Annual Prevalence of FAS in Washington State Foster Care (1999-2009).

Reduction in FAS Prevalence correlated with Reduction in Maternal Drinking

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IHE Question

- Do we know the prevalence and incidence of FAS/D in different populations and can the reporting be improved?

Approaches used to estimate FAS/D Prevalence

Passive Case Ascertainment (Uses existing records, targets geographic regions)

- Examples: CDC Birth Defect Monitoring System; CDC FASSNet
  - Least expensive, targets general population, but prone to under-estimating prevalence due to incomplete records.

Active Case Ascertainment (Directly assesses people in defined populations)

- Community-Based Populations (schools, foster care, native communities)
- Clinic-Based Populations (prenatal clinics, hospitals)
  - More expensive, actively screens individuals to identify cases, can produce the most accurate estimates for the population targeted, as long as the participation rate is high.

Two reasons to estimate FAS/D prevalence

Point Prevalence (to estimate magnitude of problem)

- Estimate the prevalence in different populations once to document the magnitude of the problem.
- Target general and high-risk populations to document variation in risk.
- Estimate the prevalence of FAS and FASD
- Use these estimates to set public health policy (what level of diagnostic, intervention, and prevention services are needed).
- Screening/Surveillance methods must be accurate

Change in Prevalence over Time (to assess prevention efforts)

- Estimate the prevalence in populations annually to document change over time.
- For efficiency and accuracy, target just FAS in high-risk populations.
  - Prevalence must be sufficiently high to accurately detect change.
  - If prevention efforts are reducing FAS in high-risk populations, the prevention efforts will also be reducing FASD in the general population.
- Screening/Surveillance methods must be accurate and reproducible

FAS/D Prevalence Estimates are derived from Screening /Surveillance Activities

- Screening: Identifies individuals at risk for FAS/D for the purpose of providing diagnosis and intervention.

- Surveillance: Tracks the prevalence of FAS/D over time to document its magnitude and to assess prevention efforts.

The WA State Foster Care FAS Screening/Surveillance Program serves both functions.

When is Screening Justified?

When all of the following exist:

- The condition is sufficiently prevalent / 'severe'.
- Early identification improves prognosis.
- The population is willing to be screened.
- Accurate / efficient screening tools exist.
- Diagnostic capacity exists.
- Effective treatment / intervention exits.

Accurate estimates of prevalence and change in prevalence over time require the following:

A Screening Tool / Method that is:

- Simple / quick to administer .
- Inexpensive.
- Accurate (screen-positives have FAS/D; screen-negatives do not)
- Acceptable to the target population (high participation rate).
- Can be implemented reproducibly, year to year.

WA State Foster Care FAS Screening Program (1999-2009)

Methods

Active case-ascertainment targeting a high-risk population.

- Foster Care sends a list of all eligible children to the FASD Clinic weekly.
- Clinic photographer goes to foster home to take digital facial photo.
- Photo is analyzed by clinic using FAS Facial Analysis Software.
- Children with full FAS facial phenotype (PFL ≤2%, Rank 4 or 5 Lip and Philtrum) screen positive.
- Screen-positives receive FASD diagnostic evaluation and intervention plan from interdisciplinary team using 4-Digit Code.
- All FAS screen (+) and (-) outcomes are submitted to medical record.

Lip-Philtrum Guide I

WA State Foster Care FAS Screening Program
Results

Results

FAS Prevalence	1 per 100
Participation Rate	>95 %
Duration of Program	10 years
Sample Size	2000+

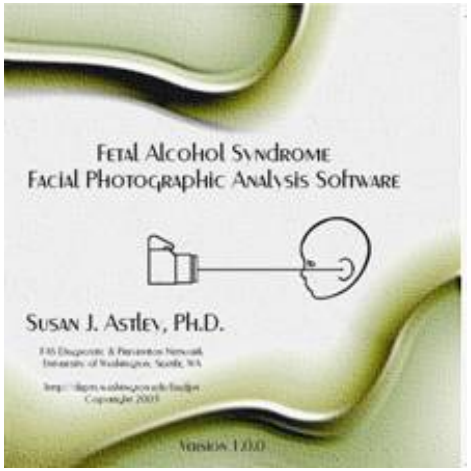

Photo Screening Tool Performance

Sensitivity	100 %
Specificity	99.8 %
Predictive Value Positive	86 %
Predictive Value Negative	100 %

For comparison: FAS prevalence in general population (IOM) 1-3 per 1,000

Foster Care Prevalence Estimates used to Assess FAS/D Prevention Efforts

FASD prevention efforts in WA, over the past 40 years, have spanned the full continuum of effort from public health education (warning labels on liquor bottles) to alcohol treatment and family planning programs designed to meet the specific needs of high-risk women.

To assess prevention efforts, one must be able to accurately and efficiently screen and diagnose high-risk populations and track the prevalence of maternal drinking and FAS in population-based samples.

In Washington State this has been accomplished through the establishment of:

- PRAMS (annual statewide CDC survey of maternal drinking during pregnancy (1993)
- WA State FAS Diagnostic & Prevention Network of Clinics (1993)
- FAS Facial Photographic Analysis Software (1995)
- FASD 4-Digit Diagnostic Code (1997)
- Foster Care FAS Screening Program (1999)

Since Washington State CDC PRAMS data documented a significant decline in maternal use of alcohol during pregnancy from 1993 to 1998,

one might expect to see a decrease in the prevalence of FAS among children born in those same years (1993–98).

Reduction in maternal drinking coincides with reduction in FAS prevalence

Washington State CDC PRAMS Data (1993-98)

Maternal report of drinking during pregnancy

Significant decline (15% to 4%) in proportion of women drinking during pregnancy from 1993 to 1998.

Prevalence of FAS in Foster Care

Among children born in 1993 – 1998.

Significant reduction in prevalence of FAS (7% to 2%) in each successive birth cohort from 1993 to 1998.

If FAS is declining in Foster Care
FASD must be declining in the General Population

One of the key goals of surveillance is to assess the effectiveness of primary prevention efforts.

- Tracking the prevalence of FAS over time in a high-risk foster care population offers a more accurate and efficient alternative to tracking the prevalence of FAS across a larger, more diffuse general population. If statewide prevention efforts and statewide reduction in maternal alcohol use are effectively reducing the prevalence of FAS in a foster care population, it would be difficult to argue that similar reductions are not also being realized across the entire general population.

- The same can be said for the impact of prevention efforts on the full spectrum of disorders caused by prenatal alcohol exposure. If maternal drinking during pregnancy is reduced, the full spectrum of disorders caused by that drinking will be reduced, not just the disorder called FAS.

Conclusion

The Washington State Foster Care FAS Screening Program is one example of a population-based, active case-ascertainment program that has generated accurate FAS prevalence rates annually for 10 years. The change in prevalence rates have been successfully used to assess WA State FASD prevention efforts.

The program is:

- Accurate
- Reproducible
- Quick to administer
- Utilizes existing programs/infrastructure (FASD Clinic and Foster Care)
- Cost Effective
- Accepted by the target population (>95% participation rate)
- Provides direct benefit to the identified cases of FAS

Key References

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