

# Diagnosis of FASD in Adolescents

**Presenters:**

Gail Andrew, MDCM, FRCP (C)  
Medical Director, Glenrose Rehabilitation Hospital FASD Clinical Services

Jacqueline Pei, R. Psych., PhD  
Department of Educational Psychology, University of Alberta

Carmen Rasmussen, PhD  
Department of Pediatrics, University of Alberta, Glenrose Rehabilitation Hospital

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The FASD Learning Series is part of the Alberta government's commitment to programs and services for people affected by FASD and those who support them.

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## Objectives: To Understand

- Complexity of the disability of Fetal Alcohol Spectrum Disorder in teens
- Need for committed support systems to prepare teen for the assessment and to access services
- Assessment process including assessment of mental health and addictions
- Need for access to training programs for employability and personal supports in transition to adulthood

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## Review of FASD

- FASD
- Secondary Disabilities

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### Review of FASD

- Alcohol exposure in pregnancy can cause damage to developing fetal cells
- Brain cells are vulnerable as the brain develops throughout the gestation and in the postnatal period
- Information from animal models and human neuroimaging studies

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### Review of FASD

- Spectrum of damage depends on amount and pattern of alcohol use, binge impact, timing in gestation
- Maternal and fetal factors: genetics, epigenetics, nutrition, other teratogens, stress
- Alcohol exposure is a risk factor for difficulties in learning and behavioral regulation and not a definite diagnosis

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### Review of FASD

- Adverse postnatal experiences can compound the already alcohol damaged brain
- In early childhood the difficulties may not be as evident, especially in a supportive environment
- Increasing difficulties appear over time, in keeping with brain damage, and impact learning, social skills, daily living

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### Review of FASD

- All children with prenatal alcohol exposure (PAE) ideally should have developmental monitoring and access to early interventions and stable homes
- Often the PAE is not known at birth and care is not optimal
- Assessment in the early years may not identify sufficient evidence for brain damage and FASD diagnosis

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### Review of FASD

- Lack of awareness of FASD in the general community may “blame” the child as not motivated or poor parenting
- Lack of access to FASD diagnostic services is a barrier to diagnosis in many areas
- For teens there can be multiple schools, home placements, dysfunctional families, no advocates for them

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### Review of FASD

- Current research has identified critical deficits in brain function in FASD: memory, executive functions (inhibition, shifting, flexible thinking, planning, sequencing, predicting, judgment) and functional communication
- Many of these brain domains cannot be assessed until ages 8 to 10 years

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### Review of FASD

- In early years, attentional difficulties, sensory reactivity, oppositional and externalizing behaviors, learning difficulties are the presenting issues
- In teens, mood regulation, anger and aggression, internalizing symptoms of anxiety, depression, low self esteem more evident

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### Review of FASD

- Risk in teens of only looking with a mental health lens and not as brain damage
- Need to go back in history to find the prenatal alcohol confirmation
- Finding the records and talking to birth mothers of teens is a challenge

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### Review of FASD

- Are the problems in teens secondary disabilities from the FASD not being diagnosed early and adverse life experiences?
- Are the behaviors and mental health symptoms an expression of primary brain damage from the PAE?
- Or both!!!!

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## Secondary Disabilities

Streissguth et al. (1996) longitudinal study. N= 415 individuals (6-51 years) with FASD.

### Among Adolescents/Adults:

- 1) More than 90% had mental health problems
- 2) 49% had inappropriate sexual behaviors
- 3) Over 60% had disrupted school experience
- 4) 60% had been in trouble with the law
- 5) 50% had been confined (incarceration, inpatient mental health or substance abuse programs)
- 6) 35% had alcohol and drug problems

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## Secondary Disabilities

- ▶ 67% had experienced physical or sexual abuse, or were victims of domestic violence
- ▶ 80% were not reared by their biological mother

### Protective Factors:

- living in a good quality stable home
- infrequent changes in living arrangement
- not being exposed to violence
- receiving services for dev. disabilities
- being diagnosed before the age of 6

**Risk Factors:** having FAE rather than FAS and having an IQ above 70

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## Studies

- ▶ Streissguth et al. (1994, 1999)
- ▶ Carmichael Olson et al. (1998)
- ▶ Executive Functioning in FASD
- ▶ Rasmussen and Bisanz (2009)
  - ▶ Schonfeld et al. (2005)
  - ▶ Lynch et al. (2003)
- ▶ FASD and the Criminal Justice System
  - ▶ Underlying Factors (Rasmussen & Wyper, 2007)

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### Streissguth et al. (1994, 1999)

- Longitudinal study of PAE (n~500)
- At age 14, PAE was significantly associated with problems in attention, behavior, memory, information processing speed, learning, and arithmetic.
- Effects were dose-dependent

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### Carmichael Olson et al. (1998)

- Compared 9 adolescents with FAS to 174 with minimal or no PAE on neuropsych tests
- Adolescents with FAS had difficulties with:
  - Behavior, social competence, school
  - Attention, memory, cognitive flexibility, and planning
  - Processing speed and accuracy

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### Executive Functioning (EF) in FASD

- Children, adolescents, and adults with PAE and FASD have significant impairments in EF (Rasmussen 2005).
- EF involves higher-order cognitive processes involved in goal-oriented behaviour (Zelazo & Muller, 2003).
  - Inhibition, set shifting, working memory, planning, fluency, strategy employment, decision making, and organization.

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## Rasmussen and Bisanz (2009)

- ▶ Looked at the profile of EF deficits in children and adolescents with FASD
- ▶ Whether there were age differences in EF

**Participants:** 27 diagnosed with FASD

- Mean age = 11 years (range 8 to 16 years)

**Tests administered**

- Delis-Kaplan Executive Function System (D-KEFS)

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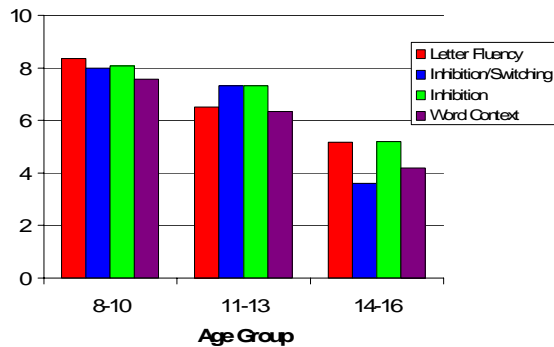
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## Results



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## Schonfeld et al. (2005)

- ▶ Moral maturity and delinquency in adolescents with PAE (ALC) and without PAE (CON)
- 27 ALC and 29 CON aged 10-18 years
- Matched on age, gender, handedness, SES, and ethnicity

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### Schonfeld et al. (2005)

- ▶ Participants completed questionnaires measuring:
  - Moral judgment - Stages:
    - 1) concern with physical consequences or benefit to self.
    - 2) reciprocal exchange between individuals to avoid negative conseq. or benefit self.
    - 3) social norms and values, prosocial responding.
    - 4) putting societal functioning before self.
  - Social desirability
  - Conduct Disorder
- ▶ Completed a test of inhibition

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### Results – Moral Maturity

- Groups did **not** differ on age, SES, gender, handedness, or ethnicity but **did** differ on VIQ and home placement (PAE <VIQ and more foster care)
- ALC group significantly **worse** on **moral maturity** than CON (CON stage 3, ALC stage 2)
- VIQ predicted moral maturity (more than group)
- PAE predicted moral judgment of relationships
- Social desirability, gender, and home placement did **not** predict moral maturity but inhibition and age **did**

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### Results - Delinquency

- ALC higher on delinquency than CON
- Age, gender, home placement, and social desirability predicted delinquency
- Among the ALC group, those in foster homes or biological homes displayed more delinquency than those in adoptive homes
- VIQ and inhibition did not predict delinquency
- Moral maturity related to delinquency
- ALC group more likely than CON to have probable Conduct Disorder

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### Lynch et al. (2003)

- Looked at the effect of risk factors (other than PAE) on delinquency in adolescents
- Found that life stress, drug use, and lower parental supervision were more related to delinquency among adolescents than PAE
- Suggest that it is important to examine multiple risk factors when looking at delinquency in PAE

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### FASD and Criminal Justice System

- Adolescents and adults with FASD are at particular risk for ending up in the criminal justice system
- In Streissguth's studies 60% of adolescents and adults with FASD had been in trouble with the law and 50% had been confined
- A Canadian study found that 23% of youth remanded for a psychiatric inpatient assessment had an FASD (Fast et al., 1999)
- A Canadian report indicated that 10% of inmates had an FASD, which is 10 times higher than in the general population (Sandrers, 2007)

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### Underlying Factors (Rasmussen & Wyper, 2007)

- The significant EF deficits in individuals with FASD likely contribute to high risk behaviors.
- Impairments in EF skills such as planning, cause-effect reasoning, learning from mistakes, and inhibition may be related to why youth with FASD are overrepresented in the justice system.

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**Underlying Factors** (Rasmussen & Wyper, 2007)

- The connection between poor EF and delinquency has been well-documented in other populations.
  - Adolescent/adult offenders are impaired on many tests of EF
  - Inhibition appears to be one aspect of EF that is strongly related to delinquency and high risk behaviors.

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**Underlying Factors** (Rasmussen & Wyper, 2007)

- Poor decision making is linked to the frontal lobe
- Individuals with frontal lobe damage show similar risky and maladaptive behaviors as those with FASD
- PAE has a negative effect on the frontal cortex, thus putting individuals with FASD at increased risk for engaging in problematic behaviors

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**Underlying Factors** (Rasmussen & Wyper, 2007)

- Risk taking increases during adolescence because they are more sensation-seeking and reward-driven but have a prefrontal cortex that is still developing
- Brain abnormalities of PAE persist into adolescence (Sowell et al., 2002)
  - Brain size and shape continues to be affected, particularly in the frontal and parietal areas

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## Underlying Factors (Rasmussen & Wyper, 2007)

- In FASD, adolescence is a time of heightened vulnerability, as these individuals have even more of a gap between their brain/cognitive development and normal development.

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## Intervention Research

- Project Step Up
  - McDaniel Youth Program
- Improving Communication and Support in the Schools
  - FASD Professional Development Program for Elementary School Teachers
    - Motor System Training
    - Attention Process Training

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## Intervention Research

- Our knowledge of FASD and adolescents has been influenced by information about brain function as well as daily functioning
- Research into interventions with adolescents has generally proceeded similarly: brain change and behavioural change, both geared towards the ultimate goal of improved function



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## Intervention Research

- Behaviour Change approaches tend to either target skill development in the youth or improved systems of support. Some examples:
  - Project Step Up
  - McDaniel Youth Program
  - Professional Development for Teachers



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## Intervention Research: Project Step Up

(Mary O'Connor)

- Ages: 6-18
- Addressing alcohol misuse and negative behavioural consequences
- Incorporates motivational enhancement techniques, normative feedback, risk assessment, and coping skills training
- Two conditions: treatment group or control
- 6 educational sessions of 60 minutes; concurrent parent/caregiver sessions
- Follow up after six months



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## Intervention Research: McDaniel Youth Program

(Henneveld, Rasmussen, Pei, Poth)

- Ages: 14-19
- One-on-one mentorship to help develop self-determined goals which will strengthen their life skills; connects to other needed supports
- Three years
- Pre, interim, and post program information collected from youth and caregiver: SSIS (social skills), ABAS-2 (adaptive behaviour), BASC2 (mental health), BERS2 (personal strengths)



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**Intervention Research:  
McDaniel Youth Program**

- Based on intake data collected, knowledge about the group increased:
  - Problems identified in all areas measured (adaptive functioning, social skills, mental health, and strength deficits) however, caregivers are reporting greater problems than youth
  - Youth identified more problems for concrete tasks and described themselves as feeling that they lack control over their behaviour
  - Caregivers report optimism for future of the youth



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**Intervention Research:  
Improving Communication & Support in  
the Schools**

- Focus groups with caregivers, teachers, administrators, and allied professionals working in schools
- How do we continue to improve interventions provided in schools
- Several themes emerged, including a need for training that takes learning from head knowledge to behaviour
- Which leads us to the next study...



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**Intervention Research:  
FASD Professional Development Program  
for Elementary School Teachers**

**(Hughes, Wakabayahsi, Clark)**

- Two day training, four half day workshops and a year-long mentorship.
- It was observed that the program changed the way teachers perceived and responded to disruptive and off task behaviour of students with FASD.
- Led to improved classroom behaviour of students diagnosed with FASD.



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**Intervention Research:  
FASD Professional Development Program**  
for Elementary School Teachers

- POPFASD is currently producing a training package that British Columbia school districts can use if they want to implement the professional development program.
- Plans underway to duplicate study in Alberta, with junior and senior high teachers as well.



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**Intervention Research**

- Brain change approaches are still intended to shape behaviour, but through less direct means. Some examples:
  - Attention process training
  - Motor system training



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**Intervention Research:  
Motor System Training**

(Kodituwakku, Tesche)

- Participants 12-18 years
- 10 children with FASD and 10 controls
- Training group practiced 3 complex sequences for ten minutes each day for eight weeks on a laptop computer equipped with a finger tapping device
- Preliminary results showed evidence of training-induced plasticity of the motor networks in children with FASD



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## Intervention Research: Attention Process Training

(Kerns, Gooch, Pei, Rasmussen)

- Participants 6-16 years
- Computer program delivered by an interventionist, 30 minute sessions, total of 24 sessions
- Attention process training
  - Repeatedly activate neural networks underlying specific attentional processes
  - Increasingly challenging
  - Strengthen neural pathways = improved attention functioning



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## Intervention Research: Attention Process Training

- Program systematically exercises and builds the capacity to sustain attention, deal with distraction (selective attention), hold information in working memory, and engage executive function skills
- Ultimately help to build self-awareness and self regulation of cognition and emotional response in response to the increasingly complex demands of the game



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## Intervention Research: Attention Process Training

- Measurement (pre and post):
  - Parent and teacher questionnaires
  - Psychological assessment
  - Diffusion Tensor Imaging - MRI technique that allows for virtual dissection of neural networks
- Is there any evidence to suggest underlying neural connections have been strengthened?
- ...But is only one small piece of a much bigger puzzle. Have to avoid 'one-stop' shopping.



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## FASD and Teens

- ▶ Complexity of FASD in Teens
  - ▶ Life Stories
    - ▶ Assessment Process
- ▶ Supports During the Assessment
- ▶ Supports After the Assessment
  - ▶ Community Responsibility
- ▶ Assessment, Diagnosis, and Intervention

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## Complexity of FASD in Teens

- Where have they been and what have they experienced?
- Who is coming to the diagnostic clinic with them?
- What do they know about the reason they are there and about risk of PAE?
- What supports are there after diagnosis and in transition to adulthood?

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## Life Stories

- 16 year old girl with her maternal grandmother since age 8, previously with birth mother and in foster care, disrespectful and defiant, ADHD, 3 Psychiatric consultations and multiple med trials, history of cutting, sexually active since 14, using alcohol
- 16 year old girl in foster care for 2 years, history of neglect, abuse, sexual exploitation, not trusting anyone, cutting, depression, sexually active, on probation for drug trafficking

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## Life Stories

- 17 year old girl with maternal grandparents since age 14, history of multiple caregivers and trauma, attended 14 schools, ADD, ODD, med trials, sexual assault counseling, suicidal attempt, sexually active
- 13 year old girl with birth mother, no placements but maternal health issues, severe tantrums, anxiety, OCD

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## Life Stories

- Almost 17 year old girl with birth father all her life, learning difficulties since kg and severe behavior issues, on antidepressants, using alcohol to feel good, sexually active
- 15 year old boy adopted at age 2, escalation in aggressive and defiant behaviors, in trouble with the law, now in group home with adoptive parents still involved

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## Life Stories

- 15 year boy with maternal grandparents since age 1 year, from remote northern community, struggles in learning, bullied in community
- 14 year old boy in group home with no advocate at time of assessment, history of severe neglect, depression, expressing no reason to try

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## Assessment Process

- Who is driving the assessment makes a difference to engagement
- School system
- Youth court
- Child welfare
- Caregiver

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## Assessment Process

- Brain domains
- Mental health
- Addiction potential
- Safety to themselves and other
- Relative strengths to use for teaching and employability
- Medical health issues

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## Assessment Process

- Data gathering prior to clinic day
- Confirming the alcohol exposure
- Engaging with the caregiver and school
- Clinic testing and formulation of the diagnosis and comorbidities
- Recommendations

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## Supports During the Assessment

- Need for a significant person who has a positive connection to the teen to be there
- How much to tell the teen prior to assessment on a case to case basis: “teen rights” vs. cognitive level and mental stability

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## Supports During the Assessment

- Do they know about the harm of alcohol use in pregnancy and that their mother drank?
- Positive approach: you are here to find out about how you learn to help with school and future planning
- Relationship building with teen

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## Supports During the Assessment

- Involvement of the birth mother needs to be sensitive and respectful vs guilt, shame, judgmental, no supports for her
- Involvement of the school who may be driving the process is critical for shift in programming and transition supports

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## Supports During the Assessment

- Need to have Children's Services Worker involved at all points including attending the debriefing and to manage the transition planning to adulthood
- Involvement of youth mentor or mental health therapist if already in place

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## Supports During the Assessment

- Informing the teen of the diagnosis and implications (consider cognitive level and emotional state)
- Respect caregivers wishes but knowledge about FASD can be positive to teen for accepting their differences and need for help
- Who informs and when?

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## Supports During the Assessment

- If no supports identified for teen or caregiver, this needs to be built as part of the assessment before the process
- Resources: school liaison worker, mental health therapist, parent coach or mentor, youth mentor, healthy family member

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## Supports After the Assessment

- Follow up on educational, mental health, community, medical recommendations, support systems
- Involving the teen over time to accept supports of the external brain
- Team for transition planning
- Transition to what?

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## Community Responsibility

- Need for education at all professional and community levels on FASD in teens and adults
- Include educators, employment training personnel, corrections, police, physicians, mental health therapists, group home workers, pharmacists

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## Community Responsibility

- Opportunities for safe recreation and supervision
- Supported workplaces
- Living opportunities with dignity but supervision
- Prevent future pregnancies that are alcohol exposed

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## Assessment, Diagnosis, and Intervention

- Do not exist as separate entities, but rather need to reflect a flow of integrated services that increasingly improve our ability to tailor interventions to best meet the need of the individual and their support teams
- Research is slowly catching up to help direct this practice

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## Assessment, Diagnosis, and Intervention

- In the meantime we need to consider the way in which we can increase the bridges between professionals and organizations, allowing opportunities for creative problem solving and flexible program delivery

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## Contact Information

### Gail Andrew, MDCM, FRCP (C)

Medical Director, Glenrose Rehabilitation Hospital FASD Clinical Services

Email: [gail.andrew@albertahealthservices.ca](mailto:gail.andrew@albertahealthservices.ca)

### Jacqueline Pei, R. Psych., PhD

Department of Educational Psychology, University of Alberta

Email: [jacqueline.pei@ualberta.ca](mailto:jacqueline.pei@ualberta.ca)

### Carmen Rasmussen, PhD

Department of Pediatrics, University of Alberta, Glenrose Rehabilitation Hospital

Email: [carmen.rasmussen@albertahealthservices.ca](mailto:carmen.rasmussen@albertahealthservices.ca)

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**For information on upcoming sessions  
in the FASD Learning Series:  
[www.fasd-cmc.alberta.ca](http://www.fasd-cmc.alberta.ca)**

**Please take the time to fill out the  
on-line evaluation**

**Thank You!**

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