

**Creating Successful Accommodations
for People with FASD:
A brief introduction to a brain-based approach**



Diane V. Malbin, MSW
FASCETS, Inc.

Presented by Nancy Hall
Lead facilitator and Co-Founder of
FASCETS Canada East

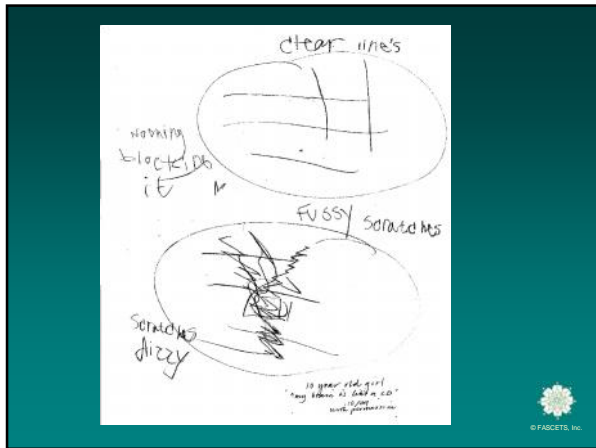


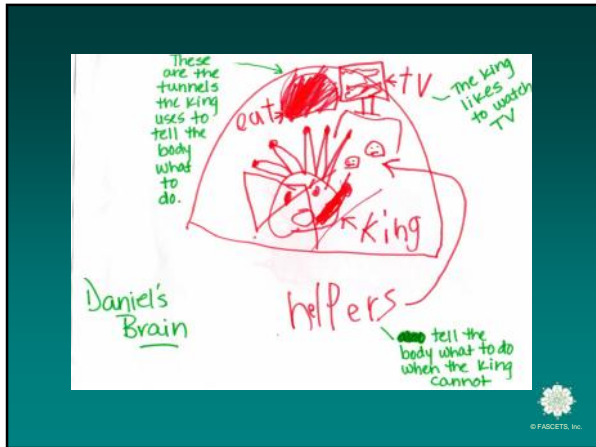
Main Points:

1. FA/NB is an invisible, brain-based *physical* condition with behavioral symptoms
2. Primary, Secondary and Tertiary Characteristics of FASD
3. Overlapping Diagnoses
4. Creating Accommodations
5. Reframing behaviors and shifting from symptoms to source redefines problems and solutions in a manner consistent with research



1. Brain = Behaviors?





What did your brain have to do... to get you to this conference today?

Brain tasks

What does your brain do for you every day?

- Plan, organize, abstract, predict
- Use language, communicate, comprehend
- Make decisions, manage money, plan time
- Multi-task, think fast, form links
- Manage emotions, negotiate
- Adapt to changes, anticipate, evaluate
- Manage sensory systems



We do these things without thinking

What if others' brains are unable
to do these tasks?

What if we are all different?

What is we are normal for
ourselves?





•What's the brain got to do with it?

Neurobehavioral Foundation

What if brain function has something to do with behaviors?

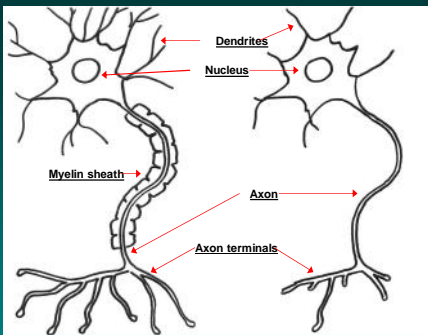
Logic model
Is FA/NB a physical disability?

1. Alcohol, drugs and other teratogens kill cells, including cells in the brain
2. These causes changes in the physical structure, neurochemistry in the brain
3. FA/NB is usually *invisible*, therefore
4. FA/NB is a brain-based physical disability; behaviors are often the only symptoms



If FA/NB is an invisible physical disability

Then Providing accommodations for people with FA/NB is as appropriate and effective as providing accommodations for people with other physical disabilities



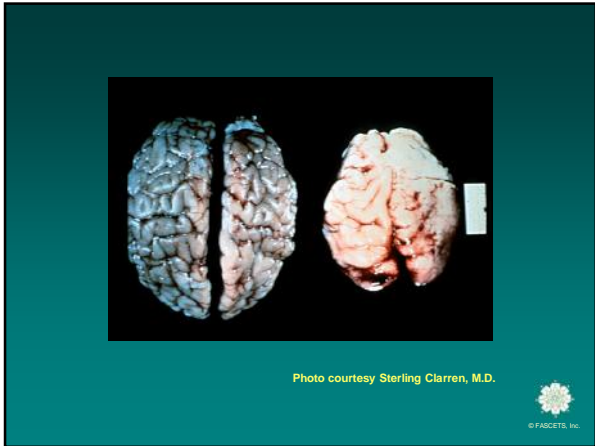
Typical brain cell

Brain cell prenatally exposed

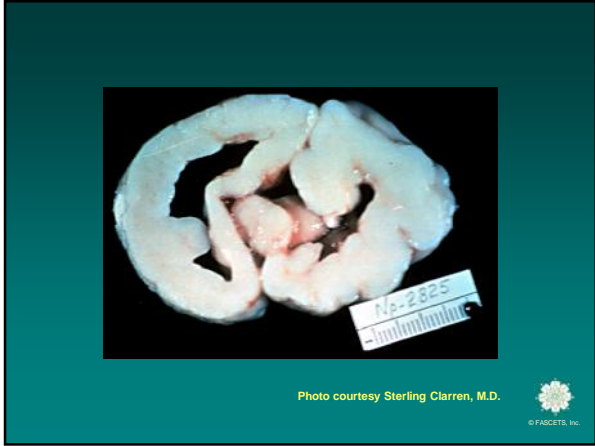
Processes quickly
Many interconnections

Demyelination processes slowly
Fewer interconnections

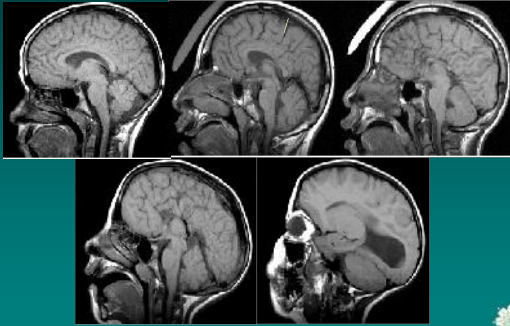








Corpus Callosum



Mattson, et al., 1994; Mattson & Riley, 1995; Riley et al., 1995



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Key points about FASD

1. FAS = leading cause ID/DD in Western world
2. 90-100% FASD still not diagnosed
3. 1-3/1,000 = FAS (requires alcohol exposure days 18-21 of gestation)
4. 3-5% births = FASD in Western World
5. FASD with no facial features at greater risk
6. 80% of all people drink, 50-75% pregnancies unplanned
7. 16-35% of all pregnancies "at risk" (Jones)
8. Average IQ 74; range 20-130
9. Epigenetics research and prenatal paternal effects



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Importance of Identification

- Pivotal: Identifies etiology and a brain-based physical condition
- Pivotal: Move from symptom to source
- Reframes the meaning of behaviors:
From won't to can't
- Redefines the nature of the problem
- Redefines focus for interventions
- Eliminates shame and blame
- Key for healing and for prevention



Neurobehavioral screening tool

Common behavioral symptoms

Definition: Primary characteristics

Behavioral symptoms associated with differences in brain structure and function

Strengths are also primary characteristics

Source: Ann Streissguth, 1996



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Primary characteristics

1. Developmental level of functioning
2. Sensory systems
3. Nutrition
4. Language and communication
5. Processing pace: How fast the brain works
6. Learning and memory
7. Abstract thinking
8. Executive functioning
9. Strengths



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1. Developmental level of functioning

1. Social behaviors are like a person half their age
2. Prefers younger friends
3. Seen as "irresponsible" for their age
4. Interests and play are more like a younger person



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Functional and academic deficits: Adolescents and Adults with FA/NB

Vineland	Chronological Age Mean	Developmental Age Equivalent
Adaptive behavior	16.6	9.1
Communication Skills	16.6	9.0
Daily Living Skills	16.6	10.1
Socialization Skills	16.6	7.5
PPVT Receptive Language	16.6	6.8

Source: Straissguth 1996



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Age-based expectations and dysmaturity

What if? 6 → 2

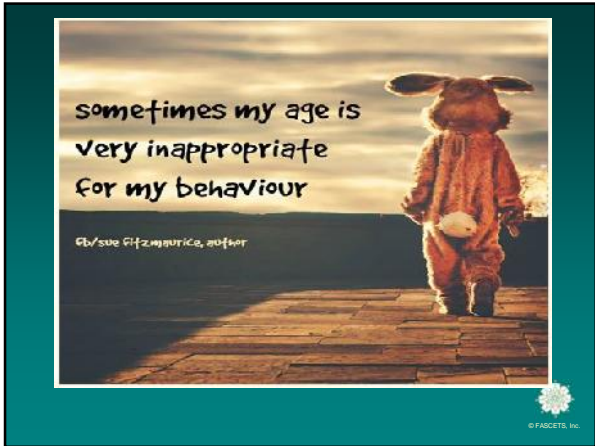
- Tie your shoes
- Play nicely with others
- Share
- Take turns
- Learn numbers, letters
- Sit still and listen for 20 min
- Follow 3 directions

What if? 16 → 6

- Drive
- Be Responsible
- Keep a part-time job
- Manage money, time
- Have a busy social life
- Be independent
- Plan for the future



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2. Sensory

1. Easily over stimulated, slow to settle
2. Highly sensitive to lights, sounds, smells
3. Over-sensitive to touch
4. Under-sensitive to touch
5. Doesn't seem to understand personal space, boundaries
6. Has trouble falling asleep or staying asleep

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3. Nutrition

1. Can't eat some foods
2. Craves sugars or fats
3. Needs to eat often
4. Doesn't seem to know when hungry
5. Doesn't seem to know when to stop eating

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4. Language and communication

1. Talks better than understands, may be "off topic"
2. Confabulates, "fills in the blanks"
3. Has trouble putting words on feelings
4. Doesn't seem to understand, "just doesn't get it"
5. Has difficulty reading body language
6. Difficulty answering questions



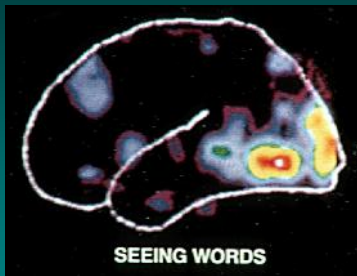
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5. Processing pace

1. Listens slowly; often asks "What?" or says "I don't know"
2. Thinks slowly; takes minutes to answer a question-- "Ten-second kids in a one-second world"
3. Slow halting speech
4. May only process every third word



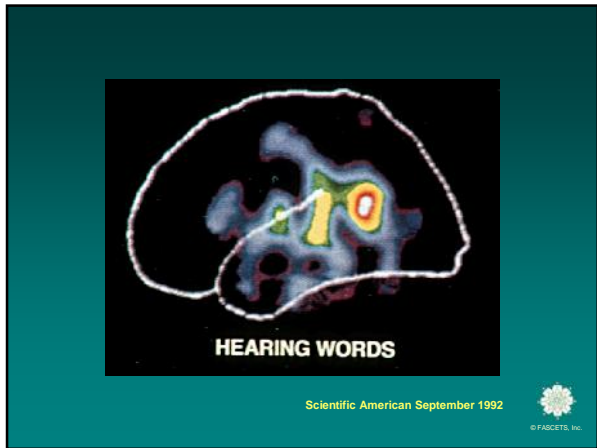
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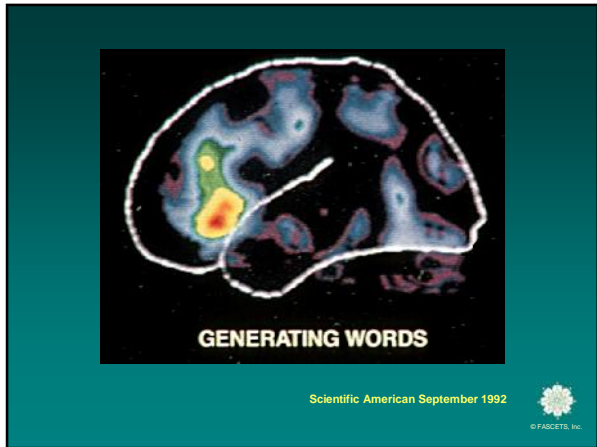


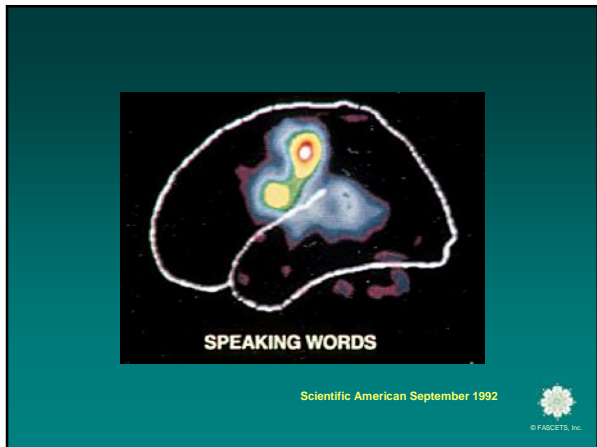
Scientific American September 1992



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6. Learning and memory

1. Poor short term memory; may do one step of three-step directions
2. Says one thing, does another, e.g., "Talks the talk, but doesn't walk the walk"
3. "On" and "off" days, "A" one day, "F" the next
4. Needs to be re-taught many times in order to learn
5. Difficulty generalizing: Learns a rule in one setting, may not be able to remember and apply it elsewhere
6. Has trouble remembering and learning from past experiences



7. Abstract thinking

1. Learning math is often hard
2. Making change or managing money
3. Often late, may have difficulty planning time, being on time for appointments
4. Difficulty predicting outcomes, seeing what's coming next
5. Making decisions may be hard



8. Executive functioning

1. Difficulty organizing and planning a day
2. Difficulty getting started or finishing multi-step tasks
3. Setting goals and planning the steps to achieve them is hard
4. Gets "stuck"; has difficulty stopping doing something -- "can't let go" in an argument



8. Executive functioning

5. May have trouble transitioning
6. May become upset by unexpected changes in tasks, schedule or routine
7. May become upset by changes in the environment, e.g., desks or furniture moved
8. Impulsive, difficulty inhibiting responses



8. Executive functioning

9. Difficulty making links:
 - Hearing into doing
 - Seeing into writing
 - Thinking into talking
 - Talking into action: Talks the talk but doesn't walk the walk



Strengths and interests

- Creative
- Artistic
- Musical
- Mechanical
- Athletic
- Hard working, determined, persistent
- Willing



Learning strengths

- Relational: 1:1
- Visual
- Auditory
- Hands-on
- Kinesthetic -- see, touch, move
- Experiential -- learns by doing
- Multimodal -- uses all senses



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Poor fit = Problems

Fit between technique and ability Strategy example: Talking

Assumptions about Brain function:

Store information.....
Retrieve information.....
Form associations.....
Abstract.....
Generalize.....
Predict.....
Conceptualize.....
Process quickly.....

Research on FA/NB has Found brain differences:

Difficulty with memory
Difficulty retrieving information
Difficulty forming links
Concrete
Difficulty generalizing
Difficulty predicting
Gets piece, not picture
Processes slowly



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**Definition:
Secondary behavioral symptoms**

Secondary defensive behaviors develop over time when there is a "poor fit"

Defensive behaviors are normal reactions to pain and are preventable.

Source: Ann Streissguth, 1996



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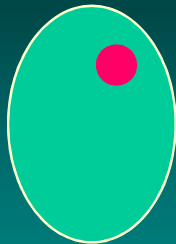
Secondary behavioral symptoms

1. Fatigued, frustrated
2. Anxious
3. Angry
4. Shut down, avoidant, blaming
5. Poor self esteem
6. Isolated
7. Depressed



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PET Scans: The better the brain is organized, the less energy is required to do the task



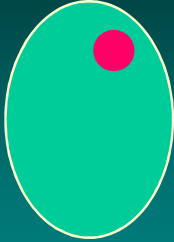
Organized, efficient less energy required for task

Conner, et al 2008



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PET Scans: The greater the disorganization, the harder the entire brain works, causing fatigue and irritability



Organized, efficient
less energy required for task



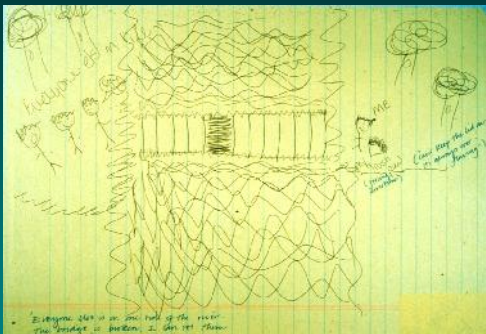
FAS: Disorganized, less
efficient, more energy

Conner, et al 2005
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Chronic Poor Fit = Patterns of Behaviours



Leading to Bigger Problems
in Different Settings

Tertiary symptoms

Are the result of a chronic poor fit,
anger, failure and alienation:

- Trouble in school
- Social services involvement
- Involvement with justice
- Addictions/ mental health issues
- Homelessness



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Overlapping Diagnoses



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DSM 5: Critiques

New DSM-5 Ignores Biology of Mental Illness
Scientific American: 4/30/2013

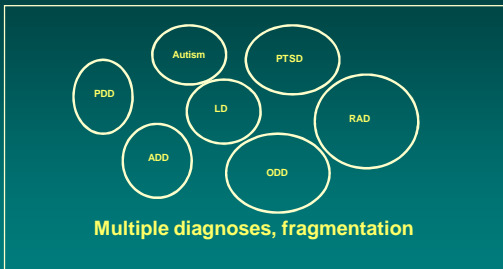
"While DSM has been described as a "Bible" for the field, it is...a dictionary, creating a set of labels and defining each. The strength of each of the editions of DSM has been "reliability" – each edition has ensured that clinicians use the same terms in the same ways. The weakness is its lack of validity."

"...symptom-based diagnosis, once common in other areas of medicine, has been largely replaced in the past half century as we have understood that symptoms alone rarely indicate the best choice of treatment."

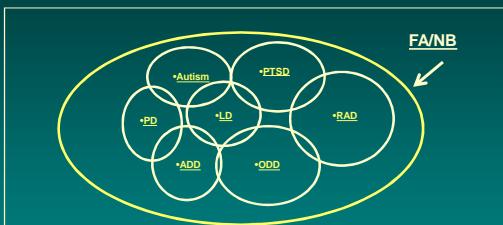
Thomas Insel, MD, Director NIMH 4/29/2013



Current model and DSM



Brain-based model



Accumulation of DSM diagnoses: Short list

Primary characteristics

Attention Deficit Disorder
Intellectual Disability (Intellectual Dev. Disorder ICD 11)
Language Disorder
Autism Spectrum Disorder

Secondary characteristics

Reactive Attachment Disorder
Oppositional Defiant Disorder
Post-traumatic Stress Disorder / Trauma
Generalized Anxiety Disorder
Personality Disorder



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Invisible conditions and accommodations

“If my daughter had a missing leg,
everyone around her would understand
how humane it is to make
accommodations.”

Mother



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Good fit: Accommodations

FA/NB Characteristic Strategy

Visual learner.....	Provide visual cues
Processes slower.....	Allow adequate time
Needs external support..	Provide supports
Difficulty organizing.....	Provide structure
Concrete.....	Teach experientially, build on strengths



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Examples of success

- Artist, musician
- Warehouse person
- Electrician
- Boat builder
- Mechanic
- Child care worker
- Animal rescue worker
- Drummer
- Dancer
- Office worker
- Special ed. teacher
- Counselor
- Massage therapist
- Truck driver
- Husband, wife
- Delivery person
- Parent
- Adult care worker

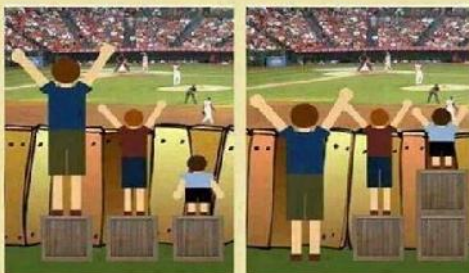


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Equality doesn't mean Justice



Equality

Justice

Equal Does Not Mean Fair!



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Brain trumps behaviors

Application: Functional Neurobehavioral Assessment


A systematic approach to developing person-specific accommodations in all settings and managing the complexity of FA/NB

Application: Functional Neurobehavioural Assessment

Setting: _____ Age: _____ Developmental age: _____

Environment: History (patterns, loss, trauma, success/failure), setting (people, sensory, schedule/ other changes, transitions) instruction method (pace)
Others:

1 Task or Expectation	2 Brain has to	3 Primary symptoms FA/NB	4 Devel. Age (estimate)	5 Secondary behaviours	6 Strengths	7 Accommodations

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Application: Functional Neurobehavioural Assessment

Setting: School Age: 6 Developmental age: 3

Environment: History (patterns, loss, trauma, success/failure), setting (people, sensory, schedule/ other changes, transitions) instruction method (pace)
Others:

1 Task or Expectation	2 Brain has to	3 Primary symptoms FA/NB	4 Devel. Age (estimate)	5 Secondary behaviours	6 Strengths	7 Accommodations
Sit still and listen						

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Application: Functional Neurobehavioural Assessment

Setting: School Age: 6 Developmental age: 3

Environment: History (patterns, loss, trauma, success/failure), setting (people, sensory, schedule/ other changes, transitions) instruction method (pace)
Others:

1 Task or Expectation	2 Brain has to	3 Primary symptoms FA/NB	4 Devel. Age (estimate)	5 Secondary behaviours	6 Strengths	7 Accommodations
Sit still and listen	Process fast, filter stimulus,					

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Application: Functional Neurobehavioural Assessment

Setting: School Age: 6 Developmental age: 3

Environment: History (patterns, loss, trauma, success/failure), setting (people, sensory, schedule/ other changes, transitions) instruction method (pace)
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1 Task or Expectation	2 Brain has to	3 Primary symptoms FA/NB	4 Devel. Age (estimate)	5 Secondary behaviours	6 Strengths	7 Accommodations
Sit still and listen	Process fast, filter stimulus, Slow processing pace					

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Application: Functional Neurobehavioural Assessment

Setting: School Age: 6 Developmental age: 3

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Sit still and listen	Process fast, filter stimulus,	Slow processing pce	3			

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Application: Functional Neurobehavioural Assessment

Setting: School Age: 6 Developmental age: 3

Environment: History (patterns, loss, trauma, success/failure), setting (people, sensory, schedule/ other changes, transitions) instruction method (pace)
Others:

1 Task or Expectation	2 Brain has to	3 Primary symptoms FA/NB	4 Devel. Age (estimate)	5 Secondary behaviours	6 Strengths	7 Accommodations
Sit still and listen	Process fast, filter stimulus,	Slow processing pace	3	Frustration		

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Application: Functional Neurobehavioural Assessment

Setting: School Age: 6 Developmental age: 3

Environment: History (patterns, loss, trauma, success/failure), setting (people, sensory, schedule/ other changes, transitions) instruction method (pace)
Others:

1 Task or Expectation	2 Brain has to	3 Primary symptoms FA/NB	4 Devel. Age (estimate)	5 Secondary behaviours	6 Strengths	7 Accommodations
Sit still and listen	Process fast, filter stimulus,	Slow processing pace	3	Frustration	Visual learner	

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Application: Functional Neurobehavioural Assessment

Setting: School Age: 6 Developmental age: 3

Environment: History (patterns, loss, trauma, success/failure), setting (people, sensory, schedule/ other changes, transitions) instruction method (pace)
Others:

1 Task or Expectation	2 Brain has to	3 Primary symptoms FA/NB	4 Devel. Age (estimate)	5 Secondary behaviours	6 Strengths	7 Accommodations
Sit still and listen	Process fast, filter stimulus,	Slow processing pace	3	Frustration	Visual learner	Provide visual cues, use fewer words, ask for what might help



Application: Functional Neurobehavioural Assessment

Setting: School Age: 6 Developmental age: 3

Environment: History (patterns, loss, trauma, success/failure), setting (people, sensory, schedule/ other changes, transitions) instruction method (pace)
Others:

1 Task or Expectation	2 Brain has to	3 Primary symptoms FA/NB	4 Devel. Age (estimate)	5 Secondary behaviours	6 Strengths	7 Accommodations
Sit still and listen	Process fast, filter stimulus,	Slow processing pace	3	Frustration	Visual learner	Provide visual cues, use fewer words, ask for what might help
Be age-appropriate	Develop "on time"	Dysmaturity	3	Isolation depression	Willing, relational	Adjust expectations: "stretch toddler"
Sit and learn, paper and pencil	Ability to abstract	Concrete, difficulty with abstraction	2	Anger, frustration, avoidance	Learns by doing, likes to please	Hands-on Kinesthetic



Difference between standard practice and a neurobehavioral approach

Standard practice addresses presenting behaviors
A neurobehavioral approach recognizes etiology, their source

Where there is anger, frustration or blame: There is missing information

What is the question?



What is the question?

- The first questions are always:
- Who is the child?
- What if? What about brain function?
- What is the fit?
- Whose needs are being met?




Importance of observation

1. Learn to see without judging
2. Step back, depersonalize
3. See the pattern of behaviors
4. Understand where the fit is poor
5. Identify points of intervention
6. Prevent problems
7. Build on strengths



Observe to Find Patterns:
Functional neurobehavioral assessment

- Are behaviors primary or secondary?
- Observe without interpreting
- What did you see?
- What happened just before?
- Describe the setting, environment
- Were there other factors? E.g. unexpected change?




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Paradigm: Way of seeing

Paradigm shift: Seeing differently

"I get it...*she* has the disability.
 We have to do the changing.


Source: Parent of child with FASD



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Paradigm Shifts and FA/NB

From	To
Won't.....	Can't
IS the problem.....	HAS a problem
Doesn't work.....	Has trouble starting
Acts immature.....	Is dysmature
Doesn't try.....	Tired of failing



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Behaviors, Misconceptions and Brain Based Interpretations

Behaviours	Misconception	Interpretation
Noncompliance	Willful misconduct, attention seeking, stubborn, everyone does this at times	Difficulty translating verbal direction into action, doesn't understand, chronic memory problems
Repeatedly making the same mistakes	Willful misconduct, manipulative, lazy	Cannot link cause to effect, can't see similarities, difficulty generalizing
Not sitting still/fidgeting	Seeking attention, bothering others, willful misconduct, normal for his age	Neurological based need to move while listening/learning, sensory overload

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Reframing: Emotional shifts

From

To

Confusion..... Understanding
 Anger..... Compassion
 Frustration..... Acceptance
 Reactivity..... Proactivity

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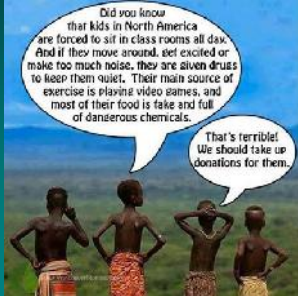
System Paradigm Shift



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Paradigm Shift

It's about realizing there is another way to look at the situation...



Starter strategies for accommodations: Home, School and Community

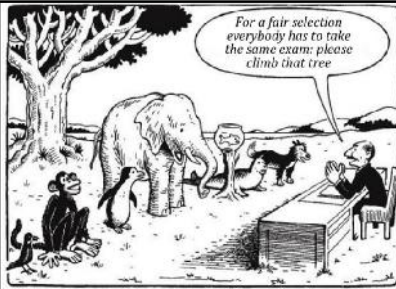
1. Think brain: Reframe perceptions
2. Observe patterns of behaviors
3. Identify, build on strengths
4. Write the IEP for the environment:
Modify environments for a good "fit"
5. Collaborate, coordinate



Additional starter strategies

- Stop fighting
- Ask: What if?
- Think younger
- Give time
- Recognize strengths
- Breathe
- Be gentle with yourself





Our Education System

"Everybody is a genius. But if you judge a fish by its ability to climb a tree, it will live its whole life believing that it is stupid."

- Albert Einstein



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Provincial application of neurobehavioral model

BC MCFD web site with FASD evaluations

<http://www.mcf.gov.bc.ca/fasd/index.htm>



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FASCETS Canada

Fetal Alcohol Spectrum Consultation
Education and Training Services

Nancy Hall

Lead Facilitator and Co-Founder

nancy@fascetscanada.com

www.fascets.org/nancy-hall



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