

Diagnosing FASD in Adults: Implications and Future Directions

Victoria FASD Adult Clinic

**Fourth Biennial Conference on
Adolescents and Adults with FASD**

**Vancouver, BC, Canada
Friday, April 16, 2010 3:30 – 5:00 pm**

Presentation Outline

- Review of 3 year FASD adult clinic
- Client profiles, findings and feedback
- Diagnostic challenges
- Mental health and addiction issues
- Needs identified and future directions

Adult Diagnostic Team

- Dr. Caron Byrne, Psychiatrist, Consultant in Developmental Disability, Vancouver Island
- Dr. Jonathan Down, Developmental Paediatrician, Victoria
- David Gerry, Manager, FASD Adult Clinic, Beacon Community Services, Victoria
- Grace Gerry, Social Worker and FASD Clinic Coordinator, Victoria
- Dr. Kathy Horne, Psychologist, Victoria

Clinic Background

- 3 year grant from FASD Action Fund
- Started late 2007, current funding expires summer 2010
- Various referral sources
- 16 women assessed by January 2010

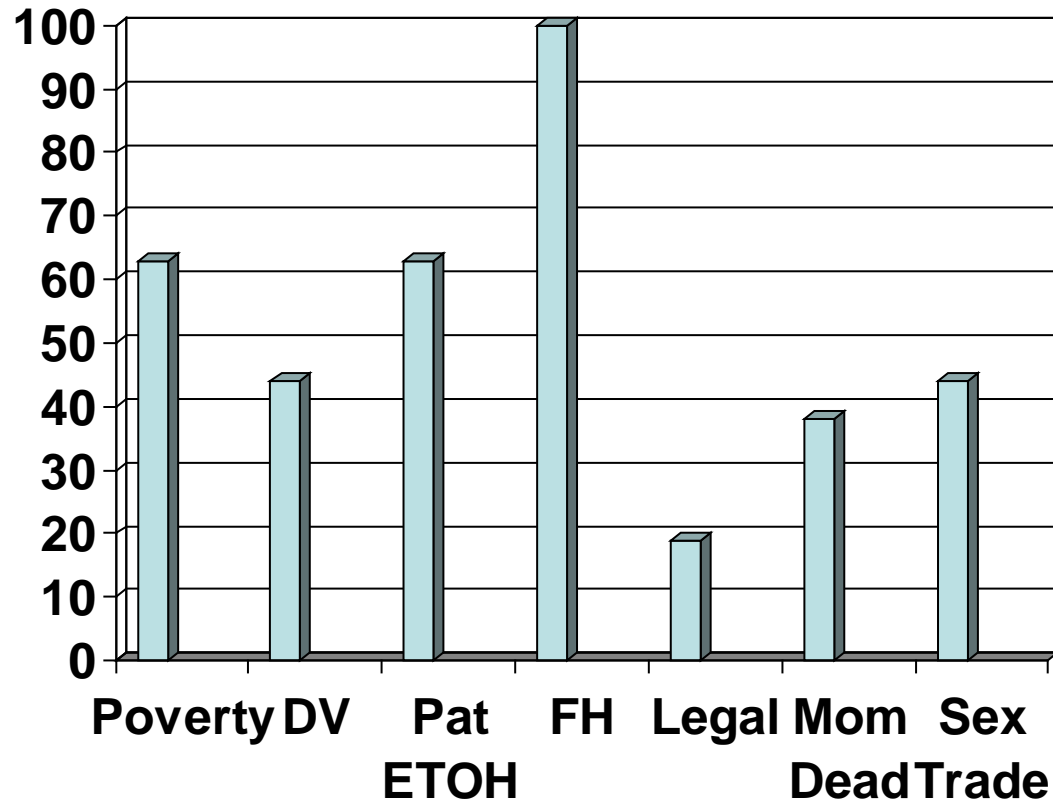
Admission Criteria

- woman over 19 years
- residing in Greater Victoria
- in stable enough living situation to be able to be contacted
- have someone to accompany them to testing and clinic days and complete questionnaires
- have access to a doctor
- high likelihood of confirming prenatal alcohol exposure.

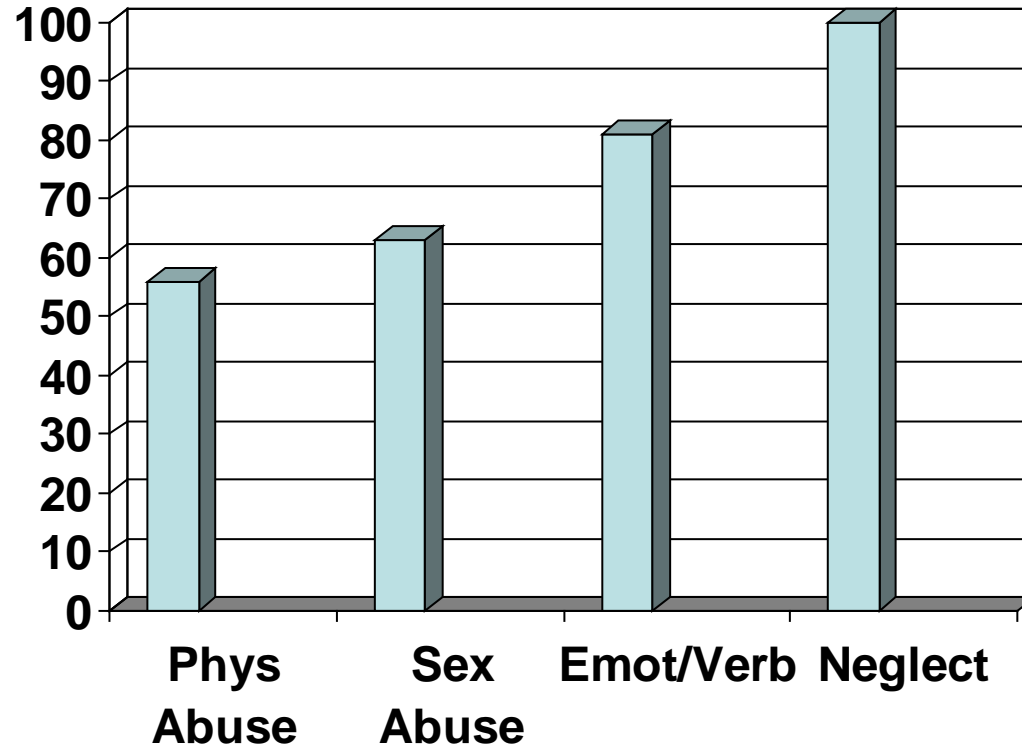
Client Demographics

- **Age:** 19 years to 45 years
- **Ethnicity:** 7 Caucasian, 8 First Nations or Métis, 1 Afro-Caribbean
- **Marital Status:** 13 single, 3 common law, only 1 had been married
- **Living Situation:** 6 alone, 5 with relatives, 3 with partner, 2 in FASD Action funded collaborative homes
- **Employment:** 1 had a part-time job (KH will complete this one)

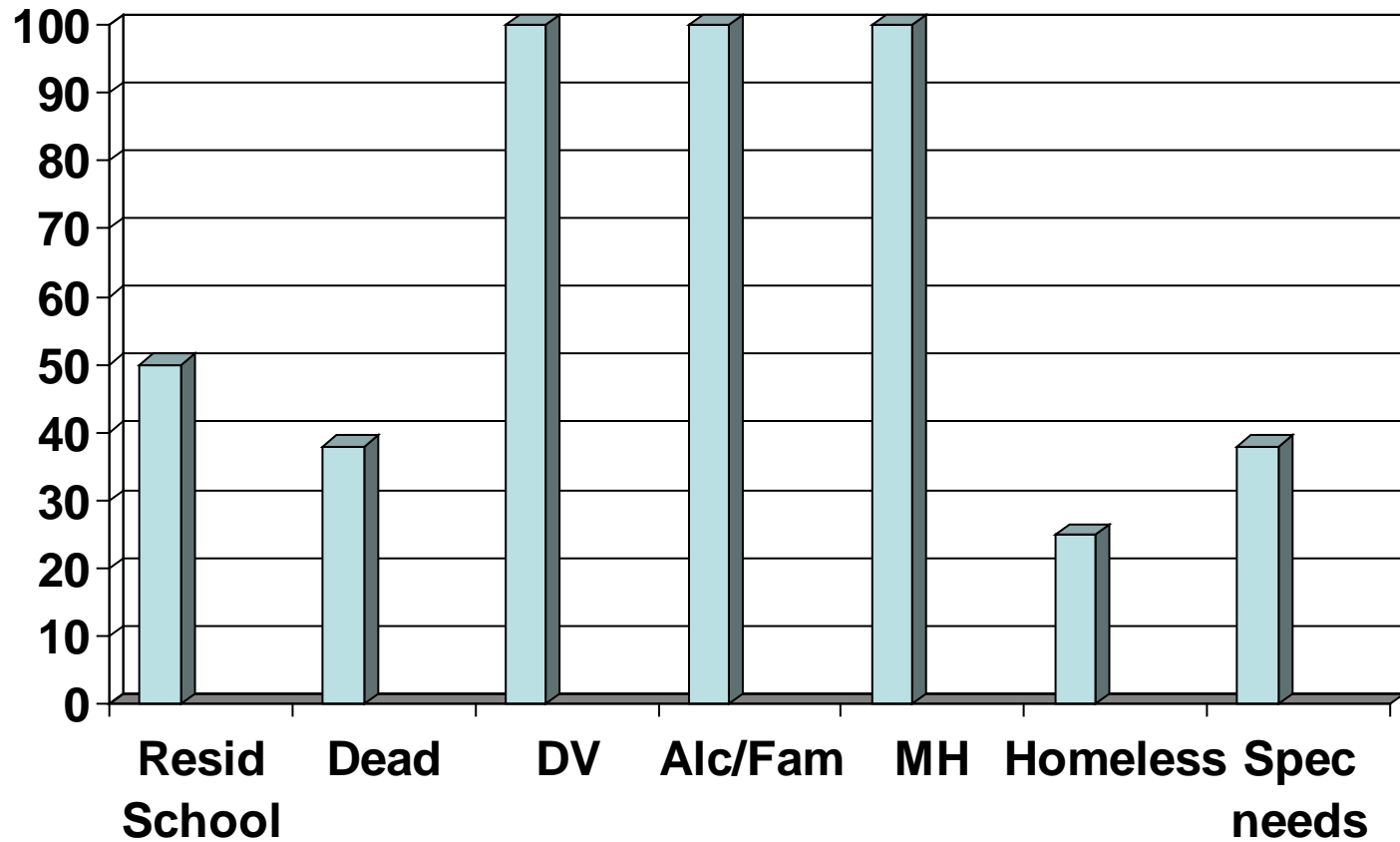
Clients' Trauma Histories



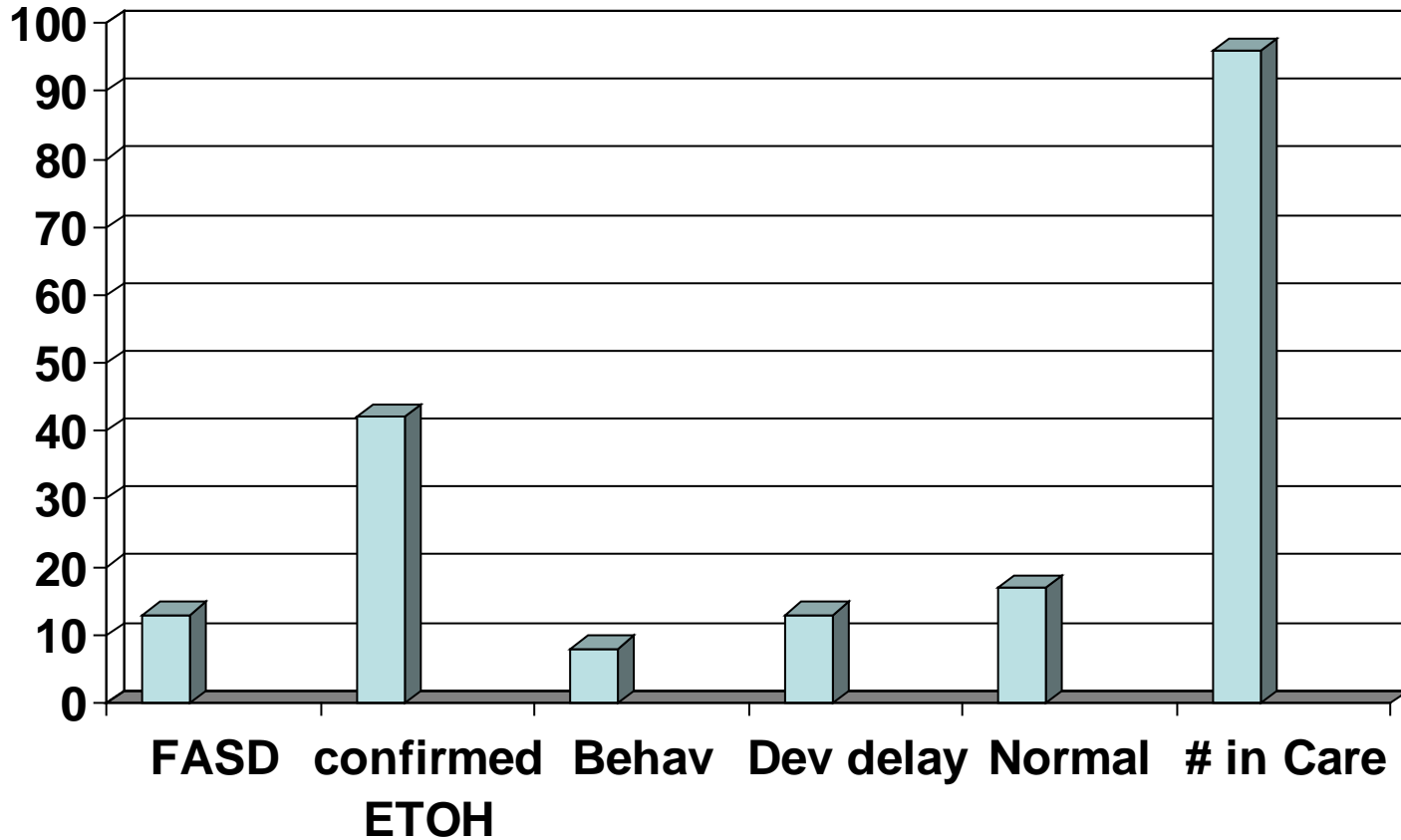
Clients' Childhood Abuse Histories



Birth Mothers' Histories



24 Children of 10/16 Clients



FASD Adult Diagnoses

- All 16 received FASD diagnosis
- 11 Partial Fetal Alcohol Syndrome (pFAS)
- 5 Alcohol Related Neurodevelopmental Disorder (ARND)

NOTE: All clients needed support to participate in the clinic process

Functional Assessment

- Most frequent areas of significant impairment:
 - Attention
 - Memory
 - Executive function
 - Adaptive functioning
- Next frequent areas of significant impairment:
 - Intellectual
 - Academic
 - Communication
 - Sensory processing
- None showed diagnostically significant problems with fine motor – all were functional for daily life

Tale of Two Women: Allie Stark and Zena Contrast

- Same diagnosis – very different presentations

Similarities

- same 4 digit diagnostic code
- Age – early twenties
- First Nations
- Apprehended at approx age 11
- Birth moms heavy drinkers, with domestic violence and mental health issues

Differences – Risk Factors

	ALLIE	ZENA
Early dating	No	Yes
Children	No	Yes
Substance abuse	No	Yes
Spousal Violence	No	Yes

Differences – protective factors

	ALLIE	ZENA
Support	Yes	No
Faith/beliefs	Yes	No
Intellectual abilities	High Average	Borderline
Insight	Yes	No
Financial resources	Yes	No

Functional Domains

	ALLIE	ZENA
Attention Executive Adaptive	Significant difficulty	Medium difficulty
Intellectual Academic Communication	No difficulty	Significant difficulty

Implications – what seemed to make a difference?

- Family support and client's openness
- Functional assessment profile
- Client's intellectual abilities and academic history
- Access to financial resources
- Faith and community support
- Dating age and not having children – birth control important

What Our Clients Tell Us

- Verbal feedback
- Video: “One Woman’s Story”

“Missed diagnosis” Challenges

“If a FASD is unrecognized, treatments may be ineffective. When the best possible diagnostic and treatment methods do not work, consider the possibility of a FASD” (SAMHSA)*

**(SAMHSA= Substance Abuse and Mental Health Services Administration- US Department of Health and Human Services www.samhsa.gov)*

“Missed diagnosis” Challenges

- Medical and systemic skepticism
- Lack of knowledge about wide ranging and long term effects of prenatal alcohol exposure
- Gaps in professional interest and expertise
- ‘Invisibility’ of FASD diagnosis, lack of diagnostic credibility

“Missed diagnosis” Challenges

- no FASD diagnoses in DSM IV, DSM-V, ICD 9 or ICD 10
- No clear path to obtaining diagnosis after age 19 years (in BC)
- Not clinically appealing to many physicians and other clinicians due to:
 - lack of knowledge
 - challenging characteristics to treat
 - fear of amount of accommodation that would be needed e.g. “We don’t have staff to do appointment reminders”, “open floodgates for funding supports”.

Canadian Guidelines for Adult Diagnosis

“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.”

- CMAJ 2005; 172 (5 suppl):S1-S21

Adult Interview

- **Learning/Memory/Information Processing:** Is there a special way that you learn? e.g. hands on, or visual?
- **Behavioural/Emotional Regulation:** What types of situations/people make you upset? e.g. what a person looks like, what they say, what they do?
- **Sensory:** Do you like or seek extra stimulation? (pain of getting a tattoo makes you feel alive)
- **Motor:** Are you accident prone?
- **Social Skills:** Has anyone ever taken advantage of you?

Adult Interview

- **Daily Living Skills:** Do you have enough money at the end of the month to buy groceries?
- **Communication:** Is it hard to find the right word in conversation?
- **Safety:** Have you ever done anything risky?
- **Planning/Temporal Skills:** Can you organize your life by yourself-or do you need help?
- **Abstract Thinking, Judgment:** Can you make good choices?
- **Working/Jobs:** Can you keep a job when you find one?

Canadian Guidelines for Adult Diagnosis

“The adult’s history may include additional traumatic head injury, alcohol and drug abuse, and mental health problems.”

“Cumulative environmental influences may distort the evaluation of brain function.”

CMAJ 2005; 172 (5 suppl):S1-S21

Prenatal Risk Factors: Genetic

- Alcoholism
- Substance Abuse
- Mental Health
- Learning Difficulty

Prenatal Risk Factors: Environmental

- Exposure to domestic violence
- Poor prenatal care
- Poor nutrition
- Nicotine exposure
- Substance exposure
- Maternal mental health
- Inconsistent housing

Post Natal Risk Factors

- Multiple home and school moves
- Inadequate/inconsistent housing
- Parental neglect/abandonment
- Parental alcohol/substance use and abuse
- Abuse as child and/or adult: physical, sexual, emotional
- Witnessed domestic violence

Post Natal Risk Factors

- Poor nutrition
- Inadequate/inconsistent housing
- Foster care placement
- Early school learning and behaviour problems
- Adolescent Alcohol and/or substance use/abuse
- Unstable housing as adult

Canadian Guidelines for Adult Diagnosis

“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.”

CMAJ 2005; 172 (5 suppl):S1-S21

Medical implications: History

- Risk is not well identified
- “Trust but verify”-reliable informant
- Life history takes time
- First time to tell full story
- Listening to their own story may help healing
- Issues of privacy/confidentiality/autonomy

Challenges : Psychometric

- domains
- ? primary mental health domain
- motor / sensory
- adaptive – CLBC
- **DON'T PANIC!** I will address only a few points from the following – most of it taken from last year - KH

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Implications of Frequent Concurrent Mental Health and Addiction Diagnoses and FASD

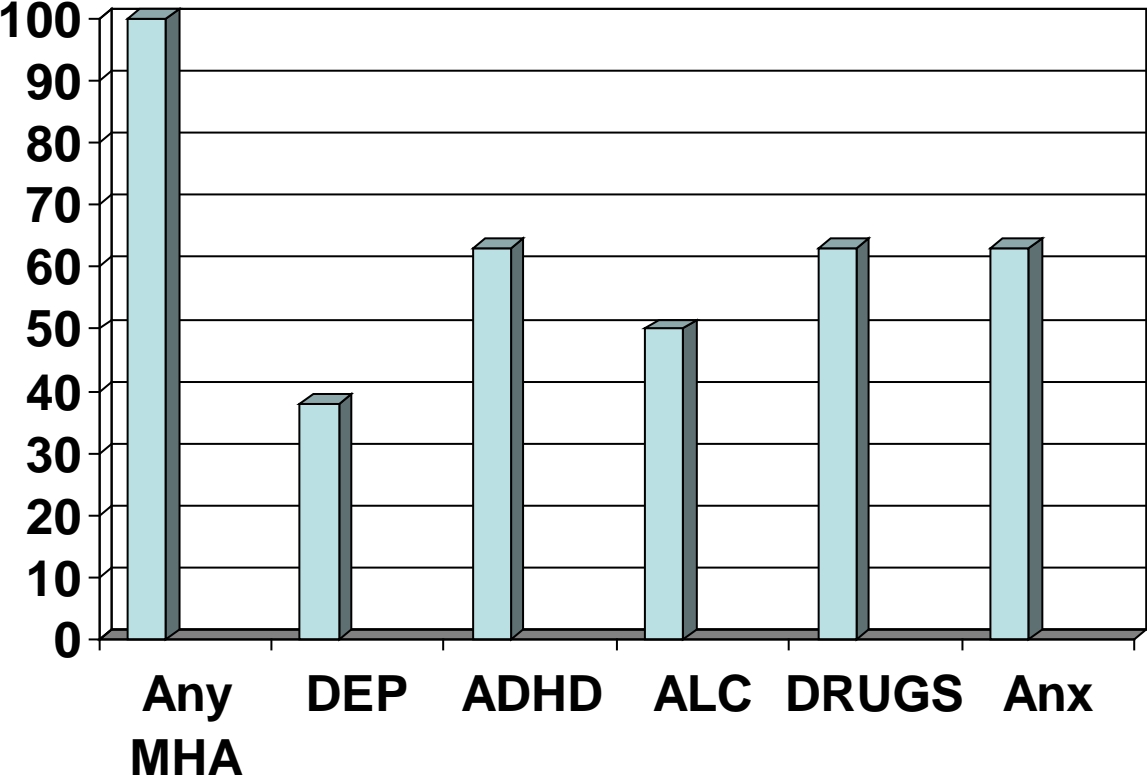
Fetal alcohol syndrome is not just a childhood disorder; there is a predictable long term progression of the disorder into adulthood, in which maladaptive behaviors present the greatest challenge to management.

Ann Streissguth, JAMA 1991

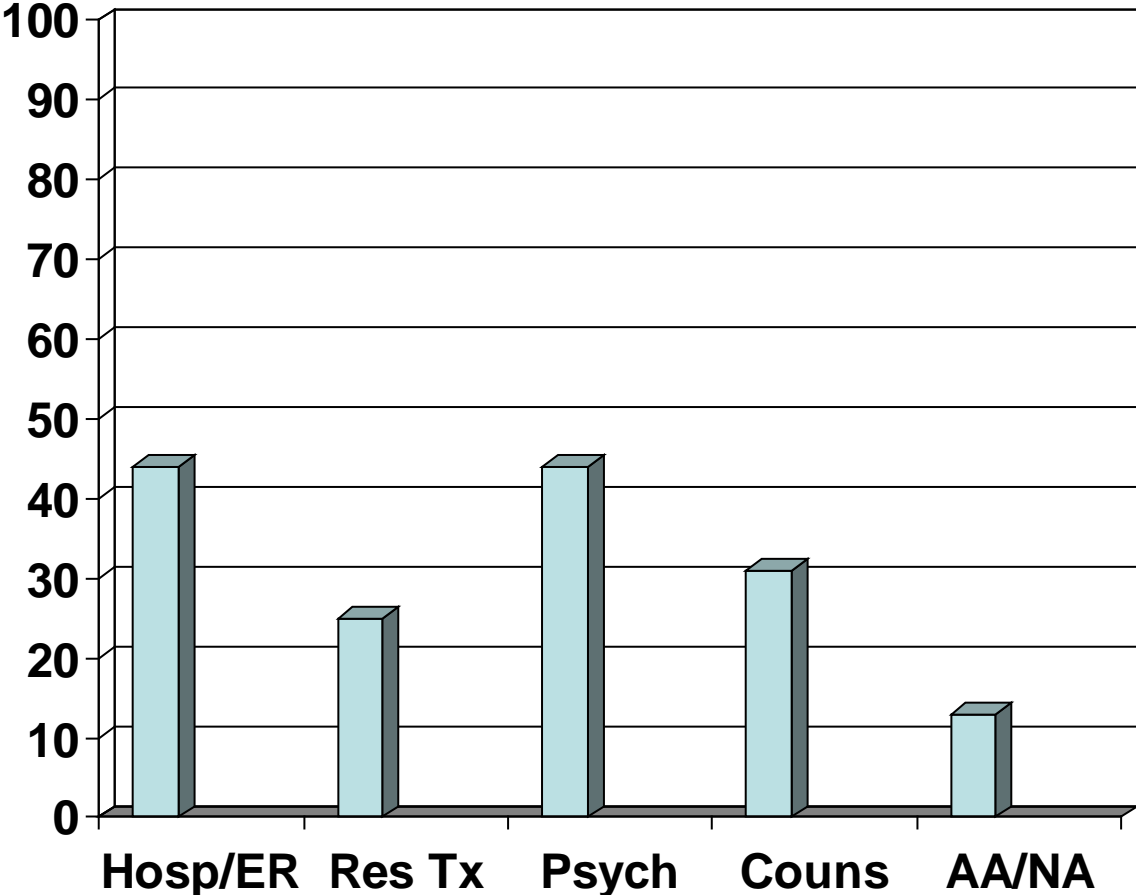
Concurrent Disorders

- Often unrecognized: the impact of mental health needs in context of FASD
- Often unrecognized: the possibility of FASD in context of mental health issues
- Less than half of our clients had a seen psychiatrist and many had only seen them when they were teenagers.
- Many have ongoing untreated mental health and addiction disorders

Mental Health or Addiction Contact



Mental Health or Addiction Contact



Concurrent Mental Health Disorders

- FASD characteristics may be misunderstood and misdiagnosed
- May be misinterpreted as resistance, denial, non-compliance, acting out, personality disorders
- All of these factors may result in a high rate of mental health and addiction treatment failure

Concurrent Disorders

- **FASD can co-exist** with any known syndrome or condition
- Prenatal alcohol exposure is ***superimposed*** on the basic embryo/fetus: e.g. Autism Spectrum Disorders, Down Syndrome, Intellectual Disability
- With any mental health or addiction disorder

Where do we go from here?

- **Addiction treatment services** need to be more available and more accommodating to those with FASD
- **Research** needed into how Mental Health and Addiction Disorders manifest themselves in those with a FASD.
- **Are characteristics/symptoms similar to or different** from general population?
e.g. ADHD

Systems used by our clients

- Child protection: 100% (as children and parents)
- Special Education: 94%
- Substance use and additions: 88%
- Income assistance: 81%
- Judicial System: 25%

Needs to be addressed

- Need for inclusive approaches for FASD clients through integrated systems of services and government ministries
- Paradox of policies that effectively discriminate against people with FASD
- Because Government cannot measure the “avoided costs” when an FASD diagnosis is missed, many areas of life are impacted with resulting huge “costs” to individuals and society

What difference does it make to **NOT** make a FASD diagnosis

- Unemployment or under employment
- Erosion of self esteem over many years
- Family breakdown/parenting skills, child protection, foster home cycle
- Mental Health and Addictions: misdiagnosis, inappropriate or ineffective treatment (misdirected health care dollars)
- Legal involvements
- Homelessness, poverty, transient life style
- Abuse: sexual, physical, emotional
- Premature death (violent deaths, suicide, untreated physical illness, alcoholism, drug abuse)
- More children with disabilities

The Future ?

- Need for communication, collaboration and data sharing with other adult assessment clinics
- Invitation to others to collaborate, how to do this
- Role of individual clinics?
- Role of FASD Northwest Network?
- Data collection and sharing
- Data base development
- Questions to address, information to gather re adult diagnoses?

References and Resources

- Astley, S. & Clarren, S (2004) - Seattle FASD DPN 4-digit coding system and revisions
- Chudley, A. E., Conry, J., Cook, J. L., Looock, 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

References and Resources

- How FASD co-occur with Mental Illness (2006). Substance Abuse and Mental Health Services Administration- US Department of Health and Human Services (www.samhsa.gov)
- O'Malley, Kieran and Nanson, Jo. (2002). Implications of a link between Fetal Alcohol Spectrum Disorder and Attention-Deficit Hyperactivity Disorder. Can J. Psychiatry (Clinical; Vol 47, No 4, May).
- Burden, et. al. (April, 2010 in press) Neuroprocessing differences in ADHD in individuals with and without prenatal alcohol exposure. Alcoholism: Clinical and Experimental Research

Contacts

FASD Adult Assessment Clinic
c/o David Gerry
Beacon Community Services
1450 Elford St.
Victoria, BC Canada V8S 3S8
250-595-6626

dgerry@beaconcs.ca
cebyrne@shaw.ca
jcdown@shaw.ca
gracegerry@shaw.ca
kahorne@shaw.ca