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**OFFICE OF SUBSTANCE ABUSE**

**Needs Assessment Report  
Deliverable 3  
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## **FASD Needs Assessment Report**

### **I. Introduction**

#### **A. Purpose**

The FASD Task Force conducted a Needs Assessment as a reference for developing strategies and activities, and an implementation plan that will likely result in improved prevention of alcohol affected pregnancies in Maine. Through the activities of the Needs Assessment, the Task Force worked to identify the needs and factors that influence our target populations. Factors under study included: alcohol consumption; behaviors and attitudes towards substance use; sexual activity; and birth control knowledge, and health access and practices. The Task Force also looked to assess the population's knowledge of the affects of alcohol during pregnancy on the developing fetus. Additional information was examined to identify activities in which women engage without using alcohol, thus providing options for the development of interventions to consider with the target population(s). Information gained from the Needs Assessment will be used to develop FASD strategic planning and implementation processes.

The Task Force researched FASD from two levels: the population level, and the systems level.

#### **B. Goal**

The goal of the initiative is to reduce the number of alcohol-affected pregnancies within the identified target population in Maine. The goal of the Needs Assessment is to provide the Task Force with information it can use to support its efforts at developing a prevention strategy and implementation plan.

Please note that a logic model will be developed by the conclusion of the planning initiative. Specific outcomes will be identified in this model.

#### **C. Project Population**

Two segments of the population of child-bearing age women were identified as being 'of interest' to the Task Force. These were: participants of the Women, Infant and Children's program (WIC), a federally funded special supplemental nutrition program designed to safeguard the health of women who have low incomes, infants, & children up to age 5 who are at nutritional risk. WIC provides nutritious foods to supplement diets, information on healthy eating, and referrals to health care. WIC clients were selected for study because Maine Pregnancy Risk Assessment Monitoring System (PRAMS) data on this population demonstrate that fifty-two percent (52%) reported drinking in the three months prior to pregnancy; sixty-seven percent (67%) reported their pregnancy was unintended; and fifty-eight percent (58%) were not using birth control at time of conception.

The second population identified as being ‘of interest’ to the Task Force was clients of The Women’s Project / PROP. The Women’s Project is a statewide program providing therapeutic case management services to women in need of substance abuse treatment, but who are experiencing barriers preventing them from either accessing or maintaining treatment, and/or recovery. The Project provides assistance in overcoming a multitude of personal, social, financial, and other related barriers preventing access to treatment. Clients have an average age of 35 years. Among this population, 38% report alcohol as their ‘primary drug of choice’. However, even among those selecting other substances as their primary drug of choice, the majority also admit to drinking alcohol. Sixteen percent (16%) entered The Women’s Project to get treatment, forty-six percent (46%) were currently in treatment but experiencing treatment access difficulties, and 38% were seeking help to maintain their recovery. Thirty-five percent (35%) of these women reported having minor (under age 18) children at time of entry to the Women’ Project.

#### **D. Additional Study Interests - Selected Service Delivery Systems**

In addition to the WIC and The Women’s Project, the Task Force identified the following systems as likely to interface with the target populations: Public Health Nursing; Planned Parenthood; Divisions of the Department of Health and Human Services, including Maternal and Child Health (MCH) Nutrition, Genetics, Healthy Families, and Children with Special Health Needs; Parents As Teachers Programs; four medical facilities in the state which operate pre natal clinics; and, the Maine Department of Education.

##### Public Health Nursing

Public Health Nursing is a public home visitation health program working in partnership with individuals, families, and communities to improve the health of the population. These programs generally work to meet the preventive health needs of low-income, uninsured families and individuals, and promote positive health behaviors. Families exhibiting a health risk, which can include substance abuse, among other risk factors, will generally receive a hospital referral to Public Health Nursing.

##### Planned Parenthood

Planned Parenthood works to meet the preventive health needs of low-income, uninsured families and individuals, and promote positive health behavior. The core of the Planned Parenthood medical services are contraception and accompanying health care and counseling. The program also provides educational programs, information to help people make responsible choices, and advocacy at federal and state levels through its Parenthood Action Network to advance comprehensive reproductive health care and responsible decision making.

##### Maine Department of Health and Human Services

Divisions of the Department of Health and Human Services, including MCH Nutrition, Genetics, Healthy Families, and Children with Special Health Needs, are state agency programs developed to serve populations presenting with specific health risks.

##### Parents as Teachers Programs

There are approximately twenty-two organizations in Maine that deliver Parents as Teachers (PAT) programming. PAT is an international early childhood parent education and family support program serving families throughout pregnancy until their child enters kindergarten, usually age 5. The program is designed to enhance child development and school achievement through parent education made accessible to all families. Participating families volunteer to the program, and represent a cross section of socio-economic levels.

### Medical Facilities

The four medical facilities of Southern Maine Medical Center, Maine Medical Center, Central Maine Medical Center, and Eastern Maine Medical Center were identified as offering pre natal clinical services. Among their other medical specialties, these facilities offer obstetrician-gynecologists, certified nurse-midwives and nurse practitioners and other professionals in the delivery of health services during pregnancy and after delivery. Services generally include: pregnancy tests, postpartum follow-up care, birth control counseling, annual physicals; pap tests / breast exams; options counseling; lactation counseling; reproductive health services; social service support; and links to community services.

### Maine Department of Education.

The Maine Department of Education reported a total of 37,573 children enrolled in special education in 2004. The special education population constitutes 18% of the total student population, and has experienced a steady increase in numbers of designated students each year. Children identified with special educational needs associated with FASD are included in these counts, but not specifically identified with an FASD diagnosis.

## **II. Methods**

The Task Force collected data through both primary and secondary sources of both quantitative and qualitative data. Secondary data sources identified and reviewed included:

- Pregnancy Risk Assessment Monitoring system (PRAMS)
- Department of Health and Human Services, Bureau of Health data on Public Health Nursing, Healthy Families, and any other data that reflected alcohol use among women of child-bearing age
- Office of Substance Abuse contracted study of training needs for alcohol-affected WIC families (contractor – AdCare Educational Institute, Inc., Augusta, Maine)
- Key informant interviews of client needs of The Women’s Project, conducted by The Women’s Project staff.
- The State of Maine Substance Abuse Treatment Needs Assessment, Study 6, Integrated Population Estimates of Substance Abuse Treatment and Intervention Needs in the State of Maine, December, 1999.
- The 2004 Office of Substance Abuse Annual Report
- Maine’s Treatment Data System (TDS)
- Maine Behavior Risk Factor Surveillance System (BRFSS)
- The Driver Education and Evaluation Program (DEEP) data
- Birth Defects Program data
- Maine Department of Health and Human Services data sets

**[Note:** While planning their studies, AdCare and The Women's Project shared drafts of their interview protocols. This resulted in both organizations deciding to use a number of similar questions in their research, which provided results to compare and contrast between the two populations being studied].

Both The Women's Project and AdCare provided their findings and observations to the Task Force. Their observations included information on alcohol use and pregnancy. Task Force staff took the raw data from both studies and developed a statistical data set which was used to run analysis on the data.

Primary research conducted by the task Force included key informant interviews with representatives of the identified systems. This data was compiled and included in a Needs Assessment Observations and Findings report and presented to the Task Force for consideration.

### **Questions of Inquiry**

At the target population level, the Task Force identified the following questions for inquiry:

1. Key demographics for the study populations
2. Identification of knowledge, attitudes and behaviors of the populations around alcohol use
3. Identification of knowledge, attitudes and behaviors of the populations around birth control.
4. Identification of ways in which the populations interface with services and service delivery systems.
5. Identification of health influences on the populations in terms of behaviors and beliefs.

In combination, the AdCare and The Women's Project studies generated information around the following:

- Population demographics
- Birth control knowledge and practices
- General knowledge around harmful affects of alcohol
- Level of knowledge regarding the effect of alcohol on the developing fetus
- Identification of normative attitudes and behavior around alcohol and other drug use.
- Plans for future pregnancies
- Sources for health information
- Health provider behaviors around alcohol use and pregnancy
- Identification of alcohol prevention interventions to consider with women of child-bearing age
- Identification of non-alcohol-related social activities in which clients engage

(Note: A list of the information asked of TWP and WIC clients is provided in Appendix C.)

At a Systems level, the Task Force identified the following questions for inquiry:

1. Which systems would be likely partners in prevention strategy delivery?
2. How do these systems address alcohol use with their clients?
3. What is the systems awareness of FASD issues?
4. What existing assets can be identified for improving FASD prevention?
5. What opportunities exist to gain access to system clients with information and prevention messaging around FASD?
6. Identification of existing resources that may be available to this project

(Note: The systems interview protocol is provided in Appendix C)

The systems level interviews developed the following information for each organization completing an interview.

- Client population
- Client presenting issues
- Service area
- Client contact frequency and duration
- Services provided
- Substance use screening practice
- Referral practices for women identified as consumers of alcohol
- Organizational knowledge of FASD
- Education practices around alcohol use
- Existence of policies on FASD
- Client contact opportunities
- Other information

### **III. Results**

#### Results Summary

#### **At Risk Status**

##### WIC Clients

- 26% of WIC clients state-wide (1,137) reported via PRAMS an unintended pregnancy and drinking 3 months prior to pregnancy in comparison to 16% of all Maine women included in PRAMS study.
- Of the 101 WIC clients recently interviewed:
  - Over half (52%) reported drinking during the 3 months prior to pregnancy.
  - Two-thirds (67%) reported their pregnancy was unintended.
  - 36% reported not using birth control
  - 40% intend to have more children.

### The Women's Project Clients

- All are known substance users; in recovery; and subject to relapse

Of the 37 Women's Project clients interviewed

- 74% reported their pregnancy was unintended
- 58% reported not using birth control
- 23% intend to have more children

### Driver Education Evaluation Program (DEEP)

For women of child bearing age who entered treatment in 2004, the single highest referral source was the Maine OSA's Driver Education and Evaluation Program (DEEP). DEEP is a program located within the Office of Substance Abuse. The FASD Project Director, as part of his role as Associate Director of OSA, oversees this program and will facilitate their participation in the FASD initiative.

## **Knowledge, Beliefs and Attitudes**

### WIC Clients

Among WIC clients interviewed:

- Just 14% selected alcohol as the most harmful substance to a fetus when presented choices of Crack Cocaine, Pot, alcohol or Heroin.
- 94% agreed that using alcohol is a harmful habit
- 66% agreed that using alcohol in moderation is OK
- 78% said 1 to 2 drinks per occasion is social drinking; 12% said 3 to 4 drinks
- 52% say they feel the effects with 1 or 2 drinks
- 36% said they don't drink
- 95% know the placenta does not protect fetus from alcohol
- 92% said it's **not** OK to drink when planning to get pregnant
- 98% said no alcohol is safe when pregnant

### The Women's Project Clients

Within the sample of 37 Women's Project Clients interviewed:

- 54% selected alcohol instead of Crack, Pot or Heroin as the substances most harmful to a fetus
- 92% know the placenta does not protect fetus from alcohol
- 64% have used Planned Parenthood services
- 53% were unaware a can of beer, a glass of wine, and a shot of hard liquor all contain the same amount of alcohol



## **Population Use of the Service Delivery System**

### WIC Clients

Of those WIC clients interviewed, they appear to utilize existing health systems. In addition to their enrollment in a pro-active service delivery system that provides education and information on alcohol use and healthy pregnancy (WIC), they also:

- Receive health information from a health care provider (78%)
- Report seeing a health care provider with regularity (100%)
- Report using family planning services (49%)

### The Women's Project Clients

With The Women's Project clients, we found a majority appears to utilize existing health systems, but 19% report no regular medical care visits. In addition to their enrollment in a pro-active service delivery system that provides education and information on alcohol use and healthy pregnancy (TWP), they also:

- Receive health information from a health care provider (80%)
- Report seeing a health care provider with regularity (81%)
- Report using family planning services (64%)

## **Population Detail - WIC**

AdCare completed 101 interviews with WIC women from 14 of the 16 counties in Maine.

- Client age ranged from 18 to 44. Mean age was 26.
- Last school grade completed ranged from 8 to 18; mean grade was 12.  
(Note: any grade number over 12 (14 – 18) is considered to be a report of higher education – Associate, Bachelor, Masters, or Ph.D.)
- Employment status - 42% of respondents were employed; of this number 35% were employed full time.
- Marital status – 50% of WIC clients were married. Of the 50% unmarried, 80% reported living with their significant other. Those not living with a significant other reported being single.
- Children present – 93% reported children in the home. Mean children = 2
- Children's ages – ranged from 1 to 24. Mode age = 1 yr.
- Children's general health – just 3% of respondents reported health problems among children. Ages of children with health problems were identified as 2, 3, 5 and 19. FAS or

FASD were not identified by any respondent. Just 2% reported children experiencing problems in school; ages 7 and 10.

- Planned pregnancy – 44% reported previous pregnancy was unplanned.
- Pregnant – 20% reported being pregnant at the time of the interview. Of these 20, 100% reported it is not ok for a woman planning to get pregnant to drink alcohol. 100% of these pregnant women also reported that no level of alcohol was safe to drink when pregnant.
- More children – 40% reported planning to have more children; 15% reported they were unsure.
- Planned Parenthood – 49% reported going to Planned Parenthood, or some other family planning service
- Birth control – of the 80% who were not pregnant, 36% reported not using birth control at this time. Reasons for non use were: allergies, by choice, religious beliefs, not sexually active or they were trying to get pregnant. Of those who are trying to get pregnant (3), 2 agree its Ok to use alcohol to relax; all 3 agree that alcohol is a harmful habit; all 3 agree alcohol use in moderation is OK; all 3 report it takes 1 to 2 drinks per occasion for them to feel its effects.
- Alcohol effects on fetus – just 14% selected alcohol out of four substances presented (Crack Cocaine; Pot; Alcohol; Heroin) as the most harmful substance.
- Alcohol use – 15% agree alcohol is an acceptable way to relax; 94% agree alcohol is a harmful habit; and 66% agree using alcohol in moderation is OK.
- Alcohol acceptance – 78% consider 1 to 2 drinks per occasion to be acceptable social drinking; 12% agreed the number was 3 to 4 drinks; 2% agreed the number was 5 drinks. 8% agreed no drinks were acceptable.
- Effects of alcohol – 36% reported they do not drink; 50% reported they feel the effects of alcohol after 1 to 2 drinks; 9% said 3 drinks; and 4% said 4 to 6 drinks.
- Placenta – 95% agreed the placenta will not protect the fetus from alcohol drunk by the mother.
- Health information – 78% reported obtaining family health information from their health care provider. Other sources reported included: brochures, TV, family and friends, and internet.
- Alcohol content – 57% believe a can of beer, a glass of wine, and a shot of hard liquor all contain the same amounts of alcohol.

- Drinking prior to pregnancy – 92% say its not ok to drink if planning to get pregnant; when pregnant, 98% say no level of alcohol is safe; 2% say a few drinks on occasion is OK.
- Receipt of information – drinking during pregnancy – 63% reported receiving such information from their doctor. 44% also reported receiving such information from a nurse or other health care provider. 55% also reported obtaining such information from another source, identified as: at work, from books and brochures, from WIC, from family and friends, at the hospital, from the internet, from magazines, from TV, and at school.
- Regular medical professional visits – 64% report seeing a General Practitioner with regularity; 26% report seeing a Nurse Practitioner; 60% report seeing an OBGYN; and 12% report seeing a Midwife.
- Location of medical visits – 34% report seeing their provider at a clinic; 68% in a private practice; 3% in a hospital.

## **Population Detail - The Women's Project / PROP**

### Population Description

The fact that the majority of these women are of child-bearing age, in treatment for substance abuse, but at high risk for relapse, generally are not using birth control (58%), and have experienced a high percentage of unintended pregnancies (74%), places them at risk for FASD. Additional compounding factors for this population is their very low income levels, the fact they are often in troubled relationships, including socializing with adults who abuse substances, and generally live lives punctuated by chaos, as identified by the number of barriers they report at enrollment, usually reporting 5 or more serious barriers to treatment.

Since 2000, data collected from over 1,500 Women's Project clients demonstrates the five most consistently reported barriers to their treatment access are: Lack of money; not knowing how or where to get help; lack of transportation; having low self-esteem; fear of what others will think. When we segment this sample to view just women with children (60% of sample), all but one of these barriers continues to rank in the top five. For women with children, 'fear of what others might think' is replaced by 'fear of losing their children'.

According to the National Institute on Alcohol Abuse and Alcoholism (NIAAA), there is evidence that approximately 90 percent of persons affected by alcoholism are likely to experience at least one relapse over the 4-year period following treatment<sup>1</sup>. Despite some

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<sup>1</sup> National Institute on Alcohol Abuse and Alcoholism. Alcohol Alert. No. 6 PH 277 October 1989. Avail at: <http://www.niaaa.nih.gov/publications/aa06.htm>

promising leads, no controlled studies definitively have shown any single or combined intervention that prevents relapse in a fairly predictable manner. Several relapse prevention models incorporate the concept of self-efficacy, which states that an individual's expectations about his or her ability to cope in a situation will affect the outcome. In this model, relapse is influenced by the interaction of high-risk environmental situations, coping skills, levels of perceived personal control, and the anticipated positive effects of alcohol. Often-times these stressors are the result of barriers to treatment and recovery maintenance, and include situations like poverty, which may negatively impact one's ability to get to treatment programming, a lack of personal supports, poor interpersonal relationships, fear, and low self-esteem, among others.

The Women's Project exists for those women who experience these types of barriers to treatment and recovery. However, the Program sees only a small fraction of the women in need. The Women's Project provides services to 600 women per year. This represents around 2% of the number in need of, but who do not enter treatment.

Of the women who entered The Project since July of 2004, their mean age is 36 years with a mode of 28 years. Thirty-three percent (33%) list alcohol as their drug of choice. Fifty-eight percent (58%) report minor children in the household.

Recently, The Women's Project completed thirty six (36) interviews with current clients from around the State addressing maternal health during pregnancy. This sample was about 6% of the total client population currently in the program. Observations provided the following information:

- Client age ranged from 21 to 49. Mean age was 31.
- Last school grade completed ranged from 10 to 17; GED. Mean grade was 12 (Note: any grade number over 12 (14 – 18) is considered to be a report of higher education – Associate, Bachelor, Masters, or Ph.D.)
- Employment status – 92% are unemployed
- Marital status – 86% of TWP clients are unmarried; and only 15% are living with a significant other. Those not living with a significant other (81% of the sample) reported being single.
- Children present – 92% report children in the home. Number of children range from 1 to 4. the average number of children per home is 1; (mode = 1)
- Children's ages – ranged from 8 months to 22 years. Mode age = 2 yrs.

- Children's general health – 6% of respondents reported health problems among children. Ages of children with health problems were identified as 12, 11, and 5 months. FAS or FASD were not identified by any respondent. 6% reported children experiencing problems in school. Of these, 2 were reported with ADHD, 1 with behavioral problems, and one simply reported with 'problems'.
- Planned pregnancy – 74% reported previous pregnancy was unplanned.
- Pregnant – three are currently pregnant (8%)
- More children – 23% reported planning to have more children; 20% reported they were unsure.
- Planned Parenthood – 64% reported going to Planned Parenthood, or some other family planning service
- Birth control – of the 92% who were not pregnant, 58% reported not using birth control at this time. 33% of these women reported not being sexually active at this time, primarily due to a lack of a partner. Other reasons for not using birth control were: medical conditions, having prior sterilizations (hysterectomy or tubal ligation), or a partner with a vasectomy.
- Alcohol effects on fetus – 54% selected alcohol out of four substances presented (Crack Cocaine; Pot; Alcohol; Heroin) as the most harmful substance.
- Placenta – 92% agreed the placenta will not protect the fetus from alcohol consumed by the mother.
- Health information – 80% reported obtaining family health information from their health care provider. Other sources reported included: brochures, TV, family and friends.
- Alcohol content – 53% believe a can of beer, a glass of wine, and a shot of hard liquor all contain the same amounts of alcohol.
- Receipt of information – drinking during pregnancy – 78% reported receiving such information from their doctor. 71% also reported receiving such information from a nurse. 72% also reported receipt of such information from another source, identified as: a counselor, hospital, at Alcoholics Anonymous meetings, from parenting classes, Planned Parenthood, at rehabilitation centers, in school, at support groups, The Women's Project, other social service agencies, WIC and from television.
- Regular medical professional visits – 66% report seeing a General Practitioner with regularity; 30% report seeing a Nurse Practitioner; 23% report seeing an OBGYN. 19% report seeing no medical professional with regularity.

- Location of medical visits – 33% report seeing their provider at a clinic; 55% in a private practice; 3% reported being seen while in residential treatment / rehabilitation.

Since active clients of The Women’s Project are currently engaged in treatment and presumably abstinent, they were not queried about alcohol use. Experience indicates that even if they were not abstinent, they would most likely deny substance use.

The Women’s Project clients were also asked what the Task Force might consider doing to help women better understand the risks of drinking before and during pregnancy. A number of suggestions were provided. In compiling these recommendations, they appear to fall into the following three categories:

1. Education – including providing women with information; teaching the subject in school, as early as grade school; publicizing the effects of FASD
2. Peer education – having client peers deliver prevention messages, the information, and education on the subject in face-to-face meetings
3. Advertising / Public Service Announcements – make better use of the available media to get information out on the effects and ways to prevent FASD

The Women’s Project also asked their clients what they would suggest as prevention strategies among women who drink up to the point they know for certain they are pregnant. Again, compiling the answers resulted in the following general categories

1. Legislative efforts – initiation of alcohol controls to restrict access
2. Education – including providing women with information; teaching the subject in school, as early as grade school; publicizing the effects of FASD
3. Peer education – having client peers deliver prevention messages, the information, and education on the subject in face-to-face meetings.
4. Advertising / Public Service Announcements – make better use of the available media to get information out on the effects and ways to prevent FASD.

### **Other Populations Under Consideration**

For women of child bearing age who entered treatment in 2004, the single highest referral source was the Maine OSA’s Driver Education and Evaluation Program (DEEP). DEEP is mandated for persons with one or more alcohol-or other drug-related motor vehicle offenses. The program’s charge is twofold:

- 1) To increase every impaired driver’s knowledge regarding the risks of alcohol and drug abuse and to provide insight into his or her own level of risk

- 2) To assess the offender's level of harmful involvement with alcohol and/or other drugs to determine if the offense was an unusual circumstance or if it was the symptom of a larger substance abuse problem.

Participants in the DEEP Program are presented research-based information on alcohol and drugs, and participate in a variety of therapeutic-educational activities designed to facilitate change in risk perception, and to increase commitment to behavioral change. Participants assess their personal level of risk for alcoholism based on their current drinking behavior, determine their location in the progression towards alcoholism, and discover how their beliefs about alcohol can contribute to alcohol-related problems.

It is a 20 hour intensive education program. The total number of women who were referred to DEEP from July 2004 through April 2005 was 1,202. Of this number, 687 women participated in the educational program, 110 participated in the program for individuals under 21 years of age and 405 waived the educational component and went directly into treatment services. Of the 1,202 women referred to DEEP, 71% were of child bearing age.

DEEP constitutes another 'system' through which women at risk for FASD can be reached. Therefore, the Task Force has chosen to include DEEP in its consideration of prevention strategy opportunities.

## **Systems Research**

Systems interviews were conducted with key persons from each of the following, to identify referral sources and other services clients use that may be relevant or that may present opportunities for partnering / strengthening Task Force efforts at prevention strategy implementation.

- Public Health Nursing
- Planned Parenthood
- Maine Department of Health and Human Services
  - Maternal Child Health (MCH) Nutrition
  - Genetics
  - Healthy Families
  - Children with Special Health Needs
- Parents as Teachers Programs
- Four medical facilities with pre natal clinics
- Maine Department of Education.

## **Summary of Findings**

- With the exception of Planed Parenthood, the organizations see women after they confirm a pregnancy, or after the child is born.
- Current data collection at the state level for FASD, with the exception of DHHS – Coordinated Care Services, Children with Special Health Needs, does not exist. Coordinated Care Service arranges for payment of services, as provided by physicians, for children from income eligible families. The program reported it has 5 out of 1,000 children enrolled who have an FASD diagnosis. Enrollments are direct referrals from physicians, and therefore diagnoses are physician designated.
- The State provides no direct client service, but sub contracts to local agencies to deliver the programming of Public Health Nursing and Healthy Families. As a result, actual practice in the field with regard to screening for alcohol use and what steps to take when such use is suspected or identified may vary. In addition, messages about alcohol use prior to and during pregnancy may also vary.
- All organizations interviewed were aware of FASD, but no organization interviewed had a policy in place regarding FASD.
- Generally, among those organizations that screen for alcohol use, screening consists of asking the client (patient). In some cases, notably hospitals and public health nursing, if substance use is suspected or confirmed, a screening tool may be used, or as in the case of hospitals, a level two ultrasound is scheduled for the second trimester to screen for abnormalities.

- All organizations shared the opinion that women should not drink during pregnancy. Most organizations also take the position that no alcohol is acceptable when planning to become pregnant.
- The majority of organizations interviewed indicated a willingness to work with the Task Force to implement FASD prevention strategies within their programming; or to at least provide for distribution of materials to their clients (patients) on FASD.
- Although the Department of Education maintains detailed records on children with Special Education needs, they utilize Federal categories of Special Education need identification. Since the Federal government does not identify FASD as a diagnosis for Special Education, the Department will not be a source of data for incidence rates.
- Planned Parenthood delivers education in schools using a Family Life Education curriculum. Although not specific about alcohol use, other than to discuss it in the context of risky sexual behaviors, the organization indicated a willingness to consider additions to the curriculum around alcohol use and pregnancy.
- Healthy Families, a program for first-time parents, also uses a curriculum focused on normal development milestones. The curriculum was developed by the University of Maine Extension Service. This may also provide an opportunity to introduce information on FASD risk factors.
- Parents as Teachers provides for a state-wide home visiting program, delivered through 22 local agencies, and therefore presents the Task Force with potential opportunities for delivery of FASD prevention messaging.

Please see Appendix B for more detailed information on systems.

## **Environmental Factors**

Because Maine has some unique environmental factors that result in relationships to alcohol that affect its use and accessibility, the Task Force also spent time considering these issues in relation to its prevention strategy task.

- Alcohol enjoys an ‘institutionalized’ status in this state. Although 50% of all treatment episodes for women are alcohol related, and the next highest reported drug of choice is Heroin at just 10% of treatment admissions, opiate use has received more attention from a prevention strategy development standpoint.
- Unlike the balance of the country, where the division of costs associated with substance abuse is about equally divided between alcohol and other substances, in Maine, a disproportionate percentage of the costs associated with substance abuse are related to alcohol abuse.

- Maine has moved away from State control of liquor sales and distribution, and has privatized these activities. As a result, there has been an expansion of new liquor outlets in the state by about 7% in the one year since privatization, increasing access to alcohol.
- As the number of liquor outlets is increasing, the State is concurrently experiencing a decrease in liquor violation enforcement personnel. Bureau of Liquor Licensing has had to eliminate 14 enforcement officer positions due to budget cuts.
- The annual cost of substance abuse in Maine, including costs associated with treatment, morbidity, mortality, crime, medical care, and other related costs, was \$618 million. Of this number, 70% (\$432 million) was from alcohol abuse.
- In fiscal year 2000, approximately \$37.4 million was transferred to the state's General Fund from the sales of alcohol and related operations. In the same year, alcohol abuse cost an estimated \$431.9 million.
- At the present time, attention to perinatal alcohol consumption has not been elevated to a level of concern warranted by the data on alcohol consumption and birth control practices.
- No State agency has been directed to accumulate FASD diagnoses, and therefore the State does not have a way to identify the incident rate of these conditions.

## **Other Considerations**

### Leverage and Sustainability

Leverage - the ability of a project to attract new resources to it. Leveraged resources include any resource - financial, human or otherwise, provided by individuals and/or organizations that did not have an initial formal relationship with the project.

Research indicates success at leveraging can be accomplished by organizations (initiatives) that engage in the following activities:

- Develop community partnerships
- Access community support for volunteer (member) development / training
- Expand or develop their volunteer base
- Access additional funding
- Foster program expansion
- Access needed equipment and supplies
- Build community awareness

Sustainability - the willingness of the community to assume responsibility for the continuation of grant initiated activities. This includes a presumption that any or all of the activities initiated by the project will continue in the community after FASD grant funding ends. Research confirms

sustainability success can be accomplished by organizations (initiatives) that engage in the following activities:

- ❑ Develop Community Partnerships
- ❑ Obtain Support of Oversight Committees or Advisory Boards
- ❑ Expand their Volunteer Base
- ❑ Access Additional Funding
- ❑ Foster Continued Program Expansion
- ❑ Continue to Build Community Awareness
- ❑ Obtain support of local volunteer oversight committees and/or advisory boards
- ❑ Provide for one or more paid positions to conduct project administrative duties.

Note: Community, as used in this context could mean the State

Research suggests that when characteristics associated with successful leverage and sustainability are present, projects are more likely to experience success at both. Moreover, similarities, or overlaps in activities indicative of successful leverage and sustainability exist. Observed characteristics common to both leverage and sustainability success include:

- Developing community partnerships
- Expanding a volunteer base
- Accessing additional funding
- Fostering program expansion
- Building community awareness

In our planning journey, we have effectively begun to build community partnerships throughout the state with an interest in FASD prevention; our volunteer task force is indicative of the energy and enthusiasm that people feel for the issue as well as project. We have begun the process of grant research to assist the Task Force in meeting other statewide goals for FASD prevention and continuously seek out additional opportunities for program expansion. One of our goals is to demonstrate the cost-benefit to FASD prevention. With this information, Maine Care (Maine's Medicaid program) and Dirigo Health (Maine's new universal coverage health care program) may also become partners in this endeavor. We see both sustainability and leverage as achievable milestones for this project.

#### **IV. Implications and Recommendations for the Initiative**

##### **Refining the Target Audience**

Based on information accumulated during the Needs Assessment, we believe the primary target populations of The Women's Project clients, WIC clients, and DEEP participants are populations that should be addressed, and offer us an opportunity to develop and implement effective prevention strategies. Results indicate we identified appropriate populations, which we consider to be 'at highest risk for FASD affected births'. Additional individuals, not otherwise enrolled in any of these three programs may also be considered for inclusion on our strategic initiatives if they present with the characteristics of those 'at highest risk'. These characteristics will be further clarified in our Strategic Plan.

## Insights Relevant to Interventions

We have learned that among mothers included in the most recent publication of Maine PRAMS data, 62% report drinking during the three months prior to pregnancy; forty-three percent (43%) reported the pregnancy was unintended. Among women not intending to get pregnant, 55% report not using birth control at time of conception. Therefore, it appears we should be considering interventions designed to modify either drinking behaviors and/or birth control behaviors among these populations.

Since our project goal is to prevent future alcohol exposed pregnancies in Maine through the reduction of risk factors associated with FASD, reflection on our Needs Assessment findings and observations lead us to conclude that strategies will be required on two levels: individual intervention strategies and community strategies.

Recent research around FASD prevention strategies, published by the U.S. Department of Health and Human Services indicates studies have found a strong predictor of alcohol use during pregnancy is the level of alcohol use prior to pregnancy. Further, essential strategies for preventing alcohol-exposed pregnancies among high-risk women can include individual, group and community level interventions. Examples noted for individual level interventions are: (a) provision of one-on-one client services that offer counseling to reduce or abstain from alcohol intake; (b) provision of assistance to clients in assessing their own behavior and planning individual behavior change; (c) providing support to sustain client behavior change; and (d) facilitate linkages to community health services in support of behaviors and practices that prevent FASD.

### Individual-level Interventions – Implications

Acknowledging our experience with The Women's Project, as well as our interest in the evidence-based Parent-Child Assistance Program (P-CAP), we believe the development of a case management approach providing clients and their families with social supports, knowledge, education, and linkages to needed community services, will be an effective strategy to result in modifications to the FASD risk behaviors presented by our populations.

Our Needs Assessment research also demonstrates that although they appear to share a number of common characteristics beliefs and behaviors, these populations are in fact quite unique. Each group of clients, The Women's Project, WIC, and DEEP, all present with unique characteristics, histories, motivations and relationships with alcohol and other substances. Therefore, our strategic planning and intervention design will have to recognize these differences, while capitalizing on the identified similarities. Women's Project clients come to the program from lives characterized by chaos. For them, significant barriers exist to continued sobriety as well as to accessing and maintaining treatment. As noted above, successful interventions with these women must first address the chaos and the barriers, most frequently identified as: 1) lack of money; 2) not knowing how or where to get help; 3) lack of transportation; 4) having low self-esteem; and 5) fear of losing their children.

In addition, issues around isolation have to be addressed with this population, who as a result of a number of factors, including domestic violence victimization, rural residence, low socio-economic status, or social networks peopled with addicted spouses and friends, are often isolated, and hindered in accessing needed helping systems.

We will also need to address our finding that in terms of FASD risk factors, WIC clients have a higher than State average report of drinking prior to pregnancy, with 2/3rds reporting no intention to get pregnant. Yet, over 1/3 report not using birth control. Further, 40% of those interviewed reported a desire to have more children. For TWP clients, we know they are currently abstinent from alcohol and other substances, but project history and national data suggest a high percentage will relapse. Of this group, 74% reported their pregnancy was unintended, yet 58% reported not using birth control, while 23% intend to have more children. It remains unclear, subsequent to the needs assessment research, why so many women who did not intend to get pregnant did not use birth control (55% per PRAMS). Therefore, our prevention strategies will need to address this phenomenon in more detail.

Other relevant information on the target populations includes their lack of knowledge around alcohol. More than half of both Women's Project clients (54%) and WIC clients (57%) believe that a can of beer, a glass of wine, and a shot of hard liquor contain different amounts of alcohol. Implications of this information are that the target population may be distinguishing among alcoholic products, and using coffee brandy, wine coolers and beer, believing these are less harmful than 'hard liquor' products.

#### Community-level Intervention - Implications

Needs Assessment evidence also indicate the need for an accompanying community-level intervention strategy. It appears that community-level interventions directed at: (a) changing community norms; (b) increasing community support of the behaviors known to reduce the risk of FASD, c). and developing ways to effectively engage the identified systems to our Strategic Planning process will also improve our ability to meet our FASD prevention goal. Changes in community attitudes, norms, and practices can be targeted through health communication, community mobilization and organization, and community-wide events.

Because a majority of women interviewed during our Needs Assessment process confirmed their primary source of health related information is their health care provider, and because the majority also report seeing a medical professional on a regular basis, we clearly see the need to partner with health care providers in delivering FASD prevention strategies. However, we must also consider that among TWP clients interviewed, 19% reported having no regular health care activity.

In addition, our systems interviews identified a number of opportunities to engage additional organizations, including Planned Parenthood, Public Health Nursing, State agencies, and pre natal clinics to our implementation strategies. Agencies and programs included in the systems research generally indicated a willingness to work with the Task Force to strengthen FASD prevention messaging among their client populations. This attitude provides the Task Force with an opportunity to engage new partners to their mission.

Among the populations investigated, TWP and WIC program enrollment provide clear opportunities to influence participants. Further, WIC, The Women's Project, and DEEP all have impact measures in place to demonstrate change in knowledge, and in some cases behaviors among participating individuals. However, these measures of change do not currently reflect all FASD risk factors, and therefore will need to be addressed.

Other 'community-level factors identified during our needs Assessment include:

- The lack of a comprehensive view of FASD in Maine points up the need to increase public awareness of the issue.
- The lack of data on alcohol use / abuse 'flags', as collected by state sponsored home visitation programs, and submitted to the State DHHS data base, indicates an immediate need to make the necessary modifications to the data management system to provide this information to the Task Force.

An important consideration for data collection is the methodology. For self reported information that cannot assure anonymity, fear and guilt may suppress much of the truth of the data. The Task Force considered this factor when reviewing the available PRAMS data.

- The FASD Task Force should recognize the benefit of engaging in leverage and sustainability activities, and establish a plan of action that targets specific objectives for both activities; assigns responsibility; and tracks progress toward established goals.

One such activity that could reap substantial benefits, but at no cost to the State is: Local television network affiliate stations are required by law to devote a percentage of revenues and air time to public service issues. Local station practice has been to 'adopt' causes for fulfilling these legal obligations. Therefore, convincing an affiliate to adopt FASD prevention would potentially infuse thousands of dollars worth of free production costs and air time to be used for FASD prevention activities and messages.

- Since any FASD prevention effort will be hindered by the lack of incidence data, and since the State lacks an FASD diagnostics capability, it is imperative the Task Force work to find ways to begin to provide methods for collecting incidence information. They might either invest resources to educate health care providers on the process of FASD diagnosis, or invest resources to provide for such diagnostic capacity.
- All forms designed to provide information to the State as provided by medical professionals, where diagnoses are requested, should be modified to include FASD.
- Lack of use of birth control among women not intending to get pregnant indicates a need for determining reasons for these phenomena, and developing ways to modify this behavior.
- The 'institutionalized' status of alcohol in Maine is having serious consequences throughout the state's population, as evidenced by the 449 million dollars in associated alcohol abuse

costs. This suggests efforts to curb alcohol use may not only reduce FASD risks, but reduce overall health expenses related to alcohol abuse.

- Increasing access to alcohol, while at the same time reducing active enforcement of liquor law violations appears counter productive. Task Force recommendations might include ways to restrict access to alcohol, or to make the product less attractive to buyers.
- Enrollment in WIC, The Women's Project, and DEEP appears to provide for effective methods for influencing participant knowledge and behaviors. FASD is specifically addressed by The Women's Project. WIC and DEEP programming might be modified to include information and recommendations to prevent FASD.
- Since peer-to-peer exchange (from family and/or friends) of information around health issues was a frequent response women gave as a way they obtain health information, and because The Women's Project women recommended it as an effective prevention strategy, PCAP programming might be developed to determine its impact on FASD prevention.
- Segmentation of the population by geographic designation may be important to our study. The area we call 'northern' Maine is different from 'southern' Maine in many ways. Population density, income levels, occupations, availability of transportation systems and infrastructure, poverty levels, cultures and norms, and of particular note – availability of medical and social services demonstrate considerable variation between the two regions of the State. Consideration of these differences is important because prevention strategies and activities may have to be designed specifically for each region, rather than for state-wide utilization.

## Appendix A

### Magnitude of the Problem of Alcohol Use Among Women of Childbearing Age and Pregnant Women

#### Female Use of Alcohol

Census figures indicate there are 267,121 women of childbearing age in Maine. Using national statistics on drug and alcohol use, obtained from the SAMHSA 2002 National Survey on Drug Use and Health, it is estimated that approximately 23% (61,437) engage in binge drinking. The Maine Office of Substance Abuse (OSA) estimates, based on its most recent treatment needs studies (2003), that there are approximately 24,000 Maine women in need of treatment, and just 54% indicating a motivation to seek treatment. According to the Maine Office of Substance Abuse, *while 52% of the State's population is female, women account for just 26.6% of the treatment admissions.*

Despite the number estimated to be in need of treatment, according to the Maine OSA's latest Treatment Data Systems reports (TDS), about 5,000 women entered treatment in FY 2004 (July 03 – June 04); addressing only about 21% of the identified need. Of those 5,000 women who entered treatment in 2004, 9% relapsed within the same year. Among the women of childbearing age, 4,200 entered treatment, and they demonstrated a 9.1% relapse rate. Fifty percent (50%) of this population reported a minor child in the home at time of treatment entry. Among this group, those with minor children present, we saw a 4% rate of relapse in FY 2004. For women of child bearing age who entered treatment in 2004, the single highest referral source was Maine's Driver Education and Evaluation Program (DEEP). DEEP is mandated for persons with one or more alcohol-or other drug-related motor vehicle offenses. Women entering treatment were referred by DEEP in 33% of cases. The next highest referral source was "self" at 25%. Eight percent (8%) were referred by a substance abuse agency and six percent (6%) as a condition of probation and/or parole.

#### Pregnant Women / Children At-Risk

Of the 5,000 women who entered treatment in 2004, roughly 5% entered pregnant. The Pregnancy Risk Assessment Monitoring System (PRAMS)<sup>3</sup> does track women who report drinking three months prior to becoming pregnant; and during the last three months of their pregnancy. The most recent count of Maine live births totals 13,546. Out of this population of women, 58% reported drinking within the three months prior to their pregnancy. Almost five percent (4.9%) reported drinking during the last three months of their pregnancy. The highest percentage reporting this behavior was among women ages 35 and older. Using PRAMS drinking during pregnancy data (4.9%), we can calculate the number of children at risk for FASD at about 663, or one in roughly twenty births. However, recognizing the limitations of the PRAMS data, if we apply national statistics to the Maine population, where it's reported that 1 in 10 births are alcohol affected,<sup>4</sup> perhaps the Maine number of at-risk children born in 2004 was closer to 1,350.

In December of 1999, OSA published the findings for our state-wide substance abuse needs assessment. This assessment was conducted with the assistance of the Research Triangle Institute. The study attempted to include hard-to-reach populations. Results of that study indicated that as many as 17.6% of Maine's pregnant women were using alcohol and/or drugs during pregnancy. If this number is more representative of the level of use among pregnant women, then the number of alcohol-affected at-risk children might be as high as 2,300.

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**Note** – PRAMS data indicate the number of women who reported an unintended pregnancy, and who drank 3 months prior to pregnancy at 2,535. Source – 2003 data, cross tabulation conducted at the request of the FASD Task Force, May 2005.

## Appendix B

### Systems Interview Details

Organization	<b>Planned Parenthood</b>
Contact Person	Christopher Clint, Director of Public Affairs
Client population	Women, ages 18 to 40
Presenting Issue(s)	reproductive health care and sexual health information
Service Area	Greater Portland, Topsham, Sanford & Biddeford
Client contact type	One to One
Services	reproductive health care and sexual health information. Annual exams Cervical and breast cancer screening; Birth control information and supplies; Emergency Contraception; Testing and treatment for sexually; transmitted infections; Abortion services; Pregnancy testing, options education, and referrals Immunizations for vaccine-preventable diseases; Services for men, including testicular cancer screening and testing and treatment for sexually transmitted infections; HIV/AIDS education and testing School, sports, and employment physicals
Time with client	Average is 40 minutes
Primary Population	Women, generally single, average age = 25
Screen for alcohol	Ask about use at intake
Knowledge of Women's Project	No
Knowledge of FASD	YES
When abuse suspected	Discussion and referral, if warranted
Provide Education	Deliver curriculum to Middle school & high school students - Family Life Education - but this does not address alcohol health implications beyond discussions of peer pressure
Policy on FASD	No
Client contact / Education opportunities	At service delivery points
Notes	Generally available to make presentations to groups. Deliver curriculum to Middle school & high school students - Family Life Education - but this does not address alcohol health implications beyond discussions of peer pressure

## Systems Interview Details

Organization	<b>DHS - Div of Family Health - Women, Infant &amp; Children (WIC)</b>
Contact Person	Mary Owen, Assistant Director
Client population	women with children; av age = 25
Presenting Issue(s)	women, infants, & children up to age 5 who are at nutritional risk. Av age = 26
Service Area	State-wide - through 14 sub contractor agencies
Client contact type	One to One; Average is 5 to 15 minutes
Services	provide food; information / education; referrals to health care; information; counseling (nutrition counseling, not medical nutrition therapy); referrals; developmental assessments
Screen for alcohol	YES - not really screened, but clients are asked about substance use and history of use
Knowledge of Women's Project	No
When abuse suspected	Local agency discretion - usually provide information and offer referral
Knowledge of FASD	YES
Provide Education around alcohol and pregnancy	Yes
Policy on FASD	No
Client contact / Education opportunities	At face to face client meetings; during group education sessions;
Notes	<p>WIC has 2 populations of women of child-bearing age: 1. Active participants – women who are either pregnant, breast-feeding, or post partum (and not breast feeding / for up to 6 months )</p> <p>2. Authorized Representatives – moms of eligible children, who are not in Active category Services provided to the 2 groups are sometimes different.</p> <p>Local agency differences            Local agencies might provide different levels of service in the following:            WIC has no set policy of when and how to refer a client to other needed services. For substance use, if and when uncovered, local agency decides how and where to refer. WIC does not have a standard 'message' around pregnancy and alcohol. Local programs decide what information to distribute, or what message to convey to client.</p>

## Systems Interview Details

Organization	<b>DHS - Div of Family Health - Public Health Nursing</b>
Contact Person	Jan Morisect, Program Director
Client population	Women and children identified with health needs. 60% of clients are pre natal to maternal & child health service needs
Presenting Issue(s)	low income, health issues in mother, health issues in child
Service Area	State-wide - through State Dept plus 6 sub contractor agencies
Client contact type	In person - home visits 45 minutes to 1 hr
Services	Information on pre natal care& newborn development and growth. Health counseling. Referrals to other providers like WIC, food stamps, based on identified needs.
Screen for alcohol	YES - ask about it, and use an assessment tool
Knowledge of Women's Project	Yes
When abuse suspected	Talk to client. If child is considered in danger, then mandated to report to Child Welfare. Variations in procedures may exist among sub contractors.
Knowledge of FASD	YES
Provide Education around alcohol and pregnancy	Yes
Policy on FASD	No
Client contact / Education opportunities	during home visitations
Notes	Receive referrals come from other programs and agencies, like: hospitals, WIC, and may be self-referred.

## Systems Interview Details

Organization	<b>DHS - Div of Family Health - MCH Nutrition</b>
Contact Person	Janet Leiter, Program Director
Client population	Non-insured children and adults diagnosed with PKU (Phenylketonuria); birth through adult
Presenting Issue(s)	PKU & lack of insurance
Service Area	Statewide - through 2 contract Registered Dieticians at Maine Med and Eastern Maine Med.
Client contact type	personal visits
Services	nutrition counseling and food
Screen for alcohol	Unsure is subs screen for alcohol
Knowledge of Women's Project	No
When abuse suspected	Not a focus of service
Knowledge of FASD	YES
Provide Education around alcohol and pregnancy	YES - pregnancy has health implications for PKU condition - information (counseling) focused on management of PKU during pregnancy
Policy on FASD	No
Client contact / Education opportunities	Statewide caseload averages 12 clients. Intervention opportunities vary by client contact frequency.
Notes	MCH Nutrition also collaborates with others to provide nutrition education - like Me Nutrition Network - which would be possible points of client contact for FASD message delivery. Janet also would like to initiate routine screening for alcohol use with clients - interested in information dieticians can use with clients.

## Systems Interview Details

Organization	<b>DHS - Div of Family Health - Genetics</b>
Contact Person	Elli Mulcahy, Program Director
Client population	women of reproductive age
Presenting Issue(s)	Pre conception, pre natal post natal risk for pregnancies potentially affected by genetic related birth defects
Service Area	Statewide through 2 sub contractors - Maine Med & Eastern Me Med
Client contact type	personal visits
Services	Genetic counseling, birth defect counseling, and screening for developmental delays in child
Screen for alcohol Knowledge of Women's Project	Screening for developmental delays (which could include FASD)
When abuse suspected	No
Knowledge of FASD	Not a focus of service
Provide Education around alcohol and pregnancy	YES
Policy on FASD	No
Client contact / Education opportunities	Pre conceptual, pre natal and post natal visits
Notes	FASD may be identified when developmental delays are identified

## Systems Interview Details

Organization	<b>DHS - Div of Family Health - Healthy Families</b>
Contact Person	Valerie Ricker (Director of Family Health and responsible for Healthy Families programming)
Client population	first time families (families volunteer for service) Families may be referred by other programs - Pub Health Nursing, pediatricians, OBGYN's
Presenting Issue(s)	first child, accompanied by personal or referral source concerns around parenting
Service Area	Statewide - through 14 sub contractor agencies
Client contact type	Home visitation - In person (some groups, like play groups & parent support groups, and parent education groups)
Services	Information, problem-solving help, options identification assistance, and positive parenting reinforcements; referrals as needed; developmental assessments; child safety assessments; and family strengths assessments (which may include use of substances including alcohol)
Screen for alcohol	No screening, but ask about substance use at intake and over time
Knowledge of Women's Project	somewhat - assumed local contractors had knowledge of
When abuse suspected	unsure of protocol in 14 sub contractors
Knowledge of FASD	YES
Provide Education around alcohol and pregnancy	YES (sub contractors are supposed to)
Policy on FASD	No
Client contact / Education opportunities	Home visits
Notes	Lack of standard procedures prescribed to sub contractors – much local discretion on how to deal with alcohol use.  All 14 sub contractors use curriculum developed by U of ME Extension Service "The Growing Years". Clients basically receive child development information via mail. Since HF visitors conduct developmental assessments on children, they may be a source of FASD information (check HF training for FASD identification)  Substance abuse training (screening) is left to local organizations – called wrap around training – although training is identified, delivery is local, and may vary.  FAS is part of the required wrap-around training.

## Systems Interview Details

Organization	<b>Maine Parent Federation - Parents as Teachers (ken/Som)</b>
Contact Person	Ellen McGuire, PAT Director
Client population	Expectant parents, parents of children 0 to 5 (Ken/Som Counties)
Presenting Issue(s)	Referred by others as maybe in need of parenting knowledge assistance
Service Area	Ken / Somerset counties  (other contractors - UM-Cooperative Extension / Advocates for Children covers Androscoggin County; The Parent Place - Parents as Teachers – Auburn; Penguins Community Action Program - Bangor; Family Focus – Bath; Healthy Kids! – Damariscotta; Downeast Health Services, Inc – Ellsworth; Franklin County Children's Task Force- Farmington; Aroostook Council to Prevent Child Abuse – Houlton; Rural Community Action Ministry – Leeds; Young Women's Christian Association of Central Maine – Lewiston; Androscoggin Head Start and Child Care – Lewiston; Lewiston School Department – Lewiston; Down East Community Hospital - Machias; Mid-Coast Children's Services – Rockland; Goodal Hospital/SMMC – Sanford; Community Concepts, Inc – S. Paris; HealthReach Community Health Center – Strong; University of Maine Cooperative Extension – Waldo; Kennebec Valley Community Action Program – Waterville; Wells-Ogunquit Adult Community Education – Wells; Youth Alternatives, Inc. – Westbrook.
Client contact type	Home visitation - In person (some groups, like play groups & parent support groups, and parent education groups)
Services	education, support and encouragement
Screen for alcohol	Ask about it on intake history, but no screening
Knowledge of Women's Project	YES
When abuse suspected	discuss with client, ask permission to refer to services, provide information to client
Knowledge of FASD	YES
Provide Education around alcohol and pregnancy	YES, provide consistent messaging - don't drink if pregnant or planning to get pregnant
Policy on FASD	NO, but message is part of education provided to client
Client contact / Education opportunities	home visits, groups
Notes	

## Systems Interview Details

Organization	<b>Eastern Maine Medical</b>
Contact Person	Abby - Women's Health Center nurse
Client population	women - pregnant and/or trying to get pregnant
Presenting Issue(s)	Pregnancy, or attempting to get pregnant
Service Area	Bangor area
Client contact type	patient visits clinic
Services	pre natal care
Screen for alcohol	YES; if substance use is identified, then level II ultrasound in 2nd trimester to check for abnormalities
Knowledge of Women's Project	
When abuse suspected	Discussion and referral if warranted
Knowledge of FASD	YES
Provide Education around alcohol and pregnancy	YES, provide consistent messaging - don't drink if pregnant or planning to get pregnant
Policy on FASD	NO - but consistent message is: no alcohol during pregnancy
Client contact / Education opportunities	During Health Center visits
Notes	

## Systems Interview Details

Organization	<b>Coordinated Care Services - Children with Special Health Needs</b>
Contact Person	Ms. Toni Wall
Client population	Any personal or familial qualifying condition
Presenting Issue(s)	Any of a number of special health needs
Service Area	Statewide
Client contact type	None – patients seeing health care professionals, not State agency
Services	financial assistance for health services
Screen for alcohol Knowledge of Women's Project When abuse suspected Knowledge of FASD Provide Education around alcohol and pregnancy Policy on FASD Client contact / Education opportunities Notes	This office has no direct contact with clients - they receive a medical report from the physician, then arrange for payment for needed services for income eligible population. They also assist in suggesting other services; and with accessing assistance from school systems. At present, only 5 children out of about 1,000 enrolled diagnosed with FASD

## State Department of Education – Special Education

FASD is not a Special Education category. Therefore children do not get identified with FASD in relation to developing a learning plan to meet their special needs. Instead, school officials identify the presenting 'adverse effects' on learning (like hearing impairments, behavior issues, physical disabilities, etc.

There has been a steady increase in Sp. Ed student count (37,573 in 2004). Sp Ed population is now 18% of total school population. Notable increases have been seen in ADHD and Autism diagnoses.

Year	Sp Ed enrollment	Regular enrollment	% SP Ed to regular
2000	35,633	212,957	16.71
2001	36,580	210,946	17.34
2002	37,139	209,745	17.70
2003	37,784	207,517	18.20
2004	37,573	204,699	18.10

Even though a child may present with an FASD diagnosis, the Education system can only use the Special Education categories established in Federal Regulations. These are:

- |  |   |
|--|---|
| <ul style="list-style-type: none"> <li>Mental Retardation</li> <li>Hearing Impairment</li> <li>Deafness</li> <li>Speech &amp; Language Impairment</li> <li>Visual Impairment including Blindness</li> <li>Emotional Disability</li> <li>Orthopedic Impairment</li> </ul> | <ul style="list-style-type: none"> <li>Other Health Impairment</li> <li>Specific Learning Disability</li> <li>Deaf Including Blindness</li> <li>Multiple Disabilities</li> <li>Developmentally Delayed</li> <li>Autism</li> <li>Traumatic Brain Injury</li> </ul> |
|--|---|

Therefore, FASD children will appear in the system under one of the above named categories. Education officials may or may not know that FASD is a compounding factor.

Eight categories showed increases and one remained the same. Other Health Impaired category continues significant growth. We believe this is due to the increases in the number of students in this category classified as Attention Deficit Disorder or Attention Deficit Hyperactivity Disorder. This is the largest increase in any disability category.

Autism showed second largest increase after other health impaired, an increase of 237 students. Multiple Disabilities showed almost no increase this year compared to a 108 student increase in 2002-2003.<sup>2</sup>

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<sup>2</sup> Special Education Child Count, Part B, IDEA, 2001-2004 Comparison by Exceptionality. ME Dept of Ed web site.

## Appendix C - Interview Questions

### WIC Interviews

AdCare Interview Questions (partial listing – includes only that information provided to Task Force)

#### Demographics

- Client age
- Last school grade you completed
- Current employment status
- If employed - full time or part time
- Marital status
- Children present in home
- Number, ages, general health status, performance in school
- Previous pregnancies planned?
- Pregnancy status
  - If pregnant, receipt of prenatal care
  - If receiving prenatal care, month of initiation of care

#### Behaviors

- Plans regarding additional children
- Utilization of Planned Parenthood
- Birth control behavior
- Barriers to use of birth control
- Number of alcoholic drinks to feel the effects
- Source for most information on health issues for family
- Source of information about drinking during pregnancy
- Regular medical care visit behavior
- Location of regular medical care visits

#### Knowledge

- Of harmful affects of substances on fetus- Crack cocaine / Pot / Alcohol / Heroin
- Placenta ability to protect fetus from alcohol mother drinks
- Alcohol content knowledge – comparison of a can of beer / glass of wine / shot of hard liquor
- Woman planning pregnancy - OK to drink alcohol
- Safe level of drinking alcohol when pregnant

#### Beliefs

- Alcohol beliefs - acceptable way to relax; a harmful habit; use in moderation is OK
- Drinks per occasion considered acceptable social drinking

#### Other

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Identify talents  
Identify social behaviors

## The Women's Project Interview Questions

### Demographics

- Client age
- Last school grade you completed
- Current employment status
- If employed - full time or part time
- Marital status
- Children present in home
- Number, ages, general health status, performance in school
- Previous pregnancies planned?
- Pregnancy status
  - If pregnant, receipt of prenatal care
  - If receiving prenatal care, month of initiation of care

### Behaviors

- Plans regarding additional children
- Utilization of Planned Parenthood
- Birth control behavior
- Barriers to use of birth control
- Number of alcoholic drinks to feel the effects
- Source for most information on health issues for family
- Source of information about drinking during pregnancy
- Regular medical care visit behavior
- Location of regular medical care visits

### Knowledge

- Of harmful affects of substances on fetus- Crack cocaine / Pot / Alcohol / Heroin
- Placenta ability to protect fetus from alcohol mother drinks
- Alcohol content knowledge – comparison of a can of beer / glass of wine / shot of hard liquor

### Beliefs

Since these women are in recovery, no alcohol belief questions or use questions were asked.

### Other

- Identify talents
- Identify social behaviors
- Suggestions to help women better understand the risks of drinking before and during their pregnancy
- Suggestions to eliminate fetal alcohol-affected births in Maine

## Systems Interview Questions

1. Please describe your primary client population?
2. For female members of that population, please tell us their presenting issue(s) (why they come to you)
  - a. Their average age
  - b. Marital status
  - c. Likelihood of children present
3. What is your service area?
4. How many times, and over what time frame, do you typically engage with the same client?
  - a. On average, how much time is spent with each client?
  - b. In general, how do you engage with your clients?
5. What type of service do you provide?
  - a. Provision of information
  - b. Counseling
  - c. Referrals
  - d. Other
6. With women clients, do you screen for alcohol and other substance use or abuse?
7. Are you aware of (knowledgeable of) The Women's Project and its mission?
  - a. If YES, have you ever referred a client to TWP?
8. Are you aware of any other program in Maine that work to help women access treatment services?
  - a. If Yes, who are they?
  - b. Have you ever referred clients to them?
  - c.
9. If you suspect abuse of alcohol or some other substance, by a female client, what do you do?
  - a. If no referral, why not?
  - b. If no referral, would you consider providing referrals?
  - c.
  - d. If NO, what prevents you from considering this?
10. Prior to this call, were you aware of FASD?
11. Does your program educate women about the potential negative affects of alcohol use on healthy pregnancies?
  - a. If **YES**, how do you educate them? What information source do you use?
  - b. If **NO**, would you consider doing so?

- c. If NO, what would be needed for your agency to begin to offer some type of educational program or service?
  - d. Who in your organization would need to make this a directive, how would this get done?
12. Does your agency (organization or program) have a position or policy statement on FASD / alcohol use and pregnancy regarding your clients?
- a. If yes, what is it?
13. Is there anyone else in your organization you feel I should talk to?