

Summary Report of the Alaska Multidisciplinary FAS Diagnostic Team Data

*Prepared by ACSES Staff
September, 2002*

Executive Summary

This report presents a thorough analysis of the diagnostic data reported by the *Alaska Multidisciplinary FAS Diagnostic Teams*. Included is a summary of the teams' data from 1999 through June 2002. The primary purpose of this report is to provide feedback to teams regarding their productivity and outcomes, with an 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, six fully functional diagnostic teams are conducting FASD diagnoses in the state of Alaska, six additional teams are in developmental stages, and two teams have been disbanded. Using the *DHSS Office of FAS Diagnostic Team Data Collection Reports*, eight of these 14 diagnostic teams submitted 314 completed datasheets. Of these 314 datasheets, two did not include a 4-digit diagnosis and nine were duplicates, leaving a total of 303 usable datasheets. The teams that submitted datasheets and their corresponding number of assessments are as follows: Barrow (one), Bethel (80; one without diagnosis), Bristol Bay (4), Copper Center (18), Fairbanks (11), Kenai/Soldotna (86), Providence Alaska Medical Center (13), and Southcentral Foundation (92; one without diagnosis). Of the 303 individuals for whom diagnoses were submitted, 32 (10.6%) were diagnosed with FAS or atypical FAS.

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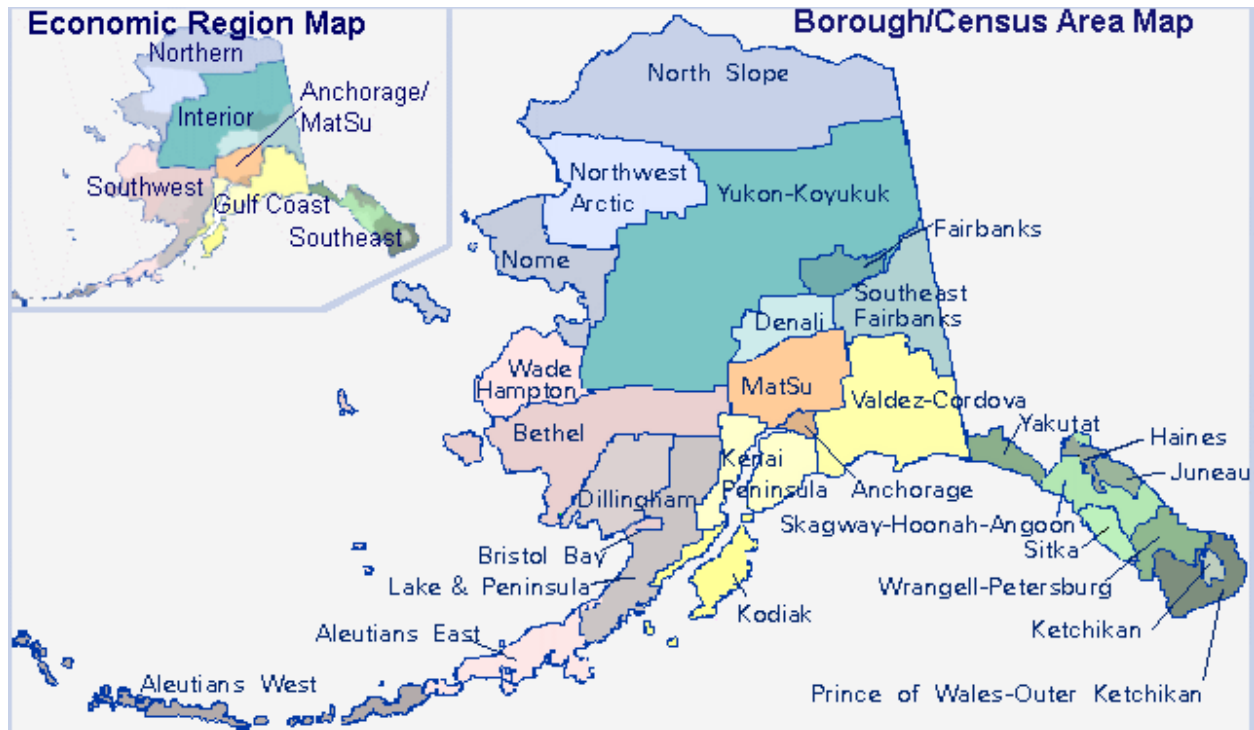
Background Information

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. 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). These high rates of alcohol use in the state of Alaska have resulted in some of the nation's highest Fetal Alcohol Syndrome (FAS), Fetal Alcohol Effects (FAE), and Fetal Alcohol and Drug Effects (FADE) rates, with regional variations of up to 20 per 1000 births (Alaska Native Health Board, 1988). The *2001 Status Update: Alaska's Response to Fetal Alcohol Syndrome* published by Department of Health and Social Services (DHSS, 2001) 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 rate of Alaskan children born with some level of prenatal alcohol exposure was much higher, being reported at 12.6 per 1,000 births. These figures translate into staggering numbers of affected infants born in Alaska every year.

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 FAS Multidisciplinary Community Diagnostic Teams for screening children particularly, those in children in state custody, at high risk and for FAS and other alcohol-related birth defects (ARBD) was perhaps the most central aspect of the Alaska FAS Prevention Project. 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. Figure One provides the geographic distribution of the *Alaska Multidisciplinary FAS Diagnostic Teams*.

At the request of the State Office of FAS, the *Alaska Comprehensive and Specialized Evaluation Services* (ACSES) 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 1999 through June 2002.

Map



Methodology

Diagnostic Team Data Processing Procedures

In response to a State Office of FAS request, ACSES provides technical support and assistance for the processing of diagnostic data collected through the diagnostic teams. More specifically, ACSES 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, ACSES 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 ACSES 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 ACSES. Following are detailed descriptions of ACSES procedures related to data receipt, 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 Reports* for each individual for which a diagnosis has been completed. The State Office of FAS, in turn, forwards copies of these datasheets to ACSES 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 ACSES 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, ACSES 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, ACSES achieves virtually error-free data entry.

ACSES, 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 FAS Project Manager always acts 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 Manager contacts the appropriate team to obtain this information when missing or illegible. During this first edit, the Project Manager reviews 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 ACSES 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 ACSES 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 FAS 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>). ACSES 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. ACSES 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 Analyses Procedures

ACSES 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 ACSES. Because data that ACSES staff handle routinely are of a critically sensitive nature, ACSES 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. ACSES 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 ACSES 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 ACSES-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 ACSES, the DEC server is accessible only by ACSES 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, ACSES 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.

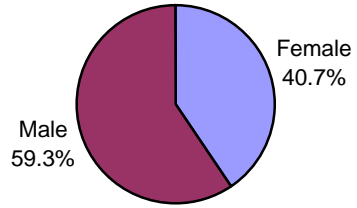
Summary of Results

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 both the data elements common across both versions, as well as the data elements unique to each version.

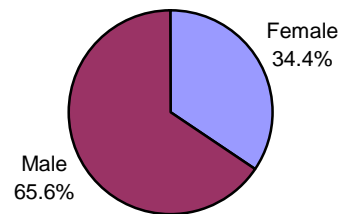
The reader is encouraged to review the data tables and graphs carefully as the bulk of the information is not repeated here in narrative format due to the wealth of information contained in the tables. A careful review of the tables will give the reader a comprehensive picture of these findings.

Client Demographics
Client's Gender

All Clients		
<i>n</i> = 305	n	%
Female	124	40.7
Male	181	59.3

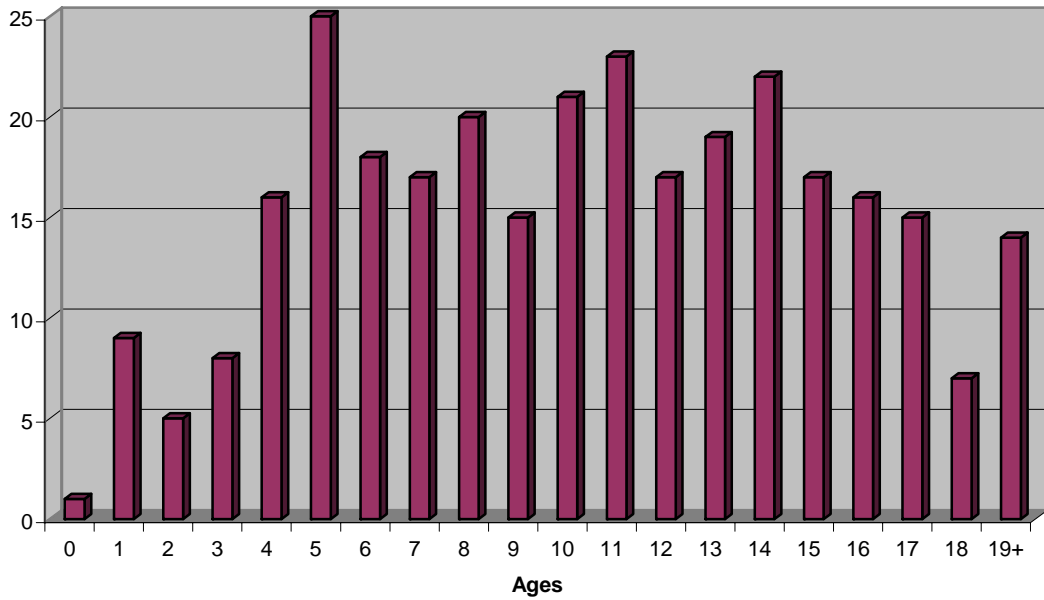


Clients with FAS/AFAS		
<i>n</i> = 32	n	%
Female	11	8.9
Male	21	11.69



Client's Age at Diagnosis

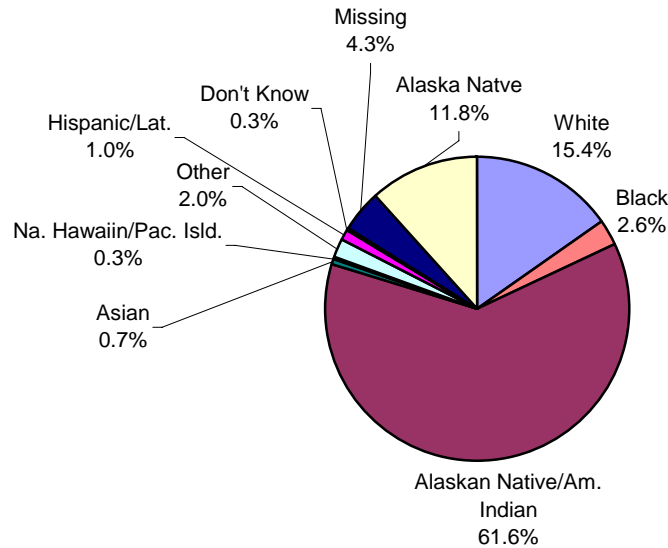
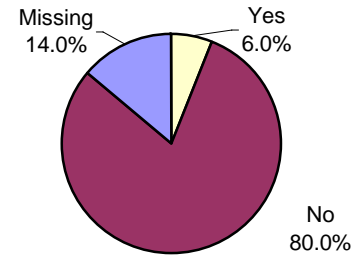
Client Age at Diagnosis <i>n</i> = 305					
Years	n	%	Years	n	%
0	1	0.3	16	16	5.2
1	9	3.0	17	15	4.9
2	5	1.6	18	7	2.3
3	8	2.6	19	1	0.3
4	16	5.2	20	1	0.3
5	25	8.2	21	1	0.3
6	18	5.9	25	1	0.3
7	17	5.6	27	2	0.7
8	20	6.6	28	1	0.3
9	15	4.9	29	1	0.3
10	21	6.9	30	1	0.3
11	23	7.5	32	1	0.3
12	17	5.6	36	1	0.3
13	19	6.2	41	1	0.3
14	22	7.2	42	1	0.3
15	17	5.6	44	1	0.3



Client's Ethnicity

Client's Primary Ethnicity		
<i>n</i> = 305	<i>n</i>	%
White	47	15.4
Black	8	2.6
Alaskan Native/Am. Indian	188	61.6
Asian	2	0.7
Na. Hawaiian/Pac. Isld.	1	0.3
Other	6	2
Hispanic/Latino	3	1.0
Don't Know	1	0.3
Missing	13	4.3
Alaska Native	36	11.8

Hispanic or Latino Heritage		
<i>n</i> = 49	<i>n</i>	%
Yes	3	6.1
No	39	79.6
Missing	7	14.3



- 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 Latino heritage. Therefore, data (*n* = 49) collected after May 2002 reflect these changes.
- As many as two ethnicities were recorded per client with the least prevalent ethnicity recorded as the client's primary ethnicity.

Client's Community of Residence

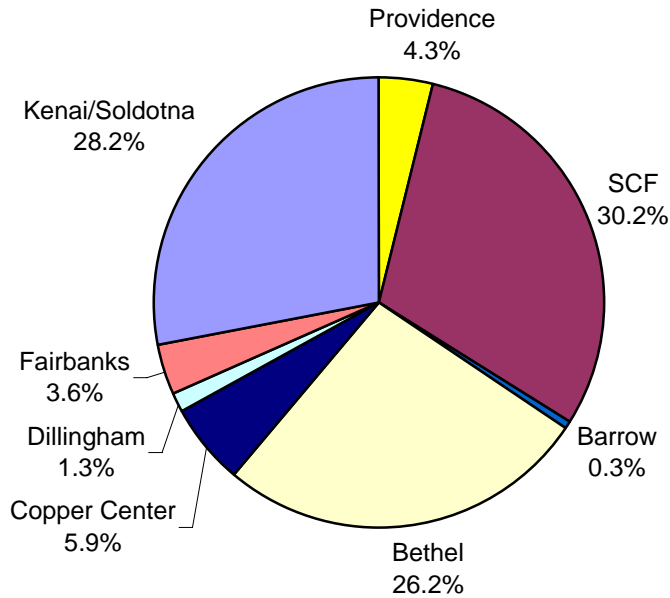
Primary Community of Residence		
<i>n</i> = 305	<i>n</i>	%
Akiachak	3	1.0
Akiak	1	0.3
Alakanuk	4	1.3
Anchor Point	0	0.0
Anchorage	83	27.2
Aniak	3	1.0
Atmautlaug	1	0.3
Barrow	1	0.3
Bethel	35	11.5
Chevak	1	0.3
Chitina	1	0.3
Chugiak	1	0.3
Clam Gulch	2	0.7
Copper Center	10	3.3
Dillingham	2	0.7
Dutch Harbor	2	0.7
Eagle River	5	1.6
Eek	1	0.3
Emmonak	4	1.3
Fairbanks	10	3.3
Fort Richardson	2	0.7
Gakona	0	0.0
Glenallen	6	2.0
Gulkana	1	0.3
Homer	9	3
Hooper Bay	1	0.3
Igiugig	1	0.3
Kaktovik	1	0.3
Kalskag (Lower)	1	0.3
Kalskag (Upper)	0	0
Kasilof	2	0.7

Kenai	25	8.2
Kwethluk	2	0.7
Mekoryuk	3	1
Mountain Village	1	0.3
Nanwalek	1	0.3
Napakiak	2	0.7
Newhalen	1	0.3
Newtok	2	0.7
Nikiski	6	2
Nikolaevsk	1	0.3
Ninilchik	0	0
Nunam Iqua	1	0.3
Nunapitchuk	2	0.7
Palmer	0	0
Pilot Station	4	1.3
Quinhagak	1	0.3
Salcha	1	0.3
Selawik	1	0.3
Seldovia	1	0.3
Seward	5	1.6
Soldotna	25	8.2
St. Mary's	1	0.3
St. Paul Island	2	0.7
Stebbins	1	0.3
Sterling	2	0.7
Tazlina	1	0.3
Togiak	1	0.3
Toksook Bay	2	0.7
Tuluksak	3	1
Tununak	1	0.3
Unknown	8	2.6
Wasilla	4	1.3

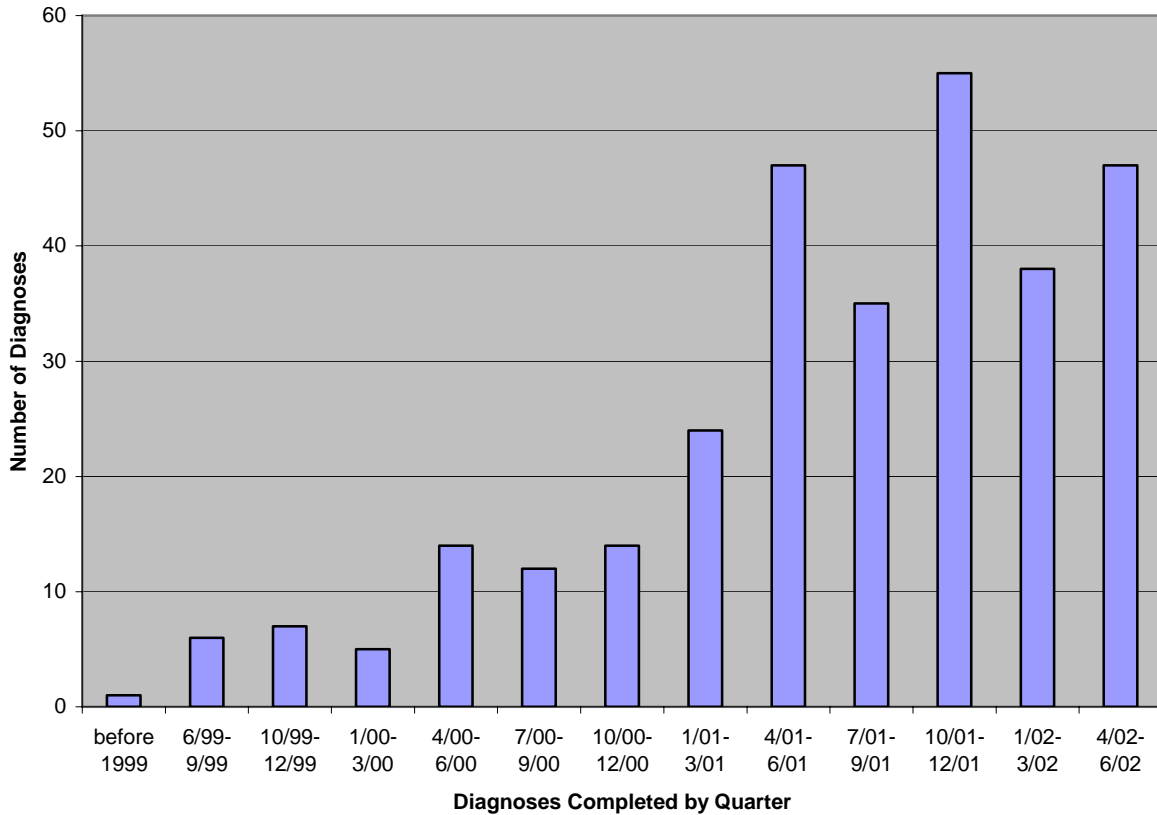
Number of Clients Diagnosed by Each Diagnostic Team

Diagnoses by Diagnostic Team			
<i>n</i> = 305	Location	<i>n</i>	%
Center for Children w/Special Needs	Anchorage	13	4.3
Southcentral Foundation (SCF)	Anchorage	92	30.2
Barrow	Barrow	1	0.3
Yukon-Kuskokwim Health Corporation	Bethel	80	26.2
Multidisc. Dev. Disab. Diag. Team	Copper Center	18	5.9
Bristol Bay Comm. FAS Diag. Team	Dillingham	4	1.3
Fairbanks Fetal Alco. Comm. Eval. Serv. Team	Fairbanks	11	3.6
Kenai Penn. Multidisc. FAS Diag. Team	Kenai/Soldotna	86	28.2

- Two forms were submitted without 4-digit diagnostic codes, one from Bethel and one from Southcentral Foundation.



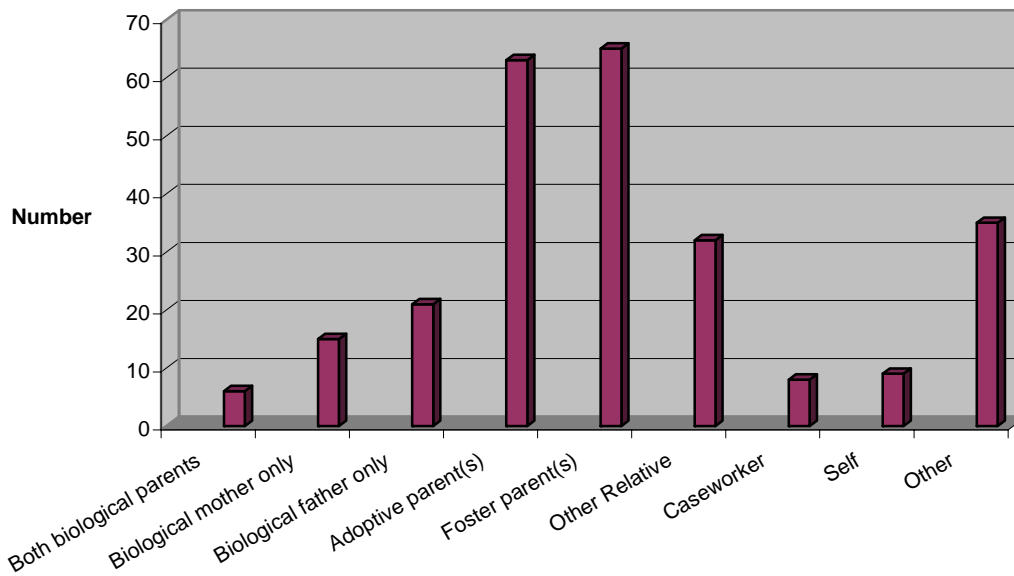
Number of Diagnoses Completed by Quarter	
before 1999	1
June 1999 to September 1999	6
October 1999 to December 1999	7
January 2000 to March 2000	5
April 2000 to June 2000	14
July 2000 to September 2000	12
October 2000 to December 2000	14
January 2001 to March 2001	24
April 2001 to June 2001	47
July 2001 to September 2001	35
October 2001 to December 2001	55
January 2002 to March 2002	38
April 2002 to June 2002	47



Client Referral and Background Information

“Who brought this client in for diagnosis?”

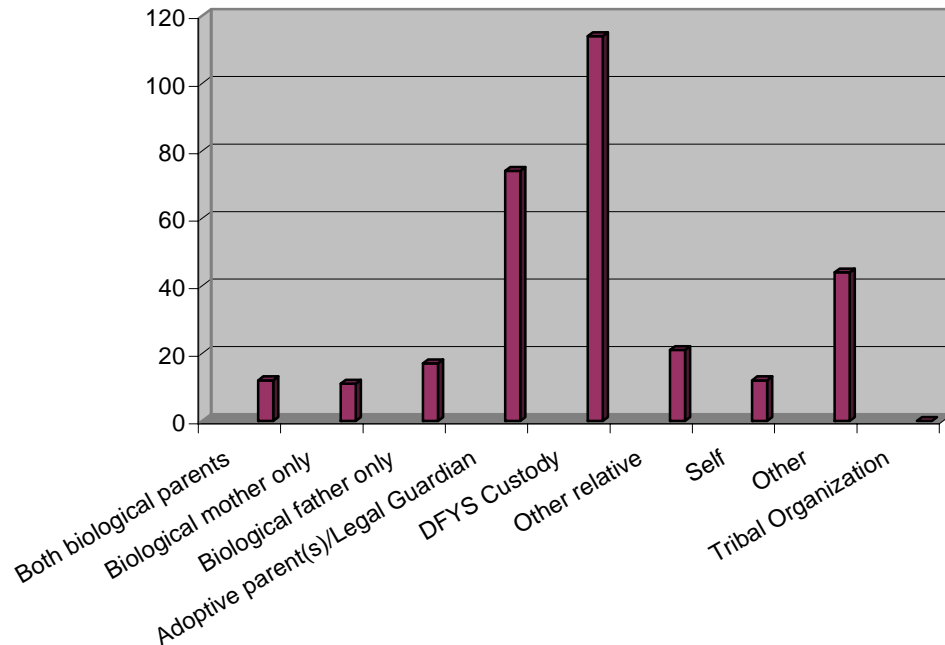
Person Accompanying Client for Diagnosis		
<i>n</i> = 256	n	%
Both biological parents	6	2.4
Biological mother only	15	5.9
Biological father only	21	8.3
Adoptive parent(s)	63	24.8
Foster parent(s)	65	25.6
Other Relative	32	12.6
Caseworker	8	3.1
Self	9	3.5
Other	35	13.8



- This data element was excluded on the revised *DHSS Office of FAS Diagnostic Team Data Collection Report* (May 2002). Therefore, only data reported on the original form during the time period between 1999 to April 2002 are presented here.
- Totals may add up to more than the total number of clients due to clients with more than one person reported as escorting the client for diagnosis. An unlimited number of escorts were accepted and entered per client.

“Who has legal custody of this client?”

Legal Custody of Client		
<i>n</i> = 305	<i>n</i>	%
Both biological parents	12	3.9
Biological mother only	11	3.6
Biological father only	17	5.6
Adoptive parent(s)/Legal Guardian	74	24.3
DFYS Custody	114	37.4
Other relative	21	6.9
Self	12	3.9
Other	44	14.4
Tribal Organization	0	0.0



- 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.

Client's Legal Custodian

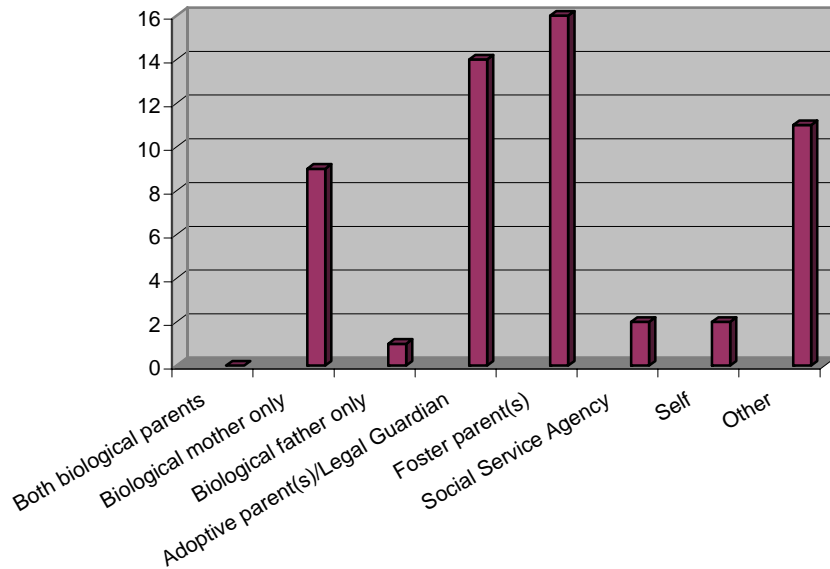
Legal Custody Other Specify		
<i>n</i> = 305	<i>n</i>	%
Attorney	2	0.7
BYF	3	1.0
DJJ	4	1.3
Foster Parents	8	2.6
Grandparents	2	0.7
JPO	1	0.3
JUV	1	0.3
Legal Guardian	7	2.3
Residential/IP Tx	1	0.3
Single Parent	1	0.3
Social Worker	3	1.0
State	1	0.3
Illegible response	2	0.7
Don't Know	7	2.3
Missing	8	2.6
Not Applicable	254	83.3

Legal Custody Other Relative Specify		
<i>n</i> = 256	<i>n</i>	%
Aunt/Uncle	5	2.0
Foster Parents	2	0.8
Grandparents	8	3.1
Sibling	1	0.4
Step parents	2	0.8
Missing	11	4.3
Not Applicable	227	88.7

- 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.

Who is the client’s primary caregiver?

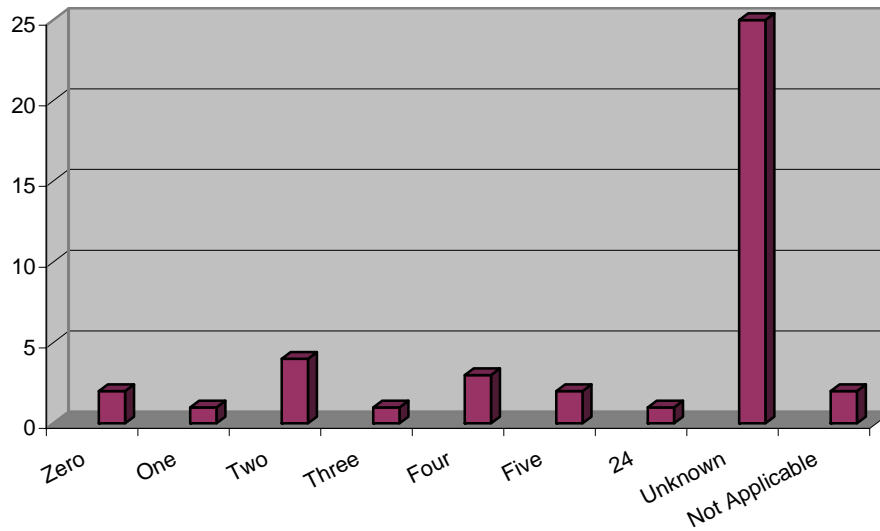
Primary Caregiver		
<i>n</i> = 49	n	%
Both biological parents	0	0.0
Biological mother only	9	16.4
Biological father only	1	1.8
Adoptive parent(s)/Legal Guardian	14	25.5
Foster parent(s)	16	29.1
Social Service Agency	2	3.6
Self	2	3.6
Other	11	20.0



- 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 from the time period beginning May 2002 to June 2002 are presented here.

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

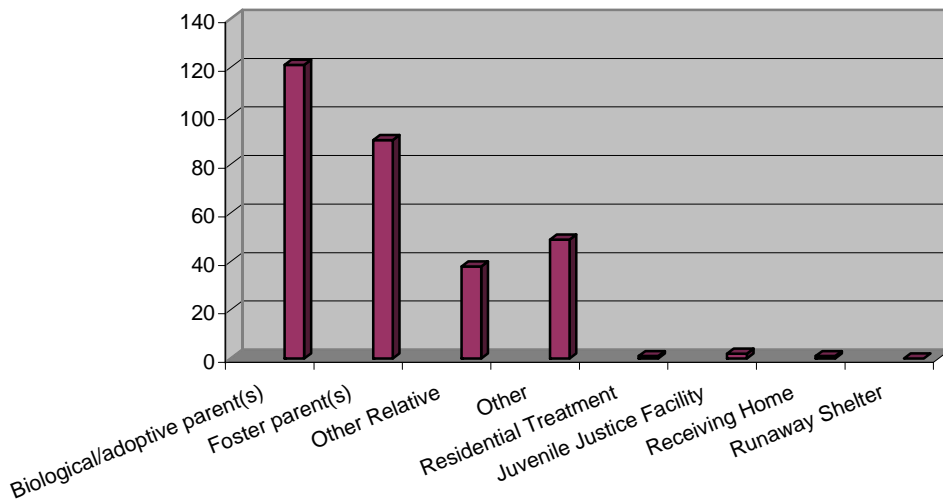
Number of Previous Placements		
<i>n</i> = 49	<i>n</i>	%
Zero	2	4.9
One	1	2.4
Two	4	9.8
Three	1	2.4
Four	3	7.3
Five	2	4.9
24	1	2.4
Unknown	25	61
Not Applicable	2	4.9



- 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 from the time period beginning May 2002 to June 2002 are presented here.

“Who does this client currently live with?”

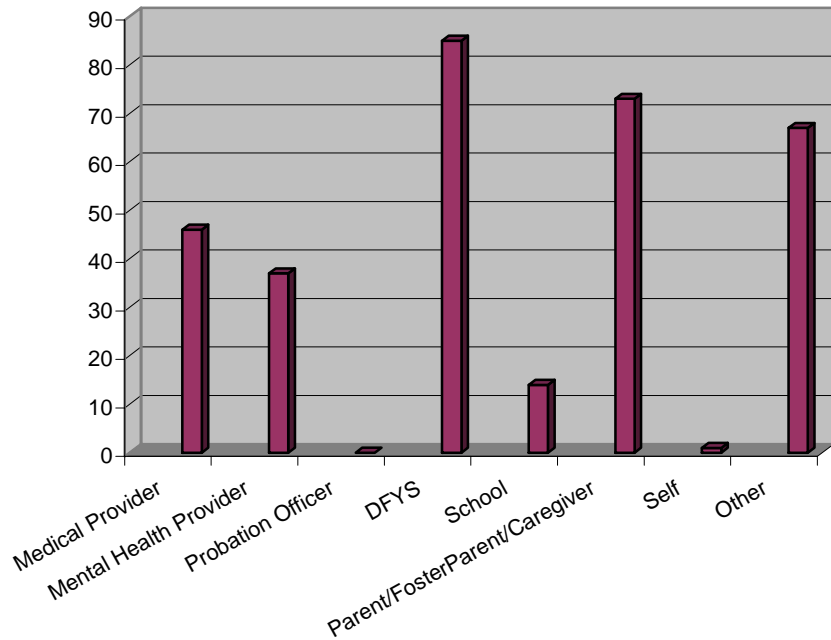
With Whom/Where Client Currently Lives		
<i>n</i> = 305	n	%
Biological/adoptive parent(s)	121	40.1
Foster parent(s)	90	29.8
Other Relative	38	12.6
Other	49	16.2
Residential Treatment	1	0.3
Juvenile Justice Facility	2	0.7
Receiving Home	1	0.3
Runaway Shelter	0	0.0



- Due to the revision of the reporting form, data reported before May 2002 maintained separate categories for *both biological parents, biological mother only, biological father only, and adoptive parent(s)*. The revised form, contains a category of *biological/adoptive parents or legal guardian*. This table collapses these data points into one category of *biological/adoptive parent(s)*.

“Who referred this client for an FASD assessment?”

Referring Agent		
<i>n</i> = 305	<i>n</i>	%
Medical Provider	46	14.2
Mental Health Provider	37	11.5
Probation Officer	0	0.0
DFYS	85	26.3
School	14	4.3
Parent/FosterParent/Caregiver	73	22.6
Self	1	0.3
Other	67	20.7

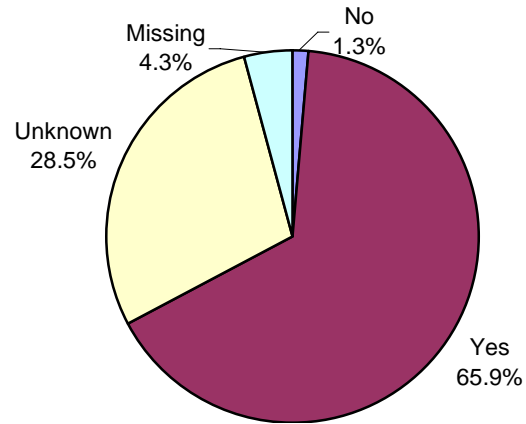


- Totals may add up to more than the total number of clients (n) due to clients with more than one recorded referring agent. An unlimited number of referral sources were accepted and entered per client.

Birth Mother's Childbirth History

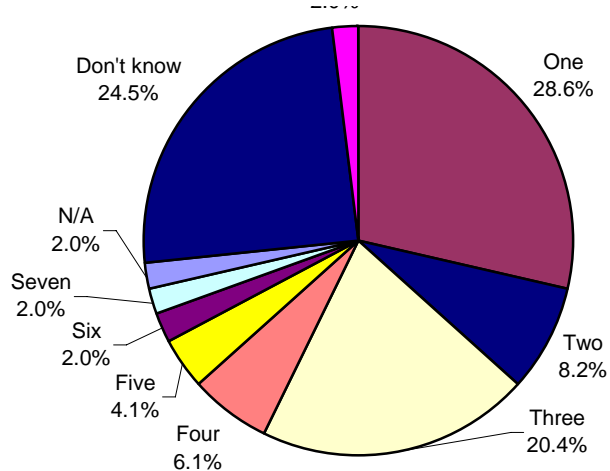
Birth mothers with other children

Biological Mother Gave Birth to Other Children		
<i>n</i> = 305	<i>n</i>	%
No	4	1.3
Yes	201	65.9
Unknown	87	28.5
Missing	13	4.3



Number of other children born to birthmother

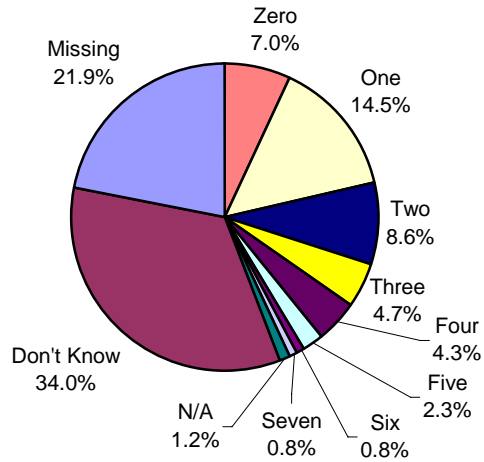
Other Birth Siblings		
<i>n</i> = 49	<i>n</i>	%
One	14	28.6
Two	4	8.2
Three	10	20.4
Four	3	6.1
Five	2	4.1
Six	1	2.0
Seven	1	2.0
N/A	1	2.0
Don't know	12	24.5
Missing	1	2.0



- This data element was added to the revised *DHSS Office of FAS Diagnostic team Data Collection Report*. Therefore, only data reported on the revised form from the time period beginning May 2002 are presented here.
- Among the 49 cases, 35 mothers were identified as having given birth to other children. The average number of children per mother was 2.49 with a standard deviation of 1.60 and ranged in number from one to seven additional children.

Number of children older than the client

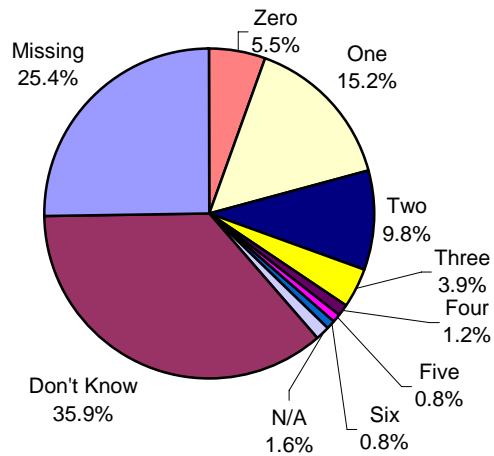
Older Birth Siblings		
<i>n</i> = 256	<i>n</i>	%
Zero	18	7.0
One	37	14.5
Two	22	8.6
Three	12	4.7
Four	11	4.3
Five	6	2.3
Six	2	0.8
Seven	2	0.8
N/A	3	1.2
Don't Know	87	34.0
Missing	56	21.9



- This data element was excluded on the revised *DHSS Office of FAS Diagnostic Team Data Collection Report*. Therefore, only data reported on the original form from the time period between 1999 to April 2002 are presented here.
- Among the 256 clients assessed, 92 had older siblings. The average number of older siblings was 2.36 with a standard deviation of 1.54 and ranged in number from one to seven siblings.

Number of children younger than the client

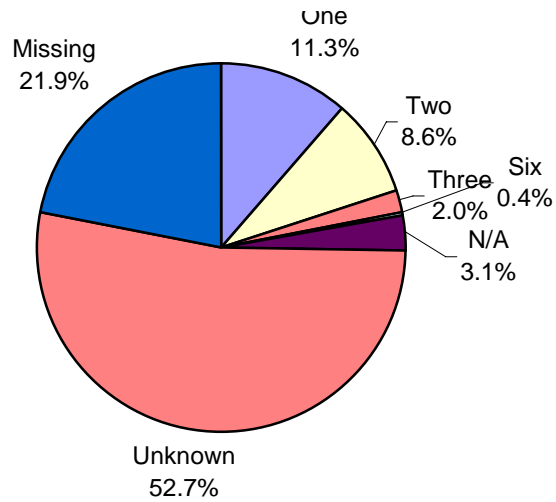
Younger Birth Siblings		
<i>n</i> = 256	<i>n</i>	%
Zero	14	5.5
One	39	15.2
Two	25	9.8
Three	10	3.9
Four	3	1.2
Five	2	0.8
Six	2	0.8
N/A	4	1.6
Don't Know	92	35.9
Missing	65	25.4



- This data element was excluded on the revised *DHSS Office of FAS Diagnostic Team Data Collection Report*. Therefore, only data reported on the original form from the time period between 1999 to April 2002 are presented here.
- Among the 256 clients assessed, 81 had younger siblings. The average number of younger siblings was 1.89 with a standard deviation of 1.17 and ranged in number from one to seven siblings.

Number of diagnosed siblings

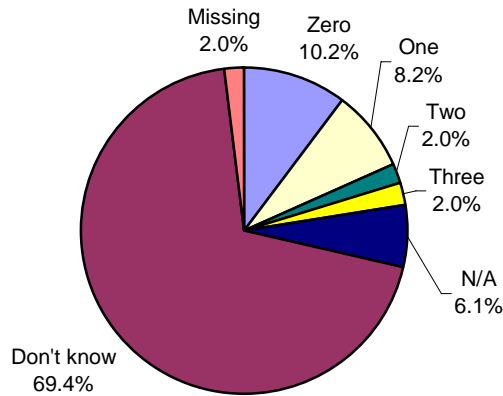
Diagnosed Siblings		
<i>n</i> = 256	<i>n</i>	%
One	29	11.3
Two	22	8.6
Three	5	2
Six	1	0.4
N/A	8	3.1
Unknown	135	52.7
Missing	56	21.9



- This data element was excluded on the revised *DHSS Office of FAS Diagnostic Team Data Collection Report*. Therefore, only data reported on the original form from the time period between 1999 to April 2002 are presented here.
- Among the 256 clients who were assessed, 57 had other siblings who had been diagnosed with FAS. The average number of diagnosed siblings was 1.65 with a standard deviation of 10.88 and ranged in number from one to six diagnosed siblings per client.

Number of diagnosed older siblings

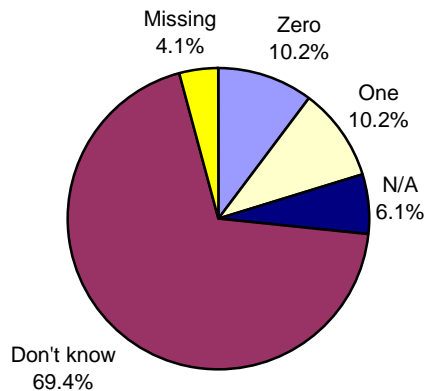
Diagnosed Older Birth Siblings		
<i>n</i> = 49	<i>n</i>	%
Zero	5	10.2
One	4	8.2
Two	1	2.0
Three	1	2.0
N/A	3	6.1
Don't know	34	69.4
Missing	1	1.0



- This data element was added to the revised *DHSS Office of FAS Diagnostic Team Data Collection Report*. Therefore, only data reported on the revised form from the time period beginning May 2002 are presented here.
- Among the 49 clients who were assessed, six had older diagnosed siblings. The average number of older diagnosed siblings was 1.5 with a standard deviation of 0.84 and ranged in number from one to three diagnosed siblings per client.

Number of diagnosed younger siblings

Diagnosed Younger Birth Siblings		
<i>n</i> = 49	<i>n</i>	%
Zero	5	10.2
One	5	10.2
N/A	3	6.1
Don't know	34	69.4
Missing	2	4.1

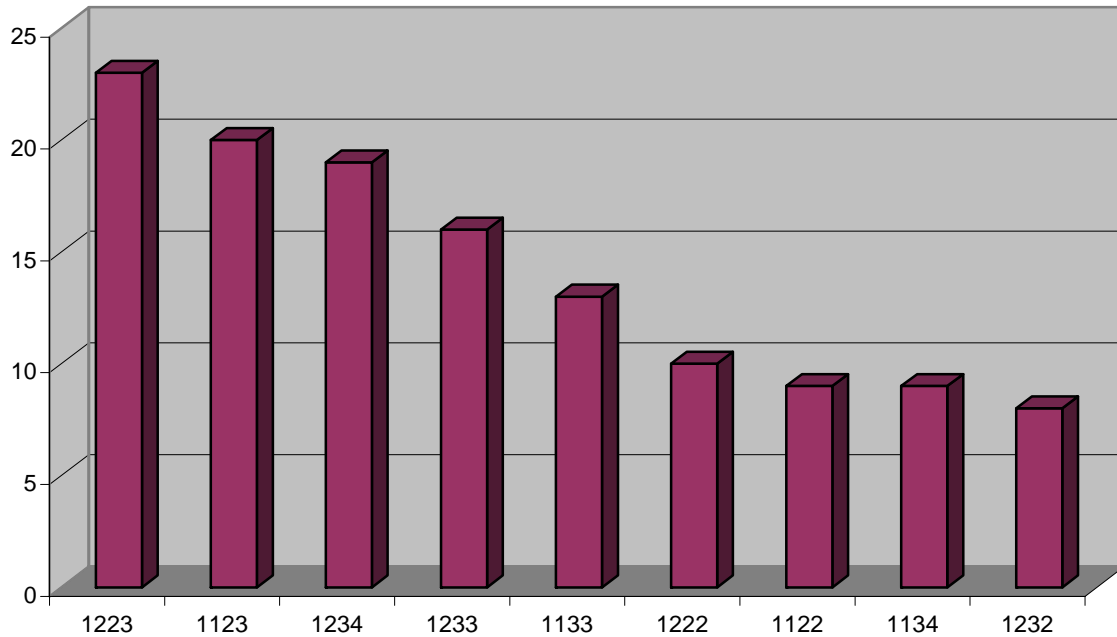


- This data element was added to the revised *DHSS Office of FAS Diagnostic Team Data Collection Report*. Therefore, only data reported on the revised form from the time period beginning May 2002 are presented here.
- Among the 49 clients who were assessed, five had younger diagnosed siblings. The average number of younger diagnosed siblings was 1.0 with a standard deviation of 0.0.

FAS Diagnostic Information

Most Commonly Occurring 4-Digit Diagnostic Categories

Most Common Dx Codes			
<i>n</i> = 303	Dx Code	<i>n</i>	%
Neurobehavioral disorder (alcohol exposed)	1223	23	7.5
Neurobehavioral disorder (alcohol exposed)	1123	20	6.6
Static encephalopathy (alcohol exposed)	1234	19	6.2
Static encephalopathy (alcohol exposed)	1233	16	5.2
Static encephalopathy (alcohol exposed)	1133	13	4.3
Neurobehavioral disorder (alcohol exposure unknown)	1222	10	3.3
Neurobehavioral disorder (alcohol exposure unknown)	1122	9	3.0
Static encephalopathy (alcohol exposed)	1134	9	3.0
Static encephalopathy (alcohol exposure unknown)	1232	8	2.6



- Appendix B provides a complete listing of 4-digit diagnostic codes.

Frequency of Diagnoses

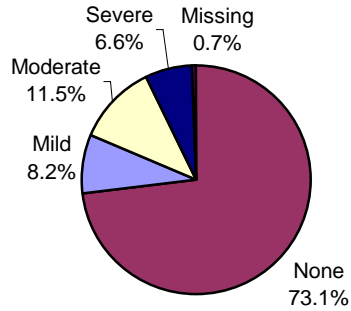
Frequency of Diagnoses			
Diagnoses: <i>n</i> = 303	Category	<i>n</i>	%
Fetal alcohol syndrome (alcohol exposed)	A	10	3.3
Fetal alcohol syndrome (alcohol exposure unknown)	B	2	0.7
Atypical fetal alcohol syndrome (alcohol exposed)	C	20	6.6
Fetal alcohol syndrome phenocopy (no alcohol exposure)	D	0	0.0
Sentinel physical findings/static encephalopathy (alcohol exposed)	E	42	13.9
Static encephalopathy (alcohol exposed)	F	81	26.7
Sentinel physical findings/neurobehavioral disorder (alcohol exp)	G	23	7.6
Neurobehavioral disorder (alcohol exposed)	H	54	17.8
Sentinel physical findings (alcohol exposed)	I	4	1.3
No cognitive/behavioral or sentinel physical findings detected (alcohol exp)	J	5	1.7
Sentinel physical findings/static encephalopathy (alcohol exp unknown)	K	12	4.0
Static encephalopathy (alcohol exposure unknown)	L	15	5.0
Sentinel physical findings/neurobehavioral disorder (alcohol exp unknown)	M	10	3.3
Neurobehavioral disorder (alcohol exposure unknown)	N	19	6.3
Sentinel physical findings (alcohol exposure unknown)	O	1	0.3
No cog./behavioral or sentinel physical findings detected (alcohol exp unknown)	P	3	1
Sentinel physical findings /static encephalopathy (no alcohol exp)	Q	0	0.0
Static encephalopathy (no alcohol exposure)	R	1	0.3
Sentinel physical findings/neurobehavioral disorder (no alcohol exp)	S	0	0
Neurobehavioral disorder (no alcohol exposure)	T	1	0.3
Sentinel physical findings (no alcohol exposure)	U	0	0.0
No cognitive/behavioral or sentinel physical findings detected (no alcohol exp)	V	0	0.0

Clients with Evidence of Organic Brain Damage

Clients with Evidence of Organic Brain Damage		
<i>n</i> = 303	<i>n</i>	%
Static encephalopathy (FAS or AFAS)	32	10.6
Static encephalopathy (not FAS or AFAS)	151	49.8
Neurobehavioral disorder	107	35.3
No evidence of organic brain damage	13	4.3
Missing	2	

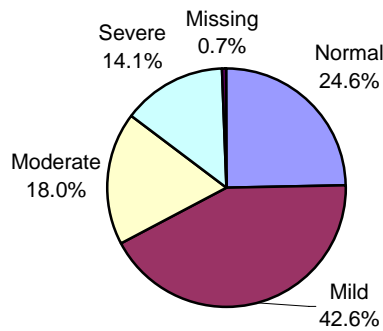
Diagnostic Ranks for Growth, Face, Brain, and Alcohol Growth

Growth Deficiency		
<i>n</i> = 305	<i>n</i>	%
None	223	73.1
Mild	25	8.2
Moderate	35	11.5
Severe	20	6.6
Missing	2	0.7



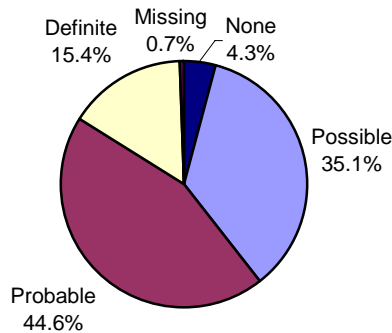
Face

Facial Phenotype		
<i>n</i> = 305	<i>n</i>	%
Normal	75	24.6
Mild	130	42.6
Moderate	55	18.0
Severe	43	14.1
Missing	2	0.7



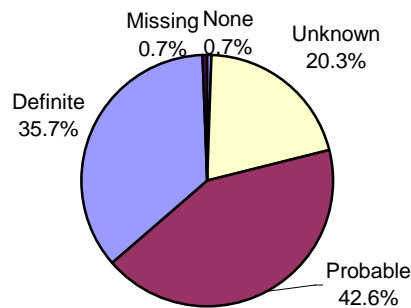
Brain

Probability of Brain Damage		
<i>n</i> = 305	<i>n</i>	%
None	13	4.3
Possible	107	35.1
Probable	136	44.6
Definite	47	15.4
Missing	2	0.7



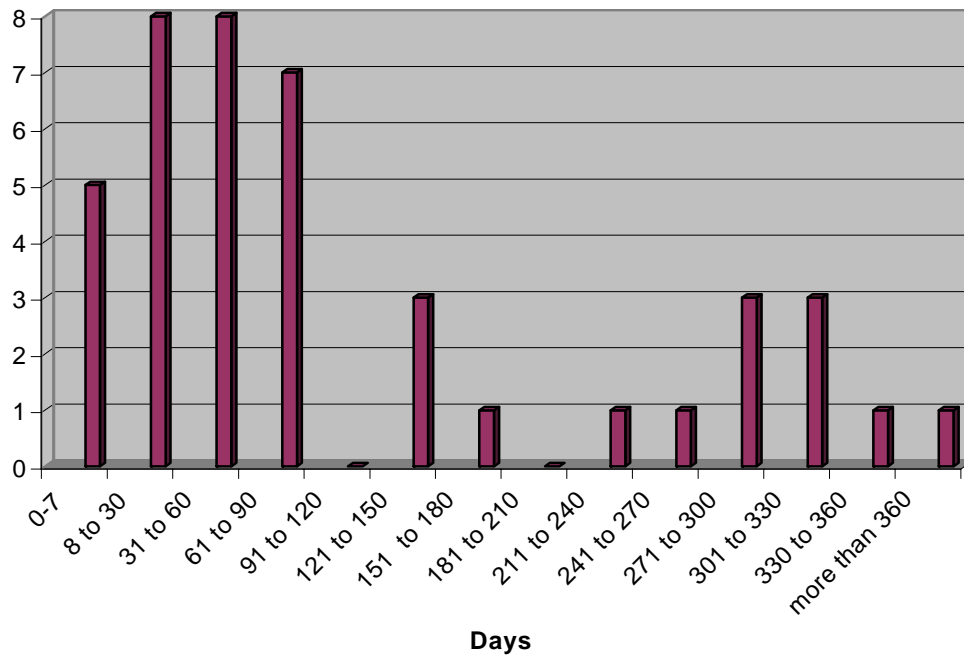
Alcohol

Prenatal Alcohol Exposure		
<i>n</i> = 305	<i>n</i>	%
None	2	0.7
Unknown	62	20.3
Probable	130	42.6
Definite	109	35.7
Missing	2	0.7



Length of time from referral to first appointment

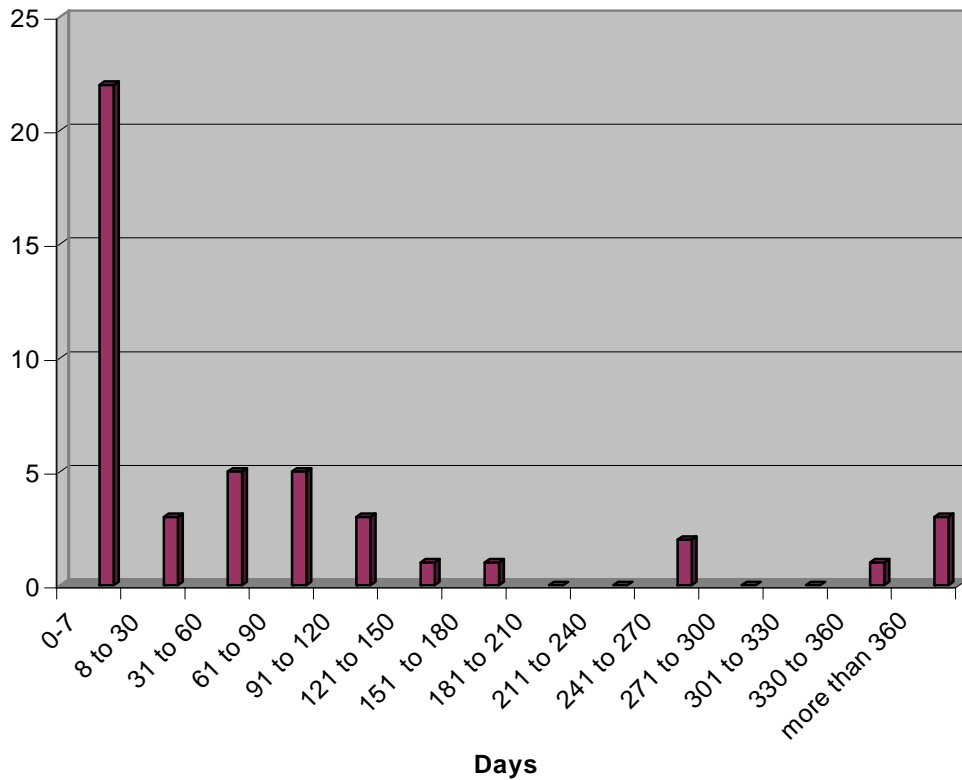
Referral to First Appointment		
<i>n</i> =42	n	%
0-7	5	11.9
8 to 30	8	19.0
31 to 60	8	19.0
61 to 90	7	16.7
91 to 120	0	0.0
121 to 150	3	7.1
151 to 180	1	2.4
181 to 210	0	0.0
211 to 240	1	2.4
241 to 270	1	2.4
271 to 300	3	7.1
301 to 330	3	7.1
330 to 360	1	2.4
more than 360	1	2.4



- The *date of initial referral* and *date of first appointment* were added to the revised *DHSS Office of FAS Diagnostic Team Data Collection Report* (May 2002). Therefore, only data reported on the revised form from the time period beginning May 2002 to June 2002 are presented here.
- Of the 42 datasheets reporting the *date of referral* and *first appointment* the average was 116.5 days with a standard deviation of 136.3 and a median of 59 days.

Length of time from first appointment to completion of diagnosis

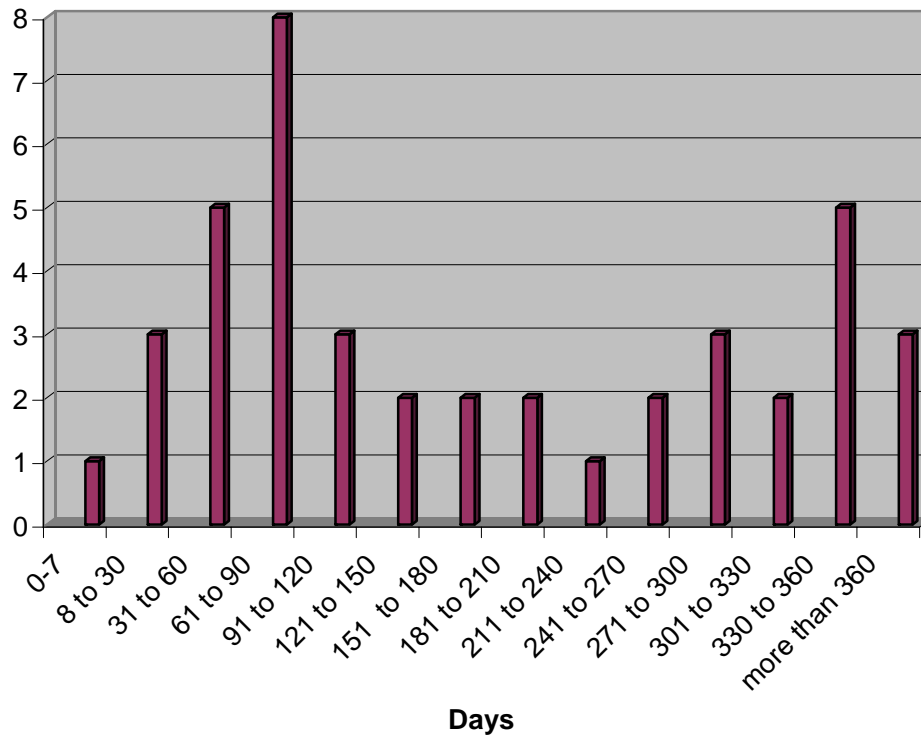
First Appointment to Completion of Diagnosis		
<i>n</i> = 46	n	%
0-7	22	47.8
8 to 30	3	6.5
31 to 60	5	10.9
61 to 90	5	10.9
91 to 120	3	6.5
121 to 150	1	2.2
151 to 180	1	2.2
181 to 210	0	0.0
211 to 240	0	0.0
241 to 270	2	4.3
271 to 300	0	0.0
301 to 330	0	0.0
330 to 360	1	2.2
more than 360	3	6.5



- The *date of first appointment* was added to the revised *DHSS Office of FAS Diagnostic Team Data Collection Report* (May 2002). Therefore, only data reported on the revised form from the time period beginning May 2002 to June 2002 are presented here.
- Of the 46 datasheets reporting the *date of first appointment* the average was 74.5 days with a standard deviation of 119.3 and a median of 9 days.

Length of time from referral to completion of diagnosis

Referral to Completion of Diagnosis		
<i>n</i> = 42	n	%
0-7	1	2.4
8 to 30	3	7.1
31 to 60	5	11.9
61 to 90	8	19.0
91 to 120	3	7.1
121 to 150	2	4.8
151 to 180	2	4.8
181 to 210	2	4.8
211 to 240	1	2.4
241 to 270	2	4.8
271 to 300	3	7.1
301 to 330	2	4.8
330 to 360	5	11.9
more than 360	3	7.1



- The *Date of Initial Referral* was added to the revised *DHSS Office of FAS Diagnostic Team Data Collection Report* (May 2002). Therefore, only data reported on the revised form from the time period beginning May 2002 to June 2002 are presented here.
- Of the 42 datasheets reporting the *date of referral* the average was 181.4 days with a standard deviation of 143.2 and a median of 136 days.