Fetal Alcohol Syndrome: Occupational Therapy

Indexing Metadata/Description

› **Title/condition:** Fetal Alcohol Syndrome: Occupational Therapy
› **Synonyms:** Fetal alcohol spectrum disorder; alcohol-related birth defects; alcohol-related neurodevelopmental disorders; FAS: occupational therapy; occupational therapy: fetal alcohol syndrome; occupational therapy: FAS
› **Anatomical location/body part affected:** Brain, central nervous system (CNS), face, cardiovascular system
› **Area(s) of specialty:** Pediatric rehabilitation, neurological rehabilitation
› **Description**

* Most preventable cause of developmental disabilities\(^{(32)}\)
* Developmental defects in fetus as a result of alcohol consumption by mother during pregnancy\(^{(1)}\)
* Most common defects are low birth weight with failure to catch up in size and weight, mental retardation, facial and cardiac abnormalities, delayed postnatal growth and delayed development\(^{(1)}\)
* Alcohol consumption interferes with the metabolism of vitamins. Many vitamins are key to typical embryonic development, and with poor vitamin absorption and impaired metabolism there is a greater risk for atypical development of the embryo\(^{(34)}\)
* Fetal alcohol syndrome (FAS) tends to be underreported\(^{(35)}\)
* A cohort study found that 70% of Australian mothers of babies with FAS lacked an alcohol-related diagnosis during their pregnancy\(^{(35)}\)
* FAS falls under the umbrella of fetal alcohol spectrum disorders (FASDs)\(^{(2)}\)
* Four categories within the continuum of FASD (from most severe to less severe), according to the Institute of Medicine (IOM):\(^{(3)}\)
  – FAS
  – Partial FAS
  – Alcohol-related neurodevelopmental disorders
  – Alcohol-related birth defects
* Diagnostic criteria, according to the U.S. Centers for Disease Control and Prevention (CDC):\(^{(2)}\)
  – Facial dysmoria: smooth philtrum, thin vermilion border, small palpebral fissures
  – Growth problems
  – CNS problems
    - Structural deformities (small head circumference)
    - Functional problems: global cognitive deficit (low IQ) or deficits in three or more of the following domains: cognitive, executive function, motor function, attention and hyperactivity, social skills, other (such as sensory processing, language, or memory problems)
  – Confirmation of maternal alcohol consumption during pregnancy
* According to the IOM, in order for a diagnosis of FAS to be made, child must have:\(^{(3)}\)
At least two or more key facial features such as palpebral fissures (short eye slit length), thin vermilion border, or smooth philtrum (vertical groove between nose and upper lip)

– Prenatal and/or postnatal growth retardation (10th percentile or less)
– Deficient brain growth, head circumference (10th percentile or less)
– If possible, confirmation of maternal alcohol consumption during pregnancy

• According to University of Washington (UW) Fetal Alcohol Spectrum Disorder 4-digit diagnostic code, in order for a diagnosis of FAS to be made, child must have:
  – Growth abnormalities
  – Facial appearance abnormalities
  – CNS structure and function abnormalities
  – History of alcohol exposure

• Mean age at diagnosis of FAS is 8 years, but it can be diagnosed at any age

› ICD-9 codes
  • 760.71 alcohol affecting fetus or newborn via placenta or breast milk

› ICD-10 codes
  • P04.3 fetus and newborn affected by maternal use of alcohol
  • Q86.0 fetal alcohol syndrome (dysmorphic)

› G-Codes
  • Mobility G-code set
    – G8978, Mobility: walking & moving around functional limitation, current status, at therapy episode outset and at reporting intervals
    – G8979, Mobility: walking & moving around functional limitation; projected goal status, at therapy episode outset, at reporting intervals, and at discharge or to end reporting
    – G8980, Mobility: walking & moving around functional limitation, discharge status, at discharge from therapy or to end reporting

  • Changing & Maintaining Body Position G-code set
    – G8981, Changing & maintaining body position functional limitation, current status, at therapy episode outset and at reporting intervals
    – G8982, Changing & maintaining body position functional limitation, projected goal status, at therapy episode outset, at reporting intervals, and at discharge or to end reporting
    – G8983, Changing & maintaining body position functional limitation, discharge status, at discharge from therapy or to end reporting

  • Carrying, Moving & Handling Objects G-code set
    – G8984, Carrying, moving & handling objects functional limitation, current status, at therapy episode outset and at reporting intervals
    – G8985, Carrying, moving & handling objects functional limitation, projected goal status, at therapy episode outset, at reporting intervals, and at discharge or to end reporting
    – G8986, Carrying, moving & handling objects functional limitation, discharge status, at discharge from therapy or to end reporting

  • Self Care G-code set
    – G8987, Self care functional limitation, current status, at therapy episode outset and at reporting intervals
    – G8988, Selfcare functional limitation, projected goal status, at therapy episode outset, at reporting intervals, and at discharge or to end reporting
    – G8989, Selfcare functional limitation, discharge status, at discharge from therapy or to end reporting

  • Other PT/OT Primary G-code set
    – G8990, Other physical or occupational primary functional limitation, current status, at therapy episode outset and at reporting intervals
    – G8991, Other physical or occupational primary functional limitation, projected goal status, at therapy episode outset, at reporting intervals, and at discharge or to end reporting
    – G8992, Other physical or occupational primary functional limitation, discharge status, at discharge from therapy or to end reporting
Other PT/OT Subsequent G-code set

- G8993, Other physical or occupational subsequent functional limitation, current status, at therapy episode outset and at reporting intervals
- G8994, Other physical or occupational subsequent functional limitation, projected goal status, at therapy episode outset, at reporting intervals, and at discharge or to end reporting
- G8995, Other physical or occupational subsequent functional limitation, discharge status, at discharge from therapy or to end reporting

<table>
<thead>
<tr>
<th>G-code Modifier</th>
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<tr>
<td>CH</td>
<td>0 percent impaired, limited or restricted</td>
</tr>
<tr>
<td>CI</td>
<td>At least 1 percent but less than 20 percent impaired, limited or restricted</td>
</tr>
<tr>
<td>CJ</td>
<td>At least 20 percent but less than 40 percent impaired, limited or restricted</td>
</tr>
<tr>
<td>CK</td>
<td>At least 40 percent but less than 60 percent impaired, limited or restricted</td>
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<tr>
<td>CM</td>
<td>At least 80 percent but less than 100 percent impaired, limited or restricted</td>
</tr>
<tr>
<td>CN</td>
<td>100 percent impaired, limited or restricted</td>
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Source: http://www.cms.gov

Reimbursement: No specific issues or information regarding reimbursement have been identified

Presentation/signs and symptoms

- Poor weight gain\(^6\)
- Heart defects, such as ventricular septal defect (VSD) or atrial septal defect (ASD)\(^6\)
- Heart murmur\(^6\)

- Behavioral regulation problems, including:
  - Mild to moderate irritability\(^2\)
  - Poor habituation\(^2\)
  - Sleep problems\(^7,8\)
  - Feeding difficulties\(^2\)

- Cognitive development
  - Delayed mental development\(^6\)
  - Problems with memory, learning, attention, and problem solving\(^9\)
  - Deficits in speech, language development\(^9\)
  - Deficits in executive function (planning, organization, inhibition)\(^8\)
  - Intellectual disability\(^8\) – some individuals with FAS have mental retardation; others are in the low average to average range on standardized intelligence tests

- Children who have prenatal alcohol exposure and postnatal traumatic stress (e.g., abuse, neglect, sexual abuse) have lower intelligence scores, than those with postnatal traumatic experience alone. Children with prenatal alcohol exposure and postnatal trauma experience more severe neurodevelopmental deficits in language, memory, visual processing, motor skills, and attention; and more defiant behavior, inattention, hyperactivity, impulsivity, and social problems than children with postnatal traumatic stress alone\(^10\)
  - Based on a study in the United States of 274 children aged 6-16 years
  - 97% of the children were moderately to severely traumatized
  - 40% of the children met the criteria for FASD
  - Children assessed using Pediatric Early Elementary Examination (PEEX 2), Pediatric Examination of Educational Readiness at Middle Childhood (PEERAMID 2), Kaufman Brief Intelligence Test (K-BIT), and Conners’ Rating Scales Revised (CRS-R)
  - Children were divided into 2 groups: children with trauma/no FASD (n=161) and children with trauma/FASD (n=113)
Performance results of 2 groups were compared. Domains with the greatest deficits were attention (p=0.004), memory (p=0.005), and language (p=0.001) for children with trauma/FASD. Oppositional behavior (p=0.04), social problems (p=0.02), attention deficit/hyperactivity (p=0.004), and impulsivity (p=0.01) were also significantly higher in children with trauma/FASD.

Children with FASDs have poor skills in the areas of social interaction and communication, personal living skills, and community-living scales.

Based on a study in the United States with 25 children with FASD and 23 children with normal development (ages 5-8 years), the comparison of adaptive skills performance using the Scales of Independent Behavior-Revised (SIB-R), caregiver report, mean standard score of the SIB-R was significantly lower for the children with FASDs than those with normal development. Significant differences in subscales for the two groups of children in the areas of fine motor, social interaction, language comprehension, language expression, eating/meal prep, toileting, dressing, personal self-care, time, money/value, and work.

Physical development:

May present with:
- Small and narrow eyes, small head, small upper jaw, smooth and thin upper lip
- Short palpebral fissure
- Maxillary hypoplasia
- Presence of epicanthal folds
- Altered palmar flexional crease patterns
- Joint disability
- Overlapping fingers
- Ear anomalies
- Hemangiomas
- Ptosis
- Hypoplastic nails
- Pectus deformities
- Microcephaly
- Short nose
- Cleft lip
- Micrognathia
- Protruding auricles
- Short/webbed neck
- Vertebra and rib anomalies
- Short metacarpal bones
- Meningomyelocele
- Hydrocephalus
- Hydroplastic labia major

Sensorimotor development:

Children with FASDs are more likely to have sensory processing deficits and problem behaviors.

Based on a retrospective study in the United States of 44 children with FASDs aged 5-10 years, data analysis of outcomes on the Short Sensory Profile (SSP) and Child Behavior Checklist (CBCL) correlation between SSP and CBCL was significant (p ≤ 0.05) – as SSP scores decreased (more sensory processing problems), CBCL scores increased (more problem behaviors).
Children with FASDs who had sensory processing deficits had more externalizing behavior problems and problems with socialization, attention, rule breaking, and thought problems.

Children with FASDs have more sensory processing deficits than children who had been prenatally exposed to alcohol but do not meet the criteria for FASD diagnosis.\(^{13}\)

Based on retrospective study in Canada of 46 children: 15 children who were exposed to alcohol prenatally but did not meet diagnostic criteria for a FASD, 16 children diagnosed with alcohol-related neurodevelopmental disorder, and 15 children diagnosed with partial FAS; all children were aged 3-14 years.

Analysis and comparison of scores on SSP, Adaptive Behavior Assessment System, Wechsler Intelligence Scale for Children (WISC) score.

Children with partial FAS scored significantly lower on sensory processing than children in the prenatal exposure to alcohol group \(p=0.042\).

Children with a diagnosis of alcohol-related neurodevelopmental disorder scored significantly lower than the prenatal exposure to alcohol group in total score \(p=0.010\), taste/smell sensitivity \(p=0.031\), and low energy \(p=0.014\).

Motor delay \(^8\)

Poor sensory modulation \(^8\)

Sensation-seeking behaviors \(^8\)

Sensory under-responsivity \(^8\)

Fine and gross motor deficits \(^8\)

Poor muscle tone, motor coordination \(^6\)

Secondary problems can occur with this diagnosis, including: \(^{14}\)

Mental health problems

Disruptive school behaviors

Illegal behaviors

Confinement for inpatient treatment/incarceration

Inappropriate sexual behavior

Alcohol/drug problems

Causes, Pathogenesis, & Risk Factors

>> Causes

- Alcohol consumption by mother during pregnancy
- Alcohol is a teratogen that interferes with nerve cell development and function \(^2\)

>> Pathogenesis

- Inhibition of NMDA receptor function in the brain \(^{15}\)
- NMDA receptors are important for immature neuron survival and differentiation \(^{15}\)
- Result of the inhibition of these receptors is microcephaly, leading to neurological deficits \(^{15}\)

>> Risk factors

- Risk factors for alcohol use during pregnancy \(^{16}\)
  - Physical abuse and violence
  - Smoking tobacco
    - Pregnant women should also eliminate their exposure to smokeless tobacco products and electronic cigarettes \(^{32}\)
  - Poor physical health
  - Psychiatric distress (including depression)
  - Previous inpatient treatment for mental health problems and/or illicit drug use
  - Prior dysfunctional alcohol use (binge drinking, abuse, and dependence)
- Blood-alcohol concentration (how much and how often alcohol is consumed during pregnancy) has most the impact on alcohol-related deficits \(^{14}\)
- Prenatal alcohol exposure in the first trimester \(^{14}\)
- Genetics – those with sensitivity to alcohol may be more at risk for damage to fetus \(^{14}\)
• The level of prenatal alcohol consumption in pregnant women increases in the following situations: 
  – Their biological mother is their primary caregiver
  – High maternal age
  – Low maternal education level
  – Maternal drug use
  – Child custody changes within a family
  – Paternal drug use
  – Low socioeconomic status

Overall Contraindications/Precautions
› Children with FASDs are at risk for unintentional injuries due to impulsivity, difficulties in behavioral inhibition, and poor judgment
› If there is suspicion of an unsafe or abusive home situation, clinician should notify the physician and youth and family services
› There may be an increased risk for suicide attempts in adults with FASD; if patient describes suicidal thoughts or ideations, immediately refer to physician or emergency services
› Obtain consent of parent/guardian before evaluating and treating a minor
› See specific Contraindications/precautions to examination and Contraindications/precautions under Assessment/Plan of Care

Examination
› Contraindications/precautions to examination
  • Children are at risk for unintentional injuries due to impulsivity, difficulties in behavioral inhibition, and poor judgment
› History
  • History of present illness/injury
    – Mechanism of injury or etiology of illness: Ask parent/caregiver about child’s prenatal history, any complications with labor/delivery, and prematurity. Ask about child’s achievement of developmental milestones
    – Course of treatment
      - Medical management: Document treatments received. Document any surgical interventions. Document therapeutic interventions received at school or another facility
      - Medications for current illness/injury: Determine what medications clinician has prescribed; are they being taken? Are they effective?
        - Because children with FASDs sometimes also meet diagnostic criteria for attention deficit/hyperactivity disorder (ADHD), ask about stimulant medications being taken for hyperactivity, impulsivity, and inattentiveness
          - Methylphenidate
          - Pemoline
          - Dextedrine
          - Dextroamphetamine
      - Diagnostic tests completed
        - In utero:
          - Blood alcohol level of mother during pregnancy
          - Pregnancy ultrasound
        - After child is born:
          - CT scan or MRI of brain
          - Lip-philtrum guides
          - FAS facial photographic analysis software
        - In a study of 34 clinics that worked with children with FASDs, routine assessments used for diagnoses included:
          - Facial photographs, facial analysis software
          - Audiology
- Genetic testing
- Vision assessment
- Neuroimaging
- Neurobehavioral assessments (behavioral, motor, visual-motor, cognitive, developmental, neuropsychometric, adaptive behavior, social skills, communication, education/academic, neurological)

**Home remedies/alternative therapies:** Document any use of alternative therapies (e.g., acupuncture) and whether or not they help. Ask about use of choline, a nutritional supplement, as it may help improve learning, memory, and cell function.

- **Previous therapy:** Document whether patient has had occupational or physical therapy for this or other conditions and what specific treatments were helpful or not helpful
  - **Aggravating/easing factors:** Ask what factors (e.g. environments or conditions) aggravate or improve the symptoms and/or behaviors, and length of time each item is performed before the symptoms and/or behaviors come on or are eased
  - **Body chart:** Use body chart to document location and nature of symptoms, if applicable, although pain is not characteristic of FASD. Use nonverbal scales as appropriate, such as the Oucher scale and FLACC
  - **Nature of symptoms:** Document nature of symptoms (e.g., constant vs. intermittent, sharp, dull, aching, burning, numbness, tingling), if applicable. Is there a time of day or length of time after a medication is taken that the patient is more cooperative?
  - **Rating of symptoms:** Use a visual analog scale (VAS) or 0-10 scale to assess symptoms at their best, at their worst, and at the moment (specifically address if pain is present now and how much)
  - **Pattern of symptoms:** Document changes in symptoms throughout the day and night, if any (A.M., mid-day, P.M., night); also document changes in symptoms due to other external variables
  - **Sleep disturbance:** Document number of wakings/night. Persons with FASDs often have disruptions in sleep cycle. In a study of 27 children with FASD in Canada, researchers found that sleep problems were often undiagnosed due to the focus on daytime behavior presentations, such as inattention, hyperactivity, and cognitive/emotional impairments.
  - **Other symptoms:** Document other symptoms patient may be experiencing that could exacerbate the condition and/or symptoms that could be indicative of a need to refer to physician. Document any alcohol or illicit drug use in older children, as persons with prenatal exposure to alcohol are at risk for drug and alcohol abuse later in life.
  - **Respiratory status:** Document any use of supplemental oxygen or complaints of breathing difficulty

- **Barriers to learning**
  - Are there any barriers to learning? Yes__ No__
  - If Yes, describe _________________________
  - Some children with FASDs have learning impairments and have difficulty at school behaviorally and academically.
  - Document academic difficulties, if any
  - Document teacher’s impressions of child’s behavior at school

- **Medical history**
  - **Past medical history**
    - **Previous history of same/similar diagnosis:** Ask parents/caregiver about any past medical history of developmental disorders
    - **Comorbid diagnoses:** Ask patients/caregiver about other problems, including diabetes, cancer, heart disease, psychiatric disorders, orthopedic disorders, etc. Mental health problems are prominent in persons with prenatal alcohol exposure. Depression, anxiety, aggression, and inattention are common. Children with FASDs sometimes also meet diagnostic criteria for attention deficit/hyperactivity disorder (ADHD).
    - **Medications previously prescribed:** Obtain a comprehensive list of medications prescribed and/or being taken (including over-the-counter drugs)
    - **Other symptoms:** Ask patient and/or family about other symptoms he or she may be experiencing

- **Social/occupational history**
  - **Patient’s goals:** Document what the patient and/or caregiver hopes to accomplish with therapy and in general
  - **Vocation/avocation and associated repetitive behaviors, if any:** Document child’s participation in extracurricular activities, recreational or competitive sports, and school
  - **Functional limitations/assistance with ADLs/adaptive equipment:** Document any adaptive equipment used by patient and the amount of assistance patient requires for self-care tasks. Indicate if specific limitations are experienced in the school setting
– **Living environment:** Document who lives with the patient, the number of stairs in home, number of floors in home, any personal care assistance, and any bathroom modifications. Identify if there are barriers to independence in the home, community, or school and if any modifications are needed. Ask about caregiver support/stress.

– **Relevant tests and measures:** (While tests and measures are listed in alphabetical order, sequencing should be appropriate to patient medical condition, functional status, and setting)

  • **Anthropometric characteristics:** Weight, height, body mass index (BMI), head circumference
  
  • **Arousal, attention, cognition (including memory, problem solving)**
    – Kaufman Brief Intelligence Test (K-BIT)\(^{10}\) – normed assessment that measures verbal and nonverbal intelligence of persons aged 4-90 years
    – Conners’ Rating Scales (CRS-R)\(^{10}\) – normed assessment that measures psychopathology and problem behavior in children and adolescents
    – Test of Non-verbal Intelligence, 2nd edition (TONI-2)\(^{11}\) – standardized assessment of cognitive ability, using abstract and figural problem solving
    – Continuous Performance Task (CPT)\(^{23}\) – objective assessment that measures sustained attention over time. Task consists of presenting visual or auditory stimuli over defined period of time, at a predetermined rate. Patients are asked to respond to stimulus – incorrect responses are omission errors (missing target stimuli) and commission errors (delayed or incorrect responses)
    – Bayley Mental Scale in Infancy\(^{2}\) – prenatal alcohol exposure is associated with lower performance on this assessment
    – WISC – 4th edition (WISC-IV)\(^{13}\)
    – WISC Preschool and Primary Scale of Intelligence – 3rd edition (WPPSI-III)\(^{12}\)
    – Differential Ability Scales\(^{24}\) – standardized assessment of cognitive function for individuals aged 2-17 years

  • **Assistive and adaptive devices:** Assess need for assistive/adaptive equipment for self-care or school tasks

  • **Balance:** Assess static and dynamic balance reactions as appropriate for age
    – Clinical observations of postural control\(^{26}\)

  • **Cardiorespiratory function and endurance:** Document patient’s activity tolerance or need for frequent rest breaks

  • **Ergonomics/body mechanics:** Observe child’s body mechanics, note any postural instability or postural compensatory movements

  • **Functional mobility** (including transfers, etc.): Assess functional mobility within patient’s environment: home, school. Assess ADL transfers (toilet/tub/bed); note how much assistance is required, and note any assistive devices used; the WeeFIM can be used for objective measure

  • **Motor function (motor control/tone/learning):** Assess muscle tone in bilateral UE and LE, trunk, and extremities
    – Bimanual Coordination Test\(^{14}\) – test of speed and accuracy of bilateral coordination. With increased task complexity, children with FASDs generally perform more poorly than controls

  • **Muscle strength:** Manual muscle strength testing for all extremities without tone or coordination issues. Note any asymmetry or abnormality

  • **Neuromotor development**
    – Pediatric Early Elementary Examination (PEEX 2)\(^{10}\) – standardized assessment for children aged 6-8 years; assesses attention, memory, neuromotor function, visual-spatial processing, temporal-sequential function, higher level cognition
    – Pediatric Examination of Educational Readiness at Middle Childhood (PEERAMID 2)\(^{10}\) – standardized assessment for children aged 9-14 years; assesses attention, memory, neuromotor function, visual-spatial processing, temporal-sequential function, higher level cognition
    – Peabody Developmental Motor Scales, Second Edition (PDMS-2) – standardized assessment for children from birth to age 5 years; assesses gross and fine motor skills and visual motor integration

  • **Perception** (e.g., visual field, spatial relations)
    – Beery-Buktenica Developmental Test of Visual-Motor Integration\(^{26}\) subtests include visual perception test, motor coordination test, Goodenough Harris drawing test
    – NEPSY (A Developmental Neuropsychological Assessment)\(^{24}\) – subsections include visual attention, visual spatial function, language, sensorimotor, learning, and memory

  • **Posture:** Observe patient’s sitting and standing posture. Note any postural instability during movement/activity

  • **Range of motion:** Assess both active and passive ROM in all extremities. Note any asymmetry or abnormality
• **Self-care/activities of daily living** (objective testing)
  – Scales of Independent Behavior-Revised (SIB-R)<sup>(11)</sup> – standardized assessment of performance of daily activities

• **Sensory testing**
  – Infant/Toddler Sensory Profile<sup>(20)</sup>
  – Sensory Profile Caregiver Questionnaire<sup>(20)</sup>
  – Short Sensory Profile (SSP)<sup>(12)</sup> – parent-reported sensory behaviors; total and section scores are classified as definite difference, probable difference, and typical performance

• **Special tests specific to diagnosis**
  – Social skills
    - Social Skills Rating System – Parent Version<sup>(27)</sup>
  – Behavior
    - Child Behavior Checklist (CBCL)<sup>(12)</sup> – parent-reported behaviors, total score classified into categories: clinical, borderline, and normal
    - Personality Inventory for Children<sup>(14)</sup> – assessment of behavioral deficits
    - Adaptive Behavior Assessment System 2nd edition (ABAS-II)<sup>(13)</sup>

**Assessment/Plan of Care**

› **Contraindications/precautions**
  • Patients with FASDs are at increased risk for falls. Follow facility protocols for fall prevention and post fall prevention instructions at bedside, if inpatient. Ensure that patient and family/caregivers are aware of the potential for falls and educated about fall prevention strategies. Discharge criteria should include independence with fall prevention strategies
  • Children with FASDs are at risk for unintentional injuries due to impulsivity, difficulties in behavioral inhibition, and poor judgment<sup>(17)</sup>

› **Diagnosis/need for treatment**: Referral to occupational therapy for difficulties with adaptive behaviors, ADL performance, and motor skills at home (e.g., for self-care) and/or at school (e.g., writing), leading to lack of independence at home and in the community and poor academic performance

› **Rule out**
  • Williams syndrome<sup>(3)</sup>
  • Down syndrome<sup>(2)</sup>
  • Brachmann-de Lange syndrome<sup>(3)</sup>
  • Fragile X syndrome<sup>(2)</sup>
  • Aarskog syndrome<sup>(2)</sup>
  • Noonan syndrome<sup>(2)</sup>
  • Dubowitz syndrome<sup>(2)</sup>
  • Toluene embryopathy<sup>(2)</sup>
  • Fetal hydantoin syndrome (fetal Dilantin syndrome)<sup>(2)</sup>
  • Maternal PKU fetal effects<sup>(2)</sup>

› **Prognosis**
  • There is no cure for FAS<sup>(20)</sup>
  • Persons with FAS can lead productive lives<sup>(20)</sup>
  • Factors that increase risk for negative outcomes (e.g., delinquency, school failure, alcohol and drug abuse problems) are:<sup>(17)</sup>
    – IQ ≥70
    - Researchers suggest the reason for this is that persons with higher IQ qualify for and receive less services
    – Diagnosis of an alcohol-related disorder
Person with history of prenatal alcohol exposure are at significantly increased risk for mental health problems, psychiatric confinement, school failure, delinquency, incarceration, sexually inappropriate behaviors, and substance abuse problems later in life\(^{(17)}\)

The impact of neurobehavioral deficits from alcohol exposure on person’s ability to function and adapt in his or her environment may be improved or worsened by postnatal experiences\(^{(2)}\)

Past or current parental abuse, poor attachment, and poor quality of childhood caregiving environment are significantly associated with poor life outcomes\(^{(2)}\)

Early diagnosis of FAS is associated with decreased risk of poor outcomes\(^{(28)}\)

**Referral to other disciplines**

- Physical therapy
- Social work
- Psychology
- Speech therapy
- Youth and family services
- Drug and alcohol counseling
- Vocational rehabilitation

**Other considerations**

- Treatment of individuals with FASDs must include providing education to parents and caregivers on the nature of the individual’s disability, including the ways deficits will manifest in their daily lives, appropriate goals, and how to advocate for services. There is a tendency for behavior problems to be misunderstood as poor motivation, lack of empathy, or defiance as opposed to a function of neurocognitive impairments. Parents and caregivers should then help to educate medical, mental health, and education professionals who may be working with the patient but lack training with this population\(^{(17)}\)

**Treatment summary**

- There is limited research-based evidence on the efficacy of interventions for children with FASDs\(^{(5)}\)
  - Based on systematic review of the literature published in 2007
  - 10 studies were identified: 3 were experimental/quasi-experimental, 4 were nonexperimental, 3 were unable to be acquired (two were in foreign languages, one was unpublished)
  - Studies included those on the effectiveness of cognitive control therapy and the effectiveness of psychostimulant medications
  - No significant differences reported in neuropsychological or intelligence testing, although anecdotally there were reported behavioral improvements
  - Authors stated that the 3 experimental studies included in the review lacked scientific rigor and that therefore no firm conclusions can be made about what are effective interventions for children with FASDs

- Children with FAS who participated in a child’s friendship training group for social skills learning reported improvement in communicating with peers and handling disappointment and frustration\(^{(27)}\)
  - Based on a description of a social skills intervention group for children with FASDs
  - 11 children, aged 7-12 years, participated in seven 90-minute sessions
  - Sessions were structured with activities that all kids could do or could be modified, that allowed development and practice of specific social skills and were fun and engaging
  - Children were also given homework to do during the week, such as inviting a friend to play a game, calling a friend, or complimenting a friend during the week
  - Pre and post program questionnaires were filled out by parents; the Social Skills Rating System – Parent Version was used
  - 7 out of 8 questionnaires that were returned indicated improvements in addressing communication and handling disappointment and frustration

- Caregiver behavior consultation may result in positive changes in parenting attitudes and knowledge and in reductions in perceived disruptive behavior\(^{(8)}\)
  - Based on a description of a caregiver consultation model, where caregivers of children with FASDs met a therapist during biweekly home visits over a span of 9-11 months
  - Sensory integration training/education to caregivers to reframe behaviors and make sensory-based accommodations in home and routine to improve function
  - Caregivers noted positive changes in parenting attitudes and knowledge and reductions in perceived disruptive behavior
A step-by-step program that mentors parents with FASDs is effective at achieving goals\textsuperscript{(28)}

- Based on retrospective analysis in Canada of 24 parents: 50% diagnosed with a FASD, 25% had possible prenatal alcohol exposure, 25% had suspected prenatal alcohol exposure but no formal assessment available during the study
- Intervention consisted of one-on-one mentorship program over 3 years; mentors helped in accessing supports such as housing, addiction treatment, financial support, parent supports
- Goals of program were to reduce risk of family breakdown, strengthen parenting skills, increase independence and success within families
- Four goal categories showed an increase pre and post intervention: self-care and health, self-reliance, community connection, and parenting

A sociocognitive habilitative program focused on improving behavior and math functioning can be effective in decreasing problem behaviors and increasing gains in math knowledge in children with FAS\textsuperscript{(24)}

- Based on a study in the United States with 61 children aged 3-10 years with FAS
- The program consisted of caregiver education; support for learning readiness, including case management services and psychiatric consultation needed to facilitate socioemotional adjustment; and focused math intervention
- Children were assessed over a period of 2 days prior to the start of caregiver workshops
- Caregivers attended two 2-hour workshops; content was related to FAS and special education and building positive behavioral regulation skills
- Children were then randomly assigned to a math intervention group or a psychoeducational control group
- Those in the psychoeducational group received neurodevelopmental evaluation and consultation with teachers about child’s individualized education plan
- Those in the math intervention group received 6 weeks of tutoring services in addition to psychoeducational consultation
- Math intervention group used the sociocognitive model, with emphasis on cognitive functions that impact academic achievement and adaptive functioning skills, such as processing speed, visual/spatial processing, working memory, interhemispheric transfer of information, graphomotor skills
- Children were evaluated post intervention within 4 weeks of completing the program
- After the workshops, caregivers reported significantly fewer problem behaviors in Internalizing Problem Behavior (p < 0.006), Externalizing Problem Behavior (p < 0.000), and Total Problem Behavior (p < 0.000) summary scales of Child Behavior Checklist
- The math treatment group had significantly more gains from pretest to posttest in math outcome measures than the control group (p < 0.008)

There is limited good quality evidence for specific interventions for managing FASD\textsuperscript{(25)}

- Based on a systematic review of the literature published in 2009
- Twelve studies met inclusion criteria; methodological weaknesses were common
- There was some evidence to suggest that virtual reality training, cognitive control therapy (CCT), language and literacy therapy, mathematics intervention, and rehearsal training for memory may be beneficial strategies
- CCT addresses body position; movement and awareness; attention; and information processing, controlling, and categorizing

Researchers of a randomized controlled trial (RCT) in the United States found neurocognitive habilitation to be a promising intervention for improving executive functioning and emotional problem solving in children with FAS or alcohol-related neurodevelopmental disorder\textsuperscript{(31)}

- Forty children were in the treatment program; there were 38 controls
- Outcome measures were the Behavior Rating Inventory of Executive Function (BRIEF) and the Roberts Apperception Test for Children (RATC)
- Intervention included components of the Alert Program (a curriculum that helps children improve self-regulatory skills by teaching them how to identify their arousal level and then how to alter it based on situational demands) and treatment strategies used with the pediatric Traumatic Brain Injury (TBI) population, such as occupational therapy, family psychoeducation, and interventions to improve memory skills, emotional awareness, and cause and effect reasoning
- Significant differences between the treatment and control groups were demonstrated

<table>
<thead>
<tr>
<th>Problem</th>
<th>Goal</th>
<th>Intervention</th>
<th>Expected Progression</th>
<th>Home Program</th>
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<tbody>
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<tr>
<td>Decreased social skills</td>
<td>Improve social skills</td>
<td><strong>Patient education</strong></td>
<td>N/A</td>
<td>Provide patient and family/ caregivers with written instructions regarding skills that can be practiced at home</td>
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<td></td>
<td>Social skills groups, such as parent-assisted social skills intervention[17] and children’s friendship training[17]</td>
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<td></td>
<td>Emphasis on rules of social behavior, modeling, rehearsal, performance feedback, coaching[17]</td>
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<tr>
<td>Decreased sensory</td>
<td>Improve sensory</td>
<td>**Compensatory</td>
<td>Progress sensory activities as patient tolerates</td>
<td>Provide patient and family/ caregivers with written instructions regarding sensory diet at home</td>
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<tr>
<td>processing</td>
<td>processing, regulation, attention</td>
<td>techniques**</td>
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<td>Altering the</td>
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<td></td>
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<td>environment, reducing stimuli, self-regulation strategies[20]</td>
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<td>The Alert Program[20]</td>
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<td>Sensory diet – use of sensory activities in the daily routine,[20] inclusion of proprioceptive (heavy work) and vestibular activities, inclusion of tactile input (deep pressure, massage, hand fidgets)</td>
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<tr>
<td>Decreased safety skills</td>
<td>Improve awareness for safety</td>
<td><strong>Patient education</strong></td>
<td>N/A</td>
<td>Provide patient and family/ caregivers with written instructions regarding safety skills that can be practiced at home/school</td>
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<td>Computer games</td>
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<td>simulating safety</td>
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<td>situations such as</td>
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<td>fire safety or street</td>
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<td>safety[17]</td>
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<tr>
<td>Decreased independent</td>
<td>Improve independent</td>
<td><strong>Patient education</strong></td>
<td>Progress skills training as patient improves</td>
<td>Provide patient and family/ caregivers with written instructions regarding skills that can be practiced at home/school</td>
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<tr>
<td>living skills</td>
<td>living skills</td>
<td>Skills and vocational</td>
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<td>skills training[17]</td>
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<tr>
<td>Decreased academic skills</td>
<td>Maximize academic performance</td>
<td>Compensatory techniques</td>
<td>N/A</td>
<td>Provide patient and family/caregivers with written instructions regarding adaptations/modifications that can be made at home/school</td>
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<tr>
<td>Adapt classroom environment, such as removing distracting visual stimuli, seating arrangements, working in small groups&lt;sup&gt;(26)&lt;/sup&gt;</td>
<td>Breaking down tasks, providing visual aids, reminders&lt;sup&gt;(26)&lt;/sup&gt;</td>
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</table>

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<thead>
<tr>
<th>Decreased motor skills</th>
<th>Improve motor skills</th>
<th>Functional training</th>
<th>Progress fine motor activities and patient’s motor skills improve</th>
<th>Provide patient and family/caregivers with written instructions regarding activities that can be practiced at home/school</th>
</tr>
</thead>
<tbody>
<tr>
<td>Practice of fine motor activities, handwriting</td>
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</table>

**Desired Outcomes/Outcome Measures**

- Desired outcomes
  - Maximize function and participation across daily living, social, and academic skills<sup>(11)</sup>
  - Improve adaptive behavior involving social, personal living, and community living<sup>(11)</sup> skills

- Outcome measures
  - Kaufman Brief Intelligence Test (K-BIT)<sup>(10)</sup>
  - Conners’ Rating Scales – Revised (CRS-R)<sup>(10)</sup>
  - Test of Non-Verbal Intelligence (TONI-2)<sup>(11)</sup>
  - Continuous Performance Task (CPT)<sup>(23)</sup>
  - Bayley Mental Scale in Infancy<sup>(2)</sup>
  - Wechsler Intelligence Scale for Children – 4th edition (WISC-IV)<sup>(13)</sup>
  - Wechsler Preschool and Primary Scale of Intelligence – 3rd edition (WPPSI-III)<sup>(13)</sup>
  - Differential Ability Scales<sup>(24)</sup>
  - Bimanual Coordination Test<sup>(14)</sup>
  - Pediatric Early Elementary Examination (PEEX 2)<sup>(10)</sup>
  - Pediatric Examination of Educational Readiness at Middle Childhood (PEERAMID 2)<sup>(10)</sup>
  - Beery-Buktenica Developmental Test of Visual-Motor Integration<sup>(26)</sup>
  - A Developmental Neuropsychological Assessment (NEPSY)<sup>(24)</sup>
  - Scales of Independent Behavior – Revised (SIB-R)<sup>(11)</sup>
  - Infant/Toddler Sensory Profile<sup>(20)</sup>
  - Sensory Profile Caregiver Questionnaire<sup>(20)</sup>
  - Short Sensory Profile (SSP)<sup>(12)</sup>
  - Social Skills Rating System – Parent Version<sup>(22)</sup>
  - Child Behavior Checklist (CBCL)<sup>(12)</sup>
• Personality Inventory for Children\(^{(14)}\)
• Adaptive Behavior Assessment System, 2nd edition (ABAS-II)\(^{(13)}\)
• Peabody Developmental Motor Scales, Second Edition (PDMS-2)\(^{(25)}\)
• Behavior Rating Inventory of Executive Function (BRIEF)\(^{(31)}\)
• Roberts Apperception Test for Children (RATC)\(^{(31)}\)

**Maintenance or Prevention**

› FAS can be prevented\(^{(8)}\)

› Alcohol abuse or dependence screening tools\(^{(29)}\)

• Alcohol Use Disorders Identification Test (AUDIT) – 10-item screening tool that asks about quantity, frequency, and 5 or more drinks on one occasion, personal/social consequences, dependence symptoms

• CAGE – 4-item screen asking about need to Cut down, Annoyed by criticisms about drinking, Guilty about drinking, need for Eye-opener in the morning

• T-ACE – alcohol screen for pregnant women, asking about Tolerance, being Annoyed by criticisms about drinking, need to Cut down and need for Eye-opener in the morning

• TWEAK – screen that asks about Tolerance, Worry by family members over drinking, need for Eye-opener in the morning, Amnesia and need to Cut down

› TWEAK and AUDIT screens more accurate in identifying problems in women than the CAGE screen\(^{(29)}\)

› In 2008 the CDC recommended that all women of childbearing aged be screened for alcohol use and educated about the consequences of alcohol consumption on pregnancy\(^{(29)}\)

› Persons with history of prenatal alcohol exposure at risk for substance abuse problems later in life; therefore, it is important to provide education about alcohol use and risks of drinking during pregnancy\(^{(17)}\)

**Patient Education**


**Coding Matrix**

References are rated using the following codes, listed in order of strength:

- **M** Published meta-analysis
- **SR** Published systematic or integrative literature review
- **RCT** Published research (randomized controlled trial)
- **R** Published research (not randomized controlled trial)
- **C** Case histories, case studies
- **G** Published guidelines
- **RV** Published review of the literature
- **RU** Published research utilization report
- **QI** Published quality improvement report
- **L** Legislation
- **PGR** Published government report
- **PFR** Published funded report
- **PP** Policies, procedures, protocols
- **X** Practice exemplars, stories, opinions
- **GI** General or background information/texts/reports
- **U** Unpublished research, reviews, poster presentations or other such materials
- **CP** Conference proceedings, abstracts, presentation

**References**


Alati R. Western Australia 70% of mothers of babies with fetal alcohol syndrome did not have an alcohol-related diagnosis recorded during pregnancy.


Alati R. Western Australia 70% of mothers of babies with fetal alcohol syndrome did not have an alcohol-related diagnosis recorded during pregnancy. Evidence Based Nursing. 2014;17(3):78. doi:10.1136/eb-2013.101456. (R)