

Developing an Adult FASD Diagnostic Clinic: The Victoria BC Experience

**FASD International Conference
Victoria, BC, Canada**

**Wednesday, March 11, 2008
3:30 – 5:00 pm**

Workshop Outline

- Review development of a multidisciplinary FASD adult assessment clinic.
- Emphasize challenges of assessing and diagnosing adults rather than children
- Where do we go from here
- Sharing some practical insights and what we have learned

Adult Diagnostic Team

- Dr. Caron Byrne, Psychiatrist, Consultant in Developmental Disability
- Dr. Jonathan Down, Developmental Paediatrician, Vancouver Island Health Authority
- Grace Gerry, Social Worker and FASD Clinic Coordinator
- David Gerry, Executive Director, FASD Community Circle, Manager, FASD Adult Clinic
- Dr. Michael Heaney, Physician
- Dr. Kathy Horne, Psychologist

Clinic Background

- 2001: Victoria FASD Community Circle
- 2005: Pediatric clinic partners Circle, University of Victoria, Vancouver Island Health Authority (VIHA)
- Assessed 15 children and supported 11 families
- Provincial Key Worker program

Adult FASD Clinic – Start-up

- Pilot project
- Collaboration between community FASD advocacy group and Health Professionals
- 3 year grant from Victoria Foundation FASD Action fund
- Funding and reporting obligations

Adult FASD Clinic – Start-up

- Resources – test materials, space, equipment
- Forms and procedures developed
- Rent space for assessments and clinic
- Admission criteria developed
- We bring **everything** we need with us to every clinic

Multi-disciplinary team - Needs

- **Professions:** Social Work, Medicine, Psychology, Psychiatry, can access Occupational Therapy consultation
- **Knowledge and skills needed:** FASD, Canadian Guidelines, 4-digit code diagnostic model, multidisciplinary collaboration
- **Recruitment:** physician, psychiatrist
- **Training and Mentoring:** observation, shadowing, Seattle course
- **Evaluation and Research:** UNBC, Program Logic Model

Challenges of assessment and diagnosis of adults rather than children

Adult Assessment: Challenges

Canadian Guidelines:

- “diagnosis of adults creates special challenges in all aspects of the diagnosis”
- “physical features may change”
- “there may be catch up growth”
- “adult’s history may include additional factors”
- “clinician should not rely solely on the self report of the individual”

CMAJ: FASD-Canadian Guidelines for diagnosis. 2005

Adult Assessment: Challenges

- Making a developmental diagnosis in adults rather than children
- Lack of professionals working with adults who are familiar with diagnostic model
- Medical training does not stress Developmental Disability / FASD as a diagnostic possibility in adults

Adult Assessment: Challenges

- No adult equivalent of a pediatrician
- Team based assessment needs team based skills
- Billing issues, fee for service model inappropriate
- Not clinically appealing to many physicians

Adult Assessment: Challenges

- Life experiences - primary impairments, secondary disabilities, psychiatric issues
- Long complex life histories – mental health, addictions, abuse, prostitution, child custody, legal issues
- Social Worker as “Detective” - difficult to get alcohol confirmation, out dated records

Information Gathering: Challenges

- Information is direct from client, not a caregiver
- Need to adapt “caregiver” interview to tap functional domains with self report
- Difficulty assembling self-report information when there are difficulties with memory, sequencing, insight, verbal expression

Information Gathering: Challenges

- **Who** – finding birth mother or others who can confirm maternal prenatal drinking, identifying significant professionals, family, friends
- **What** – crucial records, reports, other sources
- **How** – relationship building with family, professionals and ministries / departments to facilitate information gathering

Information Gathering: Who

- Key person is the **birth mother** or someone who witnessed mother drinking
- **Family members** who played significant role in client's childhood and adult life
- Past and current **professionals, agencies** involved
- **Programs** (addictions, counselling, upgrading)
- Friends, partners

Information Gathering: What

- **Client's life story** – family, childhood, school, work, partners, children, etc.
- **Prenatal risk factors** – what influenced the client before birth apart from alcohol
- **Postnatal risk factors** – what influenced the client's development after birth
- “postnatal risk factors” concept not good fit for adults

Information Gathering: What

- Birth record / medical records / photos
- School records and assessments
- Ministry of Children and Family Development
- Mental Health / Justice
- Programs and results
- Current ratings, interviews

Information Gathering: How

- **How information is gathered is crucial**
- Build relationships with client, family, professionals and ministries / departments
- Takes time, patience, compassion, determination and creativity.
- It helps if Social Worker is friendly, warm, flexible, understands FASD and is a cross between a hunter/gatherer and a detective/sleuth

Information Gathering: How

- **Client** must feel comfortable, understood, respected, not rushed, may need food, cigarettes, explanations of terms, distrustful of “system”
- **Adults with FASD need many cues** and reminders - Adult clinic Social Worker more involved with this than pediatric counterpart

Information Gathering: How

- **Birth mother** must feel respected, heard and not judged, needs gentleness, compassion
- **Professionals** – beneficial to build reciprocal appreciative relationships, explain clinic requirements, invite as observers to assessment and clinic process

Physician Assessment

- Medical concerns and issues
- Specific health concerns
- Medication review
- Specific historical questions for FASD
- Physical measurements of growth and facial features

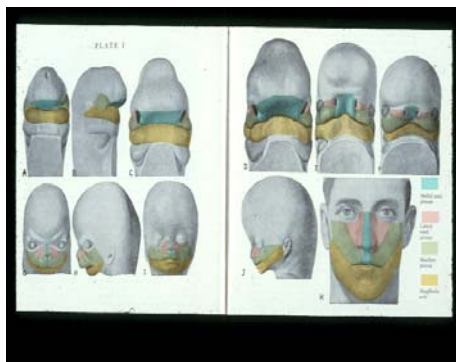
Adult Interview: Challenges

- Behaviour/Emotional Regulation
- Sensory
- Motor
- Social Skills
- Daily Living Skills
- Communication
- Safety
- Abstract thinking/judgment
- Planning/temporal skills

Adult Interview Questions

- Behaviour / Emotion: Do your moods go up and down like a roller coaster?
- Sensory: What types of situations, if any, overwhelm you?
- Planning / Temporal Skills: Can you organize your life by yourself or do you need help?

Physical Examination: Challenges

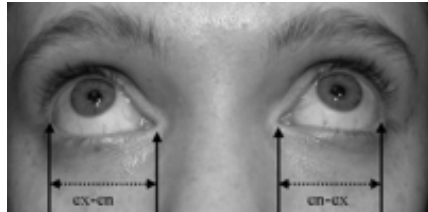


Adult Changes

- Continued growth of nose-bridge and length
- Midfacial growth
- Philtrum and upper lip modeling
- Chin growth

Facial Features: Challenges

Sentinel Facial Features



Brain Function Domains

- Cognition
- Communication
- Achievement
- Memory
- Attention
- Executive Function
- Motor Skills
- Adaptive Function

Challenges: Psychometric

- Appropriateness and relative importance of brain function domains
- Lack of detailed adult-specific diagnostic guidelines
- Limited psychometric measures in some domains
- Higher order language, social communication

Challenges: Psychometric

- Sensory and motor functions
- Validity of rating scales – self and others, bias, reading comprehension, self awareness
- Cumulative impact of life experiences, academic deficits, secondary disabilities, living situation, relationship history, plateaus and/or relative decreases in function, etc.

Canadian Guidelines: Adult Diagnosis

- “Cumulative environmental influences may distort the evaluation of brain function.”
- “The adult’s history may include additional traumatic head injury, alcohol and drug abuse, and mental health problems.”
- “Although tests for various domains are readily available, clinicians working with the adult FASD population find that the tests are often not sensitive to real-life issues.”

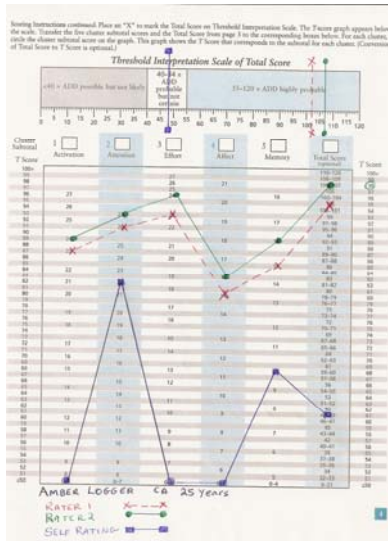
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Canadian Guidelines: Adult Diagnosis

- “In addition to the data required for the diagnosis, an assessment may include additional components such as functional literacy and numeracy, employability and quality of life, which fall within the domain of adaptive skills.”
- “The clinician should not rely solely on the self-report of the individual who is alcohol-affected; the history and abilities of the individual must be verified by a reliable source.”

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Rating Example - Attention



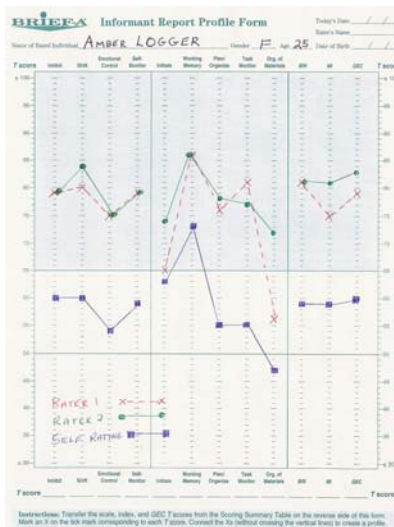
- Upper part of chart is area of difficulty
- Red and green lines by independent raters show many difficulties
- Blue line is client self-report – does not indicate much difficulty

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Rating Example – Executive



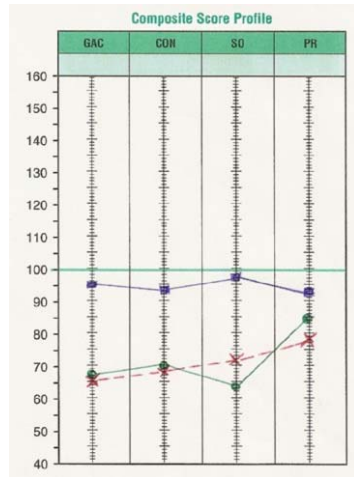
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Rating Example – Adaptive



- Lower part of chart is area of difficulty
- Red and green lines by independent raters show many difficulties
- Blue line is client self-report – does not indicate much difficulty

Maladaptive Behaviour

“Fetal alcohol syndrome is not just a childhood disorder; there is a predictable long term progression of the disorder into adulthood, in which maladaptive behaviors present the greatest challenge to management.”

Ann Streissguth, JAMA 1991

FASD and Mental Health

- Numerous and complex maladaptive behaviours and secondary disabilities
- High co-morbidity of mental health and addiction issues in FASD
- FASD can co-exist with known syndromes or conditions
- FASD can co-exist with known mental health conditions

FASD and Mental Health

- Important role of psychiatrist in Adult FASD diagnostic clinic
- Understanding Dual Diagnoses (DD) (Developmental Disability and Mental Health Issues)
- Often unrecognized impact of mental health needs in context of FASD
- Often unrecognized possibly of FASD in context of mental health issues

FASD and Mental Health

- Most clients have not seen psychiatrist before and have untreated mental health issues
- Cumulative effects of not being correctly diagnosed with FASD until adulthood
- Repeated failures academically and socially
- Cycle of neglect, abuse violence, substance abuse, breaking the law, repeated pregnancies with children removed by Social Services
- Grief, loss and attachment issues

FASD and Mental Health

- FASD characteristics may be misunderstood, misdiagnosed
- Seen as resistance, denial, non-compliance, acting out, personality disorders
- Resulting in high rate of concurrent disorders, over-diagnosis of personality disorders, misdiagnosis of mental health and addiction disorders, treatment failure
- Need awareness of the primary disability (organic brain damage) to understand causes of behaviour, reframe diagnosis and create appropriate interventions

What We Offer

- “User friendly “ verbal and visual feedback by whole team on clinic day
- The client leaves clinic with a 6 page summary report
- Team Physician and Social Worker complete Persons With Disabilities (PWD) application
- Social Worker coordinates and compiles final reports and meets the client and support person to review and explain it

What We Don't Offer

- No follow-up assessment or consultation
- Social Worker's role is short term
- Clients likely to lose supports if they lose permanent custody of their children
- Clients with no children who do not qualify for Community Living BC or Mental Health services often have no supports
- Most of our clients need ongoing support with housing, budgeting, emotional or mental health issues, parenting

Results to date

- Nine women assessed by February 2009
- All 9 received 6 page summary report
- 5/5 successful applications for Persons With Disabilities (PWD)
- Much positive feedback from clients and workers
- External evaluation in process – Clinic Logic Model

Looking to the Future

- Clinics scheduled into Fall 2009
- Need to identify other funding sources in order to continue beyond Fall 2009
- How to transition from pilot project to sustainable service within a Health Authority

Practical insights and what we have learned

Assumptions and Realities

- Takes lots of time, creativity, money
- Infrastructure needed for independent clinic: funding, technology, assessments, space
- Social Worker time commitment to prepare file – 50 hours for adult vs 20 hours for child
- Don't assume usual supports in place - doctor, reliable rater, stable living situation
- Management and incentives for client to attend - food, cigarettes, calls, phone cards, reminders

Assessment Considerations

- Value of psychiatry input
- Importance of functional literacy skills
- Have familiar support person attend psychological assessment
- Mutual benefits from clinic observers
- Plan data collection, analysis, evaluation, research, sharing information
- Get early family photos

Feedback and Reports

- Inform client that her personal information is shared within the team
- Help client understand importance of keeping clinical information secure
- Confirm with client who can get copy of clinic summary and reports
- Different forms and funding for First Nations clients
- Seek legal advice about wording and possible misuse of clinical information

Caution Wording

CAUTION: This report documents the comprehensive multidisciplinary assessment conducted to determine if First Name Last Name meets diagnostic criteria for a Fetal Alcohol Spectrum Disorder (FASD) and to inform needed supports. **This multidisciplinary diagnostic assessment is not an assessment of parenting capacity and is not intended for use in court proceedings for that purpose.**

Meetings

- Use visual aids with team and clients
- Digital projector useful for team reports, working sessions, reaching consensus
- Provide printed summary on clinic day
- Evolving team process and improving communication with clients
- “User friendly” process, forms, glossary
- Feed people – clinic lunches and other working meetings

Anticipate Client Needs

- Clarify what clinic can and cannot do
- Try to access supports needed beyond clinic mandate
- Plan for when and how to disengage
- Anticipate “turnover” in support services: help client develop coping strategies
- Keep replacement copy of reports

Some Ethical Considerations

- Autonomy, informed consent
- Privacy and confidentiality
- See client once with no medical or psychiatric follow-up available after diagnosis
- Duty of care after the clinic
- Who gets report, does follow-up, medication management?
- Lack of resources to fulfill our recommendations, especially if client does not have a child

Participant Challenge - Responses

Original term	Suggested replacement
diagnostic features	things we look at to make a diagnosis of FASD
growth deficiency	stunted growth
brain dysfunction	is offensive - use severity of differences in brain function
anomalies	unusual things
possible maternal FASD	your mother might have FASD - need to explain maternal
poor pre-natal care	it is a doctor's care
protective factors	things that help

Resources

- 2004 - Seattle FASD DPN 4-digit coding system and revisions – Astley & Clarren
- Canadian Guidelines – “harmonization” of IOM and DPN - Chudley, A. E., Conry, J., Cook, J. L., Looch, C., Rosales, T., & LeBlanc, N. (2005). Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis. Canadian Medical Association Journal, 172, 5 (Suppl), S1-S21
- The Canadian Northwest FASD Research Network – “brain summits” and assessment guidelines
- Child and Family Research Institute, Vancouver
- Individuals – Sterling Clarren, Susan Astley, Jan Lutke
- Clinics – Lakeland, Audrey McFarland, Asante Vancouver, Whitehorse

Contacts

FASD Community Circle – Victoria
#208-2951 Tillicum Rd, Victoria, B.C. V9A 2A6.
Phone (250) 383-0818. Fax (250) 598-4309
www.fasdcircle.org

gracegerry@shaw.ca
david.gerry@fasdcircle.org
jonathan.down@viha.ca
kahorne@shaw.ca
caron.byrne@viha.ca
mheaney@shaw.ca