FASD: Presentations in Youth, and Role of the PA FASD Task Force

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Disclosures

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Learning Objectives

• Learn what the umbrella term FASD means, and Basic information about FASD.
• Learn about one parent’s experience raising children with FASD.
• Learn about presentations of FASD -- especially ARND – in children and adolescents, and appropriate interventions involving child, family, and involved systems.
• Learn about the Pennsylvania FASD Task Force and its role in prevention, awareness, identification, and intervention.

Note: Not all slides will be reviewed, but are available for your reference.
Parent Perspective – Dianna Brocious

- Parent and family advocate
- Adoptive parent of children with an FASD, and grandparent of child with an FASD
- Member, OMHSAS Children’s Panning Council
- Family Involvement Specialist, PA System of Care Partnership
Awareness and Definitions
Fetal Alcohol Spectrum Disorder (FASD) as Identified by SAMHSA’s FASD Center for Excellence

...an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, behavioral, mental, and/or learning disabilities with possible lifelong implications.

The range of disorders:
Fetal Alcohol Syndrome (FAS)
Partial Fetal Alcohol Syndrome (pFAS)
Alcohol Related Neurodevelopmental Disorder (ARND)
Alcohol Related Birth Defects (ARBD)
Fetal Alcohol Syndrome (FAS) – All of the Following

Three facial abnormalities:
- Smooth philtrum (groove between upper lip and nose)
- Thin vermillion (upper lip)
- Small cerebral palpebral fissures (eye openings)

Growth retardation: height, weight, head circumference

Central nervous system involvement: cognition, intelligence, attention, behavior, memory, processing, mood, attachment, motor skills, eye-hand coordination and others

NOFAS: http://www.nofas.org/resource/CAP.asp
Fetal Alcohol Syndrome (FAS)

FAS Facial Characteristics:
- Small eye openings
- Smooth philtrum
- Thin upper lip

http://en.wikipedia.org/wiki/Fetal_alcohol_syndrome#Facial_features
Fetal Alcohol Syndrome (FAS)
Partial FAS (pFAS)

Some but not all the features of FAS are present:

Facial features
Physical birth defects
Growth retardation
Central nervous system deficits

NOFAS: http://www.nofas.org/resource/CAP.asp
Alcohol Related Birth Defects (ARBD)

ARBD describes defects in the skeletal and major organ systems.

Virtually every defect described in some patient with FAS.

They may include abnormalities of the heart, eyes, ears, kidneys, and skeleton, such as holes in the heart, underdeveloped kidneys, and fused bones.

NOFAS:http://www.nofas.org/resource/CAP.asp
Alcohol-Related Neurodevelopmental Disorder (ARND) (1)

ARND refers to various neurological abnormalities linked to prenatal alcohol exposure. These include:

- Decreased head size at birth
- Structural brain abnormalities, functional and cognitive impairments
- Pattern of behavioral and mental abnormalities

NOFAS: http://www.nofas.org/resource/CAP.aspx
ARND (2)

Children with ARND have central nervous system deficits, but do not have the facial features of FAS. Problems may include:

- Increased activity
- Attention deficits
- Learning disabilities
- Behavioral challenges
- Social skill impairments
- Poor visual focus
- Developmental delays
- Difficulty learning from experience

NOFAS: http://www.nofas.org/resource/CAP.aspx
Children with ARND typically *appear* similar to children without an FASD. As a result, they frequently are not identified.

Children with ARND are thus the group of children with an FASD most easily missed, and for this reason should be of particular concern to clinicians in the mental health system and others in human services.
FASD: Basic Facts and Neurobiology
Some Basic Facts

Alcohol is a teratogen.

The sole cause of FASD is women drinking alcoholic beverages during pregnancy.

“Of all the substances of abuse (including cocaine, heroin, and marijuana), alcohol produces by far the most serious neurobehavioral effects in the fetus.”

—IOM Report to Congress, 1996
Regarding Amount of Alcohol – No Safe Amount

In addition, binge drinking is especially hazardous because:

Women who binge prior to pregnancy are more likely to have unwanted pregnancies.

Exposure to high levels of blood alcohol is especially likely to cause teratogenicity in the first trimester.

(CDC: binge drinking for women = 4 or more alcohol drinks per occasion)
This is not only a “women’s issue.” It is one for which all of us, women and men, mothers and fathers, families and communities need to take responsibility.

FASD and the Brain

Prenatal alcohol exposure causes brain damage. Most of which is not reversible.

FASD: The leading known, preventable cause of mental retardation (e.g., intellectual disability) and birth defects.

FASD: Even greater developmental impact and cognitive and emotional functioning in those with normal intelligence.
FASD and the Brain

Normal brain of baby 6 wks old

Brain of baby same age with FAS

Photo courtesy of Sterling Clarren MD
http://en.wikipedia.org/wiki/Fetal_alcohol_syndrome
### Gestational Timing

<table>
<thead>
<tr>
<th>Period of the Ovum</th>
<th>Period of the Embryo (in weeks)</th>
<th>Period of the Fetus (in weeks)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-2</td>
<td>3</td>
<td>12</td>
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<tr>
<td>4</td>
<td>5</td>
<td>16</td>
</tr>
<tr>
<td>6</td>
<td>7</td>
<td>20-36</td>
</tr>
<tr>
<td>8</td>
<td>12</td>
<td>38</td>
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</tbody>
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**Central Nervous System (CNS)**

- **Heart**
- **Arms**
- **Eyes**
- **Legs**
- **Teeth**
- **Palate**
- **External Genitalia**

Figure 1: Vulnerability of the fetus to defects during different periods of development. The black portion of the bars represents the most sensitive periods of development, during which alcohol-induced (i.e., teratogenic) effects on the sites listed would result in major structural abnormalities in the child. The gray portion of the bars represents periods of development during which physiological defects and minor structural abnormalities would occur.

**Source:** Adapted from Moore and Persaud 1993.

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100% PREVENTABLE
FASD Prevalence: Data Until Recently

FAS prevalence: between 0.5 - 2 per 1,000 births, US

PA yearly estimates of FAS and FASD (2010, Burd):
- FAS: 284 births.
- FASD: 1,138 births,
- Total = 1,422 births per year (Burd)

FASD, much more prevalent, estimated to affect at least 40,000 newborns each year in US – 1 in 100 births

http://www.fasdcenter.samhsa.gov/educationTraining/fasdBasics.cfm
Given the challenges of establishing accurate and timely prevalence information, the number of cases of FASD is likely *far greater* than current data indicate.
Newer Perspectives on Prevalence

Carl Bell MD, Professor of Psychiatry and Public Health, University of Illinois at Chicago

• Fetal Alcohol Effects (e.g. FASD) is “the largest preventable public health problem in poor African American communities.”
• Bell’s recent review of his own 1979 evaluations of 274 children in special education in Chicago’s South Side: At least 55% of these students appear to have had an FASD.
• A 2011 audit of 162 students in school clinics = at least 32% with an FASD.
• Youth in Cook County Detention: 2/3-3/4 with signs of FASD (ADHD, ID, LDs, speech & language problems).
Risk Factors for Alcohol Use during Pregnancy: Adverse Experiences of Birth Mothers with FASD

Many, but not all, birth mothers experienced trauma and significant psychosocial adversities during childhood.

High prevalence of adverse experiences, including abuse, as an adult.

In this study, 80% of birth children with an FASD were in foster care or otherwise involved with Child Protective Services.

In many cases, abuse of woman and prenatal alcohol use occur over multiple generations.

(Astely, Bailey, Talbot and Clarren, 2000)
Identification of FASD
Challenges to Identification of FASD (1)

FASD (e.g., ARND) lacks the distinct clinical facial features of FAS, so these children appear “typical,” making identification even more difficult. An “invisible disorder.”

Facial features, when present in childhood for children with FAS, become less distinguishable during adolescence and adulthood.

Symptoms reflective of an FASD or ARND might be viewed as representing a separate psychiatric disorder rather than the presence of an FASD.
Challenges to Identification of FASD (2)

Lack of knowledge and misconceptions among primary care providers:

Many professionals believe that FASD can only occur if the mother is an alcoholic, poor, or African American or Native American.

Few know about the full range or the progressive nature of the neurobehavioral symptoms that result from prenatal exposure to alcohol.

NOFAS Curriculum for Allied Health Professionals
Challenges to Identification of FASD (3)

Fortunately, the DSM (DSM V) now has place to enter FASD:

- Use 315.8, “Other Specified Neurodevelopmental Disorder: Neurodevelopmental disorder associated with prenatal alcohol exposure.”

- This diagnosis is not prominent ("other"), but at least it exists. This is the first time it has been possible to make an FASD diagnosis via DSM nomenclature.
FASD: Distinguishing between Primary Effects and Secondary Effects
Basic Distinction

Primary effects – due directly to *in utero exposure* to alcohol and its impact on in utero development of infant, including brain development. Deficits are not reversible.

Secondary effects – due to the *impact of the FASD* (recognized or unrecognized) on the child and family, and from adversities faced by the child and family, not from the direct effect of the alcohol.

Goal: To manage primary effects of FASD, and to prevent, whenever possible, secondary effects and minimize their effect.
FASD Primary Effects (1)

- Variable effect on IQ, but *adaptive functioning* always decreased
- Learning problems, esp. mathematics & reading comprehension
- Problems with short-term memory
- Problems with processing information
- Communication difficulties, including the lack of the ability to comprehend verbal and written concepts
- Confounding element: Individual may speak well and give the impression of understanding, but may be only parroting words
FASD Primary Effects (2)

- Problems with decision-making
- Impulsivity
- Irritability and mood lability
- Difficulty with cause-and-effect reasoning and difficulty learning from experience, resulting in poor judgment and making same mistakes over and over
- Lack of awareness of own limitations, so not understand nature of his or her challenges
FASD Secondary Effects (1)

- Disrupted attachment with primary caregivers
- Disrupted school experience
- Risk of physical abuse and traumatic brain injury
- Risk of sexual victimization, or sexually inappropriate behaviors
- Risk of victimization due to suggestibility or gullibility
- Possible attachment disorders and ‘reactive attachment disorder’
FASD Secondary Effects (2)

• Substance use or abuse

• Mental health problems – ADHD, anxiety, depression, mood lability. Risk of Inpatient psychiatric hospitalization or RTF

• Difficulty maintaining employment; unemployment

• Inability to live independently

• Legal problems, including incarceration
**Causes of FASD Secondary Effects (1)**

Lack of recognition and identification of FASD

- Lack of education about disorder and what to expect
- FASD not identified, or misdiagnosed
- Punitive responses to the child
- Inappropriate interventions, treatment, and educational approaches
Causes of Secondary Effects (2)

Adverse experiences of children and their families

- Poverty, unstable housing, lack of community safety
- Poor attachment to parents/caregivers
- Parental mental illness or substance abuse
- Child maltreatment and domestic violence
- Community violence
- Child in substitute care – poor fit in foster home
- Multiple out-of-home placements

Cumulative frustration of parents, child, and others
Specific Red Flags

• The child has been diagnosed with a mental health disorder as a preschooler, such as ADHD, oppositional defiance or bipolar disorder
• The child has difficulty applying what has been learned, and may make the same mistakes over and over
• Typical interventions have not worked, despite reasonable efforts and reasonable level of expertise
• The child requires “hands on” or visual learning, rather than auditory
• The child is easily fatigued and overwhelmed by external stimulation
Possible Co-Occurring Disorders (all ages)

- Attention Deficit/Hyperactivity Disorder
- Depression
- Bipolar Disorder
- Schizophrenia
- Substance use disorders
- Medical disorders (i.e. seizure disorder, heart abnormalities)
- Sensory integration disorder
- Reactive Attachment Disorder
- Posttraumatic Stress Disorder
- Traumatic Brain Injury
- Anxiety Disorder
- Auditory processing disorder
Screening for FASD

• Screening for an FASD in children a work-in-progress – no validated screening tool for children.
• For adults, Life History Form (Dubovsky et al), but not yet validated.
• “Risk Assessment Questions” offered in SAMHSA Tip 58 on FASD (p. 22, 2014). Nine questions posed – 8 are yes/no.
• Always consider FASD in differential diagnoses, get good history, be alert to “red flags,” draw from PCP’s information.
• Identification a shared responsibility: family, PCP, school, & mental health professional, when involved.
Assessment of Suspected FASD

• History
  – Maternal history of alcohol/substances during pregnancy
  – Atypical development of child & other “red flags”
  – Underperforming student, and behavioral concerns

• Physical exam
  – Possible facial features and growth deficits
  – CNS deficits

• Psychological testing
  – Standard tests – IQ, achievement tests, adaptive functioning
Typical Findings on Psychological Testing

• IQ often normal, but may not be.
• Verbal IQ significantly greater than performance IQ
• Overall IQ greater than achievement scores (WRAT)
• Overall IQ greater than adaptive behavior scores
  (15 points, Vineland)
• Neuropsychological testing not currently routine part of assessment but can be valuable. Rationale for testing: “a possible underlying CNS condition.” Need above testing first.
Interventions
Need for a Paradigm Shift: How We View Children with FASD

• It’s not that these children won’t. It may be that they can’t. (Malbin). E.g., not intentional, laziness, or “manipulative” – a disability. Child has a problem, not to be viewed as being the problem.

• Need to recognize that some children and adolescents need more support from parents and others to succeed than typical children. This can be helpful and should not be seen as “enabling” (Dubovsky).
A Systems Approach to Intervention: Three Core Principles

• Support and collaborate with the family

• Collaborate with system partners and other involved professionals

• Help the child function more effectively
Support and Collaborate With the Family (1)

– Be “family-driven, youth-guided, & trauma informed”
– Provide education on FASD
– Identify/address family priorities & psychosocial needs
– Address trauma issues
– Promote parent-child attachments
– Build on family strengths
– Promote wellness and healthy lifestyles
Support and Collaborate With the Family (2)

– Collaborate, and promote choice
– Avoid shaming and blaming
– Identify natural supports
– Make appropriate referrals
– Consider child and family team (High Fidelity Wraparound)
– Advocate for and with the family
– Help family access respite and peer support
Collaborate with System Partners (1)

- Obtain a common understanding
- Educate others about FASD
- Help change *attitudes*, not just develop Rx/care plans
- Maintain realistic expectations
- Ensure that treatment plans are consistent with the child’s developmental level and capacities
Collaborate with System Partners (2)

– Work with child’s primary care physician, and the school.
– Ensure ongoing exchange of information
– Support consistency of approach – “same page”
– Promote lifelong support, involving modeling, mentoring, and monitoring and attention to transitions
Helping the Child Function More Effectively (1)

Importance of Early Intervention

The earlier in the child’s life that educational, clinical, medical, and support services can begin, the better the outcome.

Early intervention cannot overcome the damage that alcohol has imposed....It is doubtful that they can catch up with...their peers, even after an educational push.

However, early intervention *can* dramatically improve life skills, as well as provide the groundwork for later development. Therefore, early intervention may help to ensure more resilient individuals who can have a more productive, satisfying life.

Burgess and Streissguth, 1992; Hinde, 1993; Streissguth et al., 1996
Burgess and Streissguth, 1992; Hinde, 1993
Helping the Child Function More Effectively (2)
Protective Factors for Child with an FASD

**Early diagnosis/intervention:** A child diagnosed at a young age can be placed in appropriate educational classes and get needed social services.

**Involvement in special education and social services**

**Loving, nurturing, and stable home environment**

**Absence of violence:** Less likely to develop secondary conditions; Children with FASD need to learn to cope with anger/frustration.

http://www.cdc.gov/ncbddd/fasd/treatments.html#BehaviorandEducationTherapy
Helping the Child Function More Effectively (3)

Identify Child’s Strengths

– Friendly and outgoing
– Verbal (but can be misleading)
– Helpful
– Affectionate and lovable
– Well-intentioned
– Generous
– Determined
– Artistic, may have special abilities & skills
Help Child/Adolescent Function More Effectively (4)

Promote the Following

– Consistent routines and structure
– Limited stimulation
– Concrete language and examples – one direction at a time
– Repetition, via doing, seeing, role-playing

Source: NOFAS FASD Interventions Dubovsky
Help Child/Adolescent Function More Effectively (5)

Promote the Following

– Multi-sensory learning (visual, auditory and tactile)
– Realistic expectations- acknowledge developmental deficits or cognitive impairments
– Supportive environments
– Supervision – one to one; value of mentoring, modeling, and supervising

Source: NOFAS; FASD Interventions Dubovsky
Psychotropic Medication Use with FASD

- There is no psychotropic medication that addresses core deficits of an FASD or reverses pre-existing brain damage.
- Medication may be less effective in child or adolescent with an FASD, may result in more side effects.
- Nevertheless, there may be a role for meds:
  - Treatment of medication-responsive mental health disorders
  - Treatment of hyperactivity (inattention less likely to respond)
  - Medication alone without services is rarely indicated
  - Meds may enable child to benefit more from services
Psychotropic Medication Use with FASD

On the horizon, promise of more meaningful interventions?

– Investigation of choline, a nutrient and not a medication, for children with FASD. There have been rat and now human studies.

– Will it improve memory? Self-control? Executive functioning?
Take Home Points (1)

• Add FASD to the differential diagnosis, when working with children and adolescents with ADHD, immaturity, multiple academic and behavioral challenges, a history of ineffective mental health treatment, and other “red flags.”

• Routinely obtain information about maternal use of alcohol, drugs, and cigarettes during pregnancy. Lack of access to information about maternal alcohol use should not be the reason to eliminate consideration of an FASD.

• Obtain a clear developmental history of the child.

• In obtaining information, avoid blaming & shaming and scapegoating.
Take Home Points (2)

• Assess learning and overall functioning, don’t just focus on the child’s behavior.

• Remember that system of care principles (family-driven, youth-guided, community-based, culturally competent) and trauma informed principles (safety, trust, collaboration, choice, empowerment) all apply.

• Build on individual and family strengths.

• Try to minimize secondary FASD effects.
Take Home Points (3)

• Address psychosocial challenges faced by families, make referrals, and provide linkages.
• Recognize and address trauma when present, not just FASD.
• Avoid unhelpful approaches, which can do harm.
• Recognize key risks: punitive responses by adults, and giving up by everyone.
• Avoid assumptions of intentionality re child’s limitations.
• Make use of a team process, and consider HFW.
Take Home Points (4)

• Maintain communication and coordination with the PCP.
• Coordinate efforts with the child’s school.
• Use psychotropic medication for specific indications, with awareness that it will not improve core FASD deficits.
• Encourage wellness, including prevention of FASD, for all family members receiving behavioral health treatment.
• Encourage hopefulness and not giving up.
• Develop a lifelong service model – modeling, mentoring and monitoring.
Challenges: System Change and the FASD Task Force

• Laura Rostolsky: The FASD Task Force and opportunities for change
Resources
• BEAMS: The Fasstar Trek Method:  
http://www.comeover.to/FAS/BEAM.htm

• The Eight Magic Keys for Teachers:  

• SCREAMS:  
http://www.come-over.to/FAS/ScreamsArticle.htm

• SAMHSA:  

• 4 Digit Code – Washington State University:  
http://depts.washington.edu/fasdpn/index.htm
• National Screening Tool Kit - Canadian Association of Paediatric Health Centres:  [http://www.caphc.org](http://www.caphc.org)

• PA Families, Inc : [http://pafamiliesinc.com/about.php](http://pafamiliesinc.com/about.php)

• Fetal Alcohol Spectrum Disorder Support Group – Pittsburgh area contact kimjaxon1218@yahoo.com

• Stone Soup (support group):  [www.stonesoupgroup.org/FASDnetwork.html](http://www.stonesoupgroup.org/FASDnetwork.html)

Assessments for Infants and Children

• Recommended Evaluation Tools: (Read the articles on Early Intervention for Infants with FAS first)

• Bayley Scales of Infant Development for cognitive and motor evaluations from ages 0-2.

• K-ABC is useful for cognitive evaluations for children ages 3-5.

• Peabody Individual Achievement Test-Revised (PIAT-R) measures scholastic achievement in children, grades K-12.

• Vineland Adaptive Behavior Scales for children of all ages is essential to measure functional abilities and life skills.

Source: FAS Community Resource Center, FASstar http://come-over.to/FASCRC
Appendix: Common Presentations of FASD by Specific Developmental Stage
Infants

- Premature birth; medical issues are common
- Chronic ear infections
- Poor weight gain/difficulty with feeding
- Poor sleep-wake cycles/irritability/colic/hard to calm
- Atypical attachment behavior
- Impairment in self regulation
- Late milestones, delays in rolling over, crawling, walking
- Speech delays

British Columbia Ministry for Children and Families
NOFAS
Toddlers

• Continued motor skill delays
• Easily distracted
• Tantrums
• Disrupted sleep
• Sensory defensiveness, reactivity
• Heedless to danger, poor learning from experience or consequences
• Indiscriminate attachment – will go to anyone
• Dental problems
• Small appetites or sensitivity to food texture

British Columbia Ministry for Children and Families
NOFAS
Preschool

• Impaired patterns – interest in food, sleep
• Poor motor coordination
• Flits from things, with poor attention span and distractibility
• Overly friendly, highly social, indiscriminate relationships, poor sense of boundaries
• Expressive speech – talkative and intrusive, or delay
• Comprehends danger poorly, not respond to warnings
• Prone to temper tantrums and apparent non-compliance
• Doesn’t respond well to change
• Net effect: doesn’t learn from experience or generalize

British Columbia Ministry for Children and Families; NOFAS
School Age

- Continued sleep disturbances
- Poor social skills, making and keeping friends
- Anger and aggression associated with frustration and impulsivity
- Poor self worth, low self esteem
- Developmental delays
- Poor self care
- Boundary issues
- Attention problems, possible hyperactivity
- Easily frustrated/tantrums
- Difficulty understanding cause and effect; failure to understand consequences, so judgment impaired
- Very concrete thinking
- Onset of academic problems, especially math
Adolescence

- Less obvious FAS facial features
- Academic plateau, increased need for abstract thinking
- Memory problems/working memory – storing and retrieving information
- Inconsistent performance day to day, unpredictable
- Impulsivity, distractibility, disorganized
- Anxiety, depression and/or mood swings
- Victimization
- Increased desire for independence
- Unrealistic expectation of others
- High risk of sexual activity and pregnancy
- May become slightly obese
- Lying, stealing or antisocial behavior
- May function better in the evening
Adolescence Through Adulthood

- Memory problems
- Difficulty storing and retrieving information
- Inconsistent performance ("on" and "off") days
- Impulsivity, distractibility, disorganization
- Ability to repeat instructions, but not able to put them into action ("talk the talk but don't walk the walk")
Youth/Young Adults in Transition

• Difficulty achieving normative development: The “will” is there, but the “way” is much more challenging.
• Lack of full awareness of abilities and limitations (e.g., insight).
• Limited judgment.
• Impulsivity.
• Denial – of limitations and needs.
• Limited ability to generalize, think abstractly, learn from experience.
• Limited practical knowledge about successful community living.
• At risk to be taken advantage of.
• Ongoing tension between accepting parental support and desiring autonomy – wants to run own life, but can’t.

NOFAS; Malbin
Helping Youth and Young Adults in Transition (1)

- Key Goal: To engage the youth/young adult
- Promote, and offer, respect for youth
- Highlight and build on youth’s strengths and capabilities
- Help family avoid threats, ultimatums, and polarization
- Promote unifying theme, “We’re in this together”
Helping Youth and Young Adults in Transition (2)

– For parents/caregivers, provide education and promote balance (re strengths vs. limitations) and sense of unity.

– Help youth to “save face,” as prerequisite to engaging and accepting help.

– Externalizing the problem may be helpful – scapegoating the FASD and not the youth.

– Benefit of *modeling* for the youth, not just information and instructions.

– Importance of patience and persistence.
Common Misconceptions Regarding FASD Deficits

- “Not listening”: Attention may be poor.
- “Non-compliant”: May not understand what is expected.
- “Chooses” to make the same mistakes: Generalizing to real world situations is difficult.
- “Manipulative”: May not understand rules, or be able to follow them consistently. Unable to regulate emotions well.
- “Shows no remorse”: Child typically very caring, but may not understand social rules, or impact of own behavior.
- “He lies”: Lack of understanding is possible.
- “Won’t sit still”: Probably “can’t” sit still. ADHD common.
- “He steals”: Sense of boundaries and possession may be impaired.

Adapted from Debra Evensen, FASAlaska and Diane Malbin, consultants on FASCETS)