Complex Developmental Behavioural Conditions Network

Handbook for the Diagnosis of Fetal Alcohol Spectrum Disorder

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Introduction

Overview of CDBC

Complex Developmental Behavioural Conditions (CDBC) is a provincial network under the umbrella of the Provincial Health Services Authority (PHSA). The network consists of teams of health care professionals across the province who provide standardized assessment services within each of BC's five Health Authorities. Sunny Hill Health Centre (SHHC) is the Tier 6 provincial hub and is responsible for setting standards, guidelines, and deliverables for diagnostic assessments throughout the network.

Interior, Island and Northern Health Authorities provide oversight for the care provided in their regions. Vancouver Coastal and Fraser Health Authority programs are operated by SHHC. These teams are accountable to the network to ensure that provincial standards for assessments are met.

Mission of CDBC

CDBC partners with families to provide inter-disciplinary, diagnostic assessments for children and youth 18 months to 19 years of age who have significant difficulties in multiple areas of functioning including those with an Intellectual Disability, Fetal Alcohol Spectrum Disorder (FASD), and other neurodevelopmental disorders. CDBC aspires to provide services in a trauma-focused, culturally-informed practice.

Goal of this Handbook

The goal of this handbook is to provide an over-arching framework for FASD assessments within CDBC, and to address common questions which arise during assessments. This handbook is intended as a reference for clinicians conducting CDBC network assessments. In particular, it provides in depth description of the physicians' and psychologists' roles to ensure consistency across the province. The handbook does not cover intake, triage or eligibility criteria, as these vary between regions. Configuration of the teams are also regionally dependent.

The CDBC network uses the 2016 Canadian Guidelines (Cook, et al., 2016) for the diagnosis of FASD. To make use of this document, clinicians should first be thoroughly familiar with the Canadian FASD guidelines. At the start of this handbook, the reader will find a link to the Canadian Guidelines and a detailed Appendix to the Guidelines. This will be followed by a 2-page worksheet developed by CDBC to aide clinicians in their team diagnostic work. Many clinicians find it helpful to use this document in inter-disciplinary rounds.

The rest of this handbook will provide more expansive information which attempts to address common questions which arise in team assessments.

2016 Canadian Guidelines for the diagnosis of FASD

CDBC uses the 2016 Canadian guidelines for the diagnosis of FASD. Links to the Canadian guidelines can be found below. It is essential for clinicians to carefully review both the guidelines, and the detailed Appendix document in order to understand how to interpret complex findings.

Summary of the new Canadian guidelines 2016

Cook, J.L., Green, C.R., Lilley, C.M., Anderson, S.M., Baldwin, M.E., Chudley, A.E., Conry, J.L., LeBlanc, N., Loock, C.A., Lutke, J., Mallon, B.F., McFarlane, A.A., Temple, V.K., & Rosales, T. (2016). Fetal alcohol spectrum disorder: A guideline for diagnosis across the lifespan. *Canadian Medical Association Journal*, *188*(3), 191–197.
https://www.cmaj.ca/content/188/3/191

Detailed and supplemental information on the guidelines

Appendix 1 (as supplied by the authors): Full-text version — Fetal Alcohol Spectrum Disorder (FASD): a guideline for diagnosis across the lifespan.
https://www.cmaj.ca/content/cmaj/suppl/2015/12/14/cmaj.141593.DC1/app1.pdf

Algorithm for diagnosis from Canadian Guidelines

This algorithm (Cook et al, 2016) forms the foundation of diagnostic decision-making for FASD.

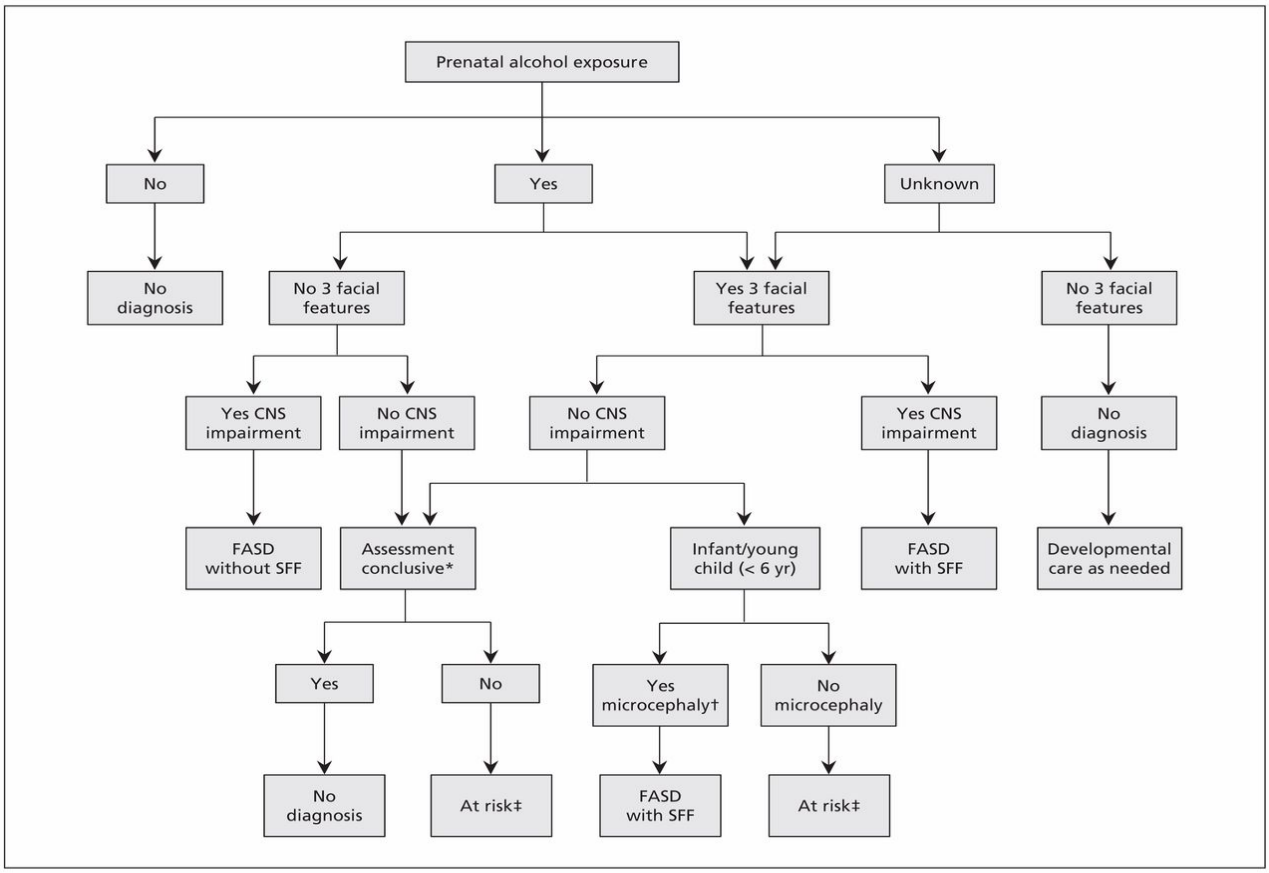

Figure 1: Diagnostic algorithm for fetal alcohol spectrum disorder (FASD).

*Assessment conclusive = clinician conducting the neurodevelopmental assessment is satisfied that the session was a true representation of the person's ability and that any deficits reported were not due to extenuating circumstances. Assessments may be inconclusive for children under six years of age, because some domains cannot be assessed with confidence until the person is older or because of other confounding factors, such as temporary life stress or illness; see the text for more information.

†Microcephaly is not the only pathway to diagnosis for infants and young children; these individuals may also receive other FASD diagnoses, as specified elsewhere in the algorithm, if they show three areas of substantial impairment on neurodevelopmental tests.

‡At risk for neurodevelopmental disorder and FASD, associated with prenatal alcohol exposure. An at-risk designation includes situations where a full neurodevelopmental assessment is not conclusive because of age or situational factors; therefore, FASD may not be the diagnosis. Clinical judgment is recommended. Note: CNS = central nervous system (yes/no impairment in ≥3 Brain domains), SFF = sentinel facial features.

From *Fetal alcohol spectrum disorder: A guideline for diagnosis across the lifespan*, by Cook et al., 2016, in CMAJ. This algorithm and the explanatory text are exempt from the handbook's license.

Worksheet for FASD diagnosis – CDBC (1)

Most domains require a summary score to be below the clinical cut-off of 2 or more standard deviations (SD) below the mean (<2nd percentile). Discrepancies amongst subdomain scores are acceptable in some domains (see the full FASD guidelines & Appendix for more details).

BRAIN DOMAINS

_____ **Motor**: Fine motor or Gross motor or Graphomotor or Visual-motor integration (composite score or multiple subtest scores)

_____ **Neuroanatomy/Neurophysiology**: Occipitofrontal circumference or imaging or seizure disorder (not due to known postnatal influences such as traumatic brain injury)

_____ **Cognition/IQ**: FSIQ, or major composite (e.g., VCI, VSI, FRI). Specific deficits in processing speed and working memory would in most cases be considered as evidence towards impairment in the domains of Attention, Executive Functioning, or Motor (with collateral evidence)

_____ **Language**

_____ **Academic achievement**

_____ **Memory** (consider a deficit in working memory under Executive Functioning)

_____ **Attention** (consider deficits in inhibition, impulse control or hyperactivity under Executive Functioning)

_____ **Executive Functioning** (evidence from at least 2 of: direct tests, questionnaire data, file review/observation)

_____ **Affect regulation** (may not be able to assess in younger children)

_____ **Adaptive behaviour or social skills or social communication** (not better accounted for by Autism Spectrum Disorder)

Criterion	**FASD with Sentinel Facial Features***	**FASD without Sentinel Facial Features**	**Designation: At Risk for Neurodevelopmental Disorder & FASD, Associated with PAE**
Facial features: 1) short palpebral fissures, 2) smooth or flattened philtrum, 3) thin upper lip	All 3 are present	Not present (0–2 facial features)	All 3 may be present
Brain	Minimum of 3 Brain domains impaired	Minimum of 3 Brain domains impaired	Criteria for impairment not met, but strong indication of neurodevelopmental disorder is present and assessment is not considered conclusive because of age or another consideration.
Prenatal alcohol exposure (PAE)	Confirmed or unknown	Confirmed	Confirmed

*Infants and young children meet criteria when all 3 facial anomalies *and* microcephaly are present even without meeting criteria in the Brain domain.

Cook, J.L., Green, C.R., Lilley, C.M., Anderson, S.M., Baldwin, M.E., Chudley, A.E., Conry, J.L., LeBlanc, N., Loock, C.A., Lutke, J., Mallon, B.F., McFarlane, A.A., Temple, V.K., & Rosales, T. (2016). Fetal alcohol spectrum disorder: A guideline for diagnosis across the lifespan. *Canadian Medical Association Journal*, *188*(3), 191–197. https://www.cmaj.ca/content/188/3/191. Appendix 1 (as supplied by the authors): Full-text version — Fetal Alcohol Spectrum Disorder (FASD): a guideline for diagnosis across the lifespan. https://www.cmaj.ca/content/cmaj/suppl/2015/12/14/cmaj.141593.DC1/app1.pdf

Worksheet for FASD diagnosis – CDBC (2)

- Domains should be assessed as though they were independent entities. A single test score should not be used as evidence of deficits in two domains, even when those domains are theoretically related.
- A domain is considered 'severely impaired' when on a standardized measure one or more of the following is true:
  - Global or major subdomain scores are 2 or more SD below the mean with appropriate allowance for test error.
  - In some domains (Cognition, Language, Memory), large discrepancies among composite subdomain scores may meet the criterion for impairment. A discrepancy must be rare, with a base rate below 3% and the lower of the two discrepant scores is at least 1 SD below the mean.
  - In the domain of Academic Achievement, discrepancy should represent a large difference between achievement and IQ. The prevalence of the difference must be rare. It must occur with a very low base rate in the population (<3% of the population), and the lower of the scores must be at least 1 SD below the mean.
  - Discrepancies between subdomains or subtest scores must account for the reliability of the scores and normal variability in the population. Discrepancies should not be solely related to situational factors or based on a single high subtest score. The clinician should feel confident that the pattern of scores logically represents brain dysfunction.
- All domains require using clinical judgment to interpret data. In areas where standardized measurements are not available, a clinical assessment of 'significant dysfunction' may be made based on converging evidence. This must take into consideration important variables, which may include the child's age, mental health factors, medical history, socioeconomic factors and disrupted family or home environments (e.g., multiple foster placements; history of abuse and neglect), and how these may affect development.
- An Intellectual Disability is in and of itself a sign of broad functional difficulties. Further domains do not have to be independent to count towards a Brain ranking. An Intellectual Disability affects cognition and adaptive behaviour, and is very likely to affect communication and academic achievement. For this reason, an individual who meets DSM-5 criteria for Intellectual Disability and presents with qualitative evidence of communication and/or academic problems *may* be scored in either of these areas of the worksheet without formal testing. Measures of communication and achievement may still be given for treatment planning purposes, but are not required for FASD diagnosis.
- To meet criteria under Academic Achievement, low scores should not be better accounted for by lack of instruction. **A diagnosis of a Learning Disorder should not be used as evidence of impairment in the absence of direct testing scores. Similarly, a diagnosis of Language Disorder or Developmental Coordination Disorder should not be used as evidence of impairment in the absence of scores which meet the cut-off.** See the CDBC FASD Handbook's FAQ for more information.
- A formal diagnosis should be deferred for some at-risk children (e.g., preschool and early school age) who have been exposed to alcohol but may not yet demonstrate measurable deficits in the Brain domains or may be too young to be tested in all the domains. Clinicians should use the diagnostic algorithm on page 195 of the Canadian guidelines to decide if giving a formal designation of "At Risk for FASD" is appropriate. This designation should allow access to supports and services in the community. See the CDBC FASD Handbook for recommendations on how to carefully and clearly word this designation.

CDBC physician's role in the evaluation of FASD

Dr. Nancy Lanphear, CDBC Medical Lead

Medical assessments are a required part of the CDBC evaluation. The medical assessment is completed by a physician who has expertise in FASD. In some instances, a community provider with CDBC specific training can provide the needed information and be part of the diagnostic synthesis and etiologic formulation.

The intent of a medical evaluation is to:

- Determine possible etiology related to concerns about development.
- Determine possible co-occurring medical conditions more common in children with developmental disabilities (e.g., seizures).
- If a team does not include an occupational or physiotherapist the MD needs to consider if motor deficits warrant further investigation or may be significant enough to affect the FASD diagnosis.
- Determine if clinically apparent behavioral issues could be due to treatable underlying medical conditions (e.g., sleep disorders, anemia).
- Consider the mental health concerns and affect regulation diagnoses that may be a component of the FASD Brain domains.
- Make recommendations regarding interventions, follow-up, and subsequent referrals to community services.

Practice Standards

A medical evaluation should include a **Medical History** with the following components**:**

- Review of referral concerns and history from parent or legal guardian. If this has been gathered by intake or another clinician, validate the concern and gather any new or pertinent information.
- Past medical history and review for neurological or systemic disease, changes in nutrition/growth/elimination/sleep, medical treatment including medication trials and use, previous medical investigations, hearing and vision status.
- Prenatal and perinatal history (including in utero toxin exposure, birth complications, gestational age, birth growth measurements, early feeding and neonatal status). Review any available medical records and consider if additional records need to be gathered at the time of review.
- Developmental profile (including history of developmental regression). Review of any previous assessments or evaluations.
- Family history.

A medical evaluation should include a **Physical Examination** with these components:

- Growth parameters (height, weight, head circumference).

- Examination for dysmorphic features suggestive of an underlying syndrome.
- Direct assessment for sentinel facial features in FASD using the University of Washington protocol.
- Skin examination for neurocutaneous abnormalities.
- Full neurological examination including coordination.
- Further examination as guided by the history and presenting concerns.

A medical evaluation should include ordering and taking responsibility for **Investigations** based on results from the history and physical as clinically indicated to address the neurodevelopmental concerns:

Genetic evaluations:

- Genetic testing in BC currently includes chromosomal microarray (CMA) and Fragile X DNA analysis. These should be considered as first tier investigations in the presence of Autism Spectrum Disorder (ASD), Global Developmental Delay (GDD), Intellectual Disability, if Intellectual Disability cannot be excluded, if there is a family history of Fragile X or undiagnosed Intellectual Disability, or if dysmorphic features are present.
- Selective gene testing should be considered if a specific single gene syndrome is suspected (e.g., Rett Syndrome, Tuberous Sclerosis). This would be initiated by referral to the Provincial Medical Genetics Program (http://www.bcwomens.ca/our-services/medical-genetics).

Additional investigations to consider:
These tests are best discussed with the referring MD who can provide longitudinal follow-up and treatment. This helps with collaboration and communication, and avoids duplication.

- EEG and neuroimaging (MRI of the brain) should be considered only if clinically indicated. Consideration for referral to neurology may be more appropriate considering the episodic nature of the CDBC diagnostic assessment. This also could be discussed with the referring MD if that individual is a pediatrician.
- Selective metabolic testing could be considered by the presence of suggestive clinical findings (e.g., seizures or regression) and physical findings (e.g., failure to thrive, organomegaly).
- Referral for additional medical specialty consultations could be considered as clinically indicated.

Sentinel facial features of FASD

To receive a diagnosis of FASD with sentinel facial features, the following three facial features must ALL be present because of their specificity to prenatal alcohol exposure:

- Palpebral fissure length ≥2 SDs below the mean (<3rd percentile).
- Philtrum rated 4 or 5 on 5-point scale of the U. of Washington Lip-Philtrum Guide.
- Upper lip rated 4 or 5 on 5-point scale of the U. of Washington Lip-Philtrum Guide.

FACIAL MEASUREMENT

General information: If this is an unfamiliar skill, please arrange for in-person training. For more information and explanatory photos, see the "FAS Facial Photography and Measurement Instruction" page on the University of Washington website: http://depts.washington.edu/fasdpn/htmls/photo-face.htm.

Facial photographic software is an acceptable alternative method to live facial measurement. It is available for $60 from the University of Washington. Note that the photograph requires practice in the technique and quality for this method to be accurate. If photos are taken, it is advised that these are destroyed after scoring and documentation of score is placed in the records. For a one page guide on how to take face photos, see: http://depts.washington.edu/fasdpn/pdfs/PHOTGUIDE012305.pdf *Taking photographs requires express written consent from the legal guardian*.

Palpebral fissure measurement: Align yourself directly and at the same height in front of the patient's eye with a clear cm ruler. If the patient wears glasses, remove them. Place the ruler as close to the eye as possible without touching the lashes so that the viewer can see the landmarks through the ruler. It is held flat and not angled. Have the patient open their eyes wide by looking up at the ceiling. The use of calipers to measure palpebral fissures should never be used due to safety concerns. We currently recommend the use of the Clarren et al., (2010) norms for children over 6 and the Stromland et al., (1999) norms for children under 6. Use the palpebral fissure length calculator from the University of Washington's website to calculate z-scores: http://depts.washington.edu/fasdpn/htmls/diagnostic-tools.htm#pfl.

Tips for ranking lip and philtrum: Use a real lip-philtrum guide from the University of Washington, not a photocopy. Copies are available at https://depts.washington.edu/fasdpn/htmls/lip-philtrum-guides.htm. Lips must be gently closed with no smile. Up or down rotation of the head will cause incorrect measurement of lip thickness. The physician's eyes must be appropriately aligned (at the same level) with the patient's face. The lip-philtrum guide should be held next to the patient's face in the same visual plane.

Timing: The diagnosis of the facial features should be based on the point in time when the features were most clearly expressed. Features may change with age.

Evaluation of prenatal alcohol exposure

When collecting information about prenatal alcohol exposure, a non-judgmental approach with a trauma informed lens is imperative. In many circumstances, pregnancies are unplanned and alcohol use may have occurred before the knowledge of pregnancy. In this interview, discussing the mother's lifestyle and situation prior to pregnancy can lead to a greater discussion of other risk factors such as overall substance use, mental health concerns, stress, adverse experiences and relationships. Identifying if the pregnancy was planned and when the mother was aware of her pregnancy can set the stage for understanding alcohol use prior to the awareness of pregnancy. It is also helpful to discuss what changes were made related to any substance exposure after the pregnancy was confirmed.

Obtaining the alcohol history should be delegated to one team member, though in some cases may be collected by more than one team member. The assigned clinician varies by region. Duplication of this sensitive information can cause unnecessary trauma.

Information about prenatal alcohol exposure may come from a variety of sources. Maternal report is optimal but not always possible. First-hand account from the birth mother should not be over-ruled by other sources. Birth records and medical records are acceptable as long as the person noting the information had a direct interview with the birth mother. Spouses, family members, and other witnesses' reports are acceptable if they represent first-hand knowledge. In using this secondary report, it is important to ensure that individual does not have a vested interest in providing misleading information.

Reports that a birth mother spoke about drinking in pregnancy to a non-professional are acceptable if that person can be reasonably specific about what was said, is willing to have his or her name recorded as the source of the information, and if they are considered reliable.

Teams can make an FASD diagnosis when exposure to alcohol is confirmed but the dose is unknown. However, teams also have the discretion not to make a diagnosis in situations where alcohol exposure is confirmed as very minimal. This approach should only ever be considered in cases that meet the DSM-5 research definition of minimal exposure: less than 2 drinks per occasion ever in the pregnancy and less than 14 drinks per month (American Psychiatric Association, 2013). Research continues to be done and this recommendation may change in the future. Remember, no level of alcohol consumption during pregnancy is known to be safe. The effects of minimal alcohol exposure should currently be considered unknown and likely interacts with factors of timing, other substance use, and maternal age and health. Reduced birth length and weight, microcephaly, and sentinel facial features are associated with alcohol exposure with specific gestational timing. Features appear to be dose related without evidence of a threshold. (Sawada et al., 2012).

What is *not* good enough for confirmation:

- alcohol exposure in another pregnancy
- alcohol use before or after this pregnancy
- confirmed exposure to other street drugs
- risk factors such as being homeless or being a sex trade worker
- a general statement about alcohol exposure that can't be traced to the source, as is sometimes made by individuals who were not involved at the time of the pregnancy with the mother.
- alcohol exposure that is described as 'probable' or 'likely.'

Brain domain: Research and assessment

This section of the handbook is based on the Canadian Guidelines (Cook et al., 2016), the Canadian Northwest FASD Research Network document *"The use of psychometric tools for evaluating individuals with FASD: Reaching Consensus"* (Canada Northwest Research Network, 2007), and a literature review conducted by the authors of this handbook.

General guideline: The Brain domains are evaluated by CDBC clinicians and may be based on previous assessments. It is important to note that there is no single profile, nor pattern of test results which is pathognomonic of FASD. Clinical training and judgment are essential to evaluate test results in the context of the overall assessment.

In general, the "clinical cut-off" is defined as 2 SD below the mean, with allowance for test error. The Canadian Guidelines recognize that while direct standardized measurements should be used whenever possible, in some cases it is not possible to use direct measures. More information on this is provided in the appropriate domains below.

Measures recommended here are not inclusive of all appropriate options. The most recent versions of measures should be used whenever possible. Use of Canadian normative data is preferable whenever it is available.

MOTOR SKILLS

Research Review: Motor impairments in children with FASD vary, but can include neurological soft signs (e.g., difficulty with complex motor movements, sensory integration challenges), diminished fine and gross motor skills and poor visual motor integration (Doney et al., 2014; Duval-White et al., 2013; Hen-Herbst, 2020; Lucas et al., 2014; Muralidharan 2013). The term "graphomotor" is used in the Canadian Guidelines. Graphomotor skills describe the motor aspect of any handwriting or drawing task which includes using a pencil or other writing implement against a paper or other surface (Doney et al., 2017).

Findings have shown that fine motor impairment is more frequent with moderate to high prenatal alcohol exposure (Doney et al., 2014). Impairment is most often seen in complex skills controlled by several neural networks (e.g., handwriting and visual motor integration) as opposed to basic skills (e.g., speed of placing pegs in a pegboard or grip strength; Doney et al., 2014; Duval-White et al., 2013). Significant gross motor impairment is also associated with FASD, particularly on the specific tests of running speed & agility and strength (Lucas et al., 2016). Therefore, evaluation of motor function should be included in assessment.

Recommended Tests:

- BOT-2 (4:0–21:11)
- Age 2:0+: Beery (all 3 subtests)
- Alternatives/Supplementary: MABC-2 (3:0–16:11), MFUN (2:6–7:11), PDMS-2 (0–5:11), Bayley-4 (0–42 months).

Given the complexity of motor impairment in FASD, it is optimal to include an OT or PT in the assessment. In settings where an OT or PT is not available, a clinical interview and/or historical assessment through file review focused on functional motor impairment is necessary. This can include reviewing the motor domain of adaptive functioning measures. PT or OT assessments conducted in the community can be considered, with guidance on test selection. If possible, clinicians are also encouraged to administer all **3 subtests of the Beery** (VMI, visual perception and motor coordination) as there is evidence supporting the accuracy of the 'motor coordination' subtest in FASD detection (Doney et al., 2016; Johnston et al., 2019).

Brain Domain Ranking: There are two key measures to consider using to assess motor skills in the context of an FASD evaluation, the BOT-2 and the MABC-2. The **BOT-2** is a thorough standardized motor assessment comprised of 8 subtests, 4 composites and a total motor composite score. For the BOT-2, the general guideline of "the motor domain is considered impaired when a composite score (or multiple subtest scores) is below the cut-off" should be used.

Note: Although the shorter BOT-2 Short Form was found to be an acceptable measure in a study in remote Australian Aboriginal communities (Lucas et al., 2013), Johnston et al. (2019) found this to be an inaccurate assessment tool for FASD diagnosis. Therefore, the use of BOT-2 Short Form is not recommended due to conflicting evidence.

The **MABC-2** is a shorter standardized motor screen, which includes 3 subtests for a total test score. Note: the MABC-2 denotes these subtests as "components" but they are composed of 3–4 items each, and should be considered a "subtest". No composite scores are available for separate areas of motor performance. In this case, a total test score is the most accurate measure (although sensitivity is considered low; Johnston et al., 2019). If one subtest ("component") score meets the FASD cut-off (≥ 2 SD below the mean), and the other subtests or the total test score does not, best practice is to supplement that score with a subtest from a separate assessment (e.g., a subtest from the BOT or the Beery). This allows the clinician to accurately meet the guideline of "multiple subtest scores" below the cut-off. When supplementary testing is not possible, a standalone MABC-2 subtest score can be considered to meet the cut-off when accompanied by a clear history of functional impairment in that area.

A diagnosis of Developmental Coordination Disorder alone is *not* sufficient to meet criteria under the Motor domain.

NEUROANATOMY/NEUROPHYSIOLOGY

Research review: Smaller head circumference and brain volume has been correlated with in utero alcohol exposure. The current guidelines include microcephaly as evidence of "deficient brain growth or abnormal morphogenesis". It is important to note that although microcephaly is more common after in utero exposure, the vast majority of children diagnosed with FASD will have head sizes within the normal range. Microcephaly alone is not diagnostic of FASD and other causes for microcephaly need to be investigated (Treit et al., 2016; Feldman et al., 2012).

In individuals with FASD, routine clinical MRI of the brain does not show a consistent pattern of brain malformation and MRIs are not utilized for diagnostic purposes unless there are other reasons for investigation (Treit et al., 2020). An early review (Mattson et al., 2001) showed structural changes in the basal ganglia, corpus callosum, cerebellum and hippocampus. This has not been replicated at a time when advanced genetic testing for other causation was available. MRI findings have been seen with advanced quantitative investigations. Recently, Treit et al. (2020) identified low lying cerebellar tonsils, polymicrogyria and ventricular asymmetry or enlargement in individuals diagnosed with FASD.

Brain Domain Ranking: Impairment in this domain is present when any of the following are present based on direct measurement or records review:

- Orbitofrontal head circumference is below the third percentile (microcephaly) without another known cause, *or*
- The individual has been diagnosed with a seizure disorder not known to be associated with a postnatal concern, *or*
- Structural brain abnormalities known to be associated with prenatal alcohol exposure are present on imaging.

COGNITION (IQ)

Research Review: In individuals with FASD, IQ may range from severely impaired to above average. In the research literature, lower mean IQ is one of the most commonly reported findings in relation to prenatal alcohol exposure. There is evidence for impairments in both verbal and visual IQ, and evidence that IQ impairments tend to remain stable over time (reviewed in Mattson et al., 2019 and Kodituwakku & Kodituwakku 2014).

Recommended Tests: Whenever possible, a comprehensive evaluation of IQ should be completed.

- Age 2:6–7:7: WPPSI-IV. Alternative: DAS-2
- 6:0–16:11: WISC-V. Alternative: DAS-2
- 16:0+: WAIS-IV
- Alternative tests of cognitive functioning may be required when the person has sensory or motor impairments, is an English Language Learner, or is severely impaired. Alternative

tests might include the WJ-IV, KABC-II, Leiter-3, WNV, CTONI-2, UNIT-2, or the SB-5.

Brain Domain Ranking: This domain is considered impaired when the overall IQ or a major subdomain composite is 2 or more SD below the mean. On a Wechsler test, major subdomains include the Verbal Comprehension Index, Visual-Spatial Index, or Fluid Reasoning Index. Impairment may also be documented in this domain if there is a large discrepancy among the major subdomain scores, with a base rate of the discrepancy below 3% and the lower of the two discrepant scores is at least 1 standard deviation below the tests' mean. Deficits in processing speed and working memory would in most cases be best considered as part of the evidence towards impairment in the domains of Attention, Executive Functioning, or Motor (with collateral evidence to support impairment in that domain), and as such should not be used as evidence of impairment in the IQ domain.

LANGUAGE

Research Review: Language development has been found to be negatively affected by prenatal alcohol exposure. Cortical and subcortical systems important for language learning may be impacted, with more severe impairments related to substantial amounts of exposure (reviewed in Kodituwakku, 2014; Thorne, 2017; & Terband et al., 2018). The proportion of children with FASD experiencing language deficits varies in the literature but may be as high as 85% (see Proven et al. 2014 in which close to 70% fell in severe range and 15% in mild/moderate range, with similar severity level whether facial features were present or not). A broad range of core language impairments have been reported in both receptive and expressive domains, and in both semantic and syntactic domains. These tend to be more global for younger children (Hendricks et al., 2019) and more evident in morpho-syntax (grammatical aspects) in older children (Mattson et al., 2019; Thorne, 2017), although global deficits may persist in a significant number of children (Proven et al., 2014).

In older children and youth, deficits have been more reliably revealed in complex tasks with higher-level cognitive and language demands (Thorne, 2017) such as those involving extended discourse (narratives), metalinguistic skills, reasoning, and complex social interaction. Weak cohesion and frequency of grammatical errors in the context of narrative productions have been found to constitute a distinctive marker in the presence of FASD (Mattson et al. 2019; Thorne 2017). Restricted use of typical structural elements of narrative scheme has also been reported with lower levels of coherence and reduced vocabulary in narrative tasks (Ganthous et al., 2017 and reviewed in Vega-Rodriguez, 2020).

Recommended Tests: Due to the multiple deficits that may be present in the language profiles of individuals with FASD, a comprehensive assessment is required that consists of standardized testing as well as language samples, clinical observations, and caregiver reporting. There is a wide range of standardized tests available depending on the child's age (see the Communication

Appendix for an expanded list). Those recommended specifically for assessment of FASD include but are not limited to:

- Core Language (including receptive/expressive composites): CELF-P-3, CELF-5
- Discourse (narratives): Renfrew Bus Story, TNL-2, SALT 20
- Abstract Language: CASL-2 (Supralinguistics easel), Tops-Elementary/Adolescent, CELF-5 Metalinguistics

Note: See the Adaptive domain (below) for information on the evaluation of social pragmatics.

Brain Domain Ranking: The language domain is considered impaired when a composite score (core language, receptive language, expressive language) is 2 or more SD below the mean, or when a composite or multiple subtest scores fall below the two SD cut-off on testing of high-level language skills. The Language domain may also be considered impaired when there is a significant discrepancy between receptive and expressive composite scores, or between core language and higher level language tasks (e.g., between CELF-5 and CELF-Metalinguistics findings), with a base rate of the discrepancy below 3% and the lower of the two discrepant scores is at least 1 SD below the mean.

A diagnosis of Language Disorder or Developmental Language Disorder is *not* sufficient to meet criteria under the Language domain.

ACADEMIC ACHIEVEMENT

Research Review: Many children with FASD have difficulty with mathematics. Difficulty with spelling and reading are also common. In math, challenges are more often found in complex math reasoning and magnitude estimation rather than simple number processing (reviewed in Mattson et al., 2019 and Kodituwakku & Kodituwakku 2014).

Recommended Tests:

- Pre-K to Kindergarten: WIAT-III, select subtests, or Bracken Basic Concept Scale: School Readiness Composite. Alternative: K-SEALS, WJ-IV
- Kindergarten+: WIAT-III, select subtests. Alternatives: WJ-IV, KTEA-3, TOWL-3 (story portion)
- Teenagers to adults: Option for screener only: WRAT-4

Brain Domain Ranking: This domain is considered impaired when a score on academic achievement (reading, math, or written expression) is below the cut-off, or when there is a large discrepancy between global cognition (or a major subdomain) and one of the tests of academic achievement, with a base rate below 3% and the lower of the two discrepant scores is at least 1 SD below the mean. The person must have had consistent exposure to academic instruction.

A composite score (e.g., Basic Reading) below two SD below the mean would meet criteria. A subdomain (e.g., reading accuracy, calculation accuracy) below the cut-off would also meet criteria. However, it is important to ensure that the score is not better accounted for by another Brain domain. For example, individuals with a language disorder are likely to show impairment in reading comprehension. If reading accuracy is not impaired, an impairment in reading comprehension may best be considered as part of the language impairment (and not separately counted as a Brain domain under Academics). Someone with motor impairment may show difficulty with the mechanics of writing which is best accounted for under the motor domain. As in all Brain domain areas, it is best practice to look for convergent clinical evidence in school records, observations of the nature of the errors, related deficits in processing, etc., and ensure that the psychologist believes that the low academic test score represents a true clinical deficit and not an artifact.

A diagnosis of Specific Learning Disorder, Nonverbal Learning Disorder, acalculia, or dyslexia is *not* sufficient to meet criteria under the Academic Achievement domain.

MEMORY

Research Review: Review of the literature shows evidence for impairment in both verbal and visual memory in individuals with FASD. As a group, children with FASD tend to initially learn less when presented with information, but do learn with repetition (reviewed in Mattson et al., 2019). Most studies suggest retention of previously learned information over time in those with FASD (with some exceptions - Lewis et al., 2015), with more impairment using a recognition format (Crocker et al., 2011). Overall, this suggests that in children with FASD, memory deficits may be more related to difficulty with encoding rather than difficulty with retrieval. That is, delayed recall deficits may be accounted for by reduced initial learning. Further, memory impairments in individuals with FASD cannot be fully explained by lower IQ (Mattson et al 1996; Vaurio et al 2011).

Recommended Tests:

- Under 6: Optional, NEPSY-2 (Narrative Memory, Memory for Faces)
- Age 5+: WRAML-3 or WMS-3. Alternatives: CMS, CVLT-C/3, CAVLT, RAVLT, ChAMP, RCFT. In the RCFT, with an impaired figure copy, delayed recall should not be considered an impairment in memory.

Brain Domain Ranking: This domain is considered impaired when a composite score of overall, verbal, or visual memory is two SD below the mean, or when there is a large discrepancy between verbal and nonverbal memory with a base rate of the discrepancy below 3% and the lower of the two discrepant scores is at least 1 SD below the mean. Consider a deficit in working memory as better represented by impairment under the domain of Executive Functioning. Also consider whether low memory scores are due to poor attention or executive functioning during the test session in which case the impairment should be documented in that other domain. In

those with an Intellectual Disability, memory testing is optional. However, it may be useful to identify potential strengths and challenges.

ATTENTION (SUSTAINED ATTENTION, SELECTIVE ATTENTION, RESISTANCE TO DISTRACTION)

Research Review: Attention-Deficit/Hyperactivity Disorder (ADHD) is the most frequent co-morbid mental health diagnosis in individuals with prenatal alcohol exposure with prevalence between 49.4% and 94%. Symptoms of ADHD are captured under the categories of Attention and Executive Function. There is more evidence for deficits in visual as compared to auditory attention. Further, there is evidence that complex (executive) aspects of attention are more impaired than simple (focused) attention. There is evidence that individuals with FASD are most likely to have impairments in establishing, organizing, and sustaining attention. Impairments in attention in individuals with FASD are independent of IQ and tend to persist into adulthood (reviewed in Peadon and Elliot, 2010; Mattson et al., 2019; and Kodituwakku & Kodituwakku 2014).

Recommended Tests:

- Rating scales: BASC-3 (Parent, Teacher questionnaires), CBCL, Connors Rating Scales, Vanderbilt Assessment Scales, SNAP-IV
- Observation during assessment
- Direct assessment (optional, recommended if unclear from other evidence): continuous performance task such as CPT-3, TOVA, Digit Span Forward. Multiple subtest scores must be below the clinical cut-off to consider direct assessment of attention to show impairment.

Brain Domain Ranking: This domain may be considered impaired based on direct and/or indirect assessment. Consider deficits in inhibition, impulse control or hyperactivity under Executive Functioning. A previous diagnosis of ADHD (without evidence of formal rating scales in multiple settings) should be reviewed before concluding the child meets criteria for an area of deficit in an FASD domain. Children with a diagnosis of ADHD may meet criteria under both Attention and Executive Functioning domains related to their ADHD symptoms.

Direct assessment of attention must include multiple subtest scores below the clinical cut-off. Indirect assessment should include converging evidence of impairment from multiple sources, including the clinical interview, questionnaire, file review, and direct observation. Information must come from more than one source. A parent or teacher questionnaire alone is insufficient.

EXECUTIVE FUNCTIONING (including working memory, inhibition/impulse control, hyperactivity, planning and problem solving, or shifting/cognitive flexibility)

Research Review: Deficits in various domains of Executive Functioning have been identified in children with FASD. These include verbal fluency, inhibition, problem solving/planning, concept

formation, shifting, and working memory (Mattson et al., 2019). The most evidence is found for deficits in planning, set-shifting (flexibility), fluency, and working memory. Attentional vigilance and response inhibition were also impaired but with smaller effect sizes. Age was a moderating variable with executive functioning deficits in FASD increasing with age, peaking around age 12 (Kingdon et al., 2016).

Parent rating scales of everyday Executive Functioning (e.g., BRIEF parent report) have demonstrated impairment across most subscales, with relative sparing of function on the subscale Organization of Materials (Rai et al. 2017; Mohamed et al. 2019, Rasmussen et al. 2007). Parent rating scales appear to have little correlation with direct, standardized measures of Executive Functioning (Gross et al., 2015; Mohamed et al., 2019). Each may be capturing different aspects of Executive Functioning.

Brain Domain Ranking: Deficits in inhibition, impulse control and hyperactivity should be coded under this domain.

Executive function is a broad and complex domain. It is not expected that all measures of executive function will show deficits. It is recommended that the domain be considered affected when three valid pieces of evidence indicate that there are deficits. This includes: 1) each subtest score on a direct test, 2) each global score on a parent rating scale, 3) each global score on a teacher rating scale, 4) multiple examples of executive deficit observed during standardized testing, 5) multiple detailed and specific examples of executive deficit reported by a parent on interview, and 6) comments strongly suggestive of executive function deficits in school records or as reported to CDBC by the school. All of these pieces of information should be evaluated together in the specific context of the child and their history. It is good practice to document your decision making process when different pieces of evidence point in different directions. Indirect assessment should include converging evidence of impairment from multiple sources, including the clinical interview, questionnaire, file review, and direct observation. Information must come from more than one source. A parent or teacher questionnaire alone is insufficient.

Direct assessment is sometimes warranted for children over approximately age 8. However, results should be interpreted cautiously due to limitations. Direct tests of executive function should be given in cases where the above methods and sources produce inconsistent data, or in cases where it is difficult to separate true executive function deficits from negative behaviour related to situational factors. Direct assessment must include multiple subtest scores below the clinical cut-off. When assessing executive function directly, one would usually give 2 to 4 subtests that seem best able to document executive function deficits given the individual's presentation. There is no real agreement on the best subtests to give. Thus, examiner clinical decision making is critical.

Assessment of executive function is optional for those with an Intellectual Disability. However, it may be useful to identify potential strengths and challenges.

Recommended Assessment:

- Rating scales: BRIEF-2, or preschool BRIEF (parent, teacher questionnaires), Alternative: CEFI
- Observation during assessment
- Some options include: WISC or WAIS Digit Span Backwards/Sequencing subtest scores; RCFT Copy; WRAML-2 Verbal Working Memory or Symbolic Working Memory; Tower of London; WCST, Children's Colour Trails, DKEFS subtests; NEPSY-2 subtests.

AFFECT REGULATION

Research Review: Human and animal research support affect regulation as an area specifically impacted by prenatal alcohol exposure. Infants prenatally exposed to alcohol show differences in temperament and stress reactivity (reviewed in Kodituwakku & Kodituwakku 2014). FASD has high co-morbidity with psychiatric diagnoses including mood and anxiety disorders (Popova et al., 2016). Further, animal studies suggest a link between prenatal alcohol exposure and hypothalamic-pituitary-adrenal axis functioning (stress response; Weinberg et al., 2008).

In a study of 335 individuals age 5 and older who were diagnosed with FASD in clinics across Canada, 41% met criteria under the domain of affect regulation (Temple et al., 2019). Meeting criteria under this category was not associated with gender, IQ, or language disorder. Meeting criteria under the domain of Affect Regulation was associated with older age at diagnosis, and increased overall neurodevelopmental impairment (more domains affected). Those with impairment in Affect Regulation were at higher risk for a diagnosis of Attachment Disorder, Conduct Disorder, Post-traumatic Stress Disorder, and a history of suicidality.

Recommended Assessment:

- Records review to look for previous diagnoses which indicate severe impairment.
- Rating scales as screeners (broad based parent and teacher rating scales such as the BASC or CBCL, or for older children, short screeners like the GAD-7 and KADS-6). Areas of concern can then be followed by short, targeted DSM-5 based clinical interviews.
- Clinicians should formally ascertain that the individual meets criteria and not base opinion on clinical impression or questionnaires alone.
- Take care to look for longstanding issues with affect regulation not short-term responses to life events or conditions.

Brain Domain Ranking: The domain of Affect Regulation should be considered to be impaired when clinical assessment or record review indicates a diagnosis such as Major Depressive Disorder (with recurrent episodes), Persistent Depressive Disorder, Disruptive Mood

Dysregulation Disorder (DMDD), Separation Anxiety Disorder, Selective Mutism, Social Anxiety Disorder, Panic Disorder, Agoraphobia, or Generalized Anxiety Disorder. Historical diagnoses or diagnoses in remission should be considered as evidence of impairment in the Affect Regulation domain. The exception would be if another explanation later emerged which better explained the condition (symptoms were later understood as an adjustment disorder rather than an anxiety disorder). Within the context of an FASD assessment, a diagnosis of Unspecified Anxiety Disorder may be appropriate when there is clear evidence for the presence of an anxiety disorder, but not enough information to specify which type. Younger children may meet criteria by meeting criteria A to F for DMDD, though the diagnosis should not be assigned due to their age.

Children and youth may present with highly complex constellations of mental health symptoms and adverse childhood experiences. Referral to mental health disciplines such as child and adolescent psychiatry or specialized psychology assessment may be necessary to clarify diagnosis if not yet fully evaluated. In such cases, an FASD diagnosis should not be withheld if adequate data is found to support the diagnosis of FASD from other Brain domains.

This domain was added in the 2016 guidelines and some controversy on its inclusion exists.

ADAPTIVE BEHAVIOUR, SOCIAL SKILLS, OR SOCIAL COMMUNICATION

ADAPTIVE BEHAVIOUR

Research Review: In individuals with FASD, deficits in adaptive functioning skills can occur across all of the adaptive domains. There is also evidence that adaptive behavior deficits may increase with age (reviewed in Peadon & Elliott, 2010, and Mattson et al., 2019).

Recommended Tests:

- VABS-3 (Interview format or questionnaire) or ABAS-3.
- For information about assessing adaptive functioning in older teens or adults who do not have a suitable informant, see p. 32–34 of Appendix 1 of the Guidelines.

A decision about which adaptive measure to be used must be made in light of 1) the amount of time available in the assessment, 2) respondent literacy, and 3) age of the child. A Vineland Interview is highly recommended when there is any uncertainly about whether the person might meet criteria in this domain. It is less essential to use the Vineland Interview when the person is clearly going to be well below or well above the clinical cut-off.

Brain Domain Ranking:

Adaptive behaviour is by its very nature a functional outcome that is influenced by other domains. Clinicians do not have to factor out the impact of other domains before rating Adaptive Behaviour. However, scores from an adaptive behaviour questionnaire are not to be substituted

for direct testing and clinical observation of other domains. It is important not to use the same score from an adaptive functioning measure to indicate impairment in this domain and another domain (e.g., Language or Academic Achievement).

The domain of Adaptive Behaviour is considered impaired when a global composite or subdomain composite score is 2 or more SD below the mean. This domain must be considered separately from the effects of mental health and social circumstances, as much as possible.

SOCIAL SKILLS/SOCIAL COMMUNICATION

Research Review: Social challenges of individuals with FASD may arise from multiple factors such as deficits in language and attention, adverse environmental conditions (Coggins et al., 2007), and underlying core deficits in socio-emotional functioning due to teratogenic effects (Kodituwakku, 2014). Social domains affected may include: social cognition (perspective-taking/theory of mind, identifying and interpreting social and affective clues, ability to recognize risk and anticipate consequences, understanding of underlying reasons for appropriate behaviors), social problem-solving (including social inferencing and reasoning), interpersonal relationships, conversational skills, and conveying of events (Hwa-Froelich, 2015; Kjellmer, 2013; Edick et al.; 2018, Kerns et al.; 2016; & Stevens et al., 2017). As in the case of language, these deficits may become more evident as demands increase in complexity and over time (Kodituwakku, 2014; Thorne, 2017).

Recommended Tests:

A direct measure of social language development should be used if age-appropriate such as but not limited to:

- Age 6:0 - 12:0: SLDT-E, SEE
- >12:0: SLDT-A

Indirect measures might include:

- Rating Scales: CCC-2, Descriptive Pragmatics Profile of CELF-P3, Pragmatics Profile of CELF5
- Social domains of Adaptive Functioning measures

Brain Domain Ranking: The Social Skills/Social Communication domain may be considered impaired based on direct and/or indirect assessment. The socialization composite of an adaptive functioning measure may be used as long as it is not also used towards the domain of adaptive functioning. Both formal and informal assessments should be used to assess social communication skills. While there are standardized tests designed to assess social communication, children's performance on the test tasks do not always reflect their actual social communication skills in real-life situations. Results of assessment must be below the clinical cut-off of 2 SD below the mean on a composite or on multiple subtest scores, and must be interpreted in light of observations, historical information, and informant ratings. If direct assessment is not possible, indirect assessment should include converging evidence of

impairment from multiple sources including informant standardized questionnaires (home/school), historical information, and clinical observations which may include findings from social language measures. A single subtest score on a direct test or a single caregiver questionnaire is insufficient. Based on clinical judgment, findings from indirect measures must be indicative of deficits at a severity level at or below the clinical cut-off.

In the case of a child presenting with Autism, social skills and social communication should not be counted as one of the Brain domains contributing to the diagnosis of FASD.

FASD assessment - FAQ

In this section, the clinician involved in an FASD diagnosis will find answers to many of the challenging clinical questions which arise during FASD assessments. This section is meant to supplement the two-page worksheet and Brain Domain section of this handbook.

General questions

Question: What are the most commonly impacted Brain domains with prenatal alcohol exposure?
Answer: Prenatal alcohol exposure does not always result in impairment or a diagnosis of FASD. When impairment is present, it can present across a wide variety of domains. There can also be a wide range of severity of impairment. The most commonly impaired areas in FASD are diminished overall IQ, motor skills, attention, executive functioning, learning and memory, mathematics, communication, and adaptive behaviour (Cook et al., 2016 Appendix, p. 23; Mattson et al., 2019).

Question: If there is strong evidence that a person has normal functioning in a domain, must I still assess it?
Answer: Extensive assessment in such a domain is not necessary. However, a file review, brief screen or direct observation of that function would be appropriate.

Question: Can I use the score from one domain (e.g., subtest of an IQ test) to count towards another domain (e.g., attention)?
Answer: Sometimes. For example, impairment on the Working Memory Index of a Wechsler scale can be counted towards impairment in Executive Functioning. However, the same score should not also be counted towards Cognition. You should not use a low score on the Communication subdomain of an adaptive functioning measure as both a measure of impairment in Language and Adaptive Behaviour. You should not use a single test score as evidence of deficits in two domains.

Question: Must the 3 impaired domains be independent of one another?
Answer: No. “The intent is to ensure that those receiving an FASD diagnosis have severe and pervasive deficits rather than three deficits that are strictly independent of one another” (Appendix 1, p.36). The Appendix gives the example of a child who has microcephaly, low cognitive ability, and low adaptive functioning. These may all be indicators of the same pervasive problem, but count as separate Brain domains. Clinicians should try to think about constructs rather than test scores in making decisions about overlap. For instance, a child who has a fine motor impairment and who is very impaired in drawing may meet criteria under the Motor domain. That child should not also be considered to meet criteria under the Memory domain based on a memory subtest which was clearly impacted by poor drawing skills.

Question: Should clinicians take test error into account when using standard score cutoffs?
Answer: Yes, best practice is to consider measurement error (e.g., by using confidence intervals around a given score). When there is a test with a mean of 100 (SD 15), clinicians may consider a composite score as high as approximately 75 as meeting criteria for impairment in that domain, depending on the confidence interval. However, it is important to look for supporting clinical evidence (e.g., interview and file review information) to confirm such usage. For example, a math composite score of 73 may or may not meet criteria for the Brain domain of Academic Achievement, depending on whether the child's report cards suggest that they have genuine deficits in math.

Question: Do standardized test scores have to be current for a diagnosis of FASD to be made?
Answer: No, past scores may be used as long as they were considered valid at the time, and no new information has come to light that brings their validity into question (for example, if it was later revealed that there were traumatic events occurring in the child's life around the time of testing). In general, neurodevelopmental challenges that are significant, but not permanent (e.g., that resolve with time or with treatment), are still seen as evidence of brain difference. For this reason, even old assessment information can be considered as long as it is seen as valid. However, clinicians do have the option of excluding a previous diagnosis that, in retrospect, seems invalid or better explained by another causal factor.

Clinicians should be cautious when interpreting historical assessments which were completed when the child was very young (e.g., below approximately age 6). It is especially important to consider how recent the data is when considering diagnoses other than FASD (e.g., Developmental Coordination Disorder, Intellectual Disability, Specific Learning Disorder).

Question: Could you use a diagnosis (previous or current) of Specific Learning Disorder as evidence of impairment in the Achievement domain, or a diagnosis of Language Disorder as evidence of an impairment in the Language domain, or a diagnosis of Developmental Coordination Disorder as evidence of impairment in the Motor domain?
Answer: No. The authors of the Canadian Guidelines wanted consistent standard score cutoffs that could be used in domains that are normally assessed with direct, standardized tests. They wanted the Achievement domain to have a standard score cutoff of 70, rather than the DSM-5 recommended cutoff of 78, or even 85 with supporting clinical evidence. Where domains are NOT normally assessed with direct, standardized tests, the authors of the guidelines recommended accepting DSM-5 diagnoses, specifically Attention Deficit Hyperactivity Disorder and affect regulation disorders. Diagnoses of Language Disorder or Developmental Coordination Disorder are not sufficient unless relevant standardized test scores fall at or below 2 SD below the mean.

Question: Can a diagnosis be made by a single clinician if there is previous assessment data from outside sources?
Answer: Sometimes. It is best practice to have a clinician with expertise in the specific domain review historical assessment data. For example, a psychologist with expertise in FASD assessment should review previous psycho-educational reports to determine if Brain criteria are met (unless the case is very clear such as with a diagnosis of Intellectual Disability). This may be done through a formal review, or via consultation. If there is no psychologist available for consultation in a health authority region, the clinician may contact Sunny Hill CDBC to see if such a review is available via Sunny Hill.

Question: Why is it important to have a network Pediatrician or Developmental Pediatrician on the FASD diagnostic team?
Answer: The physician's role is to consider if any other medical etiology could account for the neurodevelopmental difficulties found. In the absence of sentinel facial features, the diagnosis of FASD is really one of exclusion. Team members must consider if other health, genetic, or environmental causes could explain the findings. Referring pediatricians can be trained in FASD assessment. This will allow them to work with the regional diagnostic team. They would be expected to maintain competency in FASD. Diagnostic team members will have greater experience and are more likely to see a broader range of children within the CDBC framework. A Developmental Pediatrician has additional training and broader/deeper level of expertise. Children with co-occurring medical conditions, evolving neurologic presentations, genetic disorders or a past medical history that can impact brain functioning can be elevated to a tier 6 assessment with a Developmental Pediatrician through SHHC.

Question: When a person is given a diagnosis of FASD, can they also be diagnosed with Autism Spectrum Disorder, Intellectual Disability, Specific Learning Disorder, ADHD, Developmental Coordination Disorder, or Language Disorder (if they meet criteria)?
Answer: Yes, all these diagnoses are appropriate if the person meets the specific diagnostic criteria. Giving all appropriate diagnoses helps others to understand the person better and facilitates access to supports and services. All of these diagnoses should be directly addressed within the scope of a CDBC evaluation. For the question of Autism, this may involve an inter-team referral to the BC Autism Assessment Network.

Question: If the team decides that the designation of At Risk FASD is made, what is the next step?
Answer: The team should recommend the best time for follow up testing by the CDBC network. In many cases, this will be in 2–3 years. This should be clearly stated in the summary document or documents, explained to the family and request made that a new referral is made approximately one year before the assessment is needed to the network. Often, follow up standardized testing is required (e.g., a stand-alone psychoeducational assessment). At the time

of the new referral, the triage team member can review assessment needs with a senior clinician (based on updated information of the current abilities and concerns).

Dr. Nancy Lanphear has authored a letter explaining the "At-risk" designation. Clinicians are welcome to share this letter (found in the Appendix of this handbook) with families, community partners, and schools to help advocate for appropriate supports and services.

Question: Where can I find guidance for using inclusive language in written communication?
Answer: http://www.bccdc.ca/Health-Info-Site/Documents/Language-guide.pdf

Psychology-focused questions

Question: If a person has an Intellectual Disability, do I need to further establish 3 separate areas of impairment?
Answer: An Intellectual Disability is in and of itself a sign of broad functional difficulties. Further domains do not have to be independent to count towards a Brain ranking. An Intellectual Disability by definition affects cognition and adaptive behaviour, and is very likely to affect communication and academic achievement. For this reason, an individual who meets DSM criteria for Intellectual Disability and presents with qualitative evidence of communication and/or academic problems may be scored in either of these domains without additional formal testing. Measures of communication and achievement may still be given for treatment planning purposes, but are not required for a diagnosis of FASD.

Question: What are the guidelines related to direct testing of Attention and Executive Functioning?
Answer: The guidelines are not specific about this. However, we recommend that clinicians first review the evidence for indirect assessment of Attention and Executive Functioning (including rating scales). Impairment by indirect assessment is present when a clinical assessment provides converging evidence of impairment from multiple sources. If there is already clear indirect evidence of deficits, direct testing may be omitted. Notice that this approach is facilitated by collecting and scoring questionnaire data before the face to face assessment.

Question: Should teacher adaptive functioning alone count towards impairment in the Adaptive Behaviour domain?
Answer: If no parent/caregiver ratings of adaptive functioning are available, teacher ratings may be used as a sole indicator of adaptive functioning impairment**.** Clinicians should feel confident that the preponderance of the evidence supports the conclusion that there is a true deficit in adaptive functioning. Where parent and teacher ratings disagree, clinicians should review secondary information such as report cards, IEPs, and narrative information provided by parents and teachers, such as examples of how a child might act in a certain situation. Clinicians are cautioned not to assume that teachers are more reliable than parents.

Question: How does a diagnosis of GDD figure into the FASD guidelines?
Answer: Mention of a GDD in previous medical reports is not sufficient to meet Brain criteria for any domain. If a child age 4 or younger is diagnosed with a GDD based on formal testing (IQ/Developmental testing plus measure of adaptive functioning), they would meet Brain criteria for impairment in the domains of Cognitive and Adaptive Behaviour. A third area would need to be identified to meet full criteria for FASD. Children 4 years and under *may* be formally diagnosed with an Intellectual Disability, if that is deemed appropriate.

Question: When a person is given a diagnosis of FASD, should I also consider a diagnosis of Oppositional Defiant Disorder, or Conduct Disorder?
Answer: While FASD can theoretically co-exist with Oppositional Defiant Disorder or Conduct Disorder (or any other behavioural diagnoses), these are not directly related to the referral question of FASD and are somewhat outside the usual CDBC mandate of neurodevelopmental disorders. CDBC clinicians are not expected to cover this ground in their assessments. It may be more appropriate to note the concerns in these areas and recommend further evaluation via mental health if needed, and focus on suggested supports.

Question: Do specific deficits in visual perception or visual spatial IQ count towards any Brain domain?
Answer: A deficit in visual-spatial IQ could potentially be counted under the Cognition domain if it meets the criteria discussed in that area. Visual-spatial IQ measures complex, higher-level visual spatial abilities. Impairments in basic visual-perceptual skills (perceptual abilities such as measured on the Beery Visual-Spatial subtest) should *not* be counted as a Brain domain as part of a diagnosis of FASD.

Question: How should psychologists present test data?
Answer: Psychologists are encouraged to report standardized scores and percentiles for all tests. There may be times when it is not appropriate to provide all scores (e.g., if scores are not believed to be valid, or if there is a clinical contraindication to providing scores). Psychologists are encouraged to use a consistent standard for labeling of test scores. To promote consistency across providers, psychologists within CDBC are encouraged to consider using the American Academy of Clinical Neuropsychology's recommendations for test score labelling (Guilmette et al., 2020). More information on this topic can be found in the Appendix of this handbook.

Question: Should psychologists routinely administer formal tests of performance validity?
Answer: Yes. Stand-alone measures of performance validity are considered standard of care in psycho-educational assessments. For details on this, please see the Appendix of this CDBC handbook.

Motor-focused questions

Question: When a person is given a diagnosis of FASD, should I also diagnose Developmental Coordination Disorder (DCD) if they meet criteria?
Answer: Yes. A DCD diagnosis can be made based on medical and coordination assessments. If there is not an OT/PT on the team, the MD could use previously obtained coordination testing to arrive at a diagnosis of DCD. For more information, see the DCD toolkit: https://caot.ca/site/rc/caot-bc/practiceresources/dcdcadvocacytoolkit?nav=sidebar

Family, culture, and trauma questions

Question: When interviewing families about their history (including trauma history and prenatal history) how can the clinician take a trauma-informed approach?
Answer: It is good practice to inform the family, ahead of time, about the nature of the interview, including types of questions which will be asked. Families should be aware of the expected length of the interview. If the family member chooses to have a support person present, clinicians should honour that request.

During the interview, it is essential that the clinician take a non-judgmental, trauma-informed approach. This document - https://bccewh.bc.ca/wp-content/uploads/2014/08/FASD-Sheet-5_Alcohol-Pregnancy-Violence-TIP-Dec-6.pdf - has some excellent suggestions for the clinician about taking a trauma-informed approach to interviewing about prenatal alcohol exposure. Page 1 of that document can be found in the Appendix of this Handbook.

If the interview triggers past trauma or feelings of guilt, the clinician should take steps to support the family. That may include having a team member follow up with the family member via phone. It could include referral to a counsellor, community support worker, FASD parent group, or peer support group.

For more information on trauma-informed practice, please see the following resources:
BC Mental Health and Substance Use Services website (http://www.bcmhsus.ca/health-professionals/clinical-professional-resources/trauma-informed-practice)

- Healthy Families, Helping Systems: Trauma-informed Practice (TIP) Guide for Working with Children, Youth and Families (2017) https://www2.gov.bc.ca/assets/gov/health/child-teen-mental-health/trauma-informed_practice_guide.pdf
- Trauma-Informed Practice Guide (2013) http://bccewh.bc.ca/wp-content/uploads/2012/05/2013_TIP-Guide.pdf

The National (US) Child Traumatic Stress Network website (https://www.nctsn.org/) has resources for parents and professionals including fact sheets, tip sheets, webinars and podcasts

covering many topics/experiences such as early childhood trauma, grief, complex trauma, medical trauma, culture and more.

- The Impact of Trauma on Youth with Intellectual and Developmental Disabilities: A Fact Sheet for Providers https://www.nctsn.org/sites/default/files/resources/fact-sheet/the_impact_of_trauma_on_youth_with_intellectual_and_developmental_disabilities_a_fact_sheet_for_providers.pdf
- Children with intellectual and Developmental Disabilities Can Experience Traumatic Stress: A Fact Sheet for Parents and Caregivers: https://www.nctsn.org/sites/default/files/resources/fact-sheet/children-with-intellectual-and-developmental-disabilities-can-experience-traumatic-stress-for-parents-and-caregivers.pdf
- Child Trauma Academy https://www.childtrauma.org/

Question: How can the CDBC team support a family when the child is receiving a new diagnosis of FASD or another condition?
Answer: Asking questions about the family's perspective on their child can help set up the assessment and feedback for success. Exploring the family's hopes/goals for their child and the CDBC assessment can ensure the CDBC team recommendations are relevant to the family. This also provides an opportunity to clarify any misconceptions, as well as to identify gaps in knowledge to be addressed. Making sure the family is aware of the reasons for, and engaged with each step of the assessment can help reduce the likelihood of any "surprises" at the family conference.

CDBC recommends creating a brief multi-disciplinary summary document which can be provided to the parent at the time of the family conference. It can be helpful to check in with the family about their reaction to a new diagnosis. The team should answer the family's questions and ensure that the family is aware of essential next steps regarding how to connect with resources or supports. The family may need support gathering the appropriate documentation to access community resources.

Question: What is the impact of adverse childhood experiences and disrupted attachment on development and the FASD diagnosis specifically?
Answer: Adverse childhood experiences, including disrupted attachment, can cause or contribute to symptoms that overlap with those of FASD. Where there is a substantial likelihood that functioning will improve with time or treatment, that is, when there was a recent acute trauma, when the child is about to start treatment, or when the child is improving with treatment, clinicians should try to delay the FASD assessment or use the 'at risk' term. Clinicians should also avoid overemphasizing the potential role of alcohol in situations where there is strong evidence of severe trauma and only very minimal alcohol exposure. However, where both exposure and trauma are clearly present, when the child is in a relatively stable situation at the time of the assessment, and where the realistically available treatments have been accessed, we

recommend emphasizing both alcohol exposure and adverse childhood experiences as likely contributing factors. Clinicians have the option of framing the overarching diagnosis as 'neurodevelopmental disorder associated with prenatal alcohol exposure and adverse childhood experiences, while also stating that the individual meets criteria for FASD.

Question: Should CDBC teams consider the impact of adverse childhood experiences (ACEs) and developmental trauma in the diagnosis of FASD?
Answer: Yes; recognition of ACEs is relevant for understanding compounding factors in a child/youth's developmental profile. CDBC assessments should place mental health and social-emotional functioning in context. There is substantial evidence that individuals with prenatal alcohol exposure frequently experience adverse childhood experiences (ACEs), including abuse, neglect and household dysfunction (Flanagan et al, 2020; Kambeitz et al, 2019; Price et al, 2017).

ACEs include living in a household where a child/youth's safety is not assured or basic physical and emotional needs are not met consistently (Flanagan et al, 2020; Kambeitz et al, 2019; Price et al, 2017).

Disruptions in relationships with caregivers may occur in an array of circumstances, including when parents are living in separate households, primary care is being provided by someone other than a biological parent, whether it is within extended family, kith and kin or child welfare system/paid caregiver. Additionally, changes in caregivers, such as moving between a parent and alternate care provider, or changing foster care placements, can also constitute disruption. Children and youth with prenatal alcohol exposure are more likely to be in alternate care circumstances such as within child welfare systems (Lange et al., 2013).

Further, neuroscience research has recognized that the stress response system of young children is changed by early life stressors including ACEs (Price et al, 2017). Recognition of developmental trauma and striving for the provision of trauma informed care (Kaiser et al, 2018) should be inherently part of a CDBC multidisciplinary developmental assessment.

Question: What do we know about protective factors and resiliency in FASD?
Answer: Protective factors can optimize the development and outcomes for individuals with FASD. Streissguth et al (2004) identified that a stable and nurturing home environment, as well as early diagnosis and intervention are protective. CDBC assessment provides recognition of and support for adaptations in the environment (e.g., designation in school, individualized education plans), as well as enhancing adults' knowledge and insight about a child/youth's brain based conditions, such as FASD. Thus, CDBC teams can provide valuable and protective information as part of the CDBC assessment. Please see the following resources for more information on resiliency and protective factors:

- Resilience Research Centre, Dalhousie University https://resilienceresearch.org/

- Center on the Developing Child Harvard University https://developingchild.harvard.edu/science/key-concepts/resilience/
- Alberta Family Wellness Initiative https://www.albertafamilywellness.org/

Question: Should culture and relevant historical issues be considered as part of an FASD diagnosis?
Answer: The family and wider community/culture of the child should always be considered during an FASD evaluation. There may also be relevant historical issues to consider. This is a topic that will require each clinician to address in their own education and practice.

Question: How should we document these complex factors?
Answer: It can be helpful to recognize the psycho-social factors relevant to the child when documenting functional difficulties on the CDBC Diagnostic Assessment Summary (CDAS at SHHC) or Multidisciplinary Summary (MDS at NHAN). These may include factors such as trauma history, complex grief, or disruption to relationship with caregivers.

Question: Should clinicians complete the disability tax credit if it is applicable?
Answer: Yes. If a child might be eligible, clinicians are highly encouraged to complete the Disability Tax Credit. The team should decide together whether the physician or psychologist will complete this at the time of the rounds/synthesis meeting. If the document is completed concurrent to the case conference and family meeting, it will take much less time than doing so later. In addition, our most vulnerable families will struggle to have this completed by a community MD, and in the community form completion may incur an additional cost.

Communication-focused questions

Question: If a client has severe speech sound difficulties, does this meet criteria for a Brain domain?
Answer: No. With respect to communication, only language and social communication findings are included as potential Brain domains affected (if they meet severity levels) in the diagnosis of FASD. We know, however, that many children with FASD will experience speech difficulties that persist longer than would be expected for their age, with a prevalence of up to 90% (see Terband et al., 2018). Speech sound difficulties in individuals with FASD may arise from the central nervous system, may be secondary to being hard of hearing, and/or may be related to oral motor challenges. Hearing disorders associated with FASD include delays in auditory maturation, sensorineural hearing loss, intermittent conductive hearing loss due to otitis media, and central hearing loss (listening difficulties in the absence of peripheral hearing loss, McLaughlin et al., 2019). Common orofacial features that may affect speech production include malocclusion of teeth, a heightened palate, and mandibular/maxillary hypoplasia. In a recent study, deficits were found in speech production, speech perception, intelligibility, and oral motor functioning, in part associated with orofacial differences (Terband et al., 2018).

Although not contributing to an FASD diagnosis, the Speech Sound disorder (or other speech-related diagnosis) should be described and added to the list of team diagnoses.

Optimal team process

The Canadian Guidelines outline the various team members involved in the FASD diagnosis. Which team members are involved varies by age and needs of the child. All regions have a triage and intake process. Contributing team members can include psychology, pediatricians, developmental pediatricians or psychiatrists, speech language pathologists (SLP), occupational and physical therapists, social workers (SW), nurses and other clinical staff. The actual diagnosis of FASD is a medical one and needs the input from a physician. Many of the additional diagnoses can be made by a psychologist or psychiatrist. In CDBC, each region has their own process for deciding on the composition of the group, as well as each member's specific expectations and roles.

This section covers only tasks directly related to an FASD diagnosis, but it is also understood that clinicians will complete additional tasks to assess other possible medical/etiological diagnoses or neurodevelopmental diagnoses, as needed.

Before the team meeting:
1. Physician: Complete medical assessment and report. Share sentinel facial features, genetic considerations and neuroanatomical information to share. May need to speak to the question of coordination (DCD or other motor concerns) and affective concerns.

2. Clinicians (psychologist, SLP, OT, SW): Review previous assessment reports, complete direct assessment, clinical observation, informant report measures, and informant interviews. Prepare a list of possible areas of impairment to be discussed and revised as a group.

3. Designated team member gathers all available information about alcohol history. It is important to clarify who is responsible for gathering records and who is responsible for interviewing.

At the Team Rounds (ideally with all team members present):
1. Physician reports sentinel facial features and any other potential areas of concern that will impact brain functioning such as sleep disorder, prematurity, history of traumatic brain injury, etc.

2. Presentation of data from all clinicians and formulation of Brain ranking as a group.

3. Presentation of alcohol history from designated team member(s) and formulation of alcohol confirmation.

4. Assignment of diagnostic terminology according to the Canadian FASD Guidelines.

5. Confirmation or diagnosis of all other relevant conditions.

6. Completion of a team summary document (CDAS, MDS, etc.). This inter-disciplinary summary of assessment results is designed to be provided to parents at the family conference. In the summary document, record the final FASD designation or diagnosis, and include a confirmation that Canadian Guidelines were used. Include other relevant medical/etiological diagnoses and other relevant neurodevelopmental diagnoses. If possible, have the team summary document available in a central location prior to rounds, so that each team member can enter their information prior to rounds. For example, the team may place a template on STAR BC under the patient's "Documents."

7. Enter diagnostic outcome data in STAR BC or designate a person to do so after rounds.

Rounds rules

Prior to a feedback session with the family, the assessment team meets for Rounds. Following are suggestions for optimal team functioning.

1. Arrive on time and conclude on time.

2. Be prepared. Review your own information ahead of time and also review the clinical notes in STAR. Input the appropriate items from your assessment into STAR, and if you use a tool such as the CDAS or MDS to collate the team's summary, it would be helpful to draft your findings and recommendations into the summary prior to rounds.

3. Ask for clarification if you need it during the meeting and work towards consensus. If you disagree with a team member, ask a polite, curious question to explore the issue.

4. Ensure that the exact FASD diagnosis and other medical/etiological diagnoses and/or neurodevelopmental diagnoses have been agreed upon. If you do not have consensus, this is also documented in the team summary with any suggestions for future considerations or assessments.

5. Decide whether any special preparation or planning is needed for the family conference. This may include having one team member discuss with the family who should be involved in the feedback (e.g., school team, support network). Plan for inclusion of a teenager in feedback.

6. Be respectful of team members and be open to listen to team members' feedback.

7. Be sure that confidentiality is maintained during and after the meeting.

8. To ensure that the diagnoses and concerns have been articulated and discussed, we encourage a system in which diagnoses are recorded in a place visible to all team members during the Rounds meeting. This could be a computer screen or a white board.

Resources for more information

Following are resources for clinicians who are looking for more information about FASD. Many of these resources are also appropriate to share with families and community members.

CanFASD: https://canfasd.ca/ - The Canada Fetal Alcohol Spectrum Disorder Research Network (CanFASD) is a collaborative, interdisciplinary research network, with collaborators, researchers and partners across the nation.

POPFASD: https://www.fasdoutreach.ca is BC's Provincial Outreach Program for FASD (POPFASD). The website shares current research, ideas, strategies, training and resources in order to build capacity in school districts for students with FASD and their teachers.

KnowFASD.ca: This site introduces the neurobehavioural difficulties that may appear throughout the lifespan of individuals with FASD. It describes how FASD impacts various areas of functioning and talks about what can be done to help. The website and wiki is an outreach project created by the "Intervention on FASD" Network Action Team (iNAT) of the Canadian FASD Research Network (https://canfasd.ca/).

Every Day is an Adventure: What Parents and Caregivers Need to Know About Fetal Alcohol Spectrum Disorder (FASD): A booklet written by parents and professionals in Manitoba as a resource to understand how FASD may affect a child/youth/adult as well as strategies to support them. It is available on-line at: https://www.gov.mb.ca/fs/fasd/pubs/fasd_caregivers.pdf.

Let's Talk FASD: A publication which includes information and strategies. It is available online at https://www.von.ca/en/resource/lets-talk-fetal-alcohol-spectrum-disorder.

The **FASD Support Network of Saskatchewan** has a website with a lot of useful information. The website address is www.skfasnetwork.ca. Click on Network Resources to download **FASD Toolkit**, **Tips for Parents & Caregivers**, **Tips for Teachers**, **Tips for Coaches**, **Tips for Employment** as well as other resources and information.

The online resource **FASD Strategies, Not Solutions** was developed in Alberta to educate caregivers and community professionals how to better support children and youth with FASD: https://edmontonfetalalcoholnetwork.org/resources/strategies-not-solutions/.

Excluded: Increasing Understanding, Support and Inclusion for Children with FASD and their Families by BC's Representative for Children and Youth (2021) https://rcybc.ca/reports-and-publications/excluded/

Indigenous cultural resources include:

- San'yas Indigeneous Culture Safety Training https://www.sanyas.ca/
- Indigenous Cultural Safety (ICS) Collaborative Learning Series provides upcoming and archived webinars https://www.icscollaborative.com
- Aboriginal Policy and Practice Framework in British Columbia (2015) https://www2.gov.bc.ca/assets/gov/family-and-social-supports/indigenous-cfd/abframework.pdf

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Appendix

Assessment components and expectations for the CDBC medical assessment

Nancy Lanphear, M.D., CDBC Medical Lead

PRE APPOINTMENT

- Review of all available forms/assessment/records (including birth) prior to the visit with family and child/youth.

APPOINTMENT

- Family and Child/youth appointment to obtain history and physical examination.
- Debrief with family for immediate recommendations or to explain further assessments. At this time, it is *not* expected that a final diagnosis is made unless this is a Developmental Pediatric or triage only assessment. As most assessments are team based final diagnoses would be provided at the time of the family meeting and written into the summary document.
- Consider if other outside records are needed (e.g., if birth records have not been obtained or if additional information needed from school or therapists in community).
- Family questions or concerns are to be addressed or re-directed to another team member as appropriate.

POST APPOINTMENT

- STAR note with highlights of appointment (information that other team members would use in their assessments) is to be made within 48 hours of appointment.
- Consultation report to be completed in a timely manner. Expected time to completion is within 4 weeks after the appointment except in extenuating circumstances such as vacation or illness.
- Participate in rounds and complete summary document with team.
- Attend family conference.
- Follow up on any investigations or referrals.
- Liaise with referring provider regarding outstanding concerns that require their follow-up as clinically indicated.
- Consider whether Disability Tax Credit (DTC) form can be completed on family's behalf. Discuss with team who is best suited to complete the form.
- Ensure that complete STAR data and outcomes have been completed within 48 hours of family meeting. During rounds, the CDBC team should confirm which clinician will complete the STAR outcomes.

Areas typically *not* a component of the medical assessment in CDBC

- Review of immunizations. This is best done by primary MD or public health.
- School or camp forms
- Trialing medications, or renewal of prescription medications
- Urgent or acute care
- Preventive counseling (e.g., sexual health)

References

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CDBC practice recommendation: Neurodevelopmental Disorders and DSM-5 terminology

December 16, 2020
Nancy Lanphear, M.D., Developmental Pediatrician, Medical Lead CDBC
Priya Chetty, CDBC Program Manager
Jennifer Engle, Ph.D., Registered Psychologist, Psychology Education Lead for CDBC

The challenge of capturing complexity in CDBC assessments

For some children who are assessed through the CDBC network, the child's list of diagnoses does not capture the complexity of their functional needs. For these children, practitioners need some way of communicating the high level of need for support across multiple areas.

BC Ministry of Education guidelines

The BC Ministry of Education Special Education Services Manual (2016)[1] states that children assessed through the CDBC network may be categorized under Chronic Health Impairment if the child has a diagnosis of Fetal Alcohol Spectrum Disorder (FASD) or a complex developmental behavioural condition with 2 or more domains impacted (social-emotional functioning, communication, physical functioning, self-determination/independence, and academic/intellectual functioning).

Neurodevelopmental Disorders and DSM-5 terminology

Some practitioners have used the generic term "Neurodevelopmental Disorder" as a diagnosis for these complex children. In the DSM-5, the neurodevelopmental disorders are a group of conditions with onset in the developmental period (e.g., Intellectual Disability, ADHD. "Other Specified Neurodevelopmental Disorder" and "Unspecified Neurodevelopmental Disorder" are DSM-5 diagnoses which are meant to be used when the client does not meet the full criteria for ANY of the disorders in the neurodevelopmental disorders diagnostic class. A child with ADHD and a Learning Disorder has two neurodevelopmental disorders. Thus, they cannot be labeled with a DSM-5 diagnosis of "Other Specified Neurodevelopmental Disorder" or "Unspecified Neurodevelopmental Disorder". Similarly, for a child with a diagnosis of FASD, they should not also be diagnosed with a DSM-5 Other Specified Neurodevelopmental Disorder.

Neurodevelopmental Disorder Associated with Prenatal Alcohol Exposure (ND-PAE) is a condition proposed for further study (not a diagnosis) in the DSM-5. CDBC recognizes that individuals who meet Canadian Guidelines for a designation of "At Risk for FASD" or a diagnosis of FASD, would also meet criteria for ND-PAE as described by the DSM. In a multi-disciplinary clinic such as a CDBC program, the Canadian Guidelines terminology should be used.

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[1] Special Education Services: A Manual of Policies, Procedures and Guidelines (2016): https://www2.gov.bc.ca/assets/gov/education/administration/kindergarten-to-grade-12/inclusive/special_ed_policy_manual.pdf

Recommendation for practice

When DSM-5 "Other NDD" does not apply, in order to communicate that the child has a complex profile and complex needs, it would be appropriate to *describe* the child as having a "*complex neurodevelopmental disorder"* or as having a "*complex neurodevelopmental condition"*. These descriptions may be capitalized, or not, but should not be noted as a DSM-5 diagnosis (unless no other neurodevelopmental disorder is present). It is also important to outline the Ministry of Education domains in which the child has functional challenges. In the CDBC multi-disciplinary summary report (i.e., the 'CDAS or MDS' report), this could be captured in the following ways:

Diagnostic Summary Section:

1. List DSM-5 diagnoses, significant medical diagnoses affecting development, FASD, or At-Risk for FASD.
2. If there is not FASD, and no other neurodevelopmental disorders are diagnosed, it is appropriate to consider a DSM-5 diagnosis of "Other Specified (or Unspecified) Neurodevelopmental Disorder."

Functional Description Section: A brief functional description may be added above or below the Diagnostic Summary section. This section is most important when the diagnoses do not fully "capture" the complexity of the child and their functional needs. For example:

> *Sally has a complex Neurodevelopmental Disorder characterized by significant difficulty with attention, fine motor skills, and everyday living activities. Investigation into etiology is underway.*
>
> *Joey has an extensive history of disrupted attachments and early life trauma. He presents with a complex neurodevelopmental condition characterized by severe anxiety, ADHD, and academic difficulties.*
>
> *Fred was prenatally exposed to cocaine and born extremely premature. He currently shows a complex neurodevelopmental disorder consistent with this history.*

Recommendations Section: It is sometimes important to use the Ministry of Education's language of "complex developmental behavioural condition"

> *CHILD's file should be reviewed by school/district staff to determine whether the information in this report changes any decisions about supports and services. We strongly support applying for a Ministry of Education designation of "D" for Physical Disability/Chronic Health Impairment in view of HIS/HER complex developmental behavioural condition.*

CDBC practice recommendation: Labelling of test scores in psychological assessments

October 16, 2020

Jennifer Engle, Ph.D., Registered Psychologist, Psychology Education Lead for CDBC
Nancy Lanphear, M.D., Developmental Pediatrician, Medical Lead CDBC

In 2020, the AACN (American Academy of Clinical Neuropsychology) created a consensus statement on labelling of test scores[2]. Although no system is perfect, having a consistent labeling system for test scores across various tests and clinicians has obvious benefits. Here is their recommendation:

Table 1. Recommended test score labels based on standard scores and percentiles for tests with normal distributions.

Standard Score	Percentile	Score Label
≥130	≥98	Exceptionally high score
120–129	91–97	Above average score
110–119	75–90	High average score
90–109	25–74	Average score
80–89	9–24	Low average score
70–79	2–8	Below average score
<70	<2	Exceptionally low score

Table 2. Recommended test score labels based on percentiles for tests with non-normal distributions.

Percentile	Score Label
>24	Within Normal Expectations Score or Within Normal Limits Score
9–24	Low Average Score
2–8	Below Average Score
<2	Exceptionally Low Score

A few key recommendations:

1. The above labeling system is for normally distributed scores. That said, for some tests with non-normally distributed scores (e.g., Boston Naming Test), the system would also be appropriate. For some tests where near perfect scores are expected (e.g., WCST Copy), reporting only the percentile score/range (e.g., >16 percentile) with a score label of "Within normal limits" would be appropriate.

[2] Guilmette, T.J., Sweet, J.J., Hebben, N. Koltai, D., Mahone, E.M., Spiegler, B.J., Stucky, K., Westerveld, M., & Conference Participants (2020) American Academy of Clinical Neuropsychology consensus conference statement on uniform labeling of performance test scores, *The Clinical Neuropsychologist, 34(*3), 437–453.

2. The descriptive label uses the word "score" because it is a SCORE that is high, low, or average, not an ability. You assess the ABILITY/FUNCTION based on multiple factors including the score.
3. If you are not using the publisher's normative data to obtain the score, it is important to note in your report what normative data you are using.
4. If the publisher's score labels or breakdown of categories differs from the AACN guidelines, it is recommended to use the AACN guidelines for the sake of consistency.
5. If the publisher's data allows you to specify demographics (e.g., gender-specific vs. gender combined), note which you used in the report. In general, it is almost always preferred to use gender combined norms. Also note if you are reversing scores (e.g., if on a certain test a higher score equals lower performance).
6. Give careful consideration to labeling scores around cut-points, considering the error band.
7. Always include a guide to score labels (as above Table 1 from the AACN guidelines) to facilitate the reader's understanding. Here is an example which can be freely used (and edited to meet your needs) in your reports:

Classification	**Scaled Scores**	**Index, Standardized, or Composite Scores**	**Z-scores**	**T-Scores**	**Range of Percentiles**
Exceptionally High Score	16–20	≥130	2.0+	≥70	≥98th percentile
*Above Average Score	14–15	120–129	1.4 to 1.9	63–69	91st–97th percentile
High Average Score	12–13	110–119	0.7 to 1.3	57–62	75th–90th percentile
Average Score	**8–11**	**90–109**	**-0.6 to 0.6**	**43–56**	**25th–74th percentile**
Low Average Score	6–7	80–89	-1.3 to -0.7	37–42	9th–24th percentile
*Below Average Score	4–5	70–79	-2.0 to -1.4	30–36	2nd–8th percentile
Exceptionally Low Score	1–3	<70	<-2.0	<30	<2nd percentile

*Many clinicians prefer the term "Well Below Average Score, and "Well Above Average Score"

For performance Validity tests (PVTs), the guidelines suggest a three-tiered system for labeling scores – valid range, indeterminate range, invalid range.

If you would like to learn more, there is a podcast by Navneuro which talks with one of the authors of the consensus statement: https://www.navneuro.com/47-uniform-test-score-labeling-with-dr-tom-guilmette/

At Risk Fetal Alcohol Spectrum Disorder

BC Children's Hospital
Provincial Health Services Authority

Sunny Hill Health Centre
4500 Oak Street, Vancouver, BC V6H 3N1
t 604.875.2345 | tf 1.888.300.3088

March 4, 2021

RE: At Risk Fetal Alcohol Spectrum Disorder

From: Nancy Lanphear MD CDBC, Medical Lead

At Risk for Neurodevelopmental Disorder and FASD, Associated with Prenatal Alcohol Exposure is a designation in the 2015 Canadian guidelines published in CMAJ. This designation is the appropriate finding in children with known prenatal alcohol exposure who have findings of neurodevelopmental dysfunction in multiple areas that likely relates to the prenatal exposure. This designation is appropriate for the younger child who may not yet be at an age for conclusive testing in areas such as learning, executive function and affective disorders. In using this term, the typical finding is of difficulties across multiple functional domains but the deficit (gap) is not sufficient to reach the level needed for FASD diagnosis (significant impairment in 3 or more domains). Significance in domains is reached when the deficit is >2 SD below the mean. In a young child, this gap may not yet be achieved. Less frequently, this designation is also used if a child has the sentinel facial features for FASD but does not yet show significant functional concerns.

Per the Canadian guidelines, ***"Individuals in this category should receive the same services as those with a diagnosis of FASD as required to meet their current needs."***

Within the CDBC provincial program, this designation will be considered for those at a young age or whose testing is inconclusive and evidence for dysfunction in multiple areas is found. Reasons for an inconclusive assessment (other than age) may include recent trauma, or being a new English language learner. When the At Risk designation is used, the team will state the rationale for why the assessment is inconclusive. The team will also outline a plan for re-assessment, and request that the child be referred back to our network for conclusive testing. Typically, re-assessment should occur approximately 2-3 years after initial testing or no later than 10-12 years of age.

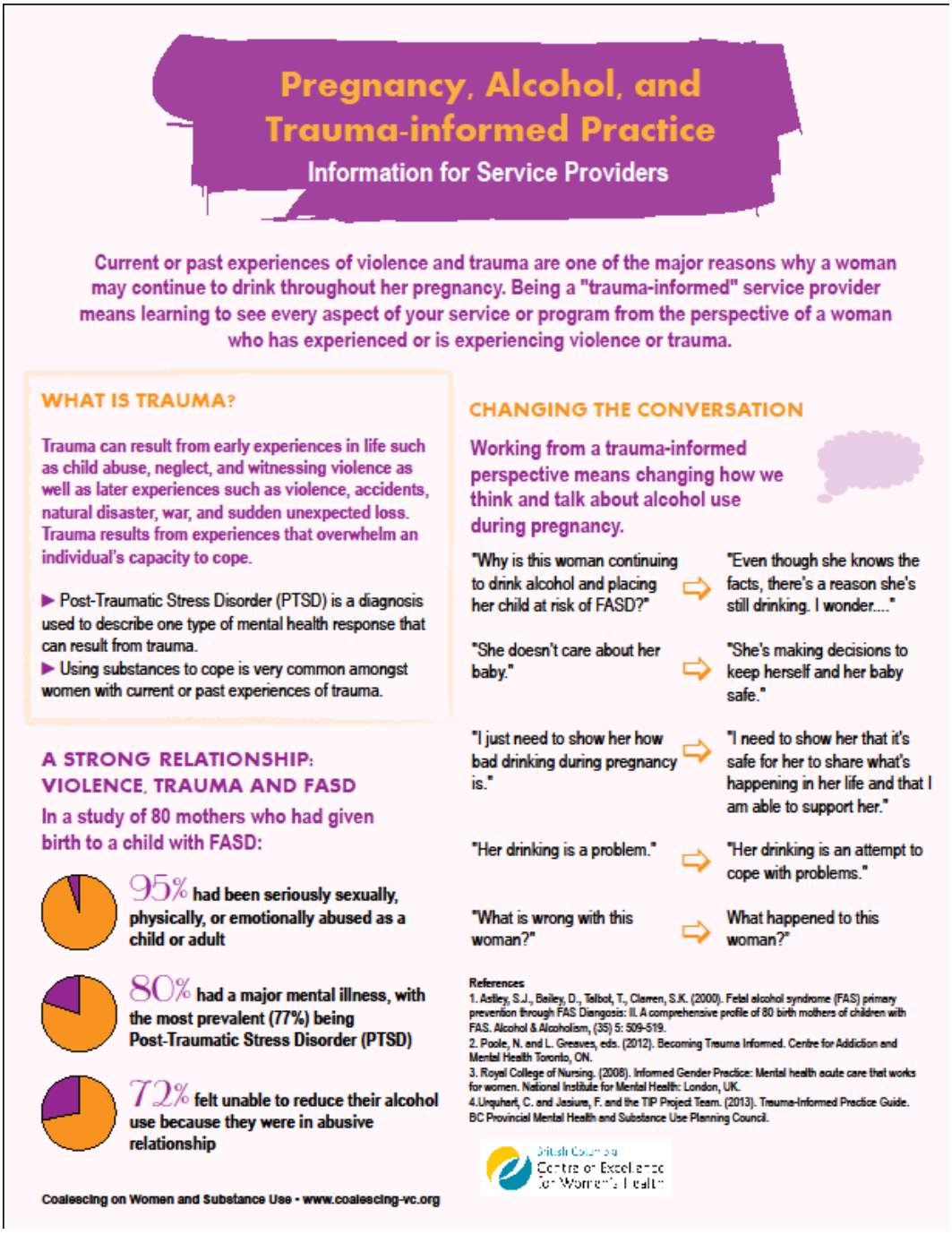
Our strong recommendation is that the school and district team accept this designation as a medical diagnosis within the umbrella diagnosis of FASD and as a complex developmental behavioral condition as described in the Ministry of Education under Category D. Team reports will illustrate multiple areas of functional concerns that can be addressed by an Individualized Education Plan and support within the school setting.

Please contact me should further discussion be needed.

Sincerely,

Nancy E Lanphear MD
Developmental Behavioral Pediatrician
Sunny Hill Health Centre, CDBC Medical Lead
Tel: 604-875-2345, ext 458383

Pregnancy, alcohol, and trauma-informed practice



Pregnancy, Alcohol, and Trauma-informed Practice

Information for Service Providers

Current or past experiences of violence and trauma are one of the major reasons why a woman may continue to drink throughout her pregnancy. Being a "trauma-informed" service provider means learning to see every aspect of your service or program from the perspective of a woman who has experienced or is experiencing violence or trauma.

WHAT IS TRAUMA?

Trauma can result from early experiences in life such as child abuse, neglect, and witnessing violence as well as later experiences such as violence, accidents, natural disaster, war, and sudden unexpected loss. Trauma results from experiences that overwhelm an individual's capacity to cope.

- Post-Traumatic Stress Disorder (PTSD) is a diagnosis used to describe one type of mental health response that can result from trauma.
- Using substances to cope is very common amongst women with current or past experiences of trauma.

A STRONG RELATIONSHIP: VIOLENCE, TRAUMA AND FASD

In a study of 80 mothers who had given birth to a child with FASD:

- 95% had been seriously sexually, physically, or emotionally abused as a child or adult
- 80% had a major mental illness, with the most prevalent (77%) being Post-Traumatic Stress Disorder (PTSD)
- 72% felt unable to reduce their alcohol use because they were in abusive relationship

Coalescing on Women and Substance Use - www.coalescing-vc.org

CHANGING THE CONVERSATION

Working from a trauma-informed perspective means changing how we think and talk about alcohol use during pregnancy.

"Why is this woman continuing to drink alcohol and placing her child at risk of FASD?"	"Even though she knows the facts, there's a reason she's still drinking. I wonder...."
"She doesn't care about her baby."	"She's making decisions to keep herself and her baby safe."
"I just need to show her how bad drinking during pregnancy is."	"I need to show her that it's safe for her to share what's happening in her life and that I am able to support her."
"Her drinking is a problem."	"Her drinking is an attempt to cope with problems."
"What is wrong with this woman?"	What happened to this woman?"

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2. Poole, N. and L. Greaves, eds. (2012). Becoming Trauma Informed. Centre for Addiction and Mental Health Toronto, ON.
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4.Urquhart, C. and Jasiure, F. and the TIP Project Team. (2013). Trauma-Informed Practice Guide. BC Provincial Mental Health and Substance Use Planning Council.

British Columbia Centre of Excellence for Women's Health

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CDBC communication assessment

The purpose of the speech-language assessment is to develop an individualized communication profile. Given the degree of complexity relating to medical and/or developmental concerns in the population served by CDBC, a comprehensive assessment is required which includes formal testing, clinical observations, file review for historical information, and informant reports of the child/youth's communication functioning across home and school environments. This entails assessment of semantics (content) and morpho-syntax (grammar) in receptive and expressive modalities. It is expected that measures will be selected to address single-word (vocabulary), sentence-level, and discourse skills. When possible and if indicated, evaluation of speech and/or social skills is recommended which may include direct and/or indirect testing, depending on file review and the child's presentation. In all cases, clinical impressions of the child's social functioning and use of language in context is expected in reports as well as an integration of test results with information from family/community sources. The assessment is planned (including which measures are selected) according to the referral question(s) and file review, and is adjusted based on the child's presentation and cooperation, and on time limitations. Whenever possible, assessment of communication should be completed by the child or youth's community Speech Language Pathologist to alleviate lengthy waitlists.

For a child under 6, assessment *will* include:

1. Assessment of **receptive language** (including comprehension of connected language) using measures such as but not limited to:
    - Clinical Evaluation of Language Fundamentals, Preschool (CELF-P3)
    - Clinical Evaluation of Language Fundamentals (CELF5)
    - Test for Early Language Development (TELD-4)
    - Preschool Language Scales (PLS-5)
    - Test of Oral Language Development, Primary (TOLD-P:5)
    - Comprehensive Assessment of Spoken Language (CASL-2)
    - Test for Reception of Grammar (TROG-2)
2. Assessment of **expressive language** (including connected language) such as but not limited to:
    - CELF-P3
    - CELF5
    - TELD-4
    - CASL-2
    - TOLD-P:5
    - Test of Expressive Language (TEXL)
    - Structured Photographic Expressive Language Test (SPELT-3)
3. Expressive **language samples**, including narrative ability such as but not limited to:
    - The Renfrew Bus Story (RBS-NA)

- Test of Narrative Language (TNL-2)
- Systematic Analysis of Language Transcripts (SALT 20)

4. **Parent/caregiver interview** about child's expressive and receptive language, social functioning and play skills
5. Clinical judgment of **speech sound skills** (e.g., articulation/phonology, oral motor speech function/overall intelligibility)
6. Clinical observation of **social/pragmatic functioning** (e.g., communicative functions, conversation, relating of events, nonverbal communication)

For a child under 6, assessment *may* include as indicated by the child's presentation:
1. Additional receptive and expressive tests such as but not limited to:
   - Receptive One-Word Picture Vocabulary Test (ROWPVT-4)
   - Expressive One-Word Picture Vocabulary Test (EOWPVT-4)
   - Peabody Picture Vocabulary Test (PPVT-5)
   - Expressive Vocabulary Test (EVT-3)
   - Rossetti Infant-Toddler Language Scale
   - Receptive-Expressive Emergent Language Test (REEL-4)
   - Evaluating Acquired Skills in Communication (EASIC-3)
   - MacArthur-Bates Communicative Developmental Inventory (MB-CDI)
   - Renfrew Action Picture Test – 5
   - Test for Auditory Comprehension of Language (TACL-4)
2. A measure of verbal reasoning and problem-solving such as but not limited to:
   - Inference subtest of the CASL-2
   - Preschool Language Assessment Instrument (PLAI-2)
   - Clinical observation of verbal reasoning (how/why questions, explanations, inferences)
3. Rating scales of social communication/pragmatics:
   - Children's Communication Checklist (CCC-2)
   - Language Use Inventory (LUI)
   - Pragmatic Language Skills Inventory (PLSI)
   - Descriptive Pragmatics Profile from the CELF-P3
   - Pragmatics Profile from the CELF5
4. Assessment of speech sound skills (articulation/phonology/oral motor) using standardized measures such as but not limited to:
   - Goldman Fristoe Test of Articulation (GFTA-3)
   - Structured Photographic Articulation Test (SPAT-D III)
   - Hodson Assessment of Phonological Patterns (HAPP-3)
   - Diagnostic Evaluation of Articulation and Phonology (DEAP)
   - Dynamic Evaluation of Motor Speech Skills (DEMSS)
   - The Apraxia Profile
   - Screening Test for Developmental Apraxia of Speech (STDAS-2)

- Oral Speech Mechanism Screening Examination (OSMSE-3)

5. A measure of phonological awareness such as but not limited to:
    - The Phonological Awareness Test (PAT-2)
    - Phonological Awareness subtest of the CELF-P3

For children/youth between 6 and 19 years, assessment *will* include:

1. Assessment of **receptive language** (including comprehension of connected language) using standardized measures such as but not limited to:
    - CELF5
    - TELD-4
    - CASL-2
    - TOLD-I-5
    - TROG-2
    - Test of Integrated Language & Literacy Skills (TILLS)

2. Assessment of **expressive language** (including connected language) using standardized measures such as but not limited to:
    - CELF5
    - TELD-4
    - TOLD-I:5
    - CASL-2
    - SPELT-3
    - TILLS
    - Expressive Language Test (ELT-2:NU)

3. Assessment of discourse using **narrative skills** such as but not limited to:
    - TNL-2
    - SALT 20

4. A measure of **verbal reasoning and problem-solving** such as but not limited to:
    - CELF-Metalinguistics (CELF-M)
    - CASL-2 subtests, e.g., Nonliteral Language, Meaning from Context, Inference, Double Meaning
    - Test of Problem Solving - Elementary (TOPS-3E:NU)
    - Test of Problem Solving - Adolescent (TOPS-2A)

5. Clinical judgment of **speech sound skills** (e.g. articulation/phonology, oral motor speech function/overall intelligibility)

6. Clinical observation of **social/pragmatic skills** (e.g. communicative functions, conversation, relating of events, nonverbal communication) and if possible, a direct measure such as but not limited to:
    - Social Emotional Evaluation (SEE)
    - Social Language Development Test – Elementary (SLDT-E:NU)
    - Social Language Development Test – Adolescent (SLDT-A)

- Test of Pragmatic Language (TOPL-2)

7. **Parent/caregiver interview and rating scales** regarding child's expressive and receptive language and social functioning such as but not limited to:

- CCC-2
- CELF5: Observational Rating Scale (ORS) or Pragmatics Profile (PP)
- PLSI

For children/youth between 6 and 19 years, assessment *may* include if indicated:

1. Additional receptive and expressive language tests such as but not limited to:

- ROWPVT-4
- EOPWPVT-4
- PPVT-5
- EVT-3
- TACL-4
- A measure of word-finding (e.g. TWF-3)
- Test of Auditory Processing Skills (TAPS-4)
- Language Processing Test (LPT-3)

2. Assessment of speech sound skills (articulation/phonology/oral motor) using standardized measures such as but not limited to:

- GFTA-3
- SPAT-D III
- DEAP
- DEMSS
- The Apraxia Profile
- STDAS-2
- OSMSE-3

3. A measure of phonological awareness such as but not limited to:

- PAT-2
- Phonemic Awareness subtest of the TILLS
- Subtests from the Comprehensive Test of Phonological Processing (CTOPP-2)

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