Fetal Alcohol Spectrum Disorder

Better Understanding for Better Programming & Interventions

Overview on FASD – Webinar Series April 16, 2013

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Before we begin…

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- This session will be recorded and the archive will be available within the next 2 weeks on the DVL website. http://dvl.ednet.ns.ca/browse/results/taxonomy%3A169
- Please post your question in the chat on the left of your screen and we will spend the last 10 minutes of the webinar as a Q/A time.
- If you have technical difficulties please call our help desk (902) 424-2450.

Our **FASD** Session at a Glance

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- **Introduction & Theoretical Understanding** to fetal alcohol related conditions
  - definitions/vocabulary – prevalence estimates - research findings on the physiological effects – diagnosis process
- **Pedagogical Understanding**
  - not labelling, using strengths and challenges, understanding environment
  - how we identify and better understand specific vs generic strengths and challenges and the way they interact in the school, home and community settings
- **Programming, Interventions & Transitions** for Students, and Implications for our Pedagogical Practice
  - what can we do? diagnosed or presenting learning profiles similar to those found in FASD
  - The Alberta Education resource, our collaborations, program planning
- **Unanswered Questions**

Special Gratitude

- ***"If you steal from one person, you're a thief, if you steal from everyone, you've done your research!"***

(Tony Bennett)

I HAVE DONE MY RESEARCH!

- **Atlantic FASD Intergovernmental Partnership** Intergovernmental & Interprovincial Partners
- **Public Health Agency of Canada**
- **Newfoundland & Labrador Government** Dave Martin
- **NS Interdepartmental FASD Exchange Group** DOE, DCS, DHW, DOJ, FNIH, PHAC

Introduction &Theoretical Understanding

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Definitions

- **FAS** – PFAS - FAE – ARND - ARBD - **FASD**
- the result of **prenatal exposure to alcohol**
- ranges from Fetal Alcohol Syndrome (**FAS** .5-2:1000) to other fetal alcohol effects causing lifelong disruptions in cognitive, linguistic, and social development. This last collection of effects is referred to as Fetal Alcohol Spectrum Disorder (**FASD** 1:100 on par with ASD) (PHAC, Gary Roberts, etc.) 3-5
- **FASD** is an umbrella term for a permanent "invisible" physical disability with behavioural symptoms often demonstrated by poor attention and concentration skills, impaired judgment, hyperactivity, and impulsivity, resulting in learning, behavioural, and functional difficulties. (Ann Streissguth, Diane Malbin, Jan Lutke, Paula Cook, etc.) 15

Statistics

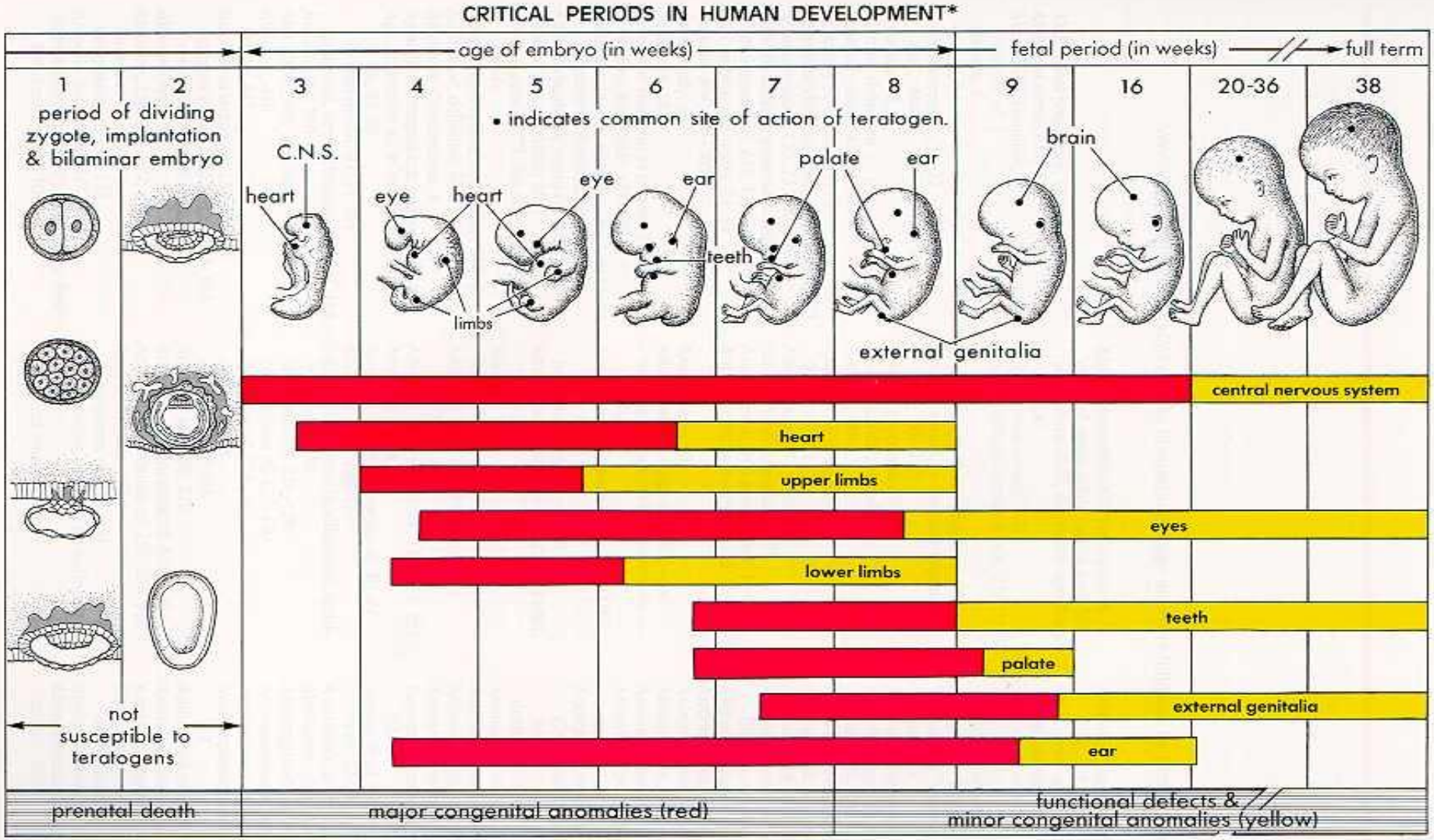
- Most **under diagnosed** physical disability
- Only **fully preventable** physical disability
- **Leading cause** of cognitive disabilities
- **81% drink alcohol** – 24% binged/month – 5% binged/wk
- Large percentage of women are **unaware of pregnancy** for weeks (almost 50%)
- 14% report **alcohol use** during pregnancy
- Not a women's issue – however, a ***Woman's Health Determinants*** *Perspective* is required (stigma)
- Of 16,000+ SLD files reviewed. 1400 could be diagnosed with FASD. 66% male - 34% female (Alberta Ed., 2007)

Kaplan and Saddock's Synopsis of Psychiatry (1998); Gary Roberts, PHAC (2006, 2008); David Wasserman (2008); Nancy Poole, 2007

Statistics

- **"Women's Health Determinants Perspective"**
  - FASD is a health issue that impacts women, their children, their families, and their communities. Social determinants of health, particularly those most related to maternal poverty and other forms of disadvantage, have been closely linked to both risks and protective factors for having a child affected with FASD.
  - Social determinants of health include income and social status; social support networks; education and literacy; employment/working conditions; social environments; physical environments; personal health practices and coping skills; healthy child development; health services; gender; and culture (PHAC, quoted in Nancy Poole 2007 canfasd – FACE poster.
    > http://www.canfasd.ca/files/PDF/FACE_poster_NAT_-_Aug_31.pdf
  - The barriers pregnant and parenting women experience to accessing services are also linked to broad determinants of health and inequities faced by women. Acting on the factors that increase or reduce women's risks for developing substance use problems and having a child with FASD requires broad based, collaborative action among women, service providers, policy makers, and researchers working across the full range of health determinants.

Pre-Natal Development Periods



* Red indicates highly sensitive periods when teratogens may induce major anomalies.

Causes

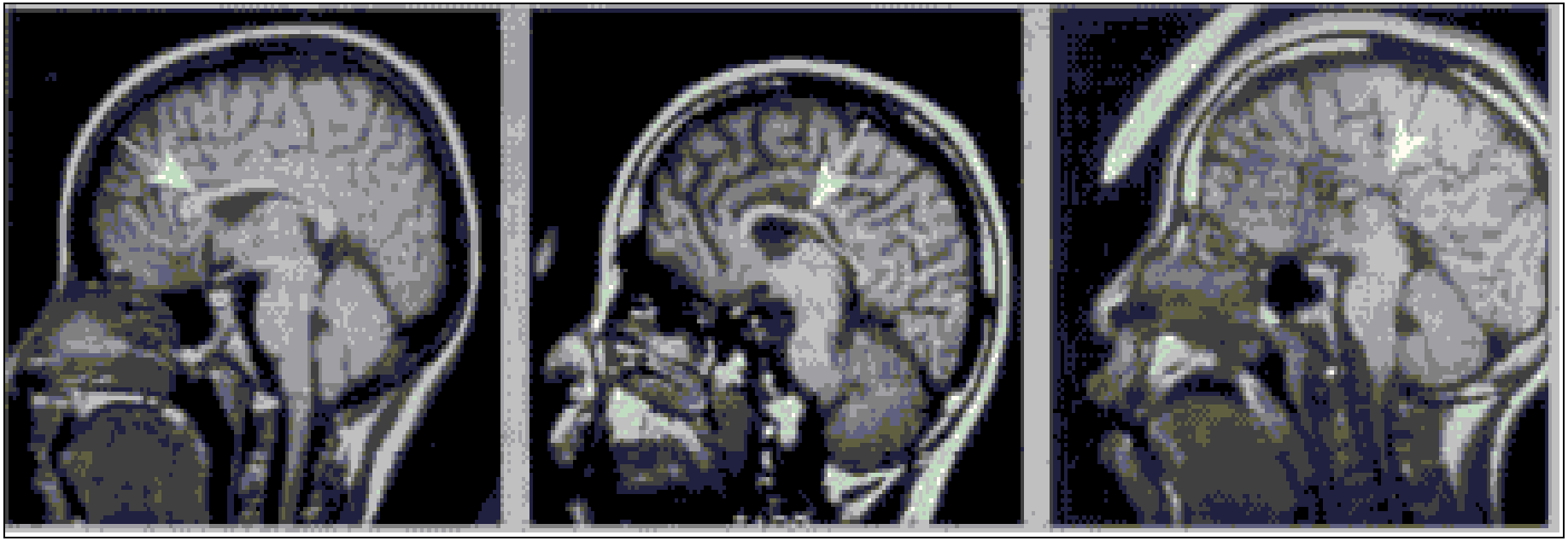
- **Alcohol is a teratogen**
  - **teratogenic agents** act in specific ways on developing cells and tissue to initiate sequences of abnormal developmental events (i.e., ionic radiations, thalidomide)
  - effects **worse than heroin or cocaine** on the developing fetus
  - affects all **organs systems** of fetus
  - **no safe level** or time established for alcohol consumption when pregnant

Teratogenic Effect on the Brain

- **Alcohol exposure** seems to damages certain areas of the brain while other areas appear unaffected

- Reduction in **volume**, change in **shape** or **location** of the:
  - -corpus callosum
- Reduction in volume of the:
  - -basil ganglia, hippocampus, amygdale
  - -cerebral cortex and cerebellum

Teratogenic Effect of Alcohol

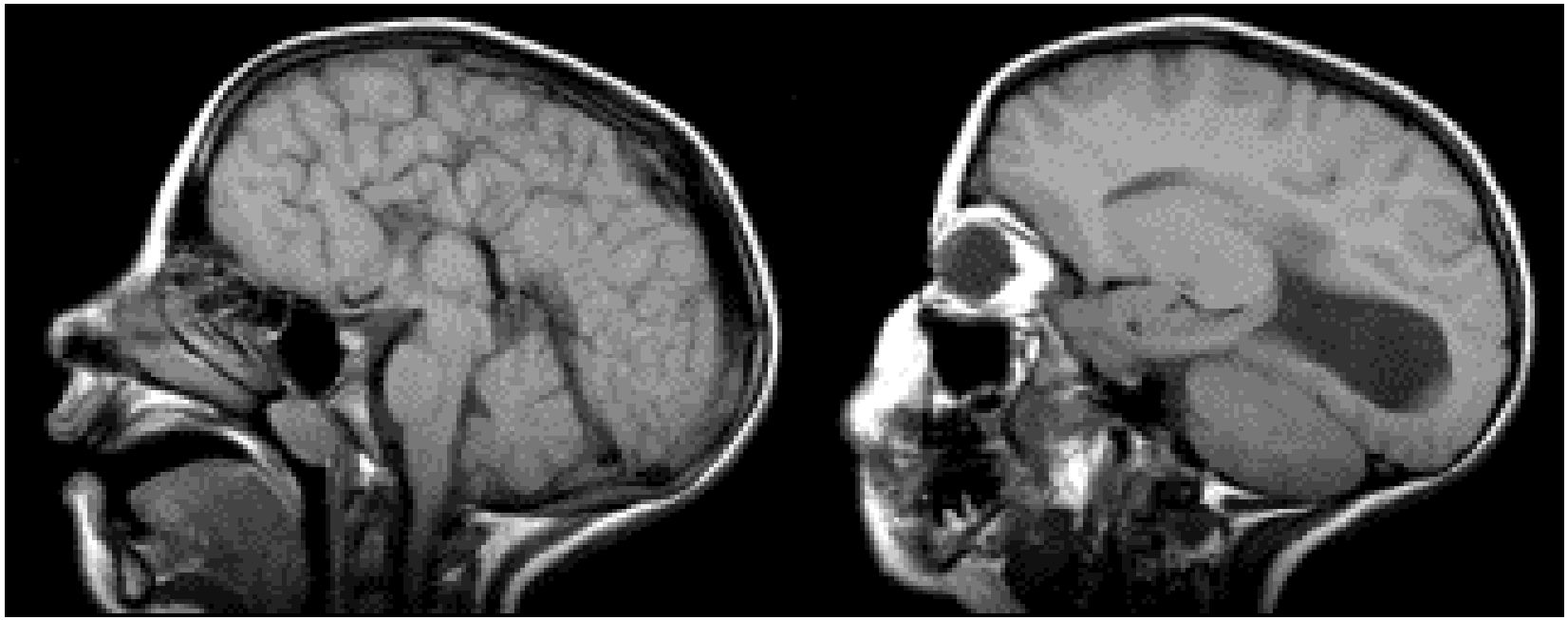


A B C

A. Magnetic resonance imaging showing the side view of a 14-year-old control subject with a normal corpus callosum; B. 12-year-old with FAS and a thin corpus callosum; C. 14-year-old with FAS and agenesis (absence due to abnormal development) of the corpus callosum.

Source: Mattson, S.N.; Jernigan, T.L.; and Riley, E.P. 1994. MRI and prenatal alcohol exposure: Images provide insight into FAS. *Alcohol Health & Research World* 18(1):49–52.

Teratogenic Effect of Alcohol



These two images are of the brain of a 9-year-old girl with FAS. She has agenesis of the corpus callosum, and the large dark area in the back of her brain above the cerebellum is essentially empty space.

Source: Mattson, S.N.; Jernigan, T.L.; and Riley, E.P. 1994. MRI and prenatal alcohol exposure: Images provide insight into FAS. *Alcohol Health & Research World* 18(1):49–52.

Diagnosis

- **Canadian Medical Association – Association médical Canadienne**
  CMAJ 2005; 172(5 suppl):S1-S21 – JAMC 2005;172(5 suppl) : SF1-SF22
- Although permanent – diagnosis before age 6 is a **universal protective factor** reducing the likelihood of **mental health**, disrupted **school experience** & **trouble with the law** - Ann Streissguth and Jonathan Kanter (1997)
- **Diagnostic process:**
  - Screening and referral
  - Differential diagnosis by qualified multidisciplinary team
  - Neurobehavioural assessment & follow-up
- **Diagnostic tools:**
  - **qualified professionals** (trained physician, psychologist, OT, SLP, nurse, social worker – multidisciplinary approach)
  - **4-digit Diagnostic Code criteria** (growth deficiency (>10%), FAS features*, CNS damage, and pre-natal alcohol exposure – rated from *no/none* to *severe/high*

*philtrum, palpebral fissure, vermilion-lip

Co-Morbidity - Mental Health Issues

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- ADD/ADHD is often diagnosed
- (Reactive) Attachment Disorder (R-AD)
- Bi-Polar Disorder/Depression
- Conduct Disorder (CD)
- Oppositional Defiant Disorder (ODD)
- Obsessive Compulsive Disorder (OCD)
- Borderline Personality Disorder (BPD)

(Kathryn Page – 2002- Ctr. For Families, Children & Courts)

May Present as ADHD

ADHD	FASD
•ADHD is the disability •Neurotransmitters (dopamine) •Genetic component •Does not affect IQ •Info retrieval problems •Medication increases attention and focus •Responds to behaviour modification	•ADHD is a symptom of FASD •Brain dysmorphology •Not genetic •Affect IQ •Short term memory problems •Medication does not increase attention but does affect behaviour •Inconsistent response to behaviour modification

Behavioural Understanding

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Our Reality Becomes Their Reality

- FASD **often not diagnosed** - leading to secondary disabilities (FAS and FASD are medical diagnosis – stigma, fear)
- Many advances have been made thanks to the **openness of adoptive parents** (history, stigma and fear) 24
- Often have **complex learning disabilities**, **behavioural difficulties**, and **problems expressing and understanding language** – They can and do learn, but often in atypical ways 11
- Questions often begin in elementary school when **higher-level executive functioning skills are questioned** and when a gap in developmental maturity is noticed

Behaviours Associated to FASD

- Primary and secondary behaviours (D. Malbin)

Secondary	Primary
•Anxious, fearful, shut down •Fatigued, irritable, frustrated •Poor self esteem, isolated •Angry, acts out, aggressive •Rigid, resistant •Avoidant, may run away •Trouble in school/justice •Alcohol and other drug use •Depressed, other mental health issues •Other diagnoses: -conduct disorder -emotional disturbance -ODD	•Memory issues (on-off days) •Impulsive (may not predict outcomes) •May not understand consequences •Slow processing pace (10 seconds child in 1 second word) •Gaps in understanding •Dysmaturity •Needs re-teaching •Over or under-sensitivity (touch, hearing, smell, sight) •Difficulty managing time, money, math •Trouble with transitions

Paradigm Shift Required 16

From seeing the child as …	To understanding the child …
Won't	**To Can't**
Annoying	Frustrated, challenged
Lazy, unmotivated	Tries hard, tired of failing
Lies	Confabulates, fills in the blanks
Fussy	Oversensitive
Acting younger, babied	Being younger
Trying to get attention	Needs contact, support
Inappropriate	Displays behaviours of younger child
Professional shift from	**To**
Stopping behaviours	Preventing problems
Behaviour modification	Modeling, using visual cues
Changing people	Changing environments

Diane Malbin M.S.W. Trying Differently Rather Than Harder, 2002

Understanding Dysmaturity 21

Age Appropriate Expectations for typically developing Children and Youth	Developmental Expectations for Children and Youth with FASD
Age 5	**Age 5 (Age 2 developmentally)**
•Attending School	...Still taking naps
•Able to follow three instructions	…Can follow one instruction
•Can sit quiet for 20 minutes	…Can only sit still for 5-10 minutes, is active
•Can share, interact and play cooperatively	…Parallel play
•Able to take turns	…Unable to take turns

Diane Malbin, *Fetal Alcohol Syndrome/Alcohol-Related Neurodevelopmental Disorder (1999)*

Understanding Dysmaturity 21

Age Appropriate Expectations for typically developing Children and Youth	Developmental Expectations for Children and Youth with FASD
Age 6 • Will listen and pay attention for an hour … • Can read and write …….. • Able to line up on their own …….. • Able to wait their turn …….. • Can remember events and requests ……	**Age 6 (Age 3 developmentally)** …Can only for about 10 minutes …Scribbles over work …Needs to be shown and reminded …Acts impulsively and can't wait gracefully …Requires reminders about tasks

Diane Malbin, ***Fetal Alcohol Syndrome/Alcohol-Related Neurodevelopmental Disorder (1999)***

Understanding Dysmaturity 21

Age Appropriate Expectations for typically developing Children and Youth	Developmental Expectations for Children and Youth with FASD
Age 10	**Age 10 (Age 6 developmentally)**
• Can read books without pictures	...Starting to ready books with pictures
• Able to learn from worksheets	...Learns by experimenting, by doing
• Can answer abstract questions	...Copies words and behaviors
• Able to structure their own recess	...Needs supervised play as well as structured play
• Able to get along with others and solve their own problems	...Learns problem solving from modeling behavior
• Able to learn inferentially, academic and social	...Needs to be taught explicitly
• Knows right from wrong	...Starting to develop a sense of fairness
• Strong physically	...Tires easily from mental work

Diane Malbin, *Fetal Alcohol Syndrome/Alcohol-Related Neurodevelopmental Disorder (1999)*

Understanding Dysmaturity 21

Age Appropriate Expectations for typically developing Children and Youth	Developmental Expectations for Children and Youth with FASD
Age 13	**Age 13 (Age 8 developmentally)**
• Able to act responsibly	...Needs reminding constantly
• Can organize themselves, plan and follow through	...Needs visual cues and modeling
• Able to meet deadlines after one instruction	...Can only comply with single expectations
• Can initiate and follow through	...Needs encouraging
• Has appropriate social boundaries	...Touchy, feel
• Able to understand body space	...Can be always in your space
• Can establish and maintain relationships ..	...Develops early friendships

Diane Malbin, *Fetal Alcohol Syndrome/Alcohol-Related Neurodevelopmental Disorder (1999)*

Understanding Dysmaturity 21

Age Appropriate Expectations for typically developing Children and Youth	Developmental Expectations for Children and Youth with FASD
Age 18	**Age 18 (Age 10 developmentally)**
• Starting to be independent	...Needs structure and guidance
• Can maintain a job and able to graduate from school	...Has a limited choice of activities
• Has a plan for their future life	...Lives in the "now" has little projection for the future
• Has relationships that are safe	...Behavior can be silly, curious and easily frustrated
• Can budget their money	...Still needs an allowance
• Can organize, finish tasks at home, at school or at their job	...Needs guidance from adults to be organized

Diane Malbin, *Fetal Alcohol Syndrome/Alcohol-Related Neurodevelopmental Disorder (1999)*

Individuals With FASD

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- Often perceived as **being** the problem not perceived as **having** a problem
- Often have mild to severe **health problems** (kidney, heart, etc.)
- Have difficulty **understanding consequences** (thinking through & reasoning; learning from past experiences; remembering appointments; making generalizations and abstractions) 54-55, 67-71
- Difficulty **understanding feelings** – theirs and others 93
- **Easily Irritated** 76, 82-83

Individuals With FASD

- Often have **speech and language** impairments 11, 93-95
- **Memory problems** – Can repeat verbatim, but do not know how to transfer that set of verbal directions into specific behaviours 11, 90-92
- **Short attention -** Inability to follow a series of directions 34, 87-89
- Their **speed** and **amount** of **verbal output** is low.
- Difficulty with **processing, organizing, retrieving, and remembering Information** 12, 34, 88-92, 98-105

Individuals With FASD

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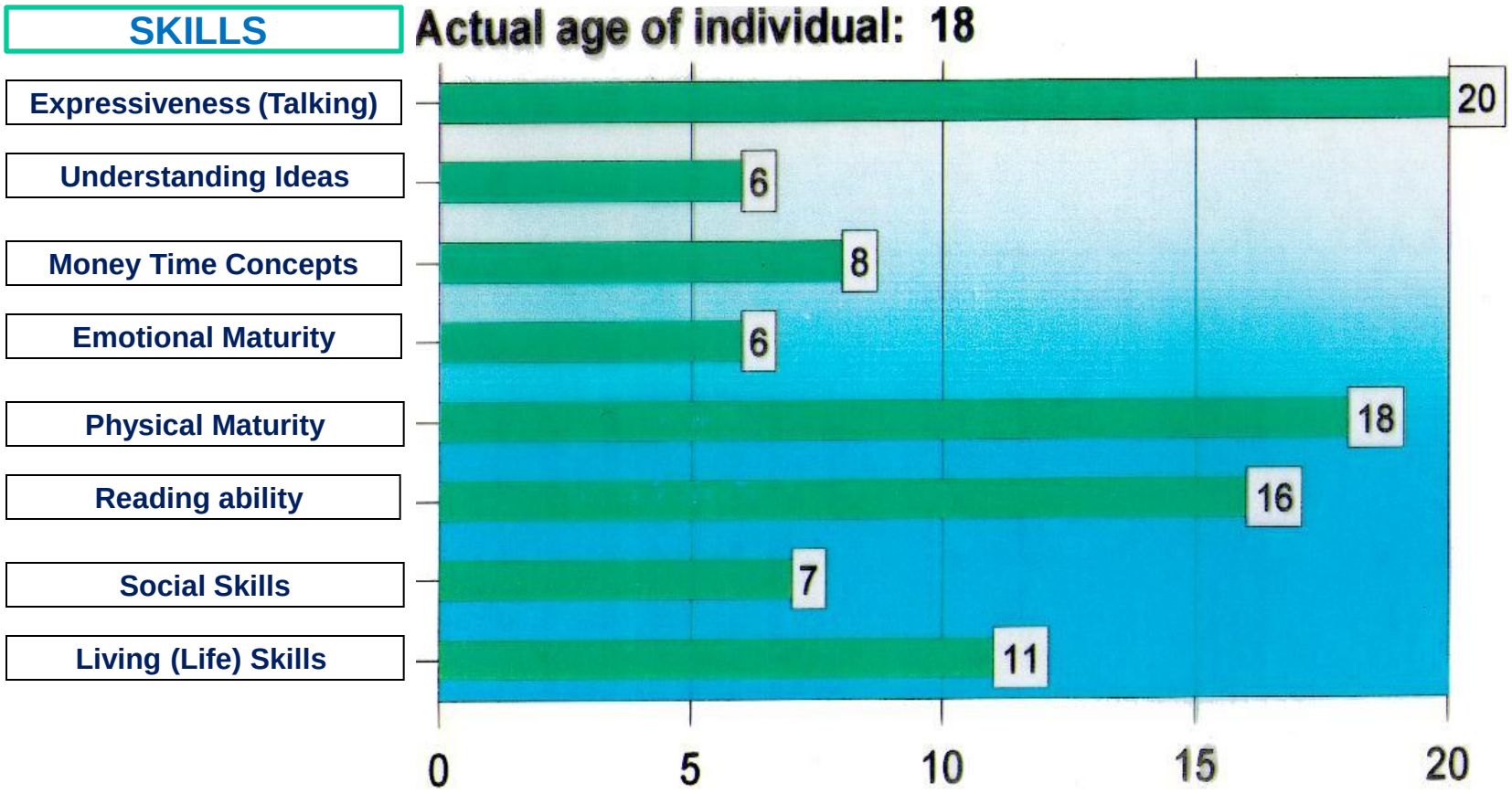
- Socially Inappropriate Behaviours - **Act Much Younger** 12-13, 21, 97
- Social Problems - **Sometimes Isolated From Peers** 37-41, 77-79, 84, 118-119
- **Secondary disabilities -** Depression; OCD; Justice 13, 54-56
- **Difficulty in Learning -** particularly math concepts (time; money); seeing similarities and differences; 108-109, 130
- **Difficulty understanding** - limited listening skills 59-61, 93-95,106-107
- **Sleeping problems** - up all night - sleep all day

Individuals With FASD

- Difficulty with **abstract reasoning** 94
- Difficulty with **cause and effect logic**
- Difficulty with **boundaries** 59, 77, 83-84 **– sense of self** 38-42, 63, 66-67 124, 135
- Difficulty with **sensory integration** 73-76
- Difficulty with **speech production** - **responding meaningfully** 96
- Difficulty with **executive functions** 98-105

Dysmaturity and FASD 12-13, 21, 97



Adapted from Streissguth, Clarren et al, by D. Malbin 94

Programming & Intervention

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Programming and Interventions

- Building a wheelchair for the brain Jan Lutke

- Successful instruction is dependent on thoughtfully matching strategies with student's strengths and challenges, trying out strategies in more than one context, observing and assessing how students respond, and using this new understanding to adapt instruction.
- A wheelchair takes the place of non-functioning limbs or muscles. It prevents an individual from falling, holds the person upright to see what is going on, allows mobility and allows participation

UNBI Training Institute, Fredericton, NB

Creating A Learning Environment

- **Start where they are**, not where you think they should be 97
- **Structure and stability** – predictability – Controlled interruptions in the classroom – changing routines must be taught & learned (2-6 weeks to learn new routines) 29-32, 75-77
- **Respect their learning style** – structured, concrete, in context – Low sensory stimulation – Small groups – Reminders 98
- **Match level of physical stimuli** with student's ability to make sense of stimuli from the environment
- **Whole brain techniques** - visual, auditory, kinesthetic – Make space visual 90-91
- **Get and keep attention** – Simplify language to basics – avoid words with many meanings – be specific – use visual and body language 34-35, 86-89, 94

Programming and Interventions

Does not complete task	Core Cause of Behaviour	Intervention
FASD	•May or may not take in information •Cannot recall information when needed •Cannot remember what to do	•Provide one direction at a time
ADHD	•Takes in information •Can recall information when needed •Gets distracted	•Limit stimuli and provide cues
ODD	•Takes in information •Can recall information when needed •Choose not to do what they are told	•Provide positive sense of control; limits and consequences

- **Sometimes we need a mediator**
  - To act as an external brain (Dr. Sterling Clarren)
  - To teach, remind, review, and re-teach – small steps or stages
  - To create order, predictability, systems, strategies, and routines
  - Remember strengths and things student is good at – emphasize the positive! – artistic – detail – sensitivity – exuberance

Programming and Interventions

Hits Others	Core Cause of Behaviour	Intervention
FASD	•Someone told them to •Misinterprets intentions of others •May sense a bump as an attack •May respond from history of abuse	•Deal with misinterpretations at the time; one-to-one support
ADHD	•Frequently an impulsive act	•Behavioural approaches to address impulsivity
ODD	•Plans to hurt others •Misinterprets intentions of others as attack or impending attack	•Consequences; cognitive behavioural approaches

- **Each student with FASD is different – Each educational response will be different as well**
  - Ensure informed decision process of program planning process
  - Understand the hidden curriculum
  - Consider the lack of structure in some settings
  - Independence is difficult and must be taught, monitored, and re-taught

Programming and Interventions

Takes Risks	Core Cause of Behaviour	Intervention
FASD	•Does not perceive danger	•Provide mentor; utilize a lot of repeated role playing
ADHD	•Acts impulsively	•Utilize behavioural approaches (i.e., stop and count to 10)
ODD	•Pushes the envelope; feels omnipotent	•Psychotherapy to address issues; protect from harm

- **Organize intervention into three categories:**
  - Classroom environment
    > Quiet zones – seating – limit distractions – organize material - rules
  - Active Learning Strategies
    > Multi-modalities/sensory – manipulatives – keep it simple – opportunities for decision making and problem solving
  - Establishing Routines
    > Daily schedule – consistency – plan for change/transition – use visual, auditory, and sensory cues.

Understanding 52

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Common Misinterpretations of Typical Responses in Students with FASD[56]

Behaviour	Misinterpretation	Accurate Interpretation
noncompliance	▪ willful misconduct ▪ attention seeking ▪ stubborn	▪ difficulty translating verbal directions into action ▪ doesn't understand
repeatedly making the same mistakes	▪ willful misconduct ▪ manipulative	▪ can't link cause to effect ▪ can't see similarities ▪ difficulty generalizing
not sitting still	▪ seeking attention ▪ bothering others ▪ willful misconduct	▪ neurologically-based need to move constantly, even during quiet activities ▪ sensory overload
doesn't work independently	▪ willful misconduct ▪ poor parenting	▪ chronic memory problems ▪ can't translate verbal directions into action
does not complete homework	▪ irresponsible ▪ lazy ▪ unsupportive parent	▪ memory difficulties ▪ unable to transfer what is learned in class to the homework assignment
often late	▪ lazy, slow ▪ poor parenting ▪ willful misconduct	▪ can't understand the abstract concept of time ▪ needs assistance organizing
poor social judgement	▪ poor parenting ▪ willful misconduct ▪ abused child	▪ not able to interpret social cues ▪ doesn't know what to do
overly physical	▪ willful misconduct ▪ deviancy	▪ hyper or hyposensitive to touch ▪ doesn't understand social cues regarding boundaries
stealing	▪ deliberate dishonesty ▪ lack of conscience	▪ doesn't understand concept of ownership over time and space ▪ immature thinking ("finders keepers")
lying	▪ deliberate ▪ sociopathic behaviour ▪ lack of conscience	▪ problems with memory and/or sequencing ▪ unable to accurately recall events ▪ trying to please by telling you what they think you want to hear

Programming and Interventions

- Remember **Program Planning Process** –
  « Only as Special as Necessary» NS Department of Education
- **8 magic Keys**
  - Concrete
  - Consistency
  - Repetition
  - Routine
  - Supervision
  - Simplicity
  - Specific
  - Structure

(FAS/E Support Network of B.C.)

Roles and Responsibilities

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` If You've Told (Someone) A Thousand Times and He Still Doesn't Understand, Then It Is Not (He) Who Is The Slow Learner '

Walter Barbee

Conclusions and Unanswered Questions

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Thank You!

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