Reid et al. (2017), the majority of diagnosed children did not have characteristic physical features. Using the 4-Digit Diagnostic Code guidelines for team evaluation, Astley (2010) reported that of 1400 individuals with PAE, a minority showed physical signs (e.g., 4% were diagnosed with FAS, 7% with pFAS). The remainder showed only CNS dysfunction (e.g., 28% were given a diagnosis of static encephalopathy alcohol-exposed, and 52% a diagnosis of neurobehavioral disorder, alcohol exposed). Importantly, it is the neurobehavioral effects, not the physical signs, that cause functional and lifestyle challenges for affected individuals and their families.

Methods

The current study examined feasibility of the SNACS Clinic to determine its use as an innovative model for short-term assessment and consultation for children with PAE, employing the ND-PAE mental health diagnostic criteria. Feasibility data were utilized for quality improvement (QI), with clinic procedures iteratively adapted while keeping the conditions of the Autism Center location in mind. While the SNACS

Clinic described here was based at an Autism Center, study results can apply to implementation of this clinic model when based at other locations. The clinic procedures outlined below represent the SNACS Clinic's most up to date procedures. QI methods essential to initial development, and to continued iterative development of the SNACS Clinic, include systematic data guided activities, designing with local conditions in mind, and iterative development and testing. These QI principles are further discussed in (27)).

Procedures: Full description of the SNACS Clinic model

The SNACS Clinic model includes a referral system followed by a structured triage process, a service delivery model, and ongoing QI procedures (shown in Figure 1). The target patient population includes children and youth aged 2 to 16 years, and their families, with very diverse demographics. The SNACS Clinic has been staffed by mental health providers (i.e., fields of clinical psychology, school psychology, and neuropsychology) who specialize in how PAE or other prenatal exposures, and neurodevelopmental disabilities, affect children and youth and their families. Currently, lead providers have been at the doctoral level (attending psychologists and postdoctoral fellows). Trainees in graduate programs (Master's and PhD) have also been involved and are helpful in augmenting the clinic work force while also receiving high-quality training.

Referral System

The SNACS Clinic is based in an Autism Center; therefore, referrals come through that infrastructure, which is further integrated within a larger Children's Hospital electronic referral and insurance review systems. In the early pilot phase, a limited number of external community referrals and patient self-referrals were accepted. Over time, capacity limitations and the need to ensure the fit of the referral and family needs with the service model led to a gradual elimination of disparate referral streams and a focus primarily on "internal" referrals. Once clinic procedures stabilized, internal referrals primarily came from providers in the Autism Center, a growing array of Children's Hospital clinics, and a few selected community service providers serving a high proportion of children with PAE (e.g., adoption medicine clinic).

Triage Process

A structured triage process was developed to maximize the possibility that all patients seen in the SNACS Clinic had: (1) confirmed or strongly suspected PAE; and (2) caregivers who were interested in exploring the possibility of an ND-PAE diagnosis (e.g., a condition on the fetal alcohol spectrum). Before SNACS Clinic scheduling, designated SNACS clinicians carry out an efficient but thorough chart review, noting documentation of any previous FASD-related evaluation, available information on presence and pattern of PAE, and available evidence of likely impairment in the three categories identified in the ND-PAE diagnostic criteria. It is important to note that because ND-PAE is a mental health diagnosis, and facial features are not assessed in the SNACS Clinic, confirmed or strongly suspected exposure is required for clinic eligibility. This means that the rare child displaying characteristic facial features without known

PAE, who could have the full fetal alcohol syndrome (FAS), might be missed by this clinic. If evidence of characteristic dysmorphism is made known in records, photographs, or by the caregiver or referring provider, SNACS Clinic staff refer such a child for medical evaluation, and to an interdisciplinary FASD Clinic. Overall, the triage phone call also allows for a “warm hand-off” for birth parents and kinship caregivers, who have been found to have higher levels of psychological distress and barriers to accessing care than caregivers in other family structures (28,29).

Service Delivery Model

The SNACS Clinic model provides mental health care, which means billing of insurance or governmental health care funding can occur. Patients are scheduled for a 3 to 5 session SNACS Clinic sequence involving overlapping assessment and consultation phases. Visits are 90 minutes in length, though amount of the time spent in direct child testing can vary. Typically, assessment billing codes are used for the first three sessions and therapy billing codes for up to two additional sessions. Therapy billing is often for family therapy since caregiver consultation is emphasized. The consultation phase provides feedback on the child’s functional profile across developmental domains, customized recommendations, and then individualized short-term consultation specific to family needs using specialized materials for this clinical population.

Materials Used In Service Delivery

The SNACS Clinic uses materials (i.e., Fact Sheets, Worksheets, Session Outlines, SNACS Specialist materials/work aids), procedures, and the logic model of the scientifically validated Families Moving Forward (FMF) Program (16,30). SNACS clinicians are initially trained in the FMF Program intervention and use a selected set of FMF Program materials that have been specifically adapted for the SNACS Clinic.

Assessment Phase

Assessment begins with a collaborative conversation with the child’s caregiver, and the child if appropriate, to formulate questions for the SNACS sequence. The assessment always includes questions that assist with determining whether a child meets criteria for ND-PAE, but also often includes items about the impact of other risk factors such as trauma or polysubstance exposure. Clinicians then gather additional medical, developmental, family and social history needed to complete a child’s developmental history, to provide insight into the three domains of impairment relevant to the ND-PAE diagnostic criteria, and to inform presenting questions posed by the caregiver and referring clinician. SNACS clinicians also carefully and sensitively collect specific information on prenatal exposures (and other prenatal/postnatal risk factors), including documentation of pattern of exposure. At the end of the first session, each family receives parent and teacher questionnaires. The questionnaire battery includes measures of adaptive function, broad behavioral and emotional functioning, executive function, sensory differences, social communication, and an autism screening instrument. Additional questionnaires, such as anxiety measures, are provided as necessary to evaluate particular presenting problems.

Depending on their scope of practice, and the extent of previously available and recent testing, SNACS clinicians supplement interview and questionnaire data with hypothesis-driven direct testing. Testing is done as appropriate and necessary to answer questions related to domains of impairment related to ND-PAE. The questionnaire and direct testing battery was informed by Doyle and Mattson's (2015) review of evidence and guidelines for assessment of ND-PAE, and by experience in FASD specialty diagnostic clinic team evaluations.

Mixed Assessment and Consultation Phase

An essential aspect of the SNACS Clinic feedback process is providing parent feedback using visual aids to support verbal feedback. The FMF Program Child/Youth Profile Graph was developed to increase caregiver understanding of their child's unique profile of relative strengths and weaknesses. This helps caregivers "reframe" their understanding of their child's difficulties in light of brain-based disabilities (neurodevelopmental disorders), and based on an understanding of alcohol as a neurobehavioral teratogen. A SNACS Clinic visual aid helps educate families about the ND-PAE diagnosis and co-occurring mental health diagnoses. Given this understanding, caregivers and SNACS clinicians work together to ascertain areas of relative weakness and growth for the child that require accommodations, and strengths and protective factors that can be drawn upon for success. As part of the mixed assessment and consultation phase, caregivers also receive customized written recommendations informed by child and family needs, and by knowledge of recommendations useful for this clinical population.

Consultation-Only Phase

The SNACS Clinic consultation phase is usually provided in 1 to 2 modular sessions, using selected FMF Program materials. Consultation sessions afford the clinician additional time to support the family in understanding assessment results and connecting these results to their understanding of their child, emotionally and cognitively processing the results and their implications, and taking first steps towards enacting recommendations. Models that include similar therapeutic and family-systems elements, such as collaborative and therapeutic assessment, find that this approach improves engagement with the assessment, improves the caregiver's ability to carry out recommendations, enhances the caregiver's view of their child, and increases self-efficacy and hope, all of which are especially relevant to families of children with PAE (31).

Examples of common consultation sessions include: (1) Further discussion of assessment results, focused on gaining an understanding of how tests results may or may not reflect the "whole child." This discussion often includes understanding co-occurring diagnoses, the impact of complex developmental trauma, and/or the impact of other prenatal exposures; (2) Provision of some level of anticipatory guidance and advocacy education. This often includes discussion of caregiver reactions to their child's diagnosis and the idea of talking to their children about their diagnosis and PAE; and/or (3) Using data from the assessment phase to provide consultation to caregivers on environmental and caregiver behavior accommodations that may help to improve their child's functioning.

After the SNACS Clinic sequence, families are transitioned to (or back to) ongoing care by offering targeted provider consultation, facilitating referrals, assisting caregivers in applying for services with social service agencies, and coordinating with schools or providing targeted school consultation. True to the FMF Program, the consultation involves techniques such as motivational interviewing, positive behavior support, and cognitive-behavioral therapy focused toward the caregiver, providers and school staff to help see the advantages of learning about ND-PAE and prenatal exposures to inform how they understand and treat the child.

Chart review of SNACS Clinic files

Sample

A retrospective review was completed for charts of 40 SNACS patients seen for complete assessments in the SNACS Clinic from December 2015 to June 2019. The period reflects up-to-date and relatively stable SNACS Clinic service delivery, although the referral system and triage process have continued to co-evolve and be refined. Within this period, a total of 46 cases were seen in the SNACS Clinic. From this initial sample, 6 cases were excluded due to patient/family drop out before completion of the assessment and diagnostic portion of the SNACS Clinic visit sequence. After applying these exclusion criteria, a total of 40 cases were available for review. This resulted in an 87.0% retention rate between December 2015 and June 2019.

Data Storage and Coding Procedures

A secure online REDCap database, meeting HIPAA compliance standards, was created to store extracted data. Two independent coders completed a review of the 40 complete SNACS Clinic cases. Coders extracted demographic information, information on PAE, diagnostic outcome of the original SNACS Clinic assessment, and information on impairment related to ND-PAE criteria.

Data extracted included demographic and PAE variables. Demographic variables included gender, age at intake, zip code (used to derive a mean yearly income from U.S. Census Bureau income statistics), primary caregiver relationship to patient (e.g., birth parent, adoptive parent, foster parent, or kinship placement), primary caregiver marital status, and discipline of the referring provider (e.g., ARNP, M.D., Ph.D.). Another variable was diagnostic outcome, coded based on the original SNACS Clinic feedback reports which integrated all available data and rendered a final diagnosis. See Figure 2 for definitions of possible diagnostic outcomes.

Bi-weekly meetings were held to discuss patient chart reviews with agreement under 80%, and coders came to consensus. Twenty percent of patient charts were completed by both independent coders and used for interrater reliability. Independent coders met 90% interrater reliability for this more complex coding process (32).

Analyses

Descriptive statistics were used to evaluate demographics, data on presence of PAE, and quality of PAE information. Frequency counts were used to quantify type of referral path for patients seen in the SNACS Clinic, SNACS Clinic diagnostic outcomes, and SNACS Clinic diagnostic outcomes by family structure type.

Results

Demographics

Table 1 presents demographics for the sample of SNACS patients ($N=40$). Mean patient age at time of the SNACS intake session was 8.9 years, with a majority of male patients. Family structure data for the SNACS Clinic sample was variable. The largest subgroup (43%) resided with adoptive parents, while only 20% resided with birth parents. . Mean estimated yearly household income, derived from income statistics for zip codes, was \$86,388.

Type of Referral Path

Most (62%) referrals came internally from the Autism Center ($n=25$), where the SNACS Clinic is based. Over a third (30%) came internally from a variety of Children's Hospital clinics ($n=12$). Of these, most came from the Neurodevelopmental Clinic, Child Psychiatry Outpatient Clinic, Sleep Disorders Clinic, and hospital-affiliated community mental health clinic. Finally, despite the eventual elimination of community referrals, included in this sample was a small number of self-referrals ($n=3$) who had learned about the SNACS Clinic despite no community publicity.

The majority of referrals were made by ARNPs ($n=21$), who typically perform most intakes at the Autism Center, and often do intakes in other clinics. Referrals were also made by doctoral-level psychologists ($n=6$) and psychiatrists ($n=8$), with a few by Master's level clinicians ($n=2$). The small number of external referrals were, as is standard for the hospital referral system, technically referred by the patient's primary care provider (PCP), who might be a physician, ARNP or other type of health care professional.

Interestingly, of SNACS patient referrals from the Autism Center, over half ($n=16$) completed an autism evaluation prior to a SNACS Clinic referral. Of these 16 children, one quarter ($n=4$) carried an ASD diagnosis prior to being seen in the SNACS Clinic. Of patients seen in the SNACS Clinic with an ASD diagnosis, only one patient was diagnosed with ND-PAE and received a dual diagnosis of ND-PAE and ASD. SNACS clinicians were in a unique position to: (1) assist with a differential or dual diagnosis when ASD was in question; (2) consult on the child's profile of relative strengths and weaknesses; and (3) provide insights on how the biological risk factor of PAE might impact treatment recommendations.

ND-PAE Diagnostic Outcomes

Given the complexity of the SNACS Clinic patient population, over time, the SNACS Clinic process moved from a rule-out diagnostic clinic to a full differential diagnostic approach (rendering other diagnoses when applicable). Results indicate these diagnoses were primarily attention deficit/hyperactivity disorder,

anxiety disorders, learning disorder, trauma and stressor-related disorders, and disruptive, impulse control, and conduct disorders. Of the 40 patients reviewed, 22 (55%) were diagnosed with ND-PAE. When insufficient information was available to indicate more than minimal PAE, or to indicate CNS impairment related to ND-PAE criteria, but clinicians felt this information might be available in the future (i.e., ability to view birth records after adoption, ability to reliably test IQ at a later age), they sometimes maintained ND-PAE as a rule out diagnosis. This meant seven SNACS Clinic patients (17.5%) left with a rule out diagnosis of ND-PAE. In addition, there were eleven children (27.5%) where ND-PAE was ruled-out during the course of the SNACS assessment (i.e., were not given a diagnosis of ND-PAE and were not left with a rule out diagnosis of ND-PAE). In an effort to improve ND-PAE diagnostic reliability in clinical practice, including use of the “rule out ND-PAE” term, a paper is underway to discuss ND-PAE diagnostic reliability within the SNACS Clinic.

ND-PAE Diagnosis and Family Structure

For the 22 children meeting criteria for ND-PAE in the original SNACS Clinic evaluation, Figure 3 depicts frequency by family structure type. The largest group of patients (23%) were brought in by adoptive parents ($n=9$). Rates were fairly similar for patients brought in by birth parents ($n=5$), from kinship placements ($n=4$) and by foster parents ($n=4$).

Discussion

This paper describes an innovative clinic model called the Specialized Neurodevelopmental Assessment and Consultation Service (SNACS Clinic). Findings indicate this clinic is feasible as a method for increasing diagnostic capacity for children with PAE, potentially preventing misdiagnosis or missed diagnosis, and improving patient access and care. Developing and implementing the SNACS Clinic on a pilot basis has meant multiple challenges, with many innovative solutions. The current research describes a specialty clinic model that could be replicated in settings with sufficient resources and expertise.

For this study, the SNACS Clinic was based in an Autism Center as one likely location where children with PAE and neurodevelopmental disabilities might be referred and screened, and could then be efficiently referred for appropriate diagnosis. Given its location, there has been clear demand in the clinic for differential or dual diagnosis of ASD versus ND-PAE. At times, there has been significant need for consultation on what additional insight knowing about prenatal exposures can offer to a family in the context of an existing ASD diagnosis. Meeting this patient care objective has been a challenge for SNACS clinicians and trainees. The ongoing need for customized provider education has meant time spent reviewing the rapidly evolving FASD literature, the small comparison literature on ASD versus FASD, and specifics of ND-PAE diagnostic criteria. Interestingly, in this sample only one SNACS Clinic patient was given a dual diagnosis of ASD and ND-PAE, and in several cases a sole diagnosis of ASD appeared to be the best explanation for the child’s symptom configuration after the SNACS sequence was completed. In response to the need for provider education, SNACS clinicians developed a parent handout [SNACS/FMF

Fact Sheet available at <https://depts.washington.edu/fmffasd/home> (33)] on ASD and the limited ASD-FASD comparison literature, and have carefully collaborated with providers specializing in ASD on specific cases. But to truly meet this patient care need, more thorough, updated, and clinically relevant comparison research on ASD versus FASD is sorely needed.

Since the SNACS Clinic was created, there has been a growing demand for provider education and consultation on PAE and its effects from providers at the Autism Center and in other clinics in this pediatric hospital setting. As a result, the SNACS Clinic has cross-trained providers from various backgrounds including psychiatrists, nurse practitioners, psychologists, and pediatricians. Requested topics for consultation and education have included how to assess prenatal exposures, the importance and benefits of ND-PAE/FASD-informed care and treatment, identifying appropriate referrals for the medical diagnosis of FASD through team evaluation or mental health diagnosis of ND-PAE, the process for accessing an evaluation, and treatment resources all over the state. Information has been provided through presentations and provider/trainee observations, with standard training materials under development. Results of the current paper will guide education efforts for providers and trainees.

There has been a growing need for SNACS Clinic services, with recent requests from the inpatient psychiatric unit for fast-track consultation and referral, interest in the adaptation of the SNACS Clinic model for a juvenile rehabilitation center, and diagnostic clarification and consultation from a hospital-based early childhood clinic. The latter has posed several challenges, particularly when young children with prenatal alcohol exposure do not yet show sufficient impairment in areas required for an ND-PAE diagnosis, but who may present with physical findings. In addition, the lack of psychological measures to assess early markers of executive functioning in this age range also pose a challenge. Current FASD diagnostic schemes show the greatest confidence, accuracy, and reliability in school-aged children. This means that current efforts to establish assessment and consultation procedures for young children with PAE for the SNACS Clinic will be informed by emerging research on the early-life predictors of FASD (34). For example, a possible recommendation would be to consider the use of developmental assessments sensitive enough to identify delays common in young children with prenatal alcohol exposure (e.g., motor, language, sensory differences). The SNACS Clinic has also built a referral pathway to the university-based interdisciplinary FASD Diagnostic Clinic for situations where a team evaluation may be indicated, and a pathway back to SNACS when FASD-informed consultation services are needed.

Slightly different challenges related to youth over the age of 13 have also led to a recent change in SNACS Clinic procedures to focus on serving children and youth between the ages of 2 to 13. This procedural change occurred due to the unique targeted parent/caregiver and provider consultation provided by the SNACS Clinic. This consultation is derived from materials created for caregivers of children ages 4-12. Adolescent-focused materials or content (e.g., substance use prevention/intervention) are not included. Providers felt the SNACS caregiver-focused approach left adolescents out of therapeutically and developmentally appropriate conversations about their test results, recommendations and diagnosis. The integration of adolescents into these conversations should be done carefully and based on their individual developmental needs (i.e., adolescents with average intellectual ability vs.

boderline intellectual functioning). Creation of an adolescent-focused SNACS model is a future clinical and research direction.

With the recent public health crisis, the SNACS Clinic model has been converted into a process that can be delivered using a telehealth modality. Early signs are that this works well, and telehealth efforts will be continued to increase accessibility to families in rural regions of the state. Improvements in accessibility will be a real benefit, as some families have driven as far as 5 hours each way for SNACS Clinic services. This is a dramatic indication of how limited diagnostic capacity and FASD-informed care is—even in a state that has historically been a leader in serving this clinical population.

As SNACS Clinic procedures have evolved, a transition was made away from the clinic's original status as simply a "rule out" diagnostic clinic. This is because the clinical complexity and needs of most families presenting to the clinic often required further diagnostic clarification from SNACS Clinic providers. The clinic's existing procedures already represented best practice standards of mental health assessment and referral, as well as work in the field of neurodevelopmental disabilities other than ND-PAE. However, a more comprehensive diagnostic aim meant a move toward thorough mental health evaluations involving screening for other areas of impairment, such as anxiety disorders. This more comprehensive approach better served these complex children and youth, and did more to meet family needs.

The current study revealed that most children seen in the SNACS Clinic were cared for outside their birth families. For children not living with birth parents, the search to ascertain accurate PAE information was sometimes time-consuming and frequently impossible. Bakhivera and colleagues documented this challenge among a large sample ($N=681$) in a pediatric specialty clinic (specializing in ASD, attention deficit/hyperactivity disorder, cerebral palsy, and FASD), finding that 66% of patients had some features of FASD but lacked a history of sufficient, reliable PAE information to render the medical diagnosis (35). Indeed, children in foster or adoptive care were 2.8 times more likely not to be diagnosed with FASD because PAE information was lacking. In the SNACS Clinic experience, even when ND-PAE could not be diagnosed (usually due to insufficient PAE information), many useful services could be provided to families. These services included diagnosis of co-occurring mental health conditions, assessment of the child's functional profile, enhancement of caregiver understanding of the child, tailored accommodations and recommendations, customized psychoeducation, anticipatory guidance and caregiver support.

Conclusion

The SNACS Clinic model is a promising, mental health-oriented service for serving affected children and their families when PAE information is available. The SNACS Clinic model has been developed intentionally and with continuous, iterative quality improvement. This innovative "therapeutic assessment" clinic model, could be based in Autism, neurodevelopmental or mental health centers to identify ND-PAE in children and youth who might otherwise be missed or misdiagnosed, and where "gold standard" FASD diagnostic team evaluation services are not available/readily accessible. Because of this,

the SNACS Clinic model has real promise for improving sorely needed diagnostic capacity for an underserved, under-recognized clinical population.

Declarations

Ethics approval and consent to participate

All procedures performed were in accordance with the ethical standards of the Seattle Children's Hospital Institutional Review Board (IRB00000277 and IRB00009311). For this type of study formal consent was not required.

Consent for publication

Not applicable.

Availability of data and materials

The dataset generated during and analyzed during the current study are not publicly available due to the small sample size and sensitive nature of the data, but relevant variables are available from the corresponding author on a reasonable request.

Competing interests

The authors declare that they have no competing interests.

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Author's contributions

CO participated in the conceptualization, data acquisition, data interpretation, and manuscript preparation for this study. MK, AO, and HCO participated in the conceptualization, data acquisition, and data interpretation. BC and RM participated in the conceptualization. All authors read and approved the final manuscript.

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Abbreviations

ND-PAE: Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure; PAE: Prenatal Alcohol Exposure; FASD: Fetal Alcohol Spectrum Disorder; DSM-5: Diagnostic and Statistical Manual of Mental Disorders- Fifth Edition

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Tables

Table 1

Demographics of SNACS Clinic Patients (2015-2018)

Demographic Characteristic	Total (<i>N</i> = 40)
Age in years (mean)	8.9
Gender	<i>n</i> (%)
Female	11 (27.5)
Male	29 (72.5)
Yearly household income (mean)	\$86,388
Primary caregiver	<i>n</i> (%)
Adoptive parent	17 (42.5)
Birth parent	8 (20.0)
Foster parent	6 (15.0)
Kinship placement	9 (22.5)

Figures

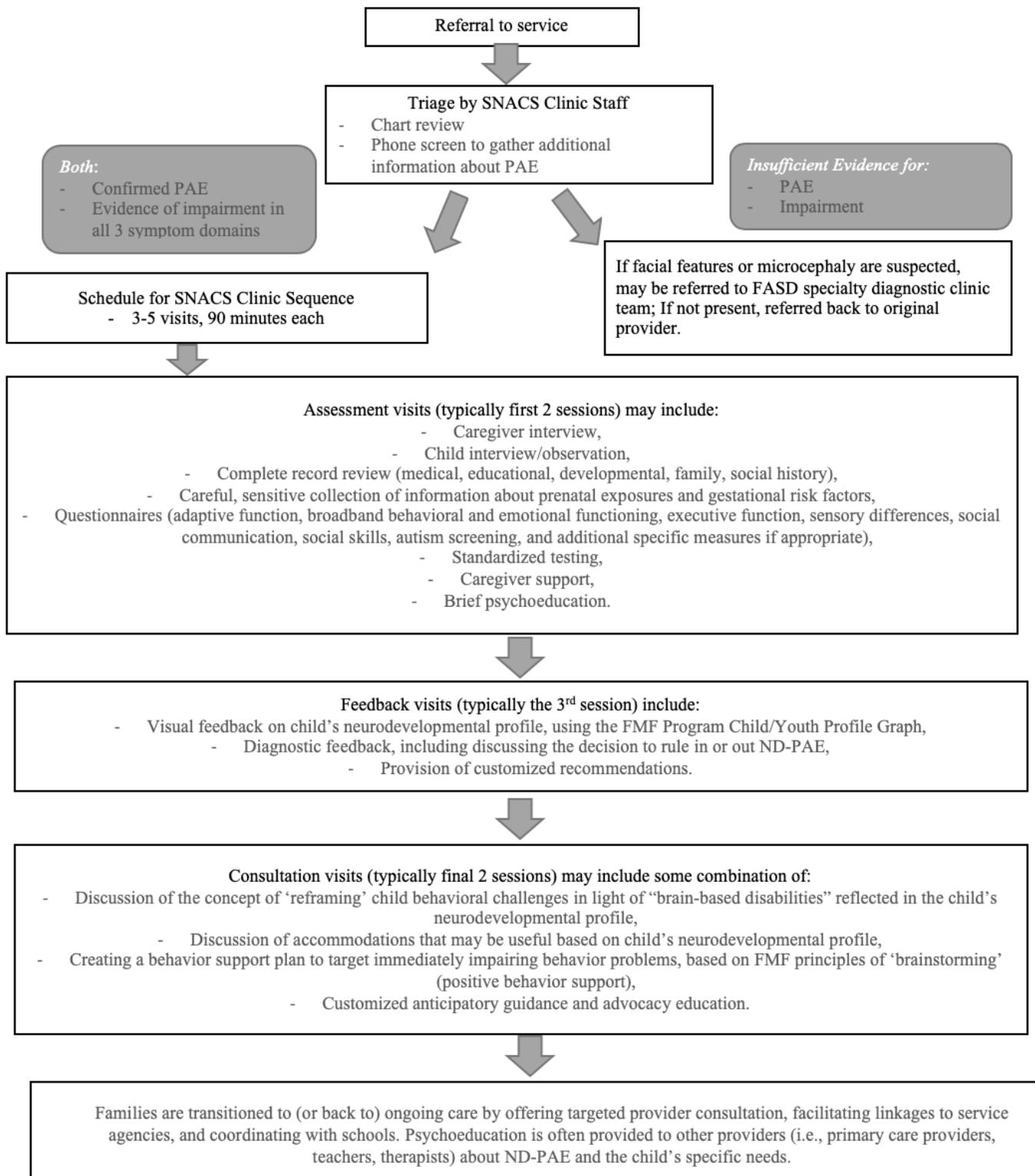


Figure 1

SNACS Clinic Process and Procedures

<p>ND-PAE</p>	<ul style="list-style-type: none"> • Assigned when the original clinician indicated the child met full criteria for ND-PAE.
<p>Rule Out ND-PAE</p>	<ul style="list-style-type: none"> • Assigned when the original clinician left ND-PAE on the child's list of diagnoses as rule out diagnosis. • Rule out was used when all ND-PAE criteria were met except for "more than minimal" alcohol exposure, and when ND-PAE could be rendered if more PAE information became available.
<p>Other Diagnosis</p>	<ul style="list-style-type: none"> • Assigned when another diagnosis was rendered or confirmed as current.
<p>No Diagnosis</p>	<ul style="list-style-type: none"> • Assigned when the SNACS Clinic report did not list any diagnoses or indicated that the child did not meet criteria for any diagnoses.

Figure 2

Categories Used to Code SNACS Clinic Diagnostic Outcomes

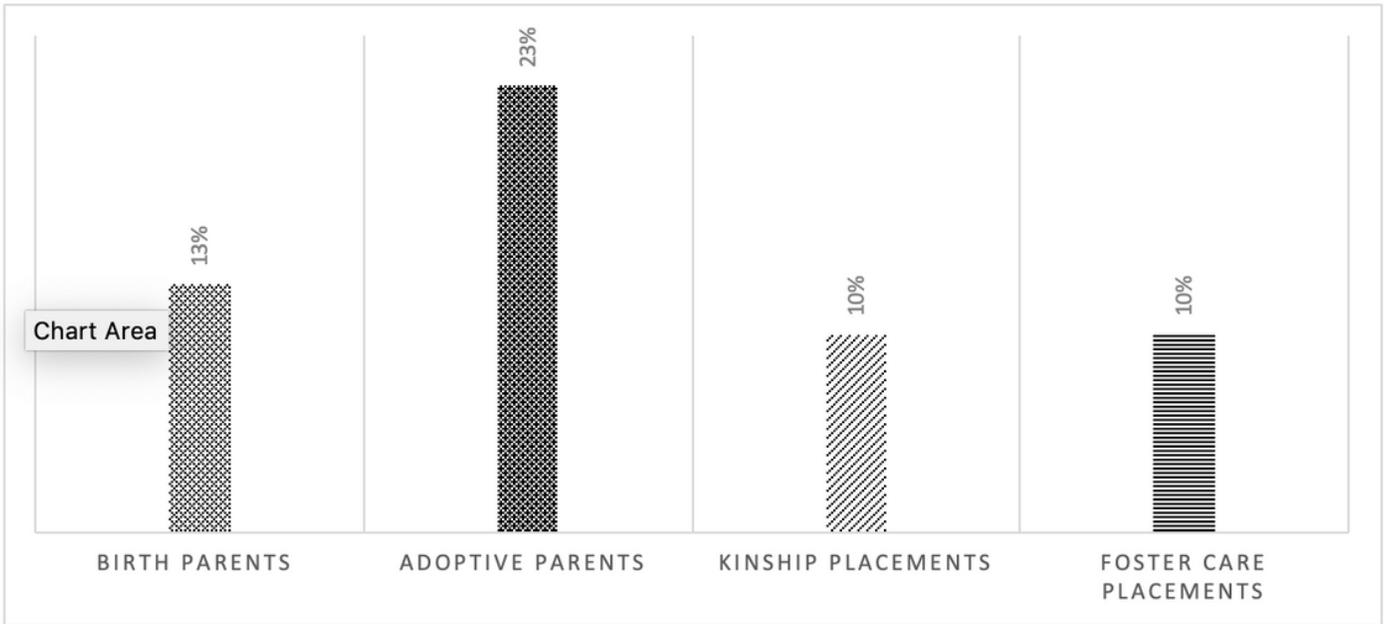


Figure 3

Percentage of Children with an ND-PAE Diagnosis by Family Structure Type (N=22)