Working with Women Who Have FASD: How Do We Meet the Challenge?

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Therese M. Grant, Ph.D.
University of Washington School of Medicine
Department of Psychiatry and Behavioral Sciences

Teratogens

- Substances that have the potential to damage the fetus when exposure occurs during pregnancy (e.g., radiation, thalidomide, alcohol).
- Degree of damage depends on timing and dose of exposure.
- If timing and dose are below the teratogenic threshold, some exposures have little risk of causing malformation.

Prenatal Alcohol Exposure

Alcohol is a teratogen

Prenatal Alcohol Exposure

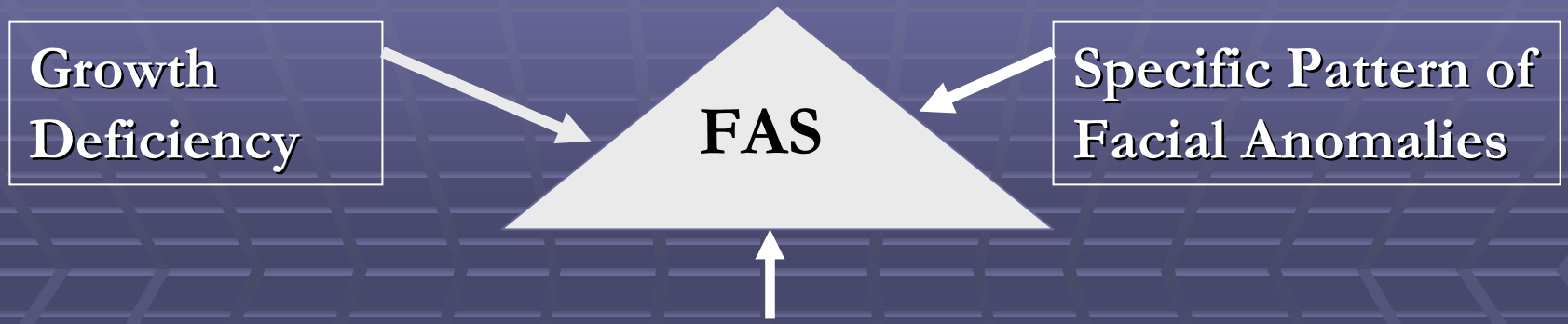
- Effects have been demonstrated in animals and humans
- Neurobehavioral effects have been found to be more injurious and long-lasting than cocaine and other drugs abused prenatally.

Teratogenic Effects of Prenatal Alcohol Exposure

- Direct toxic effect of alcohol on cells
- Hypoxia (inadequate oxygenation of blood) due to impaired placental/fetal blood flow
- Effect on cell migration in the brain
- Effect on apoptosis (a natural process of programmed cell death)

Fetal Alcohol Syndrome

- A permanent birth defect caused by maternal alcohol use during pregnancy
- 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, Downs Syndrome and Spina Bifida combined)

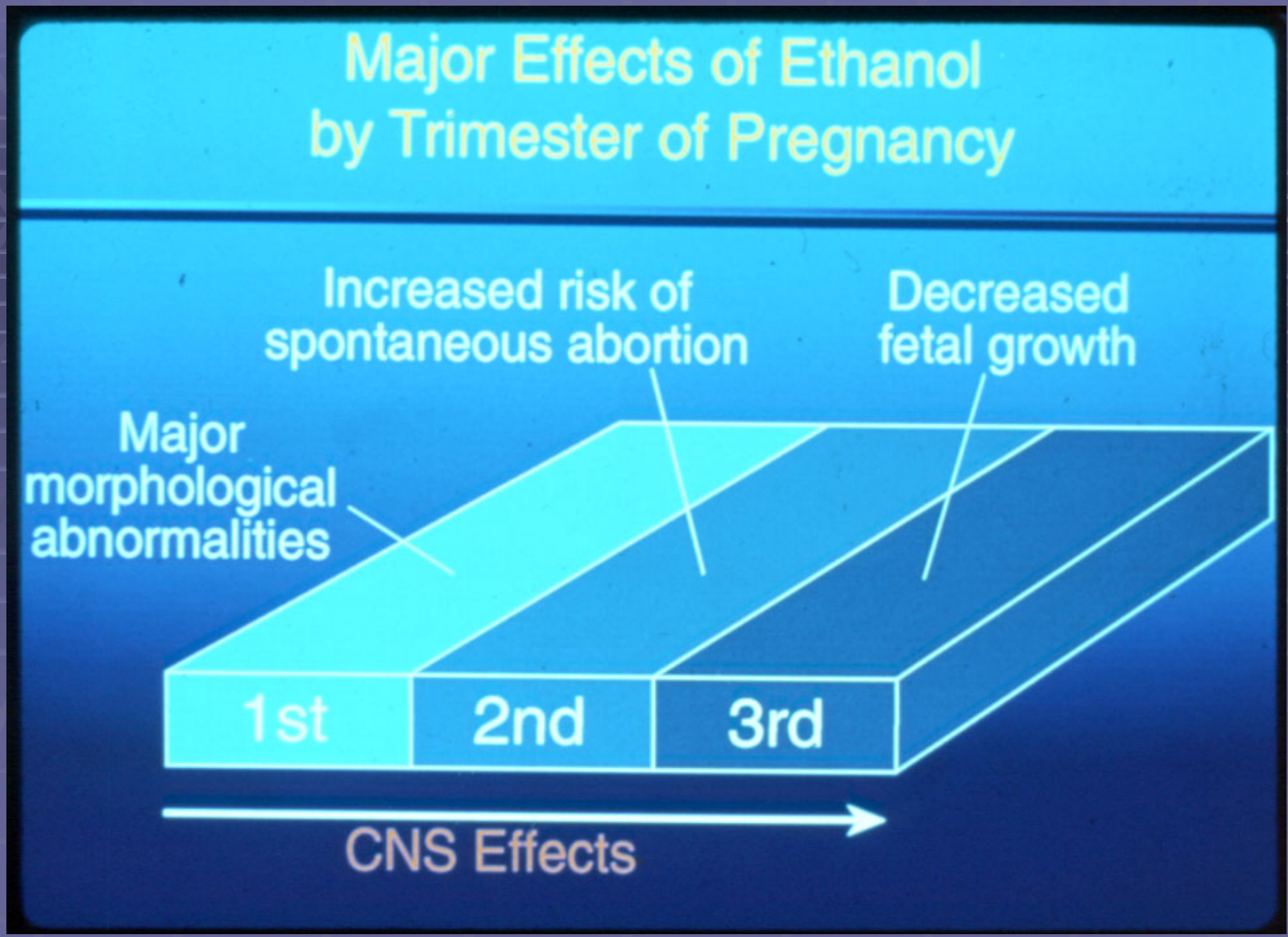


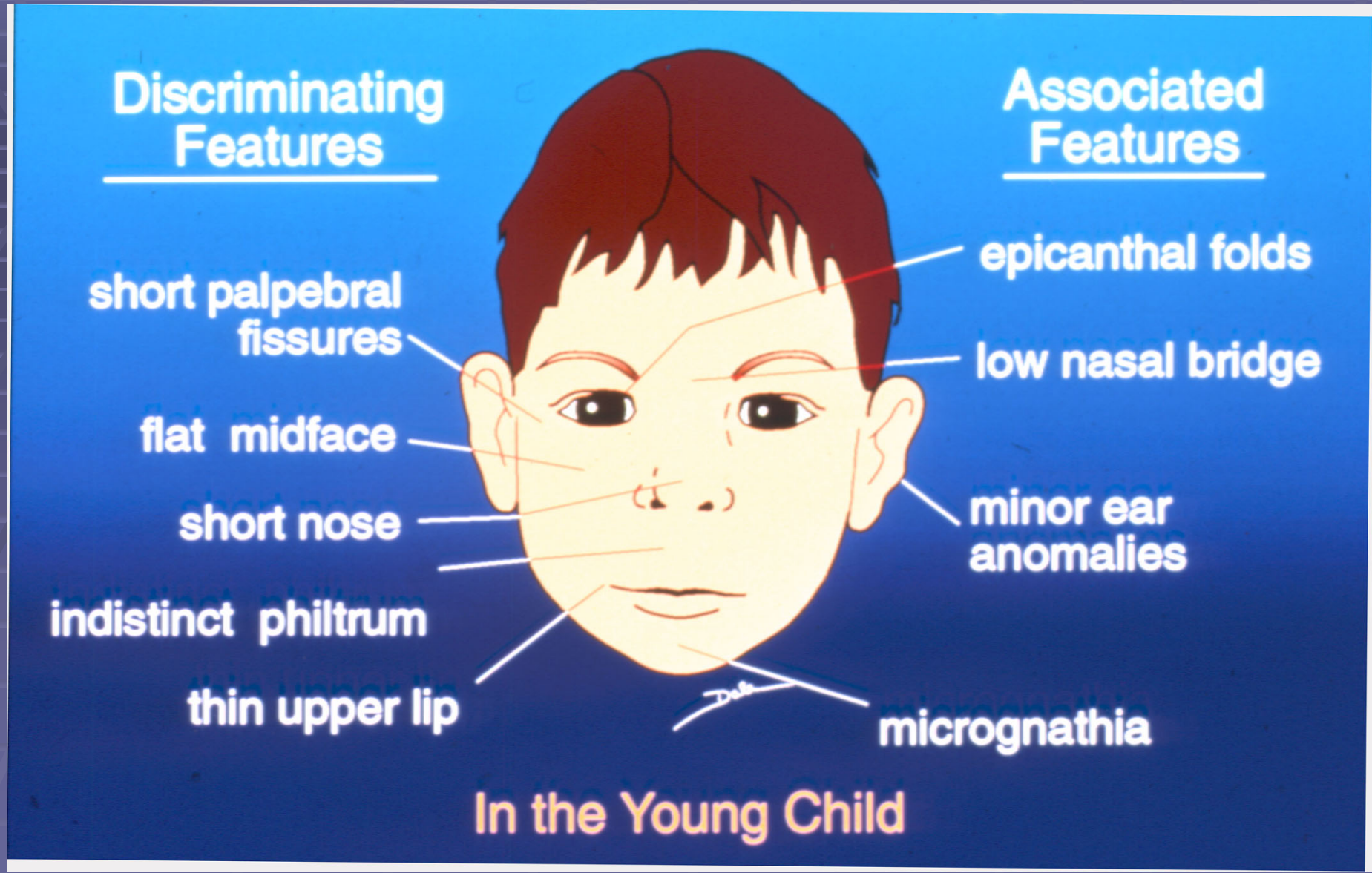
Central Nervous System Dysfunction

Organic Brain Damage

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

Major Effects of Ethanol by Trimester of Pregnancy




Discriminating Features
short palpebral fissures
flat midface
short nose
indistinct philtrum
thin upper lip
Associated Features
epicanthal folds
low nasal bridge
minor ear anomalies
micrognathia
In the Young Child

Fetal Alcohol Spectrum Disorders (FASD) can be

"Hidden Disabilities"

Central Nervous System Dysfunction
Organic Brain Damage

- Hyperactivity, attention deficits
- Intellectual deficits, learning disorders
- Problems with memory, language & judgment
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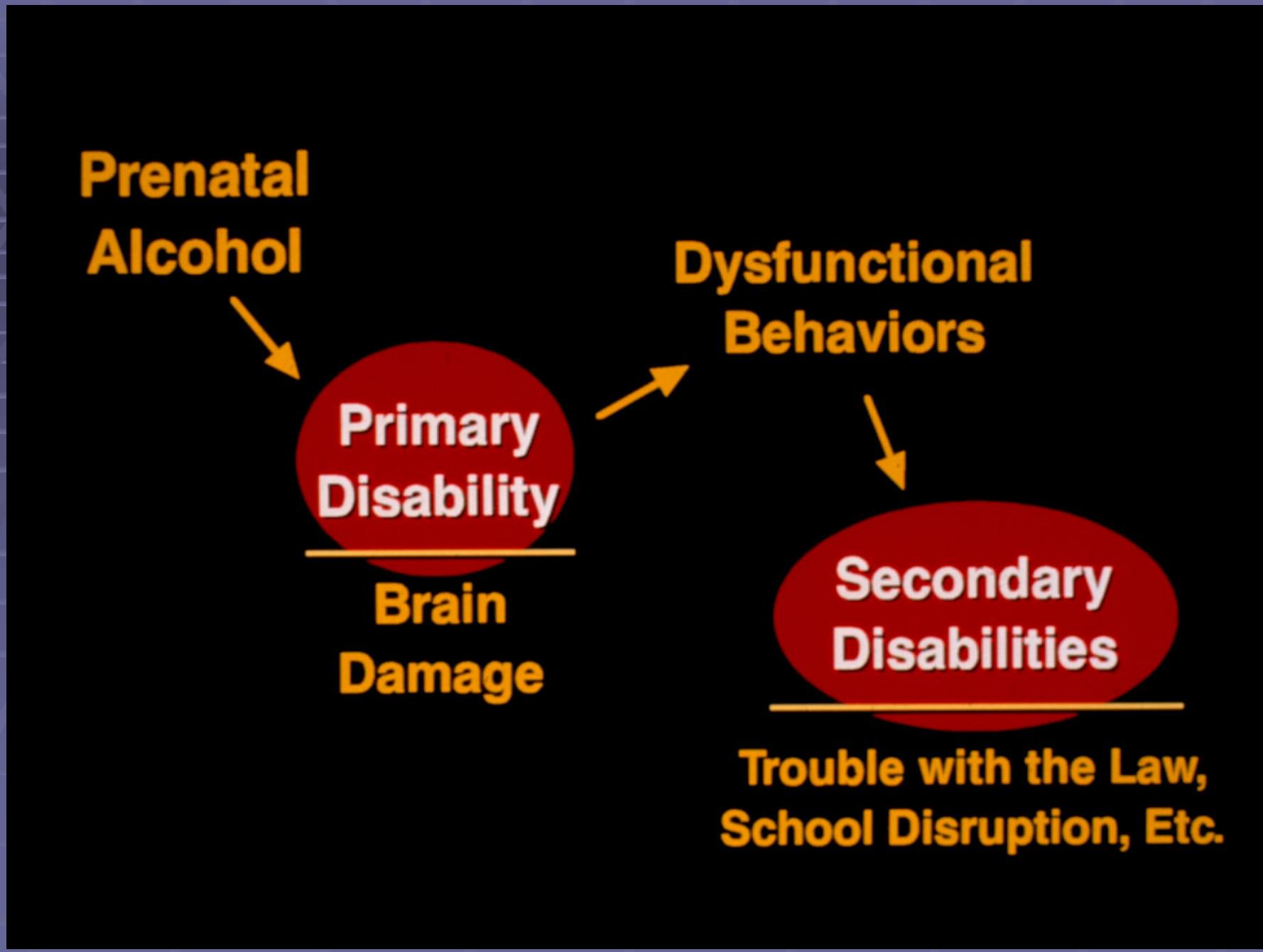
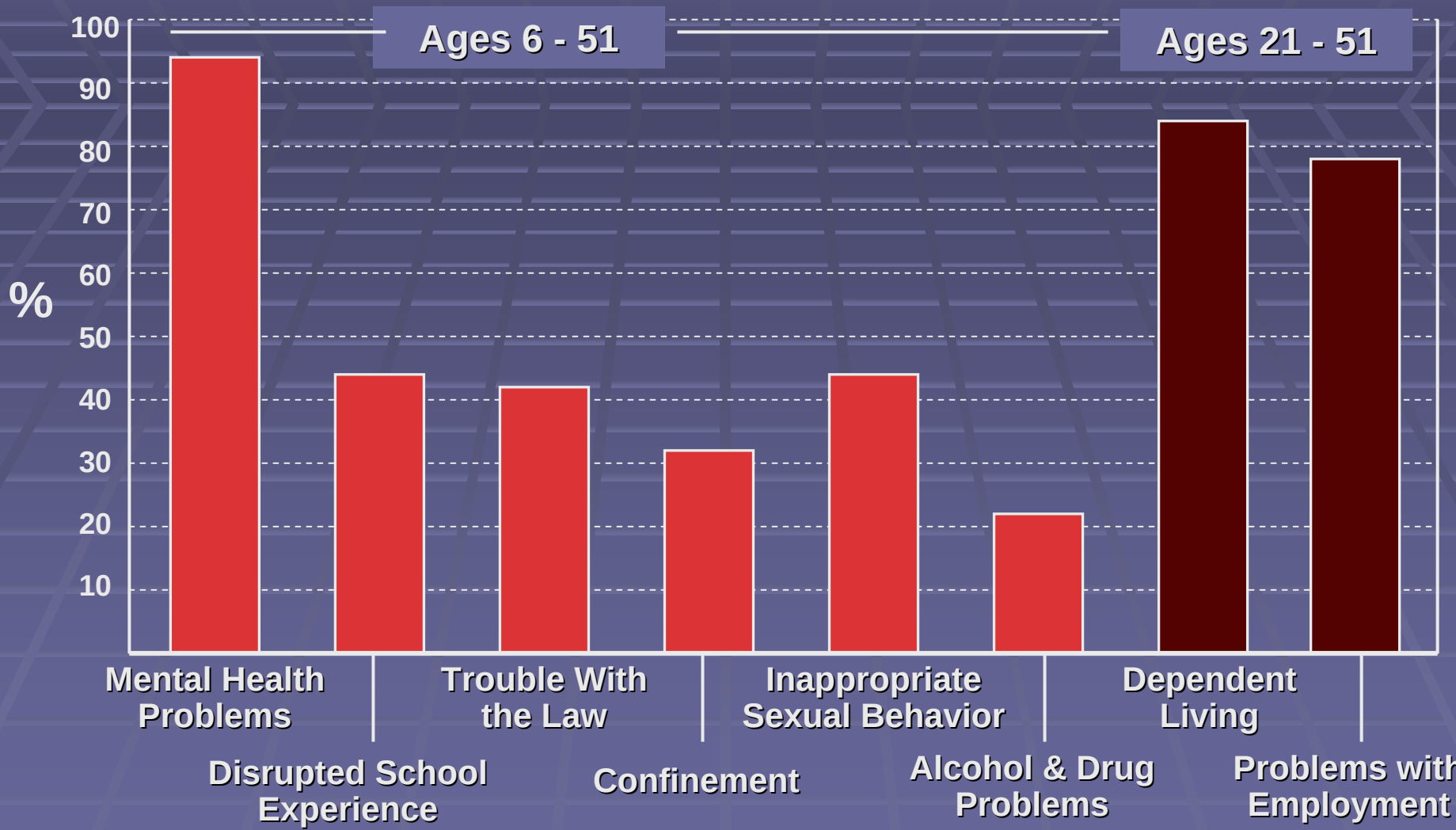
FASD: Clinical Implications

Poor judgment ……Easily victimized
Attention deficits ……Unfocused / distractible
Arithmetic disability …..Can't handle money
Memory problems ……..Doesn't learn from experience
Difficulty abstracting ….Doesn't understand consequences
Disoriented in ……..Fails to perceive social cues time and space
Poor frustration ……..Quick to anger tolerance


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



Working with Women Who Have FASD:

"Prevent Double-Jeopardy"

With thanks to the

March of Dimes

Birth Defects Foundation

for funding (2001-2002)

Aims:

To describe the mental health, psychosocial functioning, and quality of life of 19 young women with diagnosed or suspected FASD.

To share lessons learned in developing a pilot community intervention to treat, support, and meet the complex needs of these women.

The Idea for the Pilot Study

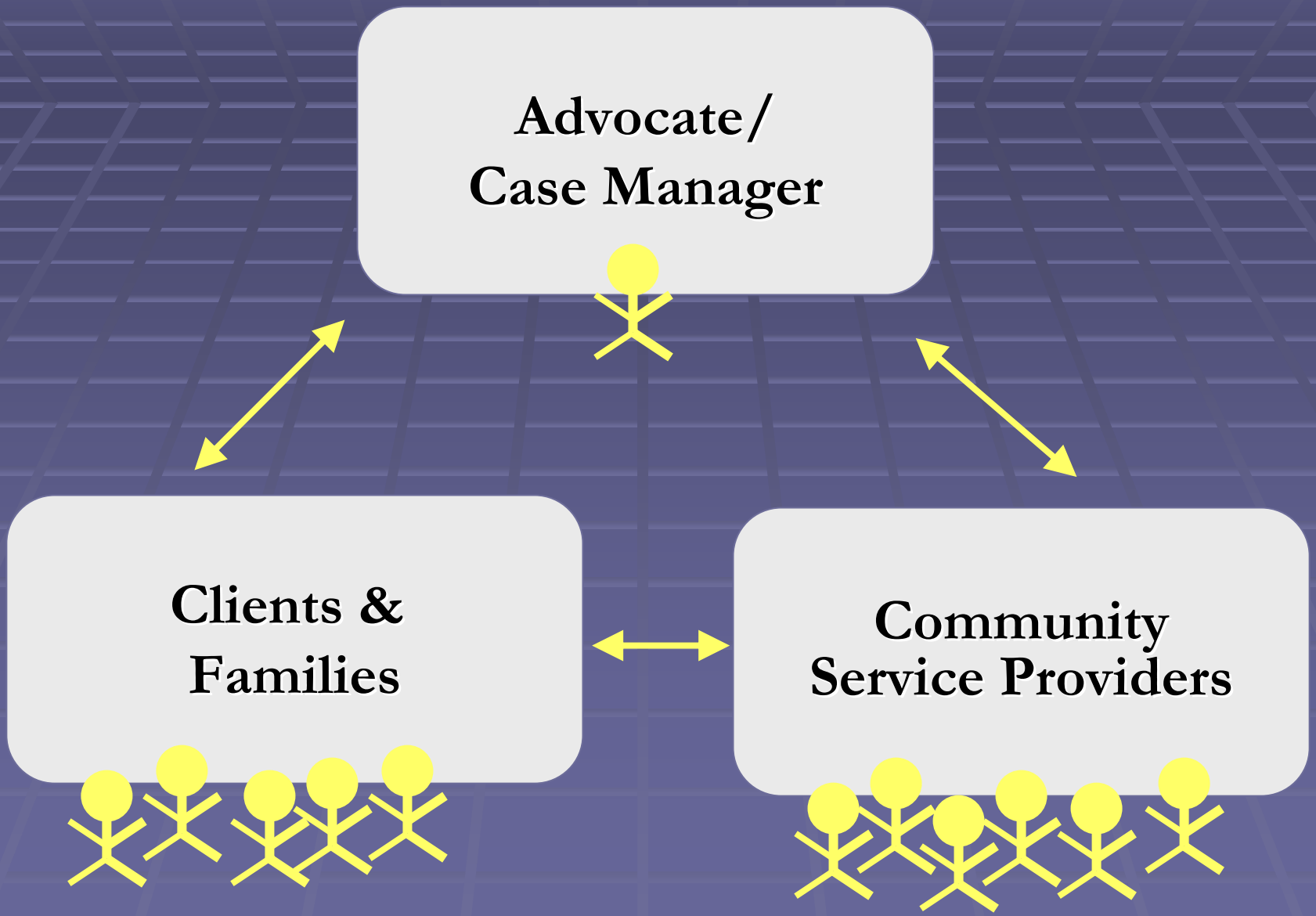
Two UW programs:

- Fetal Alcohol and Drug Unit
- Parent-Child Assistance Program

Hypothesis:

Our combined expertise on FASD and on interventions with high-risk women could be applied to the FASD population.

Parent-Child Assistance Program (PCAP)



The PCAP Case Manager

- 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
- Connects clients with services, monitors progress
- Assures that clients' children are in safe stable home environments
- Helps client families build and maintain healthy and independent lives

Pilot Study Methods

Participants were

- Recruited through community referral
- Enrolled in 3-year PCAP and assigned to a case manager who delivered home visitation and intervention services.
- Women who had FASD were invited to participate in the "nested" FASD 12-month pilot study (N=19).

Psychosocial Characteristics

- 11 had FASD diagnosis; 8 had suspected FASD
- Average age = 22 years (range 14-36)
- Mostly white (60%), unmarried (85%), poorly educated (mean = 9.9 yrs)
- 15 have children (mean = 2.3); about half of the children do not live with mother

Troubled childhood

- Family history drug/alcohol abuse (100%)
- Unstable and disrupted care giving (100%)
- Physical abuse (84%)
- Sexual abuse (79%)

Troubled adulthood

- Alcohol/illegal drug use (84%)
- History of incarceration (68%)
- Diagnosed psychiatric condition (59%)
  - Bipolar (42%)
  - Depression (25%)
- Chronic medical condition (47%)

Brief Symptom Inventory

BSI: 53-item checklist measure of psychiatric distress. Yields 9 primary symptom dimensions and a Global Severity Index (GSI).

The 9 symptom dimensions: Somatization, Obsessive-Compulsive, Interpersonal Sensitivity, Depression, Anxiety, Hostility, Phobic Anxiety, Paranoid Ideation, Psychoticism

Brief Symptom Inventory

Results:

- Over 1.5 sd above the mean on 6 of 9 primary symptom dimensions
  (higher scores are worse)

- Mean = 69.5 on the GSI
  [GSI $\geq$ 63 presumes a psychiatric diagnosis, indicates need for in-depth psychiatric assessment.]

Brief Symptom Inventory

We compared results with two BSI reference samples:

- a psychiatric inpatient sample
- a psychiatric outpatient sample

The FASD and psychiatric samples were similar: all BSI dimensions and the GSI were within one sd

Young Adult Self-Report

YASR: assesses social, emotional, and behavior problems. Yields 8 syndrome scales and a Total Problems Scale.

The 8 syndrome scales:

Anxious/Depressed, Withdrawn, Somatic Complaints, Thought Problems, Attention Problems, Intrusive, Aggressive Behavior, Delinquent Behavior

Young Adult Self-Report

Results:

- From 1 to 1.5 sd above the standardized mean on all 8 problem scales (higher scores are worse)
- Mean = 67 on Total Problems Scale. Score of 60 or more warrants further evaluation and discriminates between deviant and nondeviant groups.

Young Adult Self-Report

We compared results with two YASR reference samples:

- a normative female sample
- a sample of women incarcerated or in mental health or substance abuse services

The FASD sample had higher scores on all 8 individual problem scales and the Total Problems Scale

Quality of Life

WHO Quality of Life (QOL):

- A 26-item assessment of QOL facets across 4 domains (physical, psychological, social, environment) that are relevant in cultures worldwide
- QOL is broadly applicable across diseases and medical conditions

Quality of Life

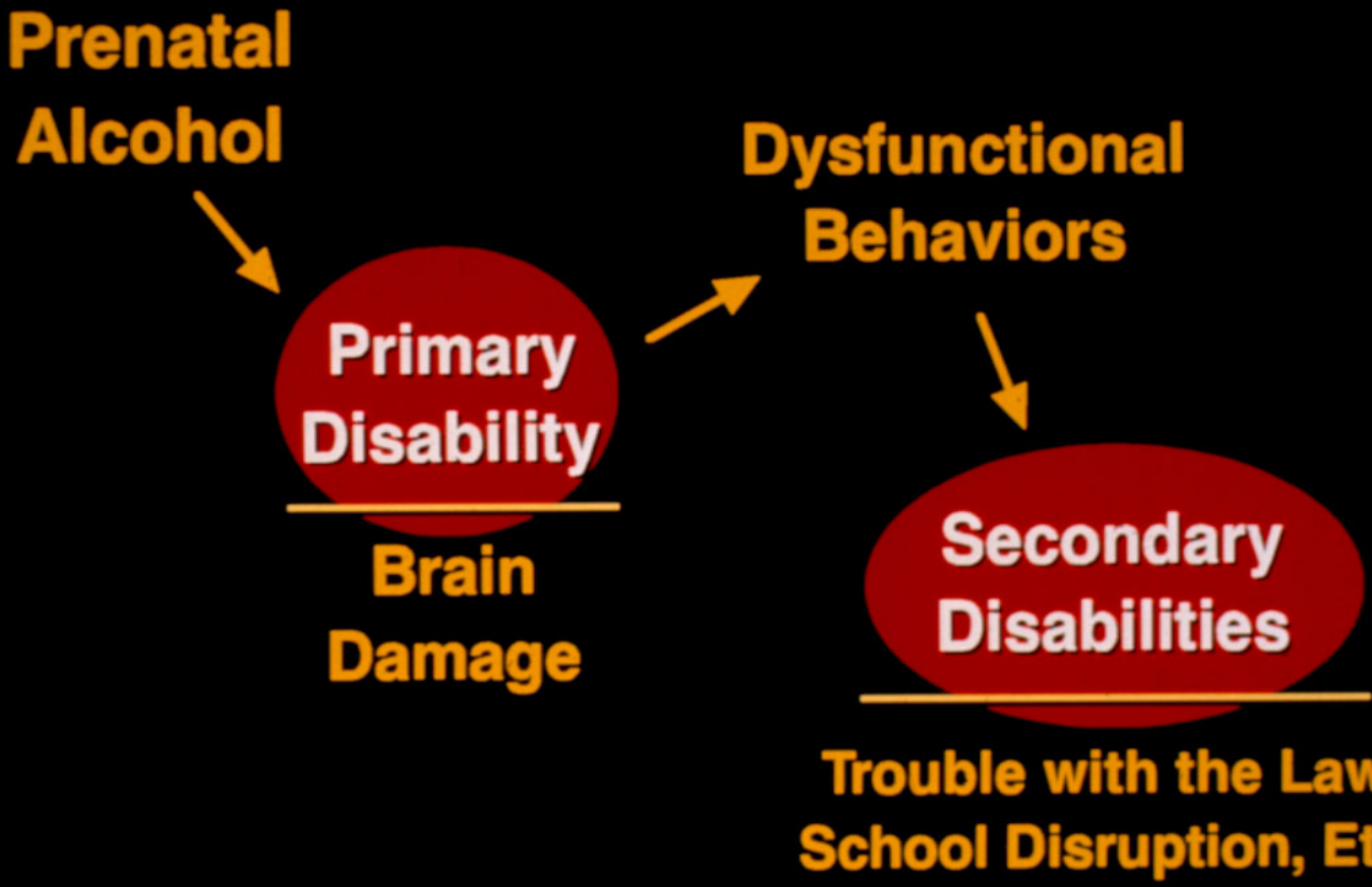
Results

QOL scores varied little across the 4 domains (49.8 on environment to 53.8 on psychological).

Quality of Life

We compared scores with 3 standardization samples (healthy; pregnant; chronically ill):

- FASD scores were lower on all 4 domains compared to healthy sample (lower scores are worse)
- FASD scores were lower than the 3 standard samples in Environment domain
- FASD scores were most similar to chronically ill sample


Prenatal
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PROTECTIVE FACTORS
Preventing Secondary Disabilities in FASD (N= 415)

Multivariate Analyses Showed
Two Strong Protective Factors:

- Living in a stable & nurturant home
- Receiving an early diagnosis

Streissguth et al., JDBP (2004) Volume 25, 228-238

Compared to women with a confirmed FASD diagnosis, those with unconfirmed FASD had more problems

Women with unconfirmed FASD

Were more likely to:

- Have a chronic medical condition (60% vs. 30%)
- Binge drink (40% vs. 0%)
- Use illegal drugs (100% vs. 60%)

They were also more likely to be non-white (60% vs. 20%)

Undiagnosed vs. Diagnosed

BSI: Undiagnosed women scored 1 sd higher than diagnosed on 7 of 9 dimensions and on Global Severity Index.

YASR: Undiagnosed had higher scores on 7 of 9 scales, particularly on the anxious/depressed, withdrawn, and total problem scales.

QOL: Undiagnosed women scored at least 20 points lower all 4 domains.

Treating, supporting, and meeting the complex needs of these women…

The Pilot Community Intervention

We knew the FASD clients needed improved quality of services & increased access and connection to those services.

We found that (even in Seattle) providers knew little about FASD and its implication for practice. They had little direct experience with this patient population.

Ongoing Challenge: Getting a Diagnosis

- 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

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?

Look at patterns that may indicate cognitive problems.

- Impulsive behavior
- Behaviors that seem 'stupid'
- 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

What if we can't get a diagnosis?

A neuropsychological assessment is like a roadmap that can help:

- to identify cognitive and functional deficits & strengths
- to obtain disability benefits

What if you can't get a diagnosis?

Do what you would do anyway!

- Teach 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.

Educating Providers:
An Approach Beyond the Classroom

We identified key providers who were interested in the problem of prenatal alcohol abuse and its effects, and who were willing to work with *one of our clients as a case study* in close collaboration with her PCAP case manager.

"She just doesn't get it!"

…experienced case manager referring to her client's lack of comprehension, poor memory, and difficulty executing a plan even with assistance.

CMs had to assume a far more directive role as they helped clients comply with appointments and recommendations. We reduced the CM caseload to 5.

We provided 3 things to providers

- FASD education
  (one-on-one & for the agency)
- A PCAP case manager
- Back-up consultation over the
  12-month pilot study

= FASD Demystified

- Community professionals and the PCAP case managers brought different but complementary skills to the intervention.
- CMs handled barriers to treatment (repeat scheduling, transportation, paperwork problems) that otherwise hinder successful service delivery.

FASD Demystified

Providers learned to deliver services appropriately tailored to specific needs of FASD patients. They were more competent and confident.

Strategies We Taught Providers to Use

- Revise your expectations
- It's usually "can't" vs. "won't"
- Set reasonable goals
- Remember this person's functional age
  - Communication & vocabulary
  - Abstract vs. concrete
  - Ability to function in daily life

"Think Younger"

Revise 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

Strategies We Taught Providers to Use

- Use short sentences, concrete examples, 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 We Taught Providers to Use

- 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
- Be consistent in appointment times, locations, and providers. If primary provider must change, an extended transition period is beneficial so current and new provider work together with the individual.

Pilot Study Outcomes (N=19)

- 19 were receiving medical &/or mental health care
- 14 were abstinent from both drugs and alcohol (11 maintained abstinence; 3 newly in recovery)
- 5 were still using drugs/alcohol, but 3 of these 5 were using reliable birth control methods (2 tubal ligations, 1 DepoProvera)
- 14 were using contraception regularly (7 Depo; 3 tubal; 2 IUD; 2 pills)
- 16 obtained stable housing

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.

Meeting the Challenges…

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?

Can Women with FASD Parent Effectively?

Will they be able to:

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

It depends!

Meeting the Challenge:

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

Meeting the Challenge:

The Good News
and
the Bad News

Alcohol Use Prior to and During Pregnancy in Western Washington, 1989-2004

We conducted three federally-funded studies on problems associated with prenatal substance abuse.

Study purposes varied, but all involved screening hospitalized postpartum women shortly after delivery for prenatal alcohol and drug use.

Description of the Studies

Study 1: Mar. 1989 – Apr. 1991 (*N= 7,178*)

Prospective study investigated neurodevelopmental outcomes of children exposed to cocaine in utero

(Obstetrics and Gynecology (1994), 83(4), 524-531)

Study 2: Jul. 1991 – Dec. 1992 (*N=2,330*)

Tested efficacy of a 3-year home visitation intervention

(Journal of Community Psychology (2003), 31(3), 211-222)

Study 3: Jun. 2002 – Mar. 2004 (*N=3,145*)

Evaluated efficacy of a 12-month intervention program using a randomized design FAS/ARBD Prevention: Research to Practice.

(APHA 133rd Annual Meeting. Dec. 2005. Philadelphia, PA.)

Results

	PRIOR TO PREGNANCY		DURING PREGNANCY	
	Any Alcohol	Binge Alcohol	Any Alcohol	Binge Alcohol
STUDY 1 1989-1991	45%	9%	30%	3%
STUDY 2 1991-1992	41%	10%	23%	4%
STUDY 3 2002-2004	43%	14%	12%	1%

Study Conclusions: The Good News

Drinking during pregnancy decreased significantly between 1989 and 2004

- **Public health messages about drinking during pregnancy have clearly had an impact.**
- **In general, when women know they are pregnant, they decrease their alcohol consumption.**

Study Conclusions: The Concern

Binge drinking "pre-pregnancy" (or prior to pregnancy recognition) increased significantly between 1989 and 2004

- Women who are heavy drinkers and not pregnant may have unexpected, unwanted, and unprotected sex resulting in unintended pregnancy. [More than half of all pregnancies in the U.S. are unintended.]
- Women who aren't planning a pregnancy or who don't know they've conceived, have no pregnancy-related reason to limit their alcohol intake. [Up to 60% of women don't know they're pregnant in early gestation.]

Prenatal Opiate Exposure

- Is not considered teratogenic; no known congenital malformation is associated.

However:

- May affect prenatal growth due to maternal malnutrition and co-morbid infections. LBW and intrauterine growth retardation increase risk of preterm birth.
- Newborns of addicted women can suffer withdrawal. If mother was IV drug user, children may be at increased risk for HIV, Hepatitis B & C.
- It's difficult to differentiate impact of prenatal heroin exposure and poor postnatal environment on child long-term outcome.

Prenatal Marijuana Exposure

- There is no consistent link between prenatal marijuana exposure and other adverse pregnancy outcomes or congenital malformation.
- Marijuana use during pregnancy may have a modest effect on prenatal growth, but results are inconsistent and diminish when potential cofounders are controlled.

Prenatal Marijuana Exposure

- The principle psychoactive substance in marijuana, △-9-tetrahyrocannabinol (THC), rapidly crosses the placenta and may remain in the body for 30 days, thus prolonging potential fetal exposure.
- Marijuana smoking produces higher levels of carbon monoxide than tobacco, which may be a potential mechanism of action of marijuana's impact on the developing fetus.

Prenatal Cocaine Exposure

- Cocaine and its metabolites readily cross the placenta, concentrating in amniotic fluid, and may produce direct neurotoxic effects, disturb dopamine, norepinephrine, and serotonin pathways, and cause vascular-mediated damage.

Prenatal Cocaine Exposure

- Associated with obstetric complications: stillbirth, placental abruption, premature rupture of membranes, fetal distress, and preterm delivery.
- Growth restriction, but may require higher levels of exposure and does not seem to persist after birth.
- The few available large, controlled, population-based studies have reached contradictory conclusions. CNS lesions (e.g., stroke, possible seizures), cardiac defects, and genitourinary anomalies have been reported.

Prenatal Methamphetamine Exposure

- Impact of meth use during human pregnancy is currently unknown.
- Animal studies have demonstrated neurotoxic effects of amphetamines and alteration of synaptic morphology in response to prenatal methamphetamine exposure.

Prenatal Methamphetamine Exposure

- Women using meth during pregnancy may have an increased rate of premature delivery and placental abruption.
- Linked to fetal growth restriction and, occasionally, withdrawal symptoms requiring pharmacologic intervention at birth.
- Clefting, cardiac anomalies, and fetal growth reduction have been described in infants and have been reproduced in animal studies.
- Later effects on child health are unknown.

Prenatal Tobacco Exposure

- Associated with poor fetal growth; the most important cause of LBW in developed countries.
- Linked to myriad perinatal complications and child health problems (along with environmental smoke exposure, or ESE). ESE is implicated in LBW, fetal death, and preterm delivery.
- Implicated in a range of adverse behavioral and cognitive outcomes.

Prenatal Tobacco Exposure

- Cigarette smoke contains tar, nicotine, and carbon monoxide.
- Tar contains substances (lead, cyanide, cadmium, and more) harmful to the fetus.
- Intrauterine hypoxia, mediated by carbon monoxide and reduced uterine blood flow, is a major mechanism of the growth impairment.
- Nicotine crosses the placenta and distributes freely to the CNS, having direct and indirect effects on neural development.