Developments in FASD research
Canadian Research Network: Intervention Network Action Team (iNAT)

Jacqueline Pei, Ph.D., R.Psych.
Approach to Intervention

- **Innovation** – building awareness of the functional needs of individuals of FASD, and mapping interventions to address these needs across their lifespan

- **Communication** – developing a central community for sharing new ideas, interventions, and research

- **Quality** – ensuring that new research reflects the needs and priorities of people living with FASD and those who support them.
iNAT

Communication

Quality

Innovation

Ongoing Information Sharing
Presentation Overview

- **FASD –** understanding areas of strength and difficulty
  - Research that informs
  - Intervention research that responds

- **FASD –** taking a process approach
  - Research that informs
  - Intervention research that responds

- **Can’t have one without the other**
  - Integrating our work through communication and collaboration

- **Conclusions: now what?**
  - your role
Understanding areas of strength and difficulty in FASD
The Impact of Alcohol

- Brain injury:
  - Communication
  - *Memory*
  - Adaptive function
  - Academics - *Math*
  - *Executive functions*
  - Attention
  - Intelligence
  - Motor functioning
Math Deficits in FASD

- Mathematics, and particularly arithmetic, has been identified as an area of specific difficulty for individuals with prenatal alcohol exposure (PAE) and FASD (see Rasmussen & Bisanz, 2009 for a review).

- Deficits in math are more pronounced than in other academic and cognitive areas and math is most strongly correlated with prenatal alcohol exposure.
Math Deficits in FASD

- Mathematics difficulties occur in children and adults with FASD even when IQ is controlled for (Rasmussen & Bisanz, 2009).
- Streissguth’s longitudinal research found math difficulties in children with PAE as young as age 4 which persisted through adolescence and adulthood (Streissguth et al., 1994).
- One study found that arithmetic among adults with FASD was at the 2nd grade level (Streissguth et al., 1991).
Executive Functioning (EF)

• **EF**: Higher-order cognitive processes involved in goal-oriented behavior (Zelazo and Muller, 2002).

• EF is a core deficit in FASD (Rasmussen, 2005).
  - Cognitive flexibility, inhibition, planning and strategy use, concept formation, verbal reasoning, working memory, and fluency.
  - Also show deficits on EF tests assessing emotion-related behaviors and decision making.
Neurobehavioral Deficits

- **Participants:** 32 children with FASD and 30 control children aged 6 to 16 years.
- Tested on the NEPSY-2
Cognitive Performance

Iowa Gambling Test (IGT)

• Measure of decision making
• Choose cards from four decks: two disadvantageous decks (large initial rewards and losses) and two advantageous decks (small immediate gains and eventual losses)
• Sensitive to prefrontal cortex damage
• **Participants:** 31 children with FASD and 31 control children aged 8-18 years
Performance on IGT – decision making

Age Effects on IGT – decision making

Verbal Memory

- Impaired learning
- Intrusion errors
- Adequate retention of learned material
- Retrieval problems
- Impact of weak language skills with more complex tasks
- More impaired on explicit than implicit memory

(Mattson & Riley, 1999; Manji, Pei, Lomes, & Rasmussen, 2009; Pei et al. 2008; Willford et al., 2004; Mattson et al., 1996 and 1998)
Visual Memory

- Spatial memory impairment
- Inadequate internal representations of spatial relations in the environment
- Spatial deficits have been found similar to those with hippocampal lesions

(Manji, Pei, Loomes, & Rasmussen, 2009; Hamilton et al., 2003; Streissguth et al., 1994; Uecker and Nadel 1996 and 1998)
Use of Memory Strategies

• Shift from visual to verbal strategies seems to occur later for children with FASD.
• This shift may be related to development of executive function.
• Even once learned strategy use appears to be less efficient, which may implicate executive dysfunction.

(Rasmussen, Pei, Manji, Loomes, Andrew, 2009)
Source Memory in FASD

• Remembering the source of information (Johnson et al. 1993)
  • Reality monitoring
  • External monitoring
  • Internal monitoring

• **Participants**: 19 children with FASD and 38 control children aged 6 to 12 years.

(Kully-Martens, K., Pei, J., Job, J., & Rasmussen, C., 2012)
Source Memory in FASD

- Like typically developing children, children with FASD have most difficulty with the internal condition
  - Show the same pattern
- However, children with FASD performed worse overall (so greater difficulty in all areas)
- The pattern of results indicates a general memory deficit in children with FASD as well as a more specific memory impairment in the domain of source monitoring

(Kully-Martens, K., Pei, J., Job, J., & Rasmussen, C., 2012)
Integration of Information in Memory

• We examined memory consolidation and organization of complicated material on the ROCF in children with FASD (Pei, et al., 2011)

• **Participants:** 35 children with FASD and 35 control children aged 6 to 12 years.
Children with FASD had difficulties with memory consolidation and organization of complicated material.

They struggled with seeing the complex figure as a whole object compared to the control group.

This lack of a “gestalt” interfered with consolidation of information and accuracy in recall (Pei, et al., 2011).
Understanding areas of strength and difficulty in FASD for intervention
Together:
Finding Answers,
Improving Outcomes.

Math Intervention
Kable et al. (2007) assigned children (3-10 years) with FASD to two groups:

- Math Intervention Group
- Standard Psychoeducational

All parents received parental instruction on FASD: the math intervention group was focused on math and the other group on standard education.

Children were assessed on behaviour and math before and after the 6 week intervention.
The MILE Program: Key Facets

- RemEDIATE underlying cognitive factors
  - General learning ability
    - Slower pace of instruction
    - Active learning
    - Touch, talk, experiment
  - Working memory
    - Small pieces of info
    - Rhymes/songs
    - Cues
    - Repetition/practice
    - Time for recall
  - Visual-spatial skills
    - Tactile objects/manipulatives
    - Guide visual attention
    - Add structure to paper
    - Vertical number line
The MILE Program: Key Facets

Pre-test: Age 6 yrs

After 6 Weeks of Tutoring

- Visuomotor/Graphomotor Skills
  - E.g., Handwriting Without Tears
- Metacognition
  - “Great answer, how did you do that?”
  - “What strategy did you use?”
  - “What do you think you need to do here?”
Results of Math Intervention

- Children in math group showed more improvements in math than the contrast group.
- Parents of children in both groups reported improvements in behaviors.
- Follow-up 6 months later: Math group still had higher math scores than contrast group, and both groups still showed improvements in behaviour (Coles et al., 2009).
Memory Intervention
Memory Training

- Does teaching children with FASD a verbal rehearsal strategy increase their memory span? (Loomes, Rasmussen, & Pei, 2008)

- 33 children (19 males and 14 females) with FASD. Age range: 4 to 11 years.

- Children were assigned to two groups:
  - Experimental group (n=17): who received rehearsal training (children were told to whisper items repeatedly in their head)
  - Control group (n=16): who received no training
Results: Rehearsal Training

- Age was not correlated with whether children showed an increase in memory span
Conclusions

• Rehearsal training is effective in improving memory for numbers among young children with FASD
  • Age was not a factor so training may be beneficial for children of all ages
  • More children in the experimental group showed behavioral evidence of using rehearsal after the intervention
    • Age was not related to behavioral evidence
    • Older children were more able to articulate that they were using rehearsal
Executive Functioning Intervention
Research in remediation/rehab of cognitive functioning

- to improve the primary deficits in aspects of attention and working memory for individuals with FASD
- Use of computer-based materials is optimized when used in conjunction with ‘meta-cognitive’ & behavioural interventions
Cognitive Carnival

- Application of:
  - metacognitive skills (monitoring cognition),
  - self-regulation (process of controlling thoughts and actions) and
  - scaffolding (step by step)

- Children are encouraged to employ additional strategies when performance is weak and ‘think’ about their performance
  - Child may help brainstorm different strategies with interventionist
Metacognitive Strategies

- We taught the students that the brain is like a muscle that grows stronger with exercise!
- The key to improvement is practice...
Metacognitive skills used with children with FASD:

- **VERBAL:**
  - Clarify directions: “So what does ‘alphabetical order’ mean?”
  - Pause: “Let’s put down the controller for a minute and read this.”
  - Shorten span: soccer ball, baseball, volleyball = “sock, base, vol”
  - List/Stack: e.g. group 6 items into two groups of 3.
Metacognitive skills used with children with FASD:

- **PHYSICAL:**
  - Tracing on screen: e.g. drawing lines between items in order.
  - Pausing: “Let’s put down the controller and make a plan.”
  - Deep breathing/relaxation: “How many deep breaths should we take to help us relax? Let’s try three together.”
  - Counting on fingers: Makes a physical association with each item.
Increased collection of information regarding strategy use and partner feedback has revealed:

- Improved use of spontaneous metacognitive strategies, e.g. “Pause and think and I can do this”
- Statements regarding observed changes:
  - “I’ve noticed significant behavioural improvements in all 3 students in the intervention”
Improving the Intervention: Cog 2 – The Caribbean Quest (Kerns and team)
A Process Approach to Understanding
A need for process...

- A combination of classroom strategies and curriculum modification is needed.
- There may be a disconnect between knowledge about FASD and application in interventions.
- What do we do “in the heat of the moment”?
- Do we need to train and support educators differently to prepare them to use alternative strategies?
Details may help us refine our approaches and closely evaluate our strategies for intervention, but they may not equip us for the variability of daily demands.
The Impact of Alcohol

- Developmental structure
- Endocrine systems
- Neural pathways
Alcohol is a teratogen - it kills brain cells during development.

(diagram courtesy Wendy Comeau)
The Impact of Alcohol

- Structures and function are affected at a basic level of development
- Consistent pattern of inconsistencies
The developing brain: a complex process of cell growth, division, migration, differentiation, and so on.
The Impact of Alcohol

- The impact is compounded at higher levels of brain development
  - Reptilian brain – basic survival and self-defense
  - Limbic brain – processing emotions, critical to learning and memory
  - Neo-cortex – synthesis and complex thought
The Impact of Alcohol

- Neocortex: Higher-order thinking
- Limbic brain: Emotions
- Brain stem: Survival
12 year old Male Control IQ 130 98th percentile for reading

12 year old Male FASD IQ 74 1st percentile for reading

Looks the same even though we know the child with FASD is clearly impaired.
White Matter Microstructure

Lebel et al 2008 ACER
Stress-Diathesis Model

- Stress, per se, does not cause mental health problems
- Pre-existing HPA abnormalities may be a major contributory factor to some forms of depression, anxiety and substance use disorders

(Weinberg 2012)
Stress-Diathesis Model

- Strong link between depression/anxiety in adulthood and adverse early life events.
  - Adverse early life experiences sensitize or prime the stress system → Hyper-reactivity to subsequent, even mild, stressful life events.
  - Repeated stress over the life course will ultimately result in a maladaptive cascade of neurobiological events → increased vulnerability to illnesses, including to depression, anxiety and substance use.
How to model in our rodent model?

- Prenatal exposure to alcohol, then expose offspring to stress in adolescence or adulthood → test for depressive-/anxiety-like behaviour.
- Stress then unmasks underlying vulnerability

(Weinberg 2012)
A Process Approach to Understanding - informing intervention
So...

- We may see an uneven pattern of performance that varies between individuals: FASD is a complex disorder with multiple influences, at biopsychosocial levels of function

- So how do we respond to this variation?
  - Move from a script to improvisation based on understanding of underlying brain and resulting behaviour

- That said some structure can still guide our improvisation
ARC Model of Practice

- Action
- Reflection
- Communication
Overview of Sessions

Urban High School

Session 1: Introduction

Session 2: ‘FASD and the Brain’ and the ARC model

Session 3: Reflection and the INVEST model

Session 4: Collaboration in the classroom and moving forward

Rural School District

Session 1: Professional Learning ‘FASD and the Brain’

Session 2: Building a community of practice

Session 3: Collaboration in the classroom and moving forward
Capturing the Impact

- Four primary sources of data:
  1. Planning meeting notes
  2. Session recordings and summaries
  3. Post-initiative survey
  4. Tools (e.g., tip sheets, completed assignment worksheets, and model diagrams)
  5. Anecdotal reports of ‘ripple effects’
Identified Shared Themes Between School and District Approaches:

1. Improved **understanding** of FASD.

   """Brain not Blame has been invaluable, a great resource! I have shared it with other teachers and parents.""" District

2. Increased focus on strategies that support **success** for students with FASD

   "I'm thinking my goal is to have them feel success, my goal is to have them feel that they belong.... " School
Brain *not* Blame Tip Sheet

Reframing FASD from disability to "dif"ability.

Try to move from seeing the student in the terms described in the [Green] to the terms described in the [Yellow]. Please see the helpful tips in the [Pink].

Student with FASD

- Just CAN'T
- Just I'M NOT
- Acting young
- Lack of understanding
- Tired
- Lazy, unmotivated
- Need positive adult relationships
- Appear insensitive
- Unable to show feelings
- Overstimulated
- Overwhelmed
- Needs contact and support
- IS developmentally young
- Lack of attention
- Tiredness
- Frustrated or challenged
- Set realistic expectations
- Be patient
- Storytelling to make up memory problems
- Overactive

Developed (with many thanks!) in collaboration with the staff at J. Percy Page High School, Edmonton, AB.
3. Increased collaboration and **stronger professional relationships** and networks

“It was just nice to collaborate and discuss this topic with others - made me feel validation!” District

4. Recognition of an **advocacy** role for individuals with FASD

“Be like her big sister that you're kind of there and looking out for her and being supportive of her, and knowing that the way she reacts to certain situations may not be like everyone else ...” School
5. Movement towards **reflective practice** that incorporates action and communication.

“The reflection was good for me, I'm not really good at reflecting on what I do, but I was able to say - Ya, I've calmed down a bit - and they in turn have changed their behaviours.” School

“It was useful to listen to a variety of perspectives... and I will use [what I learned] in my everyday teaching, learning and professional growth.” District
School vs District Differences:

- Micro - here was a clearer focus/emphasis on particular students and sharing of strategies on a more individual basis, and an emphasis on their shared perspectives/collaboration

- Macro - centered more on the challenges of being an educator, advocating within their profession/sharing their perspectives on inclusion/special education with other teachers
Can’t have one without the other integrating our work through communication and collaboration
Putting it all together

- With so much emerging knowledge about function, approach, and intervention being produced, staying informed and current can become overwhelming.

- So how do we manage an understanding of details and process, while continuing to do our jobs?
iNAT: Communication Projects

- iNAT News: E-newsletter
- Interventions Across the Lifespan Blog
- KnowFASD
iNAT: Communication Projects

- iNAT News: E-newsletter
- Interventions Across the Lifespan Blog
- KnowFASD
iNAT Enews

Tuesday, June 19, 2012

In this issue:
- Greetings from Dr. Jacqueline Pei, iNAT Lead
- Spotlight on Research: Get Involved from Anywhere in Canada!
- Spotlight on Research: Attachment Intervention Evaluation
- Follow-up from the 5th Biennial National Conference on Adolescents and Adults with FASD
- Getting Connected - FASD Community of Practice
- Upcoming Conferences and Events

Greetings from Dr. Jacqueline Pei, iNAT Lead

Hello and welcome to another edition of the iNAT newsletter!

The past few months have been a busy time for the iNAT as we continue to build upon our research and communication endeavours. Since our last newsletter, iNAT members have presented at the Banff International Conference on Behavioural Science and the 5th National Biennial Conference in Vancouver.

Our blog FASD Interventions Across the Lifespan continues to share current news, events, research, and perspectives on FASD interventions. Viewer numbers are increasing steadily and we have had some great feedback. Thank you to all of you who have read the blog and commented. We love hearing from you! Click on the link above, visit the blog, tell us what you like, and tell us what you’d like to see more of.

Our latest project involves an interactive website designed to display the common neurobehavioural difficulties (as illustrated by research findings) experienced within the lifespans of individuals with FASD. The website then links viewers to a wiki which houses information on the neurobehavioural issues involved with FASD along with intervention options for each issue. Stay tuned - the website will be up and running soon.

The iNAT Advisory Panel

Policy

Anne Fuller
FASD & Nursing Support Services Policy Consultant
Children and Youth with Special Needs Policy
Ministry of Children and Family Development
Victoria, BC

Denise Milne, MSW, RSW, MSA, MC (Counselling Psychology)
Senior Manager, FASD/Children’s Mental Health Community Partnerships, Alberta Children and Youth Services

Holly Gammon
Manager, FASD Programs Healthy Child Manitoba Office
iNAT Enews

- Goal:
  - Connect researchers, policy makers, and service providers in a conversation about emerging best practice and community needs
We achieve this goal by:

– Opportunities to share research
– Glimpse of emerging research with research contact information
– Educational links
– Networking opportunities
– Event information
iNAT Enews

- Stats and evidence of success:
  - Increased readership
  - Clicks
FASD Interventions Across the Lifespan

School on the Brain
August 20, 2012 in Academics (Edit)

Given that individuals with FASD tend to have academic difficulties (studies have found that reading, spelling, and math are common areas of impairment\(^1,2\)), why not continue academic practice throughout the summer to ease the transition back into school?

“Great Schools” has put together a list of creative activities for practicing reading.
iNAT Blog

- **Goals**
  - Share current news, events, research, resources, and perspectives on interventions for individuals affected by FASD across the lifespan
  - Information that is easily accessible to any population through the web
What are people searching for?

Number of Searches

- FASD interventions: 200
- FASD: 150
- Person/organization/resource: 100
- Intervention related-Not FASD specific: 100
- Research related: 50
- Event/learning opportunity: 50
- News: 10
- Blog: 10
- Unrelated: 10

Search term
iNAT Blog

- We achieve these goals by posting:
  - Current **news** articles
  - New intervention **research** papers and research opportunities
  - **Events/Learning opportunities** (Conferences, webinars, workshops)
  - **Perspectives** on FASD (i.e. personal stories, other blogs or information sources)
  - **Resources and links** to relevant information or sites.
Percentage of Posts in Each Category

- Resources/Links: 38%
- Events/Learning Opportunities: 17%
- Research: 19%
- News: 19%
- Personal Story/Perspective: 7%
Stats and evidence of success:
- Viewer feedback
- Increasing number and diversity of viewers
- “Clicks”
Viewers in 66 countries

- Canada: 50%
- USA: 34%
- United Kingdom: 3%
- Other: 13%
Number of Viewers per Month

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iNAT KnowFASD

KnowFASD: alcohol in utero knowledge base

“I do well in school, so people expect me to do just as well everywhere else, but I can’t.”

Learn more on our wiki

Age:
- 0-1
- 2-3
- 4-5
- 6-8
- 9-11
- 12-13
- 14-16
- 17-20
- 21-25
- 26-35
- 35+

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Canada FASD Research Network

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iNAT: KnowFASD

- Goals:
  1. Provide reliable information on neurobehavioural difficulties of FASD
  2. Provide solutions
  3. “One stop shopping”
  4. User friendly and Interactive
  5. Relatable and true to life
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<th>Goal</th>
<th>We achieve these goals by:</th>
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<td>Provide reliable information on neurobehavioural</td>
<td>• Wiki</td>
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<td>difficulties of FASD</td>
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<td>Provide Intervention Options</td>
<td>• Tips, Resources, Links</td>
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<tr>
<td>“One Stop Shopping”</td>
<td>• Issue $\rightarrow$ Explanation $\rightarrow$ Support</td>
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<td>User friendly and interactive</td>
<td>• Viewer directed, interactive learning</td>
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<td>• Visual and accessible to general public</td>
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<td>Relatable and true to life</td>
<td>• Pictures of real people</td>
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<td>• Real issues</td>
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Future Directions:

- KnowFASD is still undergoing development.
- Subscribe to our newsletter
or our blog
  [http://fasdintervention.wordpress.com/](http://fasdintervention.wordpress.com/) to be informed when KnowFASD is launched
- Follow us on Twitter: @FASDIntervene
What we know:

- The scientific evidence is still emerging, but there is evidence that change can happen. Therefore: reasonable expectations are not the same as no expectations.

- Targeted intervention programs geared towards improving specific areas of functioning can have a positive impact (e.g., memory, math, etc.).

- Inclusion of a parent training component is important to any intervention program, combined with targeted direct treatment.
What we know:

- Information garnered through these intervention studies as well as our growing understanding of the neurocognitive profile of FASD can inform our approaches. Early training can have positive effects later in life; later intervention can still have a positive impact.

- We need an integrated system of support and information sharing
Contact us with ongoing research or new research to be distributed – we are means of knowledge mobilization

Add to wiki on website - are there links or resources we should add

What role do you see for yourself in contributing to communication, research, or practice activities?
iNAT Contact

- inat@ualberta.ca
- jpei@ualberta.ca

We want to hear from you!

Questions?