TEN BRAIN DOMAINS: A PROPOSAL FOR FUNCTIONAL CENTRAL NERVOUS SYSTEM PARAMETERS FOR FETAL ALCOHOL SPECTRUM DISORDER DIAGNOSIS AND FOLLOW-UP

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ABSTRACT

Background

Significant progress has been made delineating criteria for diagnosis of Fetal Alcohol Spectrum Disorders (FASD). FASD has been researched by geneticists, psychologists, neurological medical professionals, and others, for the past 35 years. However, functional central nervous system (CNS) diagnostic parameters have not yet been adequately defined to address the life-long challenges facing people with this disability.

Objective

This presentation proposes specific brain domains, within central nervous system parameters, to be used as a framework for FASD evaluation, diagnosis and to derive intervention recommendations for clients and their families. The proposed brain domains are clearly defined, including behavior clues to be used as a way to identify potential clients for evaluation.

Methods

Functional CNS parameters as described in recent literature (by CDC, IOM, U of W, and Canadian) are compared with six years of experience of the Fetal Alcohol Diagnostic Program (FADP). FADP is a community-based, family-focused diagnostic program located in Duluth, Minnesota.

Results

Ten specific brain domains are identified as critical to CNS diagnostic parameters for successful FASD identification and management. The ten brain domains include: achievement, adaptation, attention, cognition, executive functioning, language, memory, motor, sensory/soft neurological, and social communication. These brain domains are easily understandable by medical professionals, families, social service workers, educators etc. who are initially identifying those potential clients and/or working with them after FASD evaluation.

Conclusions

Incorporation of these ten brain domains into the national conversation about FASD diagnosis can demystify the referral, diagnosis, and follow-up procedures needed to adequately work with individuals with disabilities related to fetal alcohol spectrum disorders.

Key Words: fetal alcohol spectrum disorders diagnosis, brain domains, central nervous system parameters

etal alcohol spectrum disorders¹ is the umbrella term that describes the broad range of effects alcohol has as a teratogenic substance, however, the medical diagnosis of Fetal Alcohol Syndrome (FAS)^{2,3} is the term or phrase most widely recognized by lay people and professionals alike. FAS incorporates physical, facial, central nervous system, and historical data

that results in a diagnosed disability for individuals. The related diagnostic terms of Partial FAS, Fetal Alcohol Effects (FAE), Alcohol-Related Birth Defects (ARBD), and Alcohol-Related Neurodevelopmental Disorder (ARND) have been prevalent in the past, but are not recognized in the ICD9, DSMIV, or other diagnostic coding resources in the USA. The terms 'static encephalopathy' and

'neurobehavioral disorder' have also been used regarding FASD diagnoses.⁴ Common definitive diagnostic criteria involve assessing areas of prenatal exposure to alcohol, facial dysmorphology, growth indicators, and central endpoints.^{4,6,7,8} system nervous Secondary physical anomalies characteristic to FASD are also presented in a number of research articles, summarized by Hoyme in Dysmorphology Scoring System⁷, but whether these secondary anomalies should be added to the list of 'definitive' diagnostic criteria has not been proposed to date. The literature does agree that FASD assessments need to be conducted by multi-disciplinary teams, although currently there is not a common definition regarding the composition of those terms.

CNS assessments review structural. neurological and brain function in an overall way and are key to understanding the long-term implications of FASD for a client. Structural and neurological diagnostic criteria are linked to decreased brain size and/or imaging reports.9 Neurological diagnostic indicators are based on evidence of seizure activity, spasticity, hemiparesis, or other hard neurological signs not linked to postnatal insult. 10 While these areas are important to the diagnosis, functional central nervous system assessment parameters are critical to assessing the extent of impact for each client, vet the literature does not consistently address definitive functional CNS parameters

LITERATURE REVIEW

Four recent manuscripts discuss CNS parameters as follows:

University of Washington⁴ – The U of W 1. Third edition Guidebook includes a functional brain domain page within the fetal alcohol spectrum disorder diagnostic form, but the brain domains are not identified or defined. The Guidebook indicates that patients typically have problems across multiple domains that may include, but are not limited to executive functioning, memory, social/adaptive cognition, skills, academic achievement, language, motor skills, and attention or activity level (deficit areas are linked to -2SD in testing results). Domain definition discussions are included in the psychometric behavior observations training guide.⁵

- 2. **Centers for Disease Control** ⁶ The CDC guidelines are written only for the FAS *syndrome* diagnostic assessment, but indicate that they should include global cognitive deficits or significant developmental delay in children too young for an IQ assessment (-2SD); *OR* Cognitive deficits or significant developmental discrepancies, executive functioning deficits, motor functioning delays or deficits, attention or hyperactivity problems, social skills problems, "other"–sensory problems, pragmatic language problems, memory deficits, difficulty responding appropriately to common parenting practices. (-1SD) No domain definitions are provided.
- **Hoyme's Interpretation of the Institutes** of Medicine⁷ – IOM suggests using evidence of a complex pattern of behavioral or cognitive abnormalities inconsistent with developmental level that cannot be explained by genetic predisposition, family background, or environment alone....marked impairment in the performance of complex tasks (complex problem solving, planning, judgment, abstraction metacognition, and arithmetic tasks), high-level receptive and expressive language deficits, and disordered behavior (difficulties in personal manner, emotional liability, motor dysfunction, poor academic performance, and deficient social interaction). Domain definitions are not included in this document.
- Canadian diagnostic guidelines⁸ recommends using neurobehavioral assessments to include the following domains: Hard and soft neurological signs (including sensory/motor signs), Cognition (IQ), Communication (receptive and expressive), academic achievement, memory, executive functioning and abstract reasoning, attention deficit/hyperactivity, adaptive behavior, social skills, and social communication (-2SD, or -1SD between subdomains, or -1.5 to -2SD among subtests on a measure). There is an excellent set of notes defining "assessment" and "impairment" in this article (pg.9-10) but no domain definitions are provided.

The Fetal Alcohol Diagnostic Program (FADP) has been evaluating clients for FASD since September, 1999. The FADP's mission is to provide fetal alcohol assessment of children, adolescents and young adults, intervention plans and services to families, and training for professionals, in order to effectively identify, advocate for and serve those living with the

disability. The program began with one clinic each month and currently holds thirty clinics each year, assessing 85-90 clients under the age of 21. The FADP diagnostic methodology is based on the University of Washington's 4-Digit Diagnostic Code, although mild variations have been adopted.

The FADP is staffed by a multi-disciplinary team of professionals including a physician, clinical behavior analyst, psychologist, occupational therapist, speech-language pathologist, intervention specialist and clinic coordinator. FADP has developed ongoing training programs involving professional awareness of the disabilities related to fetal alcohol exposure, multi-disciplinary team diagnosis, and has collaborated with others in the state of Minnesota in research efforts and to develop consistent diagnostic guidelines to be used throughout the state. The diagnostic clinic staff is community-based (as opposed to being linked to one academic institution or medical facility), and family-focused in all aspects of its operation. FADP is located in Duluth, Minnesota, initially sponsored by Arc Northland and MN Department of Health, and funded for three years (2000-2003) by the Bush Foundation. FADP currently maintains a non-profit status operating as a program managed by Generations Health Care Initiatives, Inc.

OBJECTIVE

The objective of this manuscript is to present ten specific brain domains FADP has defined to communicate about CNS involvement related to FASD and for use during fetal alcohol spectrum disorders assessments and intervention recommendations.

METHODS

FADP staff reviewed the literature during the program's regular quality assurance meetings and staff retreats. After identifying similarities and differences found in the literature, staff modified that information into useful domains. During training program development, the domain definitions were finalized and red-flags and clarification questions were added. The resulting document (see Table 2) has been used in training and education presentations throughout Minnesota.

FADP over the past six years developed a process for CNS assessment that while based on the University of Washington's 4-digit diagnostic method (see Table 1), is refined to address specific brain functions. The FADP multi-disciplinary team collaborated to create the definitions and clarify testing and reporting responsibilities. This team collaboration is an ongoing effort as part of research and quality assurance objectives for the program.

The FADP clinical refinement of the 4-digit code clarified the functional CNS parameters as a way to:

- 1. provide clear definitions of brain dysfunction for professionals and lay people to use;
- 2. specify empirical data needed for accurate diagnosis; and,
- 3. define intervention considerations that address the complex nature of the life-long disability with the intention to avoid common secondary disabilities.¹¹

Additionally, interviews with caregivers and professionals working with children assessed in the program led to the development of descriptors and observation endpoints as well as probing questions to determine referral criteria for professionals and lay people to use as they work to refer children to our program.

TABLE 1 Summary of the 4-Digit Diagnostic Code

The four digits re	fiect the magnitude of			
expression of the four key diagnostic features of				
FASD, each ranked independently on a 4-point				
Likert scale as follows:				
Growth deficiency	1=none to 4=severe			
FAS facial features	1=none to 4=severe			
CNS damage	1=unlikely to 4=definite			
Pre-natal alcohol	1= no risk to 4=high risk			
exposure				
D' .' G'! C E . I . I . I . G				

Diagnostic Guide for Fetal Alcohol Spectrum Disorders: The 4-Digit Diagnostic Code, Third Edition, 2004, Susan Astley, PhD., FAS Diagnostic and Prevention Network, University of Washington, Seattle

Tho

RESULTS

FADP proposal of specific brain domains for functional CNS parameters for diagnosis and follow-up include the following ten brain domains with a corresponding definition:

1. ACHIEVEMENT

Achievement domain assesses skills in core academic areas-reading, math, and written language. A primary focus includes comparison of the child's academic skills to their own intellectual potential and to their peer's abilities.

2. ADAPTATION

Adaptation refers to the degree to which a person is able to meet the challenges of daily living when compared to others their age.

3. ATTENTION

Attention domain refers to the processing capacity for selective, focused, sustained, and flexible attention, as seen, for example, in behaviors of concentration, hyperactivity and impulsivity.

4. COGNITION

Cognition domain refers to the general level of thinking ability. An important facet of assessment in this domain is comparison of verbal with nonverbal thinking abilities.

5. EXCUTIVE FUNCTIONING

Executive functioning domain encompasses the capacity for goal-directed behavior; including self-regulation, initiation, working memory, planning, organizing, and self-monitoring.

6. LANGUAGE

The language domain encompasses all aspects of expressive and receptive language. It includes the ability to integrate the specific language skills such as grammar and sentence structure and the use of words to convey meaning.

7. MEMORY

Memory domain encompasses the capacity to consolidate, store, and retrieve information for short and long term application.

8. MOTOR

Motor domain encompasses general abilities to use and coordinate large and small muscles. Gross motor skills include walking, running, hopping and climbing. Fine motor skills include hand writing and eating. Eye hand coordination refers to the ability to coordinate vision with movement.

9. SENSORY/SOFT NEUROLOGICAL

Sensory Domain refers to an individual's ability to process and make sense of incoming sensory information from the surrounding environment. Soft neurological signs are indicators of an immature nervous system. Those signs can be seen in an individual's motor control, balance, rhythm, strength, motor planning and sequencing.

10. SOCIAL COMMUNICATION

Social Communication domain refers to the ability to communicate appropriately and effectively in a variety of social situations with both peers and adults, including the ability to relay verbal information coherently and cohesively.

DISCUSSION

References to brain domains or CNS functions in the literature either do not have clear, simple definitions related to the brain domains or "lump" so many domain areas into the descriptions that they are confusing. Developing intervention recommendations linked to specific functional CNS deficits can maximize the value of the assessment and assist individuals and their families to learn to live with the FASD disability. Hence, the multi-disciplinary diagnostic team of professionals creates the roadmap for the future rather than just pronounce the diagnosis, utilizing the assessment data as the basis for help.

Why these brain domains?

- 1. These brain domains are a concise, specific listing including virtually all of the CNS parameters mentioned in the recent literature. These ten brain domains incorporate easily understood and teachable symptoms or clues that can be used by professionals and/or laypeople to determine if an individual should be evaluated for FASD.
- 2. These ten brain domains are used to collect standardized data indicating the likelihood of organic changes in the brain. This standardized data is key to identifying both deficit and strength areas for each individual assessment. The use of standardized testing is also an important way to communicate with professionals about challenges each client may face as they work to intervene on the client's behalf.
- The brain domain assessments and related data are used to write interventions recommendations as well as to qualify clients for additional services needed in educational or social service

planning. FADP uses both anecdotal data and standardized information to create meaningful intervention recommendations aimed at maximizing the potential for clients we assess. Additionally, these brain domains can be key to assessing the efficacy of interventions over time.

The summaries of important articles (see Literature Review) are similar in intent. The common objectives are to determine ways organic changes in the brain may be identified or tested using standardized measures. The overall desire to help define the 'spectrum' of difficulties apparent in the client's functioning is admirable. The challenge in interpretation may be minimal for medical professionals, but looms large for laypeople, and is daunting for use and application by non-medical caregivers. It is those laypeople who often are the ones who refer individuals for evaluation. Many times professionals are being educated by laypeople that advocate for children under their care; foster parents, extended family members, school aids, personal care attendants, etc. Those laypeople are aware of problem behaviors and, using the common language of the ten brain domains, can inform and refer to professionals for assistance.

FADP has further refined the understanding of the proposed ten brain domains by identifying indicators and red-flags. At the FADP we hear many consistent descriptors by caregivers, teachers, social workers, etc., who call to see if they have an appropriate referral to the clinic. See Table 2 for complete description of indicators, caregiver descriptors and probing questions to discern if there are concerns in the ten brain domains leading to the need for a full evaluation.

These brain domains can be tested, compared to standardized norms, and the data used as the basis for interventions. The creation of understandable, usable domain categories empowers caregivers, teachers, judicial and social service workers, as well as others, to view FASD as worthy of their attention and within their knowledge-base to implement change for individuals affected.

CLINICAL IMPLEMENTATION OF BRAIN DOMAINS

When receiving a referral at FADP, a client is determined as appropriate for evaluation during an intake interview with questions posed in relation

to the 10 brain domains. Through record review, physician examination and behavior analyst interview, the brain domains are screened by reviewing behaviors of concern. Referrals are then made to the clinical psychologist, occupational therapist and speech-language pathologist for standardized testing to document deficit and strength areas.

The team meets together to review the test data, developmental history and to derive the diagnosis. CNS deficits are based on standard of deviation results based on standardized test data. Deriving the FASD diagnosis based on empirical data leaves little room for "gestalt" (not based on data) determination of FASD, and is convincing for those who use the data to plan for the client's interventions. Additionally, a secondary diagnosis list is created in order to address many of the mental health or DSM-IV and past history parameters important to the client. Finally, at that same meeting, the full team defines the intervention recommendations, once again using the brain domains and secondary diagnosis list as the basis for that work.

Team meetings are efficient, being completed in less than 40 minutes per client, and the full evaluation is completed in two FASD appointment days, usually one to two weeks apart. The ten brain domains are the focus of our clinical process, our testing and reporting, and to explain our findings and recommendations to the family or care-givers during the family meeting. The FADP uses CDC criteria for an FAS diagnosis, and -1.5 SD as deficit criteria for standardized tests related to the brain domains for other FASDrelated conditions. This is in accordance with State of Minnesota diagnostic guidelines aimed at consistent evaluation for clients regardless of location of evaluation and diagnosis.

AREAS FOR FURTHER WORK AND DISCUSSION

1. Mental health problems are not proposed as being included in the ten brain domains. The need for data-driven assessments precludes the use of mental health diagnoses as explained in the CDC reference (pg 17-18). The FADP staff concurs with the CDC's rationale and approach to diagnosis, however, we address the mental health diagnoses through the development of a secondary

- diagnosis list as part of the multi-disciplinary team conference. The secondary diagnoses are taken into consideration as recommendations for interventions are written for each client.
- 2. Hopefully in the near future, fetal alcohol spectrum disorders diagnoses will be referenced in both ICD and DSM diagnostic resources. The appropriately diagnosed FASD population is growing and is in need of supports. Future insurance, legal and social support systems are going to be impacted by this population and accurate diagnostic categories are required for incidence and prevalence statistics.
- National consensus is needed for the fetal alcohol spectrum disorders diagnoses. FAS is clearly defined, and now we need to define the rest of that spectrum and agree to diagnostic criteria leading to those diagnoses.
- 4. Age specific assessments for the 10 brain domains listed above may need further study. Additionally, the ten domains may be appropriate for adult evaluations, but determination of how to differentiate deficits that are related to prenatal alcohol exposure versus the client's own alcohol, drug or traumatic injury activities is challenging.
- 5. Finally, and the most daunting challenge defined by this author, remains evaluation of those individuals with *suspected* alcoholexposure e.g. international adoption, noncorroborated history of maternal use, etc. The number of assessments where maternal use is absolutely unknown does not preclude the fact that the client may still have deficits in the ten brain domains related to teratogenic insult. How we assess those individuals and presuppose their challenge of brain damage related to teratogenic insult remains a concern nonetheless.

CONCLUSION

This presentation proposes functional CNS diagnostic parameters for FASD diagnosis and follow-up. These ten brain domains are used in concert with the remaining diagnostic criteria including maternal alcohol exposure history, facial dysmorphologic indicators, and growth parameters related to FASD.

The definitions of the ten brain domains may provide a framework by those who want to refer individuals for evaluation and consequently may be used to write intervention recommendations for clients receiving a fetal alcohol spectrum disorder diagnosis. The result is a demystification of the FASD disability and the hope that a wider audience will be more likely to understand the ramifications of individuals living with the life-long challenge.

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TABLE 2 Brain Domain Chart*

Brain Domains	General Definition	Observations of Behaviors Common Descriptors		Caregiver Questions
Cognition	Cognition domain refers to the general level of thinking ability. An important facet of assessment in this domain is comparison of verbal with nonverbal thinking abilities.	"Not too bright or dull" "Not trying" "Lazy" "Slow learner"	 Needs lots of help in school Normal IQ but immature Limited skills and unrealistic goals Repeats grades in school 	 Does the individual: Act their age? Perform jobs or chores appropriate for their age? Use good judgment?
Attention	Attention domain refers to the processing capacity for selective, focused, sustained, and flexible attention, as seen, for example, in behaviors of concentration, hyperactivity & impulsivity.	"Busy body" "Just can't sit still" "Can't focus" "Spaces-out sometimes"	 Poor impulse control Volatile behavior Short attention span Fidgety behavior 	 Is the individual: Easily distracted? Able to pay attention? Able to concentrate? Able to transition from one activity to another?
Achievement	Achievement domain assesses skills in core academic areas – reading, math, and written language. A primary focus includes comparison of the child's academic skills to their own intellectual potential and to their peer's abilities.	"Report cards are messed up" "Can't do math" "Simply not motivated" "Doesn't learn from mistakes"	 Poor reading comprehension Not well organized and poor study skills School is becoming increasingly difficult after 3rd, 4th, or 5th grade. Tries hard but is often disappointed with their results. 	How is the individual: Doing in school? Math? Reading for learning? Writing compositions? Organized? At home? At school?

TABLE 2 Brain Domain Chart* cont'd.

Brain Domains	General Definition	Observations of Behaviors Common Descriptors		Caregiver Questions
Executive Functioning	Executive functioning domain encompasses the capacity for goal-directed behavior; including self-regulation, initiation, working memory, planning, organizing, and self-monitoring.	"Doesn't seem to learn from experiences" "Doesn't know the difference between stealing, borrowed, or found" "So easy to tease" "Big change in school learning success in 3-4 grade" "JUST DOESN'T GET IT!"	 Won't accept responsibility Poor problem solving Lacks understanding of safe sex and birth control Doesn't understand right from wrong Does not understand jokes or figurative speech Is always late Homework is messy 	Does the individual: Plan their time? Link action and consequence? Have difficulty with judgment? Learn from experience? Have trouble making predictions? Understand figurative language like, "like two peas in a pod"? Understand the passing of time? Understand earning money or using money to buy something?
Memory	Memory domain encompasses the capacity to consolidate, store, and retrieve information for short and long term application.	"Everyday is a new day" "Not learning from experiences" "Tends to lose or misplace things a lot" "Can't remember how to do chores" "Can't do more than one thing at a time" "Quick recovery from a crisis"	 Incomplete knowledge Needs to relearn often Can't follow directions Can't remember rules to a game Trouble memorizing multiplication tables Trouble coming up with answer so just makes one up 	Does the individual: Recall what they have learned? Remember directions? Follow directions? Have trouble getting around? Recall problems and solutions? Learn from mistakes?

TABLE 2 Brain Domain Chart* cont'd

Brain Domains	General Definition	Observations of Behaviors Common Descriptors		Caregiver Questions
Motor	Motor domain encompasses general abilities to use and coordinate large and small muscles. Gross motor skills include walking, running, hopping and climbing. Fine motor skills include hand writing and eating. Eye hand coordination refers to the ability to coordinate vision with movement.	"Late walker" "Long time to be able to tie shoes" "Clumsy and uncoordinated" "Poor posture at the dinner table and doing homework" "Took a long time to learn how to ride a bike"	 Late and/or toe walking Babies have poor suck & swallow ability Poor balance Clumsy, tends to upset or spill things more than others Poor handwriting or messy homework Difficult to understand 	Does the individual: Ride a bike? Skip? or Jump rope? Act clumsy? Have particularly messy school work? Play on sports teams? Have hobbies like beading or airplane models? Have poor posture?
Sensory and Soft Neuro	Sensory Domain refers to an individual's ability to process sensory information from the surrounding environment. Soft neurological signs are indicators of an immature nervous system. It can be seen in motor control, balance, rhythm, strength, motor planning and sequencing.	"Seems to need to touch or be touched more than others" "Sensitive to loud noises" "Rough material or tags are irritating" "Sleeps with lots of blankets" "Smells stuff all the time" "Difficulty writing"	 Rocks back and forth, Starts easily Either high or low hearing threshold Either high need for stimulation or is easily over stimulated. Perseveration on activities or ideas. 	Does the individual have: History of body rocking or head banging? Calming rituals? Odd sleep pattern? Sensitivity to lights, sounds, smells? Sensitivity to cloths or bathing? Only eats favorite foods?
Language	The language domain encompasses all aspects of expressive and receptive language. It includes the ability to integrate specific language skills such as grammar and sentence structure and the use of words to convey meaning.	"Child's statements don't make sense" "Not good at problem solving" "Understands with pictures, but does not understand with words" "Talks all the time"	 Late onset talking Can't follow multi-step directions Repetition of ideas or thoughts Difficult to understand 	Does the individual: Follow directions with more than one or two steps? Understand what others are saying? Learn from listening? Tell stories that make sense? Speak in a way that is understandable?

TABLE 2 Brain Domain Chart* cont'd

Brain Domains	General Definition	Observations of Behaviors Common Descriptors		Caregiver Questions
Social Communication	Social Communication domain refers to the ability to communicate appropriately and effectively in a variety of social situations with both peers and adults, including the ability to relay verbal information coherently and cohesively.	"Socially naive" "Can't read body language" "Doesn't have any friends" "Bossy with peers" "Chatty but with shallow content" "Blames others for problems" "Does not have empathy" "Disrespectful to teachers"	 Doesn't understand personal boundaries or body language Acts much younger Difficulty coping with change in social situations Can't apply interaction skill Difficulty relaying information to others 	 Does the individual: Use social skills with friends? Have a group of friends? Have younger friends? Have stranger danger? Understand danger signs? Use a "tough" or antisocial demeanor? Have appropriate behavior towards authority figures?
Adaptation	Adaptation refers to the degree to which a person is able to meet the challenges of daily living when compared to others their age.	"Doesn't consider brushing hair or teeth or bathing" "Loves to be center of attention" "Kids need 24 hour supervision" "No stranger danger" "Plays with younger kids" "Child acts much younger than age"	 Poor daily living skills Erratic sleeping pattern Erratic eating pattern Unable to handle teenage freedom Pathological liar Sexually inappropriate behavior 	 Is the individual: Aware of what is happening around them? Careful with personal hygiene? Able to use self-help skills? Able to transfer rules from one environment to another? Playing with kids younger than themselves?

^{*}FADP Diagnostic Clinic Staff, 2004, 2005. ARC Northland, 2004. FASDPN, Univ.

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