Working Effectively with Mothers who have Fetal Alcohol Spectrum Disorders: The Parent-Child Assistance Program (PCAP) Experience

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Topics We’ll Cover

- Fetal Alcohol Spectrum Disorders (FASD)
- FASD Intervention and Prevention
  - The Parent-Child Assistance Program (PCAP)
- Identifying Clients Who May Have FASD
- Working With Women Who Have FASD
- How to Keep Women with FASD in Treatment
- Can Women with FASD Parent Effectively?
- Strategies for Preventing Alcohol/Drug Exposed Births
Fetal Alcohol Syndrome

A permanent birth defect caused by maternal alcohol use during pregnancy

It is the leading *preventable* cause of mental retardation in the Western world.

Annually: 40,000 infants born with FASD (more common than Muscular Dystrophy, Cystic Fibrosis, Down Syndrome and Spina Bifida combined).
Alcohol is a Teratogen ...

... that causes damage to the embryo or fetus when consumed during pregnancy.

... whose effects have been demonstrated in animals and humans.

...whose neurobehavioral effects have been found to be more injurious than cocaine and other drugs abused prenatally.
Central Nervous System Dysfunction
Organic Brain Damage

- Hyperactivity, attentional deficits
- Intellectual deficits, learning disorders
- Problems with memory, language & judgment
- Developmental delay, microcephaly
- Fine & gross motor problems, seizure disorder
- Mental retardation, structural brain damage
Discriminating Features

- short palpebral fissures
- flat midface
- short nose
- indistinct philtrum
- thin upper lip

In the Young Child

Associated Features

- epicanthal folds
- low nasal bridge
- minor ear anomalies
- micrognathia
Fetal Alcohol Spectrum Disorders Can Be Hidden Disabilities
Central Nervous System Dysfunction
Organic Brain Damage

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- Intellectual deficits, learning disorders
- Problems with memory, language & judgment
- Developmental delay, microcephaly
- Fine & gross motor problems, seizure disorder
- Mental retardation, structural brain damage
IQ distributions in the Primary Disabilities Sample: FAS and FAE

- FAS (n=178)
- FAE (n=295)

N = 473; test ages 3-51 yrs

Mean IQ: 79 (FAS)
90 (FAE)

IQ ≤ 70: 27% (FAS)
9% (FAE)
Prenatal Alcohol

Primary Disability

Brain Damage

Dysfunctional Behaviors

Secondary Disabilities

Trouble with the Law, School Disruption, Etc.
PREVALENCE OF SECONDARY DISABILITIES Across the Life Span

Ages 6 - 51

Ages 21 - 51

Mental Health Problems

Disrupted School Experience

Trouble With the Law

Confinement

Inappropriate Sexual Behavior

Alcohol & Drug Problems

Dependent Living

Problems with Employment

%
FASD
Intervention and Prevention
The Parent-Child Assistance Program (PCAP)
Maternal alcohol and drug use puts children at risk because of:

- Possible effects of prenatal exposure on the child’s health
- Likelihood of a compromised home environment
- Likelihood that these mothers will have more exposed, affected children

These problems are costly to society and are completely preventable
WHEN CASE MANAGEMENT ISN’T ENOUGH

P C A P

A 3-year case management home visitation intervention for high risk mothers who abuse alcohol and/or drugs during pregnancy
Parent-Child Assistance Program

Primary Goal:

To prevent future births of alcohol and drug exposed children
PCAP Enrollment Criteria

1) Used alcohol/drugs heavily during pregnancy

2) Not effectively connected with community resources

3) Are currently pregnant, up to six months postpartum
Many of the mothers enrolled in PCAP were themselves exposed prenatally to alcohol or drugs.
PCAP Client Characteristics (N=458)

- Client's mom abused alcohol and/or drugs: 65%
- Client's mom had a psychiatric problem: 47%
- Client's mom drank alcohol heavily when client was a child: 42%
- Client's mom drank alcohol heavily while pregnant with client: 21%
We suspect that some of these PCAP mothers may have FASD, but very few of them have had an opportunity to obtain a diagnosis.
PCAP: A Two-Pronged Approach

Advocates

Clients & Families

Community Service Providers
Parent-Child Assistance Program

The Advocate:

- Works with a caseload of 16 families
- Helps client identify personal goals, coordinates these with program goals
- Collaborates with network of providers to develop a specific service plan with client input
- Connects clients with services, monitors progress
### Two-Pronged Approach Includes...

<table>
<thead>
<tr>
<th>Assessment</th>
<th>Planning</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Determine client’s strengths, needs, and weaknesses.</strong></td>
<td><strong>Develop specific service plans.</strong></td>
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</table>
The Difference Game

IT WOULD MAKE A DIFFERENCE IN MY LIFE IF I HAD:

MORE EDUCATION
HELP WITH HEALTH PROBLEMS
BIRTH CONTROL
DRUG AND ALCOHOL TREATMENT

Journal of Contemporary Human Services, 78(4): 429-432
<table>
<thead>
<tr>
<th>Linking:</th>
<th>Collaborate with network of providers to implement specific service plan. Connect client/family to services.</th>
</tr>
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<tbody>
<tr>
<td>Monitoring:</td>
<td>Continuous evaluation of progress.</td>
</tr>
<tr>
<td>Advocacy:</td>
<td>Intercede on behalf of client and children.</td>
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</tbody>
</table>
The Formula for Preventing Alcohol/Drug Exposed Births

- Motivate women to stop drinking or using drugs before and during pregnancy.
- Help women who can’t stop drinking or using drugs to avoid becoming pregnant.
Preventing Alcohol and Drug Exposed Births in Washington State:

Intervention Findings from Three Parent-Child Assistance Program Sites

American Journal of Drug and Alcohol Abuse, 2005
## Parent-Child Assistance Program

### Treatment & Abstinence Outcomes


<table>
<thead>
<tr>
<th>36-Month Outcomes</th>
<th>Original N=60</th>
<th>Seattle PCAP N=76</th>
<th>Tacoma PCAP N=80</th>
</tr>
</thead>
<tbody>
<tr>
<td>Follow up rate</td>
<td>92.3%</td>
<td>85%</td>
<td>85%</td>
</tr>
<tr>
<td>Inpatient or Outpatient tx complete or in progress</td>
<td>52%</td>
<td>76%</td>
<td>73%</td>
</tr>
<tr>
<td>Abstinent at exit for ≥ 6 mo</td>
<td>28%</td>
<td>43%</td>
<td>39%</td>
</tr>
<tr>
<td>Abstinent at exit for ≥ 1 yr</td>
<td>17%</td>
<td>34%</td>
<td>33%</td>
</tr>
<tr>
<td>Longest abstinence in PCAP ≥ 1 yr</td>
<td>37%</td>
<td>59%</td>
<td>46%</td>
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## Parent-Child Assistance Program

### Family Planning Outcomes

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<th>36-Month Outcomes</th>
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<th>Tacoma PCAP N=80</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birth control at intake</td>
<td>3%</td>
<td>13%</td>
<td>16%</td>
</tr>
<tr>
<td>Birth control at exit</td>
<td>73%</td>
<td>74%</td>
<td>71%</td>
</tr>
<tr>
<td>More reliable method</td>
<td>43%</td>
<td>49%</td>
<td>53%</td>
</tr>
<tr>
<td>Subsequent birth, (% women)</td>
<td>28%</td>
<td>29%</td>
<td>25%</td>
</tr>
<tr>
<td>Clean &amp; sober throughout pregnancy</td>
<td>18%</td>
<td>32%</td>
<td>40%</td>
</tr>
<tr>
<td>Entered treatment</td>
<td>47%</td>
<td>50%</td>
<td>55%</td>
</tr>
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</table>
Identifying Clients Who May Be Affected by Prenatal Alcohol Exposure
Identifying Clients Who May Be Affected By Prenatal Alcohol Exposure

When interviewing the woman, ask:

- Did your mother ever have a problem with alcohol?
- Did she drink alcohol while she was pregnant with you?
- Did she drink alcohol when you were young?
- Is your natural mother alive? If not, how old were you when she died?
- Were you raised by someone other than your biologic parents?