

*Behavioral
Health
Research &
Services*

FAS Evaluation

*Summary Report of the Alaska Multidisciplinary
FASD Diagnostic Team Data*



(FAS-Related Technical Report No. 32)

***Summary Report of the Alaska Multidisciplinary
FASD Diagnostic Team Data***

Submitted by:

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Summary Report of the Alaska Multidisciplinary FASD Diagnostic Team Data

*Prepared by BHRS Staff
June 10, 2005*

Executive Summary

This report presents a thorough analysis of the diagnostic data reported provided to the State Office of Fetal Alcohol Syndrome by all *Alaska Multidisciplinary FASD Diagnostic Teams* currently conducting FASD diagnosis in Alaska. Included is a summary of all teams' data from the time they began to conduct diagnosis through March 2005. The primary purpose of this report is to provide feedback to teams regarding productivity and outcomes, with emphasis placed on providing information that will be useful to individual teams, the State Office of FAS, and, ultimately, the citizens of Alaska.

As of the writing of this report, 14 diagnostic teams are conducting FASD diagnoses in the state of Alaska, and three teams have been disbanded, for a total of 17 diagnostic teams that function or functioned in Alaska since 1999. Using the *DHSS Office of FAS Diagnostic Team Data Collection Reports*, 14 of these 17 diagnostic teams have submitted 757 completed datasheets to date, including the current period. Of these 757 datasheets, one did not include a 4-digit diagnosis and one did not provide a complete 4-digit diagnosis, for a total of 756 usable datasheets (including 755 datasheets with complete diagnoses). All duplicate datasheets received have been eliminated from the database. Of the 755 individuals for whom complete diagnoses were submitted, 76 (10.0%) were diagnosed with FAS or atypical FAS; 378 (49.9%) were diagnosed with Static Encephalopathy; 251 (32.2%) were diagnosed with Neurobehavioral Disorder; and 50 (6.6%) were found to have no evidence of organic brain damage.

During the last 12 months (April 2004 to March 2005), 131 datasheets were submitted. There were 11 teams that submitted datasheets this period and their corresponding number of assessments were as follows: Alaska Psychiatric Institute (2), Bethel (10), Bristol Bay (4), Fairbanks (14), Juneau (13), Kenai/Soldotna (27), Ketchikan (11), Mat-Su Borough (3), Sitka (11), Southcentral Foundation (34), and Tok (2). Of these 131 individuals, 15 (11.5%) were diagnosed with FAS or atypical FAS; 56 (42.7%) were diagnosed with static encephalopathy; 49 (37.4%) were diagnosed with neurobehavioral disorder; and 11 (8.4%) were found to have no evidence of organic brain damage.

Background Information

The State of Alaska Department of Health and Social Services (1990) has reported that 12% of all Alaskan adults have current alcohol-related mental health or other problems and that per capita consumption of alcohol was 3.21 gallons per person per year, the fourth highest rate in the nation. According to a report by the Municipal Health and Human Services Commission in Anchorage (1994), the acute drinking rate (percent of people having five or more drinks at least once per month) in Alaska was 23.9% in 1992, as compared to a national rate of 14.3%. The chronic drinking rate (60 or more alcoholic drinks per month) was 5.25% as compared to the national rate of 2.91%. Approximately one-quarter of all alcohol and drug dependent individuals in Alaska are women, a proportion that is rising steadily (Alaska State Office of Alcohol and Drug Abuse and Addiction, 1989; Brems, 1996; Hisnanick, 1992). Data reported by the Alaska Regional Hospital indicated that 16% of all women admitted for childbirth had detectable alcohol or drug levels in their blood during labor and/or delivery (Phillips, 1995).

These high rates of alcohol use in the state of Alaska have resulted in some of the nation's highest Fetal Alcohol Spectrum Disorders (FASD) rates. The *2002 Fetal Alcohol Syndrome Prevalence in Alaska: New Findings from the FAS Surveillance Project* published by Department of Health and Social Services (DHSS, 2002) reported a statewide population FAS prevalence rate of 1.4 per 1,000 live births in Alaska, based on all recorded births between 1995 and 1998. The population prevalence rate of 1.5 per 1,000 live births in Alaska between 1995 and 1997 was approximately four times higher than the prevalence rates in Arizona, Colorado, and New York – other states in the CDC Fetal Alcohol Syndrome Surveillance Network (FASNet; CDC, 2002). The higher prevalence rates in Alaska are reflective of higher prevalence rates among children born to Alaska Native mothers, which may be attributed to increased awareness and documentation of maternal alcohol use by Alaska Native health organizations (CDC, 2002; DHSS, 2002).

Recognizing the importance of addressing the issue of FAS in the state of Alaska, in the year 2000, the State of Alaska Department of Health and Social Services (DHSS) applied for and was awarded funding through the Substance Abuse and Mental Health Service Administration (SAMHSA) to support a statewide Alaska FAS Prevention Project. SAMHSA awarded the project \$5 million per year for five years, spanning calendar years 2000 to 2005. Funding of the *FASD Multidisciplinary Community Diagnostic Teams* for screening children was the most central aspect of the Alaska FAS Prevention Project. Children in state custody, at high risk for FASD and other alcohol-related birth defects (ARBD), were of particular concern. Several diagnostic teams are fully functional in the state of Alaska and several additional teams are being developed; two teams have been disbanded. The teams are in various stages of development and implementation. It is anticipated that all teams will be fully functional and financially self-supporting by the end of the SAMHSA granting period in 2005.

At the request of the State Office of FAS, *Behavioral Health Research and Services* (BHRS) formerly known as *Alaska Comprehensive and Specialized Evaluation Services* (ACES), received a contract to process the datasheets submitted to the Alaska State Office of FAS by the diagnostic teams. This report represents a summary of the teams' data from the time they began

to conduct diagnoses through March 2005. Data are shown both cumulatively across the entire time period and for the most recent year (April 2004 to March 2005).

Methodology

In response to a State Office of FAS request, BHRS provides technical support and assistance for the processing of diagnostic data collected through the diagnostic teams. More specifically, BHRS receives and processes copies of the *DHSS Office of FAS Diagnostic Team Data Collection Reports* submitted by all diagnostic teams, and prepares summary reports to be submitted to the State Office of FAS. The State Office of FAS has created two versions of these data collection reports. The original version was used by teams from the inception of the FAS Project through the third quarter of fiscal year 2002. Starting with the fourth quarter of fiscal year 2002, the diagnostic teams have been using a revised version of this form. Appendix A includes copies of both versions of the *DHSS Office of FAS Diagnostic Team Data Collection Reports*.

To process these diagnostic data, BHRS has relied upon its established infrastructure, including staff, computer resources, and data entry and analyses procedures, to provide accurate, timely, and error-free processing of data. Data management at BHRS is coordinated by the Data Manager. This individual is responsible for receiving and logging data, developing the filing system for the data, assigning data editing and keying duties, and preparing data for statistical analyses. Having one individual assigned to coordinate all of these activities not only ensures that data are received, logged, and keyed in the most time-efficient manner possible, but also ensures the ongoing integrity and safety of the data once they are received at BHRS. Following are detailed descriptions of BHRS procedures related to data receipt, data editing, data entry, data analysis, data security, and report dissemination.

Data Receipt

As part of their obligations for receipt of state grant funds, diagnostic teams submit a *DHSS Office of FAS Diagnostic Team Data Collection Report* for each individual for which a diagnosis has been completed. The State Office of FAS, in turn, forwards copies of these datasheets to BHRS via secure postal delivery or direct hand delivery on a quarterly basis. These datasheets contain no personal identifiers of individuals receiving services and are released to BHRS for the purpose of data processing. As described below, confidential data management procedures are strictly adhered to.

Data Editing Procedures

As a method of reducing inconsistent decision-making and keying errors, BHRS applies rigorous data handling procedures that ensure accuracy of data entry and final data analysis. These procedures include careful data preparation prior to data entry, development of customized data entry programs with built-in error reduction, and rekey verification (entering the same data twice). With these procedures, BHRS achieves virtually error-free data entry.

BHRS, having procedures to ensure that data are prepared for entry in a consistent manner, requires that any paper data received be edited twice by two different individuals. Data editing involves reviewing paper data, making any decisions about response inconsistencies or anomalies in a consistent and logical manner, and obtaining missing information. Such data editing ensures that consistent and logical rules are applied before data entry, eliminates the need for decision-making at the input level, and speeds up data entry.

To maintain consistency, the FASD Project Managers always act as the first data editor. This editing process first includes a review of the data for completeness. Having identified four critically important data points (namely, the date of birth, date of diagnosis, gender, and 4-digit diagnostic code), the Project Managers contact the appropriate team to obtain this information when missing or illegible. During this first edit, the Project Managers review all data, making decisions on any response anomalies and assigning numbers in the margins to reflect respondents' answers.

The Data Manager acts as the second data editor. This is the same person for all projects at BHRS to ensure consistency in editing across projects. The Data Manager reviews all paper data to ensure the consistency of the decisions made by the first data editor in regard to data anomalies. To indicate that a given question was edited by an BHRS staff member, edits are made in a different color marker than that used by the respondent. Although this data editing process takes additional time, the net result is much more accurate and expeditious data entry.

Data-Editing Decisions Specific to the FASD Diagnostic Team Data

As described above, to maintain consistency, several decisions were made regarding the handling of response anomalies. These decisions included the following:

- In instances of duplicate data (e.g., submission of two or more forms for one individual), the following system was used to determine which form to enter into the system in the sequence listed:
 - If duplicated forms are on two different versions of the data reporting form, the revised form dated 5/2002 is selected.
 - If two original forms were submitted, the form with the most complete information is used.
- In instances where an incomplete date was recorded for a data point, the following system was used to assign a value for subsequent calculations in the sequence listed:
 - If the month and year are recorded as the same for the *date of first appointment* and *date of diagnosis* one data point has a missing day of the month, the day recorded for the other data point is used.
 - If the month and year for the *date of first appointment* and *date of diagnosis* are different, the missing day is arbitrarily assigned the 15th.
 - If the month and/or year are missing the data is coded as a missing data point and no subsequent calculations were performed.

Data Entry Procedures

Quantitative data obtained from the data reports are entered using Viking Data Entry System (Viking Software Solutions, Tulsa, OK; <http://www.vikingsoft.com>). BHRS maintains a site license for this software and uses it for data entry on all projects. Viking Data Entry software, ideal for clean data entry, ensures accurate data entry by restricting data entry to predefined, valid field parameters and requires rekey verification of each data point.

Use of the Viking Data Entry software allows development of a data entry program to be customized specifically to the dataset. Each field in the Viking program is defined as to the type of data to be entered and parameters established. By setting these parameters, any attempt to enter a number other than those identified as acceptable will be unsuccessful. This is the first screen to ensure accuracy of data entry. The second screen for accuracy is the rekeying function that requires all data to be entered twice. BHRS procedures require this to be completed by two different individuals. When the data is rekeyed (reentered), the computer screen appears to the second keyer as if no data had been previously entered. However, if this second keyer attempts to enter a number that is different than the number entered by the first keyer, the computer alerts the keyer of this discrepancy and the discrepancy must be rectified manually.

Data Analysis Procedures

BHRS maintains a site license for SAS, a comprehensive statistical software package (SAS Institute, Chicago; <http://www.sas.com>). SAS is capable of a full range of statistical analyses, including those requested for the current project.

Data Safety and Confidentiality

Data safety and confidentiality are paramount concerns at BHRS. Because data that BHRS staff handle routinely are of a critically sensitive nature, BHRS has established rigorous and explicit procedures and infrastructure that protects data. Paper data are secured in lockable fire-proof, tamper-resistant file cabinets that are kept locked at all times except during business hours and that are stored in a separately keyed file room with bars on the outside window. BHRS organizational policies and procedures dictate that all hard copy data must stay in the file cabinets at all times except when being used for data entry or related purposes. Further, all BHRS staff members have signed a confidentiality statement that clarifies the need to keep data confidential and private and that describes ramifications of breaking this agreement.

Once entered, all electronic data are maintained on the BHRS-owned dedicated Digital Equipment Corporation Alpha 4000 server; no data are ever maintained on the hard drives of local PCs or on other media. Dedicated exclusively to BHRS, the DEC server is accessible only by BHRS staff. Electronic data are backed-up to tape on a weekly basis to prevent loss of data.

Dissemination of Data Reports

Upon completion of data analyses, BHRS generates a report for each team that presents only that team's data. A complete report providing both aggregate data across all teams and individual

teams' data is prepared for the State Office of FAS. These reports are delivered to the State Office of FAS for dissemination to the respective teams.

Summary of Results

It is important to note that the *DHSS Office of FAS Diagnostic Team Data Collection Report* was revised in May 2002. Revisions to the form included exclusion of some data elements and additions of others. As a result, some data elements are only available on the original version and some only on the revised version. The tables and graphs that follow include data elements from the most recent version of the data collection form.

As of the writing of this report, 14 diagnostic teams are conducting FASD diagnoses in the state of Alaska, and three teams have been disbanded, for a total of 17 diagnostic teams that function or functioned in Alaska since 1999. Using the *DHSS Office of FAS Diagnostic Team Data Collection Reports*, 14 of these 17 diagnostic teams have submitted 757 completed datasheets to date, including the current period. Of these 757 datasheets, one did not include a 4-digit diagnosis and one did not provide a complete 4-digit diagnosis, for a total of 756 usable datasheets (including 755 datasheets with complete diagnoses). All duplicate datasheets received have been eliminated from the database. Of the 755 individuals for whom complete diagnoses were submitted, 76 (10.0%) were diagnosed with FAS or atypical FAS; 378 (49.9%) were diagnosed with Static Encephalopathy; 251 (32.2%) were diagnosed with Neurobehavioral Disorder; and 50 (6.6%) were found to have no evidence of organic brain damage.

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Data based on the datasheets submitted to date are shown in the following tables, both cumulatively across the entire reporting period and for the last period. The reader is encouraged to review the data tables and graphs carefully as the information is not repeated here in narrative format due to the wealth of information contained in the tables. A careful review of the tables will give the reader a comprehensive picture of these findings.

References

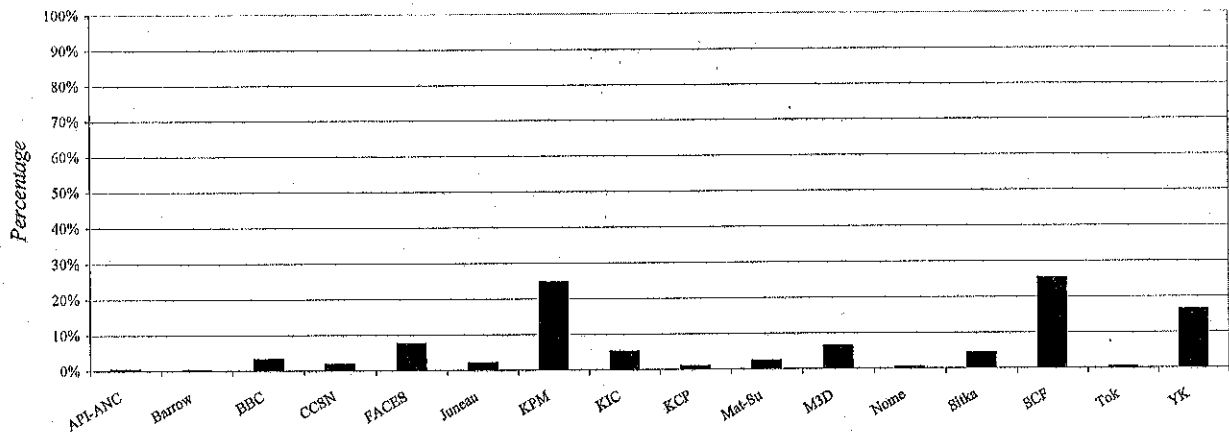
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Number of Diagnoses Completed by Diagnostic Team

<i>Diagnoses by Diagnostic Team</i>	Abbreviation	Location	<i>All To Date</i>		<i>This Period</i>	
			n	%	n	%
API-Anchorage Multidisciplinary FAS Diagnostic Team	API-ANC	Anchorage	2	0.3%	2	1.5%
Barrow FAS Diagnostic Team	Barrow	Barrow	1	0.1%	0	0.0%
Bristol Bay Community FAS Diagnostic Team	BBC	Dillingham	24	3.2%	4	3.1%
Center for Children with Special Needs-Providence Medical Center	CCSN	Anchorage	13	1.7%	0	0.0%
Fairbanks FAS Community Evaluation Services Team	FACES	Fairbanks	57	7.5%	14	10.7%
Juneau FASD Diagnostic Clinic	Juneau	Juneau	15	2.0%	13	9.9%
Kenai Peninsula Multidisciplinary FAS Diagnostic Team	KPM	Kenai/Soldotna	186	24.6%	27	20.6%
Ketchikan Indian Corporation FAS Diagnostic Team	KIC	Ketchikan	38	5.0%	11	8.4%
Kodiak Compass Project	KCP	Kodiak	6	0.8%	0	0.0%
Mat-Su Fetal Alcohol Resource Project	Mat-Su	Mat-Su Borough	17	2.2%	3	2.3%
Multidisciplinary Developmental Disabilities Diagnostic Team	M3D	Copper Center	48	6.3%	0	0.0%
Nome Multidisciplinary FAS Diagnostic Team	Nome	Nome	2	0.3%	0	0.0%
Sitka Neurodevelopmental Clinic	Sitka	Sitka	32	4.2%	11	8.4%
Southcentral Foundation	SCF	Anchorage	190	25.1%	34	26.0%
Tok Multidisciplinary FAS Diagnostic Team	Tok	Tok	2	0.3%	2	1.5%
Yukon-Kuskokwim FASD Diagnostic Clinic	YK	Bethel	124	16.4%	10	7.6%
Total			757	100.0%	131	100.0%

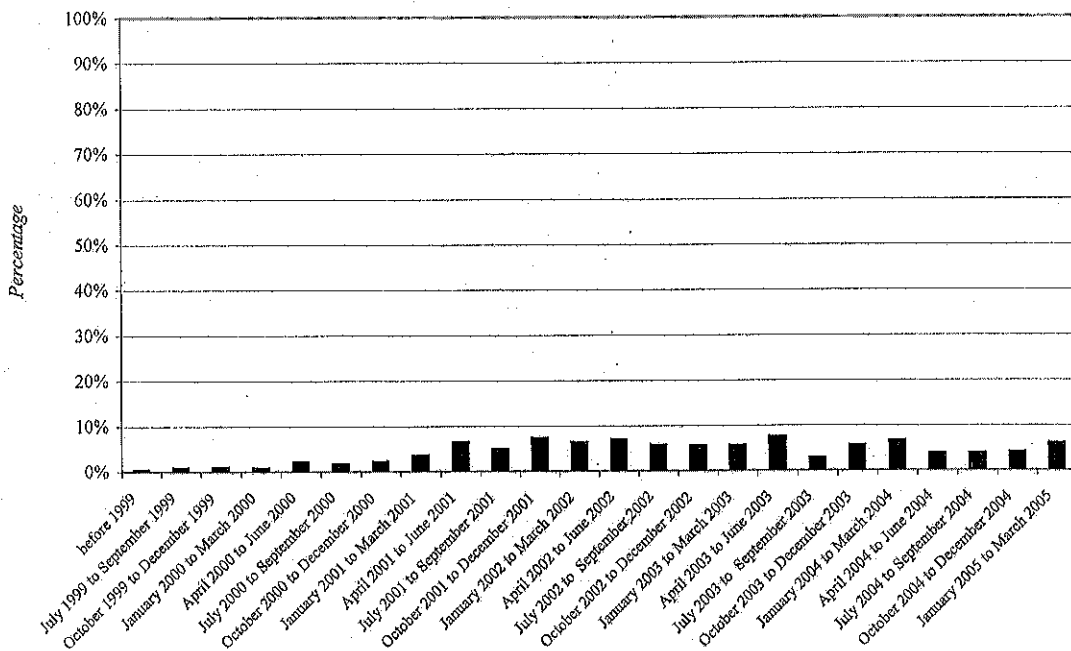
Note: The "period" referred to in this report is April 2004 through March 2005.

All Diagnoses/Clients To Date



Number of Assessments Completed by Quarter

<i>Number of Assessments Completed</i>		<i>n = 757</i>
<i>Quarter</i>	<i>n</i>	<i>%</i>
before 1999	2	0.3%
July 1999 to September 1999	6	0.8%
October 1999 to December 1999	7	0.9%
January 2000 to March 2000	6	0.8%
April 2000 to June 2000	16	2.1%
July 2000 to September 2000	12	1.6%
October 2000 to December 2000	16	2.1%
January 2001 to March 2001	26	3.4%
April 2001 to June 2001	48	6.3%
July 2001 to September 2001	37	4.9%
October 2001 to December 2001	55	7.3%
January 2002 to March 2002	47	6.2%
April 2002 to June 2002	52	6.9%
July 2002 to September 2002	43	5.7%
October 2002 to December 2002	42	5.5%
January 2003 to March 2003	42	5.5%
April 2003 to June 2003	56	7.4%
July 2003 to September 2003	21	2.8%
October 2003 to December 2003	42	5.5%
January 2004 to March 2004	50	6.6%
April 2004 to June 2004	28	3.7%
July 2004 to September 2004	28	3.7%
October 2004 to December 2004	30	4.0%
January 2005 to March 2005	45	5.9%



Client Demographics

Client's Gender

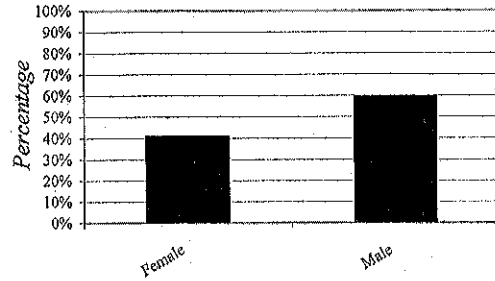
<i>All Clients To Date</i>		<i>n = 757</i>	
Gender	<i>n</i>	<i>%</i>	
Female	308	40.7%	
Male	449	59.3%	

<i>Clients This Period</i>		<i>n = 131</i>	
Gender	<i>n</i>	<i>%</i>	
Female	59	45.0%	
Male	72	55.0%	

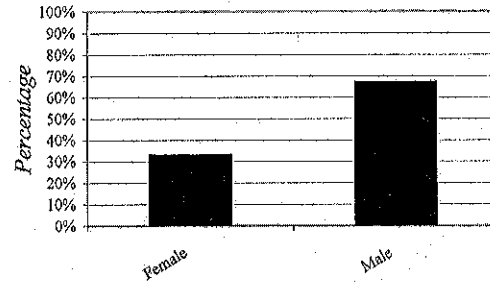
<i>All Clients to Date with FAS/AFAS</i>		<i>n = 76</i>	
Gender	<i>n</i>	<i>%</i>	
Female	25	32.9%	
Male	51	67.1%	

<i>Clients This Period with FAS/AFAS</i>		<i>n = 15</i>	
Gender	<i>n</i>	<i>%</i>	
Female	8	53.3%	
Male	7	46.7%	

All Clients To Date



All Clients To Date (FAS/AFAS)



Note: The "period" referred to in this report is April 2004 through March 2005.

Client Demographics, Continued

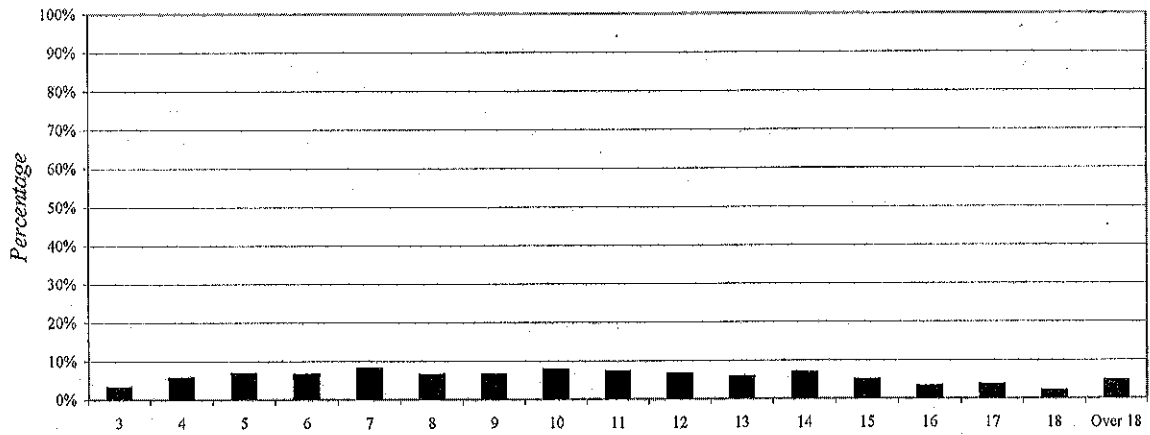
Client's Age at Diagnosis

<i>All Clients To Date</i>		<i>n = 757</i>	
Years	<i>n</i>	<i>%</i>	
0	6	0.8%	
1	13	1.7%	
2	14	1.8%	
3	24	3.2%	
4	43	5.7%	
5	51	6.7%	
6	50	6.6%	
7	62	8.2%	
8	49	6.5%	
9	49	6.5%	
10	58	7.7%	
11	54	7.1%	
12	50	6.6%	
13	44	5.8%	
14	52	6.9%	
15	37	4.9%	
16	24	3.2%	
17	27	3.6%	
18	15	2.0%	
Over 18	35	4.6%	

<i>Clients This Period</i>		<i>n = 131</i>	
Years	<i>n</i>	<i>%</i>	
0	2	1.5%	
1	1	0.8%	
2	2	1.5%	
3	6	4.6%	
4	7	5.3%	
5	9	6.9%	
6	14	10.7%	
7	14	10.7%	
8	6	4.6%	
9	7	5.3%	
10	8	6.1%	
11	8	6.1%	
12	9	6.9%	
13	8	6.1%	
14	4	3.1%	
15	8	6.1%	
16	5	3.8%	
17	6	4.6%	
18	2	1.5%	
Over 18	5	3.8%	

Note: The "period" referred to in this report is April 2004 through March 2005.

All Clients To Date



Client Demographics, Continued

Client Ethnicity

<i>All Clients To Date</i> <i>n</i> = 757		
Primary Ethnicity	<i>n</i>	%
White	163	21.5%
Black	8	1.1%
Alaska Native/Am. Indian	183	24.2%
Alaska Native	349	46.1%
American Indian	18	2.4%
Asian	1	0.1%
Native Hawaiian/Pac. Islander	3	0.4%
Other	9	1.2%
Hispanic/Latino	3	0.4%
Unknown	1	0.1%
Missing	19	2.5%

<i>Clients This Period</i> <i>n</i> = 131		
Primary Ethnicity	<i>n</i>	%
White	39	29.8%
Black	0	0.0%
Alaska Native/Am. Indian	0	0.0%
Alaska Native	80	61.1%
American Indian	8	6.1%
Asian	0	0.0%
Native Hawaiian/Pac. Islander	1	0.8%
Other	1	0.8%
Hispanic/Latino	0	0.0%
Unknown	0	0.0%
Missing	2	1.5%

<i>All Clients To Date</i> <i>n</i> = 508		
Hispanic or Latin Heritage	<i>n</i>	%
Yes	20	3.9%
No	458	90.2%
Missing	30	5.9%

<i>Clients This Period</i> <i>n</i> = 131		
Hispanic or Latin Heritage	<i>n</i>	%
Yes	4	3.1%
No	125	95.4%
Missing	2	1.5%

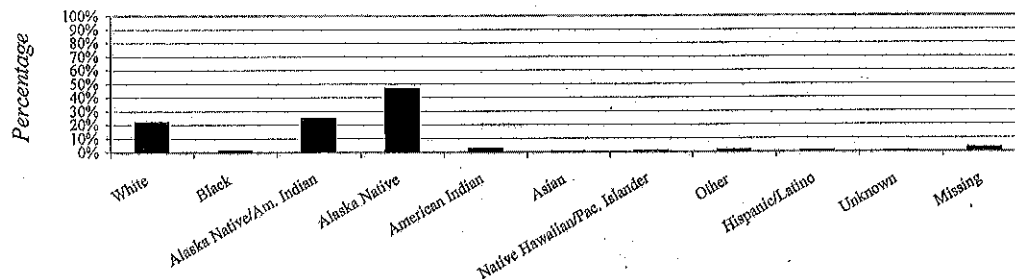
<i>All Clients To Date</i> <i>n</i> = 757		
Secondary Ethnicity	<i>n</i>	%
White	30	4.0%
Black	10	1.3%
Alaska Native/Am. Indian	0	0.0%
Alaska Native	0	0.0%
American Indian	6	0.8%
Asian	1	0.1%
Native Hawaiian/Pac. Islander	1	0.1%
Other	1	0.1%
Hispanic/Latino	0	0.0%
Unknown	0	0.0%
Missing	708	93.5%

<i>Clients This Period</i> <i>n</i> = 131		
Secondary Ethnicity	<i>n</i>	%
White	11	8.4%
Black	1	0.8%
Alaska Native/Am. Indian	0	0.0%
Alaska Native	0	0.0%
American Indian	0	0.0%
Asian	0	0.0%
Native Hawaiian/Pac. Islander	0	0.0%
Other	0	0.0%
Hispanic/Latino	0	0.0%
Unknown	0	0.0%
Missing	119	90.8%

Note: The "period" referred to in this report is April 2004 through March 2005.

Due to the revision of the reporting form, data reported before May 2002 combine the Alaska Native and American Indian ethnic categories and include Hispanic or Latino as an ethnicity. The revised form, reflecting the Government Performance Reporting Act (GPRA) categories, differentiates Alaska Native and American Indian ethnicities and provides a separate question for Hispanic or Latin heritage. Therefore, data collected after May 2002 reflect these changes. Of the 757 forms submitted, 508 were revised forms.

All Clients To Date



Client Referral and Background Information

Who has legal custody of this client?

<i>All Clients To Date</i> <i>n</i> = 757		
Legal Custody of Client	<i>n</i>	%
Both biological parents	36	4.8%
Biological mother only	75	9.9%
Biological father only	58	7.7%
Adoptive parent(s)/Legal Guardian	211	27.9%
DFYS/OCS Custody	258	34.1%
Other relative	21	2.8%
Self	24	3.2%
Other	68	9.0%
Tribal Organization	5	0.7%
Missing	17	2.2%

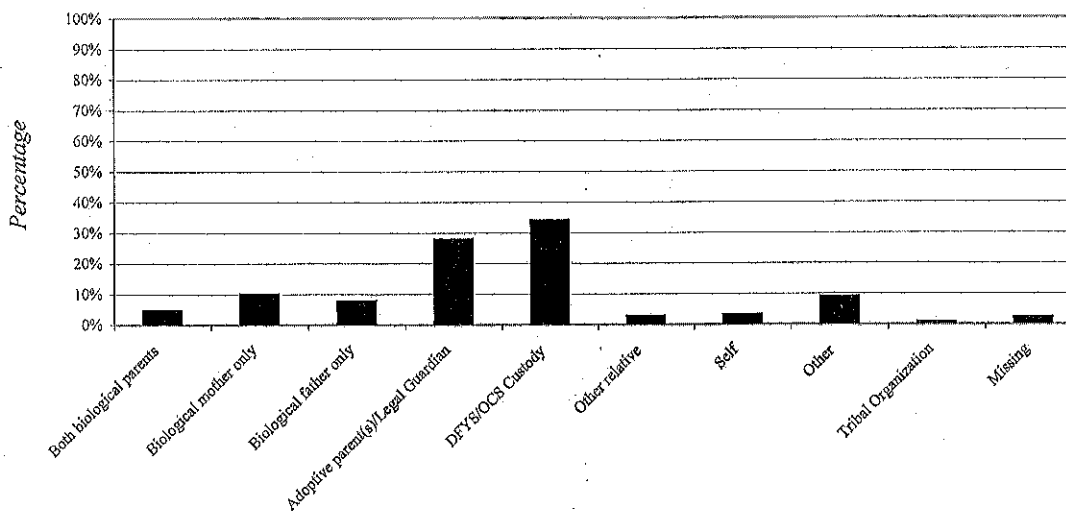
<i>Clients This Period</i> <i>n</i> = 131		
Legal Custody of Client	<i>n</i>	%
Both biological parents	7	5.3%
Biological mother only	13	9.9%
Biological father only	9	6.9%
Adoptive parent(s)/Legal Guardian	48	36.6%
DFYS/OCS Custody	39	29.8%
Self	3	2.3%
Other	9	6.9%
Tribal Organization	1	0.8%
Missing	3	2.3%

Note: The "period" referred to in this report is April 2004 through March 2005.

This data element was revised on the May 2002 *DHSS Office of FAS Diagnostic Team Data Collection Report*. Changes to the custodial options included the addition of *legal guardian* to *adoptive parent* category and the addition of *tribal organization*. Therefore, data collected prior to May 2002 may only reflect these other selections as *other* by the recorder. The classification *other relative* was excluded in the revised form and, as such, is reported only during the time period from 1999 to April 2002.

Totals may add up to more than the total number of clients due to clients with more than one person reported as having custody of the client. An unlimited number of legal custodians were accepted and entered per client.

All Clients To Date



Client Referral and Background Information, Continued

Who has legal custody of this client?

Client's Legal Custodian - Breakdown of "Other" Category

<i>All Clients To Date</i>		<i>n = 757</i>	
Legal Custody: Other-Specify	<i>n</i>	<i>%</i>	
Attorney	2	0.3%	
Aunt/Uncle	6	0.8%	
Bio Mom/Adopted Dad	1	0.1%	
Bethel Youth Facility	3	0.4%	
Custody Other State	1	0.1%	
Court Appointed Guardian	1	0.1%	
Division of Juvenile Justice	11	1.4%	
Foster Parents	10	1.3%	
Grandparents	18	2.3%	
Juvenile Probation Officer	1	0.1%	
Legal Guardian	7	0.9%	
Residential/Inpatient Treatment	1	0.1%	
Self	1	0.1%	
Sibling	1	0.1%	
Single Parent	1	0.1%	
Social Worker	3	0.4%	
State	2	0.3%	
State Prison	1	0.1%	
Stepparents	3	0.0%	
Illegible response	2	0.3%	
Unknown	7	0.9%	
Missing	17	2.2%	
Not Applicable	672	87.0%	

<i>Clients This Period</i>		<i>n = 131</i>	
Legal Custody: Other-Specify	<i>n</i>	<i>%</i>	
Attorney	0	0.0%	
Aunt/Uncle	0	0.0%	
Bio Mom/Adopted Dad	0	0.0%	
Bethel Youth Facility	0	0.0%	
Custody Other State	1	0.8%	
Court Appointed Guardian	0	0.0%	
Division of Juvenile Justice	3	2.3%	
Foster Parents	0	0.0%	
Grandparents	3	2.3%	
Juvenile Probation Officer	0	0.0%	
Legal Guardian	0	0.0%	
Residential/Inpatient Treatment	0	0.0%	
Self	1	0.8%	
Sibling	0	0.0%	
Single Parent	0	0.0%	
Social Worker	0	0.0%	
State	0	0.0%	
State Prison	0	0.0%	
Stepparents	1	0.0%	
Illegible response	0	0.0%	
Unknown	0	0.0%	
Missing	3	2.3%	
Not Applicable	119	90.8%	

Note: The "period" referred to in this report is April 2004 through March 2005.

Responses indicating *other* were grouped when possible into logical categories (e.g., combining responses such as aunt, maternal aunt, paternal aunt, auntie).

Although *foster parent* was not a selection on either form nor can it be a correct response, due to the large number of *other* responses that specified foster parent as the *legal* custodian, the data are reported as they appeared in the datasheets.

Although the *State* was not a selection on either form, due to the insufficient information to determine what state agency maintained client custody, the data is reported as it appeared in the datasheets.

Client Referral and Background Information, Continued

Who is the client's primary caregiver?

<i>All Clients To Date</i>		
	<i>n = 508</i>	
Primary Caregiver	<i>n</i>	<i>%</i>
Both biological parents	26	5.1%
Biological mother only	75	14.8%
Biological father only	38	7.5%
Adoptive parent(s)/Legal Guardian	155	30.5%
Foster parent(s)	146	28.7%
Social Service Agency	12	2.4%
Self	11	2.2%
Other	54	10.6%
Missing	10	2.0%

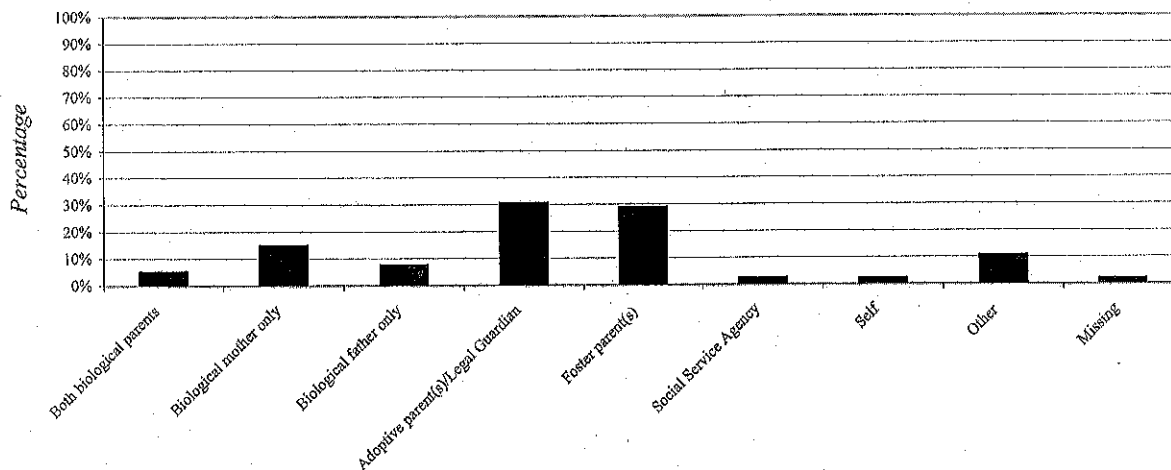
<i>Clients This Period</i>		
	<i>n = 131</i>	
Primary Caregiver	<i>n</i>	<i>%</i>
Both biological parents	6	4.6%
Biological mother only	14	10.7%
Biological father only	10	7.6%
Adoptive parent(s)/Legal Guardian	50	38.2%
Foster parent(s)	34	26.0%
Social Service Agency	2	1.5%
Self	2	1.5%
Other	12	9.2%
Missing	3	2.3%

Note: The "period" referred to in this report is April 2004 through March 2005.

Totals may add up to more than 100% as more than one caregiver may be listed.

This data element was added to the revised *DHSS Office of FAS Diagnostic Team Data Collection Report* (May 2002). Therefore, only data reported on the revised form are presented. Of the 757 forms submitted, 508 were revised forms.

All Clients To Date



Client Referral and Background Information, Continued

If this client is an adopted or foster child, how many home placements have there been prior to his or her current placement?

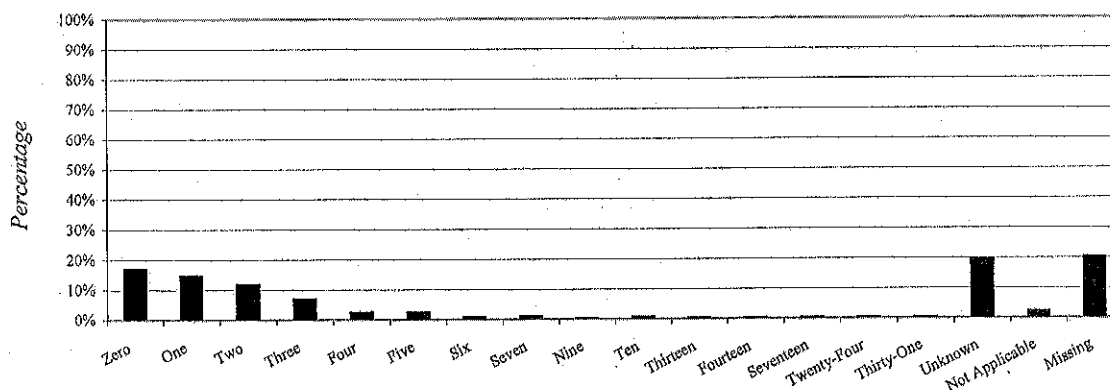
<i>All Clients To Date</i>		<i>n = 508</i>	
Number of Previous Placements	<i>n</i>	<i>%</i>	
Zero	86	16.9%	
One	74	14.6%	
Two	59	11.6%	
Three	35	6.9%	
Four	12	2.4%	
Five	12	2.4%	
Six	4	0.8%	
Seven	5	1.0%	
Nine	1	0.2%	
Ten	3	0.6%	
Thirteen	1	0.2%	
Fourteen	1	0.2%	
Seventeen	1	0.2%	
Twenty-Four	1	0.2%	
Thirty-One	1	0.2%	
Unknown	99	19.5%	
Not Applicable	11	2.2%	
Missing	102	20.1%	

<i>Clients This Period</i>		<i>n = 131</i>	
Number of Previous Placements	<i>n</i>	<i>%</i>	
Zero	23	17.6%	
One	21	16.0%	
Two	13	9.9%	
Three	10	7.6%	
Four	0	0.0%	
Five	3	2.3%	
Seven	1	0.8%	
Fourteen	1	0.8%	
Unknown	16	12.2%	
Not Applicable	1	0.8%	
Missing	42	32.1%	

Note: The "period" referred to in this report is April 2004 through March 2005.

This data element was added to the revised *DHSS Office of FAS Diagnostic Team Data Collection Report* (May 2002). Therefore, only data reported on the revised form are presented. Of the 757 forms submitted, 508 were revised forms.

All Clients To Date



Client Referral and Background Information Continued

Who does this client currently live with?

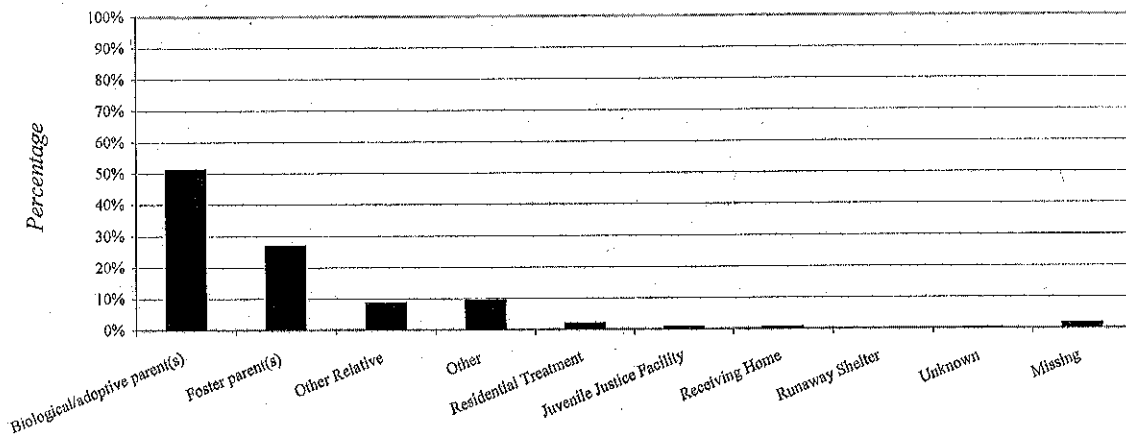
<i>All Clients To Date</i>		
<i>n = 757</i>		
Living Arrangement	n	%
Biological/adoptive parent(s)	387	51.1%
Foster parent(s)	203	26.8%
Other Relative	64	8.5%
Other	71	9.4%
Residential Treatment	14	1.8%
Juvenile Justice Facility	5	0.7%
Receiving Home	3	0.4%
Runaway Shelter	0	0.0%
Unknown	1	0.1%
Missing	12	1.6%

<i>Clients This Period</i>		
<i>n = 131</i>		
Living Arrangement	n	%
Biological/adoptive parent(s)	77	58.8%
Foster parent(s)	28	21.4%
Other Relative	8	6.1%
Other	7	5.3%
Residential Treatment	4	3.1%
Juvenile Justice Facility	2	1.5%
Receiving Home	0	0.0%
Runaway Shelter	0	0.0%
Unknown	0	0.0%
Missing	5	3.8%

Note: The "period" referred to in this report is April 2004 through March 2005.

Totals may add up to more than 100% as more than one living arrangement may be listed.

All Clients To Date



Client Referral and Background Information, Continued.

Who referred this client for an FASD assessment?

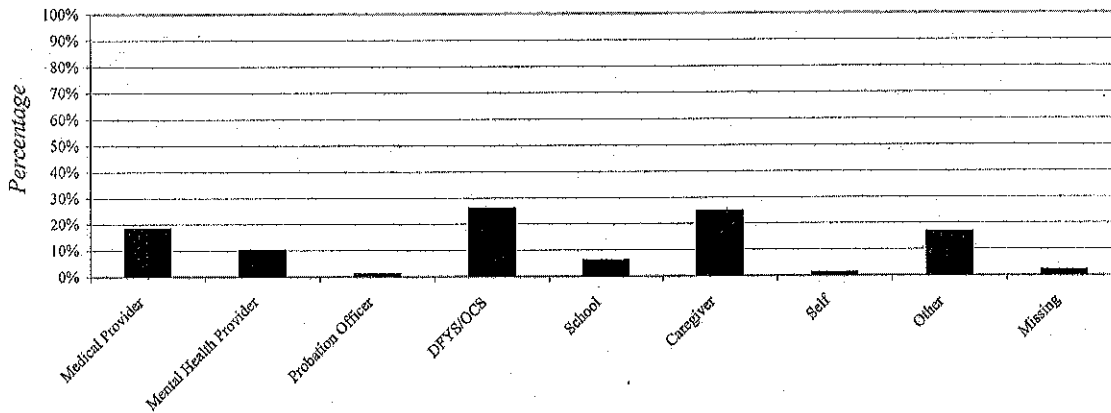
<i>All Clients To Date</i>		<i>n = 757</i>	
Referring Agent	n	%	
Medical Provider	138	18.2%	
Mental Health Provider	76	10.0%	
Probation Officer	7	0.9%	
DFYS/OCS	196	25.9%	
School	45	5.9%	
Caregiver	186	24.6%	
Self	8	1.1%	
Other	125	16.5%	
Missing	15	2.0%	

<i>Clients This Period</i>		<i>n = 131</i>	
Referring Agent	n	%	
Medical Provider	40	30.5%	
Mental Health Provider	18	13.7%	
Probation Officer	3	2.3%	
DFYS/OCS	23	17.6%	
School	8	6.1%	
Caregiver	21	16.0%	
Self	2	1.5%	
Other	16	12.2%	
Missing	5	3.8%	

Note: The "period" referred to in this report is April 2004 through March 2005.

Totals may add up to more than 100% as more than one referring agent may be listed.

All Clients To Date

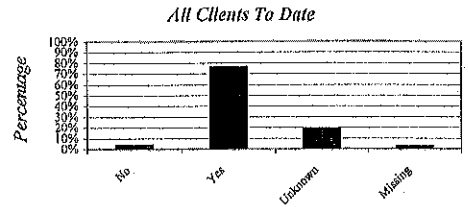


Birth Mother's Childbirth History

Birthmothers with Other Children

<i>All Clients To Date</i> <i>n = 757</i>		
Gave Birth to Other Children	<i>n</i>	<i>%</i>
No	27	3.6%
Yes	573	75.7%
Unknown	140	18.5%
Missing	17	2.2%

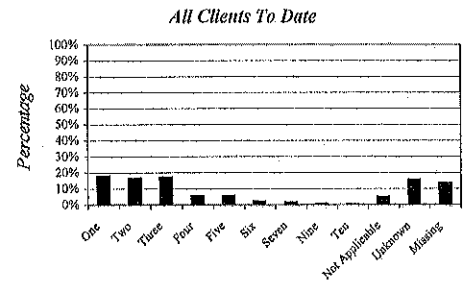
<i>Clients This Period</i> <i>n = 131</i>		
Gave Birth to Other Children	<i>n</i>	<i>%</i>
No	7	5.3%
Yes	101	77.1%
Unknown	19	14.5%
Missing	4	3.1%



Number of Other Children Born to Birthmother

<i>All Clients To Date</i> <i>n = 508</i>		
Other Birth Siblings	<i>n</i>	<i>%</i>
One	91	17.9%
Two	83	16.3%
Three	87	17.1%
Four	28	5.5%
Five	28	5.5%
Six	10	2.0%
Seven	7	1.4%
Nine	2	0.4%
Ten	1	0.2%
Not Applicable	24	4.7%
Unknown	79	15.6%
Missing	68	13.4%

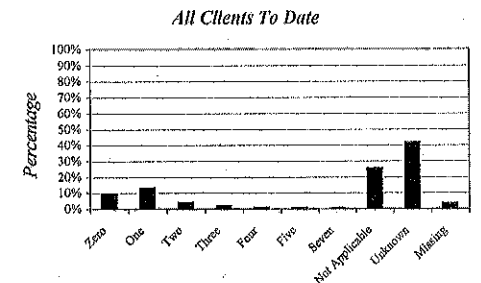
<i>Clients This Period</i> <i>n = 131</i>		
Other Birth Siblings	<i>n</i>	<i>%</i>
One	24	18.3%
Two	23	17.6%
Three	19	14.5%
Four	10	7.6%
Five	5	3.8%
Six	1	0.8%
Seven	2	1.5%
Nine	1	0.8%
Ten	1	0.8%
Not Applicable	7	5.3%
Unknown	21	16.0%
Missing	17	13.0%



Number of Diagnosed Older Siblings

<i>All Clients To Date</i> <i>n = 508</i>		
Diagnosed Older Birth Siblings	<i>n</i>	<i>%</i>
Zero	47	9.3%
One	66	13.0%
Two	20	3.9%
Three	9	1.8%
Four	4	0.8%
Five	2	0.4%
Seven	2	0.4%
Not Applicable	129	25.4%
Unknown	212	41.7%
Missing	17	3.3%

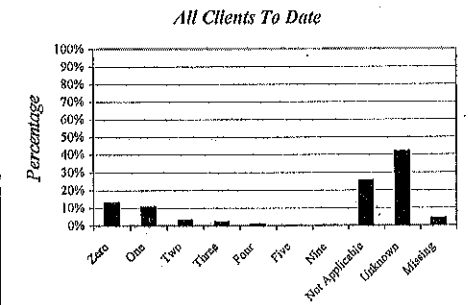
<i>Clients This Period</i> <i>n = 131</i>		
Diagnosed Older Birth Siblings	<i>n</i>	<i>%</i>
Zero	11	8.4%
One	14	10.7%
Two	5	3.8%
Three	2	1.5%
Four	2	1.5%
Five	2	1.5%
Seven	2	1.5%
Not Applicable	34	26.0%
Unknown	54	41.2%
Missing	5	3.8%



Number of Diagnosed Younger Siblings

<i>All Clients To Date</i> <i>n = 508</i>		
Diagnosed Younger Birth Siblings	<i>n</i>	<i>%</i>
Zero	65	12.8%
One	53	10.4%
Two	15	3.0%
Three	10	2.0%
Four	3	0.6%
Five	1	0.2%
Nine	1	0.2%
Not Applicable	129	25.4%
Unknown	211	41.5%
Missing	20	3.9%

<i>Clients This Period</i> <i>n = 131</i>		
Diagnosed Younger Birth Siblings	<i>n</i>	<i>%</i>
Zero	16	12.2%
One	13	9.9%
Two	4	3.1%
Three	3	2.3%
Four	1	0.8%
Five	1	0.8%
Nine	0	0.0%
Not Applicable	34	26.0%
Unknown	53	40.5%
Missing	6	4.6%



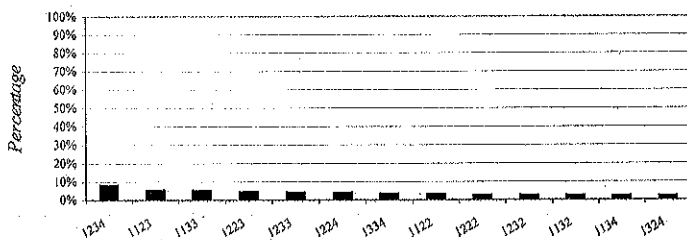
Note: The "period" referred to in this report is April 2004 through March 2005.

These data elements were added to the revised *DHSS Office of FAS Diagnostic Team Data Collection Report*. Therefore, only data reported on the revised form are presented. Of the 757 forms submitted, 508 were revised forms.

FAS Diagnostic Information

Most Common 4-Digit Diagnostic Codes

All Clients To Date		n = 757	
Most Common Diagnostic Codes	Dx Code	n	%
Static encephalopathy (alcohol exposed)	1234	60	7.9%
Neurobehavioral disorder (alcohol exposed)	1123	41	5.4%
Static encephalopathy (alcohol exposed)	1133	40	5.3%
Neurobehavioral disorder (alcohol exposed)	1223	34	4.5%
Static encephalopathy (alcohol exposed)	1233	32	4.2%
Neurobehavioral disorder (alcohol exposed)	1224	30	4.0%
Sentinel physical findings/static encephalopathy (alcohol exposed)	1334	25	3.3%
Neurobehavioral disorder (alcohol exposure unknown)	1122	24	3.2%
Neurobehavioral disorder (alcohol exposure unknown)	1222	19	2.5%
Static encephalopathy (alcohol exposed)	1232	19	2.5%
Static encephalopathy (alcohol exposed unknown)	1132	18	2.4%
Static encephalopathy (alcohol exposed)	1134	16	2.1%
Sentinel physical findings / neurobehavioral disorder (alcohol exposed)	1324	16	2.1%



Frequency of Diagnoses

All Clients To Date		n = 757	
Diagnoses	Category	n	%
Fetal alcohol syndrome (alcohol exposed)	A	21	2.8%
Fetal alcohol syndrome (alcohol exposure unknown)	B	3	0.4%
Atypical fetal alcohol syndrome (alcohol exposed)	C	52	6.9%
Fetal alcohol syndrome phenocopy (no alcohol exposure)	D	0	0.0%
Sentinel physical findings/static encephalopathy (alcohol exposed)	E	84	11.1%
Static encephalopathy (alcohol exposed)	F	211	27.9%
Sentinel physical findings/neurobehavioral disorder (alcohol exp)	G	49	6.5%
Neurobehavioral disorder (alcohol exposed)	H	129	17.0%
Sentinel physical findings (alcohol exposed)	I	10	1.3%
No cognitive/behavioral or sentinel physical findings detected (alcohol exp)	J	29	3.8%
Sentinel physical findings/static encephalopathy (alcohol exp unknown)	K	28	3.7%
Static encephalopathy (alcohol exposure unknown)	L	46	6.1%
Sentinel physical findings/neurobehavioral disorder (alcohol exp unknown)	M	20	2.6%
Neurobehavioral disorder (alcohol exposure unknown)	N	44	5.8%
Sentinel physical findings (alcohol exposure unknown)	O	1	0.1%
No cog./behavioral or sentinel physical findings detected (alcohol exp unknown)	P	9	1.2%
Sentinel physical findings /static encephalopathy (no alcohol exp)	Q	1	0.1%
Static encephalopathy (no alcohol exposure)	R	8	1.1%
Sentinel physical findings/neurobehavioral disorder (no alcohol exp)	S	0	0.0%
Neurobehavioral disorder (no alcohol exposure)	T	9	1.2%
Sentinel physical findings (no alcohol exposure)	U	0	0.0%
No cognitive/behavioral or sentinel physical findings detected (no alcohol exp)	V	1	0.1%
Missing		2	0.3%

Clients This Period		n = 131	
	n	%	
	5	3.8%	
	0	0.0%	
	10	7.6%	
	0	0.0%	
	10	7.6%	
	32	24.4%	
	8	6.1%	
	26	19.8%	
	2	1.5%	
	6	4.6%	
	6	4.6%	
	6	4.6%	
	2	1.5%	
	8	6.1%	
	0	0.0%	
	3	2.3%	
	0	0.0%	
	2	1.5%	
	0	0.0%	
	5	3.8%	
	0	0.0%	
	0	0.0%	
	0	0.0%	

Clients with Evidence of Organic Brain Damage

All Clients To Date		n = 757	
Clients with Evidence of Organic Brain Damage	n	%	
Static encephalopathy (FAS or AFAS)	76	10.0%	
Static encephalopathy (not FAS or AFAS)	378	49.9%	
Neurobehavioral disorder	251	33.2%	
No evidence of organic brain damage	50	6.6%	
Missing	2	0.3%	

Clients This Period		n = 131	
	n	%	
	15	11.5%	
	56	42.7%	
	49	37.4%	
	11	8.4%	
	0	0.0%	

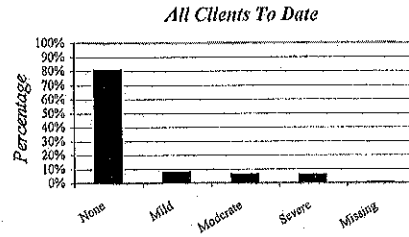
Note: The "period" referred to in this report is April 2004 through March 2005.

Diagnostic Ranks for Growth, Face, Brain, and Alcohol Exposure

Growth

All Clients To Date			n = 757		
Growth Deficiency	n	%			
None	609	80.4%			
Mild	58	7.7%			
Moderate	46	6.1%			
Severe	43	5.7%			
Missing	1	0.1%			

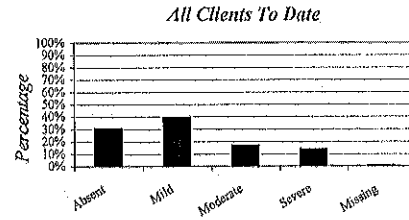
Clients This Period			n = 131		
Growth Deficiency	n	%			
None	109	83.2%			
Mild	9	6.9%			
Moderate	5	3.8%			
Severe	8	6.1%			
Missing	0	0.0%			



Face

All Clients To Date			n = 757		
Facial Phenotype	n	%			
Absent	229	30.3%			
Mild	297	39.2%			
Moderate	127	16.8%			
Severe	102	13.5%			
Missing	2	0.3%			

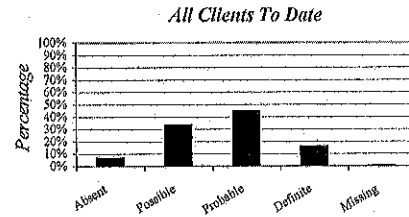
Clients This Period			n = 131		
Facial Phenotype	n	%			
Absent	50	38.2%			
Mild	45	34.4%			
Moderate	16	12.2%			
Severe	20	15.3%			
Missing	0	0.0%			



Brain

All Clients To Date			n = 757		
Brain Damage	n	%			
Absent	50	6.6%			
Possible	252	33.3%			
Probable	335	44.3%			
Definite	119	15.7%			
Missing	1	0.1%			

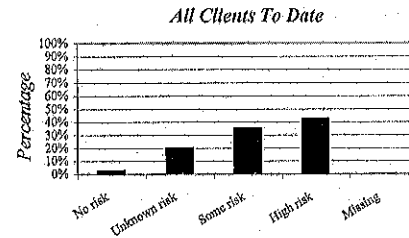
Clients This Period			n = 131		
Brain Damage	n	%			
Absent	11	8.4%			
Possible	49	37.4%			
Probable	50	38.2%			
Definite	21	16.0%			
Missing	0	0.0%			



Alcohol Exposure

All Clients To Date			n = 757		
Prenatal Alcohol Exposure	n	%			
No risk	19	2.5%			
Unknown risk	151	19.9%			
Some risk	266	35.1%			
High risk	320	42.3%			
Missing	1	0.1%			

Clients This Period			n = 131		
Prenatal Alcohol Exposure	n	%			
No risk	7	5.3%			
Unknown risk	25	19.1%			
Some risk	50	38.2%			
High risk	49	37.4%			
Missing	0	0.0%			



Note: The "period" referred to in this report is April 2004 through March 2005.

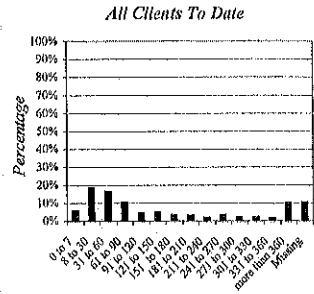
Summary Report of Alaska Multidisciplinary FASD Diagnostic Team Data
Page 22

Lengths of Time Between Referral, First Appointment, and Diagnosis

Time Between Referral and First Appointment

All Clients To Date			n = 508		
Referral to First Appointment	n	%			
0 to 7	30	5.9%			
8 to 30	95	18.7%			
31 to 60	84	16.5%			
61 to 90	53	10.4%			
91 to 120	24	4.7%			
121 to 150	25	4.9%			
151 to 180	17	3.3%			
181 to 210	16	3.1%			
211 to 240	10	2.0%			
241 to 270	18	3.5%			
271 to 300	12	2.4%			
301 to 330	11	2.2%			
331 to 360	8	1.6%			
more than 360	52	10.2%			
Missing	53	10.4%			
		Mean:	141.20		
		SD:	192.64		
		Range:	0-1,097		
		Median:	61.00		

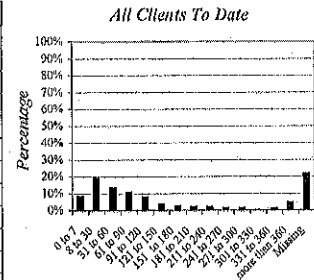
Clients This Period			n = 131		
Referral to First Appointment	n	%			
0 to 7	6	4.6%			
8 to 30	24	18.3%			
31 to 60	19	14.5%			
61 to 90	12	9.2%			
91 to 120	9	6.9%			
121 to 150	4	3.1%			
151 to 180	2	1.5%			
181 to 210	7	5.3%			
211 to 240	5	3.8%			
241 to 270	3	2.3%			
271 to 300	4	3.1%			
301 to 330	1	0.8%			
331 to 360	3	2.3%			
more than 360	22	16.8%			
Missing	10	7.6%			
		Mean:	173.10		
		SD:	224.22		
		Range:	0-1,097		
		Median:	77.50		



Time Between First Appointment and Completion of Diagnosis

All Clients To Date			n = 508		
First Appointment to Completion of Diagnosis	n	%			
0 to 7	42	8.3%			
8 to 30	98	19.3%			
31 to 60	68	13.4%			
61 to 90	54	10.6%			
91 to 120	39	7.7%			
121 to 150	18	3.5%			
151 to 180	13	2.6%			
181 to 210	11	2.2%			
211 to 240	11	2.2%			
241 to 270	7	1.4%			
271 to 300	7	1.4%			
301 to 330	1	0.2%			
331 to 360	6	1.2%			
more than 360	23	4.5%			
Missing	110	21.7%			
		Mean:	84.78		
		SD:	147.39		
		Range:	0-1,621		
		Median:	34.00		

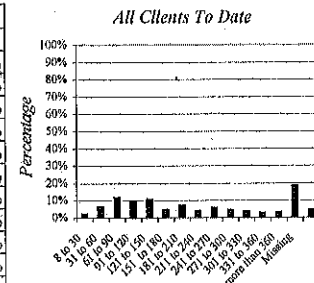
Clients This Period			n = 131		
First Appointment to Completion of Diagnosis	n	%			
0 to 7	7	5.3%			
8 to 30	24	18.3%			
31 to 60	18	13.7%			
61 to 90	14	10.7%			
91 to 120	12	9.2%			
121 to 150	4	3.1%			
151 to 180	6	4.6%			
181 to 210	2	1.5%			
211 to 240	4	3.1%			
241 to 270	4	3.1%			
271 to 300	2	1.5%			
301 to 330	0	0.0%			
331 to 360	1	0.8%			
more than 360	3	2.3%			
Missing	30	22.9%			
		Mean:	77.26		
		SD:	111.67		
		Range:	0-744		
		Median:	40.00		



Time Between Referral and Completion of Diagnosis

All Clients To Date			n = 508		
Referral to Completion of Diagnosis	n	%			
0 to 7	11	2.2%			
8 to 30	33	6.5%			
31 to 60	60	11.8%			
61 to 90	50	9.8%			
91 to 120	54	10.6%			
121 to 150	24	4.7%			
151 to 180	37	7.3%			
181 to 210	20	3.9%			
211 to 240	29	5.7%			
241 to 270	22	4.3%			
271 to 300	19	3.7%			
301 to 330	14	2.8%			
331 to 360	16	3.1%			
more than 360	95	18.7%			
Missing	24	4.7%			
		Mean:	225.37		
		SD:	227.36		
		Range:	0-1,639		
		Median:	143.50		

Clients This Period			n = 131		
Referral to Completion of Diagnosis	n	%			
0 to 7	1	0.8%			
8 to 30	8	6.1%			
31 to 60	15	11.5%			
61 to 90	6	4.6%			
91 to 120	16	12.2%			
121 to 150	7	5.3%			
151 to 180	11	8.4%			
181 to 210	7	5.3%			
211 to 240	9	6.9%			
241 to 270	9	6.9%			
271 to 300	4	3.1%			
301 to 330	2	1.5%			
331 to 360	4	3.1%			
more than 360	29	22.1%			
Missing	3	2.3%			
		Mean:	250.96		
		SD:	236.92		
		Range:	7-1,187		
		Median:	181.00		



Note: The "period" referred to in this report is April 2004 through March 2005.

The dates reflected in these graphs were added to the revised DHSS Office of FAS Diagnostic Team Data Collection Report (May 2002). Therefore, only data reported on the revised form are presented. Of the 757 forms submitted, 508 were revised forms.

Appendix A
Diagnostic Team Data Collection Reports

