Identifying Clients Who May Be Affected By Prenatal Alcohol Exposure

Look at patterns that may indicate cognitive problems:

- **Impulsive behavior**
- **Behaviors that seem 'stupid,' repeated mistakes**
- **Out of control behavior precipitated by a stressor**
- **Assaults because the person overreacted**
- **Crimes as a secondary participant**
- **Repeated minor offenses**
- **Failure to follow through with services / recommendations**

Diagnosis Challenges

- Little access to diagnostic clinics/ assessment for adults
- Documentation of prenatal exposure is unavailable
- Facial features & growth deficiency absent in adulthood; no childhood photos or records
- Inability of client to follow through with all the steps required, without assistance

So what if we can't get a diagnosis?

We strongly recommend that the client get a neuropsychological assessment:

- **by someone who has *thorough knowledge about FASD;***
- **to identify cognitive and functional deficits & strengths;**
- **to obtain social security benefits;**
- **or to obtain disability benefits (but IQ level may pose a barrier).**

If you can't get a diagnosis?
Do what you would do anyway!

- **Teach the client about her disability.**
- **Help the client identify her strengths.**
- **Teach her to ask for help from those in her community in a way that works for her.**

If you can't get a diagnosis?
Do what you would do anyway!

Remember:

People with FASD learn best from the behavior modeled by those around them.

Working With Women Who Have Fetal Alcohol Spectrum Disorders (N = 19)

Funding from the March of Dimes Birth Defects Foundation (2001-2003)

"Prevent Double-Jeopardy"

***Community Mental Health Journal*, 40(6): 499–511, 2004**
***Mental Health Aspects of Developmental Disabilities*, 8(2): 33–39, 2005**

Client Characteristics (N = 19)

Age (yrs)	22.3 (5.7%)
Race	
White	12 (63.2%)
American Indian	4 (21.0%)
African American	3 (15.8%)
Unmarried	16 (84.2%)
Education (yrs)	9.9 (1.9%)
≤ 9 years	9 (47.4%)

FASD Client Characteristics (N = 19)

Physical/sexual abuse as child	94.4%
Parity (among 15 with children) mean	2.3%
Alcohol/illegal drug use	
None	15.8%
Any alcohol	68.4%
Any illegal drugs	78.9%
History of incarceration (jail)	68.4 %

FASD Client Characteristics (N = 19)

Ever had psychiatric evaluation	70.6%
Bipolar	41.7%
Depression	25%
Schizophrenia and PTSD	8.3%
Diagnosis unknown	16.7%

Psychological Assessment

We administered 3 standardized self-report measures to the women with FASD:

- ***The Brief Symptom Inventory (BSI)***
- ***The Young Adult Self-Report (YASR)***
- ***The World Health Organization Quality of Life (WHOQOL-BREF)***

BSI Findings

- Scores from the FASD group were similar to standardized scores of psychiatric inpatients and outpatients.
- Compared to a standardized non-patient sample, FASD client scores indicated more psychiatric distress.

YASR Findings

- **Compared to a normative reference sample, FASD scores were higher (more problematic) on all scales;**
- **Compared to a clinically referred sample of high-risk women, the group with FASD had higher scores on 6 of 8 individual problem scales and on the Total Problem Scale.**

WHO-QOL Findings

- **The group with FASD reported lower (poorer) quality of life scores on all 4 QOL domains compared to a healthy standardization sample.**
- **In the Environment domain, the FASD group scored lower than the three standardization samples.**
- **Scores were most similar to individuals who have a chronic illness.**

Educating Providers About FASD

- We identified key service providers interested in the problem, and willing to work with a PCAP client with FASD.
- We provided: FASD education, a PCAP case manager to work with the client for a year, and back-up consultation.

Education + hands-on experience = FASD demystified

- Providers learned to deliver services appropriately tailored to specific needs of FASD patients.

Strategies to Use with Clients Who Have FASD

- Use short sentences, concrete examples, and avoid analogies
- Present information using multiple modes.
- Simple step-by-step instructions (written and/or with pictures)
- Role-playing
- Ask patient to demonstrate skills (don't rely solely on verbal responses)
- Revisit important points during each session

Strategies to Use with Clients Who Have FASD

- **Teach generalization: Don't assume a lesson learned in one context will transfer to another**
- **Help client identify physical releases when escalating emotions become overwhelming**
- **Be alert for changes/transitions—monitor more carefully, do advance problem-solving**

Revise Your Expectations

- Can't vs. won't
- Help set up structure
- Set reasonable goals
- Remember this person's functional age
  - Communication & vocabulary
  - Abstract vs. concrete
  - Ability to function in daily life

“Think Younger”

Adjust expectations to be more congruent with the individual’s developmental level of functioning.

Diane Malbin: FASCETS
(Fetal Alcohol Syndrome Consultation Education and Training Services, Inc.)
www.fascets.org dmalbin@fascets.org

An experienced and clinically supported case manager, working in collaboration with her client and a network of educated providers, might reasonably expect to accomplish a number of intervention steps over a 12-month period.

FASD clients may need life long advocacy, but intervention steps can be taken in the short term:

1. Securing stable housing, and safe placements for the children.
2. Securing a measure of financial stability for the future (SSI, DDD).
3. Assisting clients in choosing a reliable contraceptive method.
4. Establishing an educated network of service providers and committed mentors who will continue to work with clients as most will require long-term support.

Discussion: How to Keep Women with FASD in Treatment?

Do you change treatment expectations?

- Group vs. individual
- Rules of the house
- Harm reduction: What does it mean for these clients?
- How do you deal with outbursts/ poor impulse control?
- Can you alter their environment to support their disability?

Discussion: Can Women with FASD Parent Effectively?

It depends!

Is there a supportive, caring, wraparound network available?

Will the parent with FASD be able to:

- **deal with emergencies/ illness**
- **pick safe people to be in their kids' lives**
- **maintain housing and pay their bills**
- **provide appropriate learning opportunities**
- **bond and attach to their kids**

Lessons Learned: Strategies for Preventing Alcohol/Drug Exposed Births

- **Alcohol/Drug Treatment**
- **Family Planning**

Lessons Learned: Alcohol & Drug Treatment

- Mandated treatment may be necessary
- Seek women-only treatment setting
- Seek treatment where children can stay or arrange for child visitation
- Arrange for post-treatment, transitional housing
- Introduce client to relevant support groups
- Relapse is part of the disease

Family Planning: Rates of Unintended Pregnancy

U.S.

Unintended Pregnancy.....57%

of these:

Mistimed, live births	20%
Unwanted, live births	8%
Abortions	29%

Canada

Unintended Pregnancy.....39%

WA State

Unintended Pregnancy.....>50%

Using contraception at time of pregnancy	43.4%

Forrest, 1994; Washington State DSHS RDA April 2004

Lessons Learned: Family Planning

- **Does NOT mean never having another baby**
- **DOES mean having more control over whether, and when, to have another child**

Family Planning Strategies

Education

- Basic anatomy, how pregnancy occurs
- How various family planning methods work
- Possible contraindications
- Consider lifestyle and health status
- Consider cognitive and functional status

Family Planning Strategies

- Encourage clients to discuss, acknowledge previous experiences.
- Motivational Interviewing: Help client identify pros and cons of having another child; revisit this topic.
- Reestablish client goals every 4 months. How will having another child affect achieving goals?

Cost Savings

Preventing Future Alcohol-Exposed Births

Preventing Future Alcohol-Exposed Births

At PCAP replication sites, 78 women were binge drinkers (≥5 drinks/occasion) during the index pregnancy.

At PCAP exit, 51 (66%) were no longer at present risk of having another alcohol exposed pregnancy:

- **24 (31%) using reliable contraception;**
- **18 (23%) abstinent from alcohol/drugs >= 6 months;**
- **9 (12%) both reliable contraceptive and abstinent.**

Preventing Future Exposed Births

- **Without PCAP about 30% (or 23) of 78 drinking mothers would have had another highly exposed birth.**
- **We reduced that by 66%, preventing about 15 alcohol-exposed births.**
- **The incidence of FAS is estimated at 4.7% to 21% among heavy drinkers.**

Therefore, we estimate PCAP prevented at least one and up to three new cases of FAS.

Cost Savings

- **The average lifetime cost for an individual who has FAS is $1.5 million.**
- **PCAP costs about $15,000 / client for 3 years (intervention, administration, evaluation).**
- **If we prevented just <u>one</u> new case of FAS, the estimated lifetime cost savings = cost of PCAP for 102 women.**

Ongoing Challenge:

Maternal Alcohol Use During Pregnancy

It's not "*just alcohol*"

February 21, 2005
U.S. Surgeon General Releases Advisory on Alcohol Use in Pregnancy

Women who are pregnant or who may become pregnant should abstain from alcohol consumption in order to eliminate the chance of giving birth to a baby with any of the harmful effects of the Fetal Alcohol Spectrum Disorders (FASD).

This updates a 1981 Surgeon General's Advisory.

If I'm Pregnant, Can I …

…Fly a plane?
Yes – if you could before, says Dr. Donald Gibb of London's Portland Hospital. In commercial jets, he says, short rides are fine up to 36 weeks.

…Have a beer?
The Centers for Disease Control says "no level of alcohol…has been determined safe," but some doctors feel limited drinking – no more than a pint a day, suggests Dr. Gibb – after the first trimester is okay.

…Bleach or dye my hair?
Many doctors give a thumbs up after the first 12 weeks, so long as chemicals are kept away from the scalp.

- People Magazine, April 17, 2006, pp 102-107

Resources

National task force on FAS/FAE: (Government involvement)
www.cdc.gov/ncbddd/fas/taskforce.html

UW Fetal Alcohol Syndrome Diagnostic & Prevention Network (Diagnosis) http://depts.washington.edu/fasdpn

The FAS Family Resource Institute (Information and Support)
www.fetalalcoholsyndrome.org

UW Fetal Alcohol and Drug Unit (Research)
http://depts.washington.edu/fadu

UW Parent-Child Assistance Program (Community Intervention)

King Co.: (206) 323-9136
Pierce Co.: (253) 475-0623
Cowlitz Co.: (360) 425-9600
Skagit Co.: (360) 428-7835
Yakima Co.: (509) 248-1800
Spokane Co.: (509) 324-1677
Grant Co.: (509) 765-5402