NEVADA STATE HEALTH DIVISION

A Special Report on Children born to

HIV Positive Parents in Nevada, 1991-1999.



Bureaus of Disease Control and Intervention Services

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Health Planning and Statistics

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SPECIAL REPORT ON CHILDREN BORN TO HIV POSITIVE PARENTS IN NEVADA, 1991-1999.

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TABLE OF CONTENTS

BACKGROUND 1
GOALS 1
SUMMARY AND HIGHLIGHTS 2
CHILDREN BORN TO HIV POSITIVE PARENTS, 1991-1999
CHILDREN BORN TO HIV POSITIVE PARENTS REPORTED IN NEVADA, 1991-1999
CHILDREN BORN TO HIV POSITIVE MOTHERS REPORTED IN NEVADA, 1991-1999
OUTCOMES OF CHILDREN BORN TO HIV POSITIVE MOTHERS REPORTED IN NEVADA, 1991-199911
KNOWN PERCENTAGE TRANSMISSION OF HIV (MOTHERS) 12
CHILDREN BORN TO HIV POSITIVE FATHERS REPORTED IN NEVADA, 1991-1999
OUTCOMES OF CHILDREN BORN TO HIV POSITIVE FATHERS REPORTED IN NEVADA, 1991-1999
COST SUMMARY OF HIV POSITIVE CHILDREN
SPECIAL DEMOGRAPHIC AND HEALTH RISK INFORMATION ON THE 332 CHILDREN AND THEIR BIRTH MOTHERS
1. BIRTH COUNTY & FACILITY
 A. BIRTH WEIGHTS

SPECIAL DEMOGRAPHIC AND HEALTH RISK INFORMATION ON THE HIV POSITIVE PARENTS (N=256)	25
1. RACE/ETHNICITY	25
2. AGE GROUPS OF HIV POSITIVE PARENTS AT HIV DIAGNOSIS	27
3. MORTALITY STATUS	28
4. MODE OF EXPOSURE	28
5. MEDICAL COVERAGE	30
6 GEOGRAPHIC CONSIDERATIONS	32
	02
TECHNICAL NOTES	34
	0.
A. SURVEILLANCE OF HIV INFECTION	34
B. MATCHING METHODOLOGY	35
C. ISSUES RELATED TO THE MATCHING METHODOLOGIES	36
D HIV/AIDS REPORTING SYSTEM (HARS)	36
	37
	27
F. INTERPRETATIONS AND QUALIFICATIONS OF THE DATA	31

BACKGROUND

This report encompasses an effort to look at the number of children born to **HIV** (Human Immunodeficiency Virus) and/or **AIDS** (Acquired Immunodeficiency Syndrome) infected parents during the years 1991 to 1999 in Nevada.

According to the Healthy People 2000 (**HP 2000**) Review for the years 1998-1999, infants of untreated or undetected HIV positive women have been identified as a distinct population at risk for contracting the virus that causes AIDS.

The State of Nevada's Bureau of Disease Control and Intervention Services in collaboration with the Bureau of Health Planning and Statistics has taken the initial step to "cross match" two databases that are housed within the two bureaus. "Cross match" refers to a process whereby records pertaining to a person, household, event, etc. in one database are matched to records pertaining to that same person, household, event, etc. in another database. For our purposes, this process involves using records from the database known as **HARS** or the HIV/AIDS Reporting System*, and records from the birth registry for the years 1991 to 1999 to be linked or cross-matched.

By cross matching these two databases, it is first possible to determine the number of HIV/AIDS infected parents who gave birth in Nevada from 1991-1999. Additionally, it is possible to determine the number of children born to these parents, analyzing specific variables such as their demographic and birth weight information recorded on the birth certificate.

GOALS

The overall goal of this project is to find children who may not have been detected with current surveillance measures and determine why and how they did not get the help they needed in preventing infection with the virus.

A secondary goal is to develop a report that may be used in directing resources within Nevada communities where HIV/AIDS prevention and intervention are needed most.

A tertiary goal is that this report will enhance understanding of the HIV/AIDS epidemic and the surveillance system in place to deal with the epidemic.

^{*}HARS has been recently replaced with a new surveillance system known as the "Integrated HIV Surveillance Information System" or IHSIS. Future reports will be based on information from this database system.

SUMMARY AND HIGHLIGHTS

CHILDREN BORN TO HIV POSITIVE PARENTS, 1991-1999

- 332 children were born to HIV positive parents during the time frame studied, 1991-1999, 169 (50.9%) male and 163 female (49.1%).
- Twenty-one (6.3%) of the 332 children had contracted HIV and were confirmed positive with the virus.
- The cost of just seven of these twenty-one HIV positive children totaled \$395,170.33 in Medicaid claims to the State of Nevada (an average of \$56,452.90 per child)!
- Nine of the 332 (2.7%) children had developed AIDS as of October, 2000.
- Nine (2.7%) of the 332 children had died as of October, 2000. All were under the age of four.
- Of the 9 children who died, 4 (44.4%) had AIDS.
- Thirty-five of the 332 children (10.5%) had at least one parent die as of October, 2000.
- Drug use was prevalent among the birth mothers of these children. Nearly 14% (45 of the 332) self-reported using drugs that were not prescription or over the counter (OTC) during pregnancy.
- Of the 21 children who were HIV positive, 10 (47.6%) had a mother who was an IV drug user or had had sex with an IV drug user.
- Of the 332 children born to HIV infected parents, 61 (18.4%) were of low birth weight (LBW) (LBW <2500g and >=1500g), much higher than the State (7.7%) and National (7.5%) averages. Nine babies (2.7%) were of very low birth weight (VLBW) (VLBW < 1500g), higher than the State percentage (1.3%).
- Of the 332 children, 146 (44.0%) of their mothers received prenatal care in the first trimester, much lower than the State 77.3% and National 81.9% levels.
- Thirty-four children (10.2%) received no prenatal care. (No state or national comparative statistics available).

HIV POSITIVE CHILDREN, 1991-1999

- Of the 332 children, 21 (6.4%) were confirmed HIV positive as of October, 2000.
- Of the 21 HIV infected children, 9 (42.9%) were female, while 12 (57.1%) were male.
- In terms of age, 18 children (85.7%) were under 1 year old at the time of their HIV diagnosis. One child (4.8%) was one year old, while another was two (4.8%), and one (4.8%) child's age was unknown at the time of HIV diagnosis.
- Ten (47.6%) of these 21 children were Black. Seven children were White, Non-Hispanic (33.3%), and the remaining four children (19.0%) were Hispanic.
- Nine (42.9%) of the 21 children had developed AIDS.
- Five (23.8%) of these 21 children had died as of October, 2000.
- In terms of the mode of exposure to the virus for these 21 children, all (100.0%) contracted HIV from their mothers.
- Eleven of the 21 children (52.4%) had contracted the virus from a birth mother that was either an injecting drug user or had had sex with an IV drug user. The other 10 children (47.6%) had contracted the virus from a birth mother that had had heterosexual relations with someone with the virus.
- In terms of insurance coverage, 13 of the 21 children (61.9%) were under Medicaid, two were privately insured (9.5%), one (4.8%) was under some other publicly funded coverage, and in the remaining 5 children (23.8%) insurance coverage status was unknown.
- The cost of just six of these twenty-one HIV positive children totaled \$329, 222.74 in Medicaid claims to the State of Nevada (an average of \$54,870.46 per child)!
- Birth weights of these 21 children were as follows: 16 (76.2%) were of normal birth weight (>=2500g, and <=8000g), and 5 (30.0%) were low birth weight (LBW) infants (<2500g). No children (0.0%) were classified as very low birth weight (VLBW) infants (<1500g).

HIV POSITIVE PARENTS, 1991-1999

- A total of 256 HIV positive parents were found in the birth registry from 1991-1999. Among them, 160 (62.5%) were mothers and 96 (37.5%) were fathers.
- Of these parents, 130 (48.7%) had developed AIDS. Sixty-nine (53.1%) were mothers, and 61 (46.9%) were fathers.
- Men Having Sex with Men (MHSWM) and Injecting Drug Use (IDU) were the top two modes of exposure (62.5% combined) among the 96 fathers.
- Injecting Drug Use and Heterosexual relations with an Injecting Drug User were the leading modes of exposure (55.1% combined) among the 160 mothers.
- The racial/ethnic makeup of these 256 parents was 44.5% Black, 2.3%
 Asian, 38.7% White, not Hispanic, 12.1% Hispanic, and 2.3% Native American.
- The majority of the HIV positive parents resided in Clark county (205 of the 256, or 80.1%). Las Vegas, a city with over 1,000,000 people, is in Clark County. Thirty-nine of the 256 parents (15.2%) did not indicate a resident county.

CHILDREN BORN TO HIV POSITIVE PARENTS REPORTED IN NEVADA, 1991-1999.



*Reporting of HIV infections became mandatory in 1992

FIGURE 1.

Children born to HIV positive parents in Nevada from 1991 to 1999 totaled **332**.

In 1991, **56 children** were born to HIV positive parents reported in Nevada. This number *increased* to **63** in 1992.

In the two years following (1993-1994), the number of children born to HIV positive parents had *declined to 25 in 1994*.

The three years following 1994 saw an increase in the numbers of children born to HIV positive parents. By 1997, the number of births had increased to **35 births.** Finally, in 1999, the number of births had dropped to **19.**

This last decrease may be attributable to the more recent availability of anti-retroviral drug therapies to reduce the transmission of the virus from mother to fetus. (The 1994 landmark study by the Pediatric AIDS Clinical Trials group showed a three fold decrease of mother to child transmission of HIV with Zidovudine (ZDV) treatment).



OUTCOMES OF BIRTHS TO HIV POSITIVE PARENTS REPORTED IN NEVADA, 1991-1999.

*HIV reporting in NV became mandatory in 1992 *** See definition below

**Delays in reporting due to incomplete data

Unknown = children born to HIV positive parents that DO NOT appear in the HIV/AIDS reporting system and therefore their HIV status cannot be determined.

Indeterminate = children born to HIV positive parents that DO appear in the HIV/AIDS reporting system, but their HIV status cannot be confirmed at the present time for a number of possible reasons (See technical notes at end of report for full explanation).

Of the 332 children born in Nevada between 1991 and 1999, 21 (6.3%) are known to be HIV positive, and 227 (68.4%) are known to be HIV negative. The status of the remaining 84 (25.3%) children is either unknown or indeterminate.

Between 1991 and 1993, the highest numbers of reported HIV positive children were five born in each of those three years.

Only one child born in 1994 in Nevada was reported to be HIV positive. The number of children reported HIV positive remained the same in 1995 at one birth.

No children born to HIV positive parents reported in 1996 were HIV positive. However, in 1997, **four children born in that year were reported HIV positive.**

Although **no children born in 1998 and 1999** were reported to be HIV positive, **data in these years are incomplete**.*

^{*} The reader is referred to the article, "2000 Revised Surveillance Case Definition for HIV Infection" which appeared in Volume 48/No. RR-13 *Morbidity and Mortality Weekly Report* (MMWR) dated December 10, 1999 for a more detailed explanation of why data in these last two years are incomplete. Also, please see the technical notes at the end of this report for important information.

CHILDREN BORN TO HIV POSITIVE MOTHERS REPORTED IN NEVADA, 1991-1999.



*Reporting of HIV infections became mandatory in Nevada in 1992

Figure 3.

Children born to HIV positive mothers reported in Nevada totaled **246** from 1991-1999.

In 1992, the number of children born to HIV positive mothers in Nevada was **44, up three from the previous year.** Children born to HIV positive mothers dramatically declined from 1992 to 1994, with only 20 children born in the latter year.

The three years following 1994 saw an increase in the numbers of children born to HIV positive mothers. By 1997, the number of births was at **27**. Finally, in 1999, the number of births had dropped to **16**.



OUTCOMES OF CHILDREN BORN TO HIV POSITIVE MOTHERS REPORTED IN NEVADA, 1991-1999.

Figure 4.

Of the **247 children born to HIV positive mothers** in **Nevada**, **158** (64.0%) are known to be HIV negative, and **19 (7.7%)** are known to be **HIV positive** (1991 to 1999).

From 1991 to 1992, the number of children born to HIV positive mothers who themselves became HIV positive remained at **four for each year**. In **1993, five children** born to HIV positive mothers in that year became HIV positive.

One child born in 1994 and one in 1995 was known to be HIV positive.

1996 did not have any reported cases of children born to HIV positive mothers who themselves became HIV positive. In **1997, four children** born to HIV positive mothers were known to be HIV positive.

No children were reported HIV positive born in 1998 and 1999 (Data incomplete).

^{*} HIV Reporting in NV became mandatory in 1992 **Incomplete Data ***See definition on page 8

KNOWN PERCENTAGE TRANSMISSION OF HIV FROM HIV POSITIVE MOTHER TO CHILD REPORTED IN NEVADA, 1991-1999.

YEAR	No. Of Births	No. Of HIV +	No. Of HIV Neg.	No. of Unknown or Indeterminate**	% HIV Transmission	% HIV Negative of Births to HIV + Mothers	% Unknown or Indeterminate of Births to HIV+ Mothers
1991	41	4	32	5	9.8	78.0	12.2
1992	44	4	31	9	9.1	70.5	20.5
1993	26	5	17	4	19.2	65.4	15.4
1994	20	1	12	7	5.0	60.0	35.0
1995	23	1	17	5	4.3	73.9	21.7
1996	23	0	12	11	0.0	52.2	47.8
1997	28	4	15	9	14.3	53.6	32.1
1998*	26	0	14	12	0.0*	53.8	46.2
1999*	16	0	8	8	0.0*	50.0	50.0
Total	247	19	158	70	7.7	64.0	28.3

Table 1.

Transmission of HIV from the birth mother to her child occurs during delivery and through breast-feeding. Without proper prenatal care, testing for HIV, and drug therapies administered prior to, during, and after the delivery, transmission of HIV to the newborn child is a very real possibility.

In Nevada, from 1991 to 1999, the overall percentage of HIV transmission from reported HIV positive mother to child was nearly eight births per 100 (7.7%). The overall percentage of births to HIV positive mothers that were HIV negative was 64.0%. The percentage "Unknown or Indeterminate" for the nine year period was 28.3%.

In **1996, 1998*, and 1999***, there were **no births to HIV positive mothers** that resulted in children becoming HIV positive. However, in **1997**, of the **28 children** born to HIV positive mothers, **four** became **HIV positive or 14.3%.**

*1998 and 1999 data are incomplete. See technical notes for further explanation. **See page 8 for definitions.

CHILDREN BORN TO HIV POSITIVE FATHERS REPORTED IN NEVADA, 1991-1999.



*Reporting of HIV infections became mandatory in NV in 1992.

Figure 5.

Children born to HIV positive fathers reported in Nevada totaled **86** from 1991-1999.

In **1991**, **15 children** were born to reported HIV positive fathers in Nevada. This number *increased* to **19** in **1992**.

In the two years following **(1993-1994)**, the number of children born to HIV positive fathers had *declined to* **five in 1994**.

By **1996**, the number of births had increased to **10**. Finally, in **1999**, the number of births had *declined* to **three**.

OUTCOMES OF CHILDREN BORN TO HIV POSITIVE FATHERS REPORTED IN NEVADA, 1991-1999.



Figure 6.

Of the 85 children born to HIV positive fathers in Nevada, 69 (81.2%) are known to be HIV negative, 2 (2.4%) are known to be HIV positive, and 14 (16.5%) are "Unknown or Indeterminate" (1991 to 1999).

1991 and 1992 were the **only two years** where children born to HIV positive fathers **became HIV positive** themselves.

COST SUMMARY OF HIV POSITIVE CHILDREN

MEDICAID						
No. of HIV+	Matches	% Represented	Total Cost			
21	7	33.3	\$ 395,170			

Average Cost per Child = \$56,453

HOSPITAL DISCHARGE							
No. of HIV+	Matches	% Represented	Total Cost				
21	4	19.0	\$	232,136			
Average Cost per Child = \$58,034							

Table 3.

The Medicaid Claims and Hospital Discharge databases contain valuable medical cost information.

A special data linkage project was carried out to determine the cost these HIV positive children incurred during a three-year period (1997 to 1999).

It **should be noted** by the reader that the information found **only represents a small portion of the HIV positive children** due to limitations in matching.

Seven children were found in the Medicaid claims database, while four children were found in the Hospital Discharge database. The cost summaries are presented above, separately, and should be interpreted as such (See Table 3).

SPECIAL DEMOGRAPHIC AND HEALTH RISK INFORMATION ON THE 332 CHILDREN AND THEIR BIRTH MOTHERS

1. BIRTH COUNTY & FACILITY

The county where the majority of these children were born was Clark at **82.5%**. Washoe County had 47 of these 332 births (**14.2%**), while other counties within the state made up the remaining **3.3%** (see map below).

Figure 7.



2. HEALTH RISKS OF THE 332 CHILDREN

The birth registry contained information regarding the children's prenatal care, medical risk factors of their respective mother's pregnancies, as well as the birth mother's self-reported use of alcohol and tobacco during pregnancy. This information has been requested in numerous Centers for Disease Control (CDC) summary reports on Perinatal Transmission of HIV. One in particular was the Perinatal HIV Transmission Grantee Meeting summary from January 2000 which can be found on the World Wide Web at the following address:

<u>http://www.cdc.gov/hiv/projects/perinatal/materials/summary.pdf</u> In this summary report, prenatal care is stressed as one of the most important factors in eliminating the transmission of the virus to children.

A. BIRTH WEIGHTS

While nearly 80% (**78.6%**) of the 332 children were of normal birth weight (>=2500g and <= 8000g), over 20% (**21.1%**) were low or very low birth weight (**VLBW**) children (<2500g). Low birth weights (**LBW**) are well established as predictors of infant mortality. * Sixty-one children (**18.4%**) were classified as LBW infants, compare to the State of Nevada 1999 average (**7.6%**), and the 1998 national average (**7.5%**). Additionally, the percentage of low birth weights in this population is nearly four times as high as the HP2000 objective of **5%** (Figure 8 and 9).



Figure 8. Birth Weight Categories (N=332 Children)

*Source: Preventive Medicine 1994 November, volume 23, issue 6, pages 793-9.

Figure 9. Percentage of LBW (Low Birth Weight Children) Born to HIV Positive Parents (N=332) compared to State and National Averages



*See Figure 6 for LBW designation

If we look at the racial/ethnic make up of this small population of women giving birth to low birth weight children (n=61), the majority are **Black.** Of the 61 mothers, **42 (68.9%)** were of this racial group (Figure 10).





*Not Hispanic

The age of the birth mothers in this special population were largely in the groups of 20-24 and 30-34 (Figure 11).



Figure 11. Age Groups of the Birth Mothers of the LBW Children (N=61)

B. ALCOHOL AND TOBACCO USE DURING PREGNANCY

The following information on alcohol and tobacco use during pregnancy was **self-reported** on the birth record. It should be noted that numerous studies have been done on the use of self-reported information regarding alcohol and tobacco use. In one study, 220 women were asked about their use of alcohol during pregnancy. One group was told that their results would be checked physiologically to verify they were telling the truth. The other group was told nothing about verification of their self-reported use of the substance. **Twenty-seven percent (27%)** of those in the former group reported using alcohol compared to only **14%** in the latter. These findings *suggest* that self-reporting may be skewed as much as half in cases such as these. *

Forty-nine (14.8%) of the 332 children had mothers that self-reported the use of alcohol during pregnancy. The Healthy People 2000 **(HP2000) objective is 5%.**

Tobacco use was even greater than the use of alcohol during pregnancy. **One hundred thirty-eight children (41.6%)** had mothers who self reported the use of tobacco during pregnancy, compared to the HP2000 objective of **10%** (Figure 12).

^{*}Source: Lowe, JB, Windsor, RA, Adams, B, Morris J, and Reese, Y. (1986), Use of a bogus pipeline method to increase accuracy of self-reported alcohol consumption among pregnant women. *Journal of the Study of Alcohol.* **47**(2):173-5).

Figure 12. Alcohol and Tobacco Use Among the Birth Mothers of the 332 Children



With regard to age groups, the mothers in this special population were largely 30-34 years old. The percentage of teenage mothers was less than 4% (Figure 13).

Figure 13. Age Groups of the Birth Mothers of the 332 Children who used Alcohol or Tobacco during Pregnancy (N=49 and N=138, respectively)



C. PRENATAL CARE ISSUES

The Kessner Index is a measure of adequate prenatal care. Among the 332 children, fewer than 35% (34.3%) received adequate prenatal care. The majority had received less than adequate care (58.1%), while 7.5% of the children's care status remained

unknown (Figure 14). For a more complete discussion of the Kessner Index, please refer to the technical notes at the beginning of this report.





If we look at just the children who received **inadequate prenatal care (n=101)**, the racial/ethnic makeup is very similar to the above findings. Of the 101 children, **66** (65.3%) had **Black mothers**. **Eighteen** children (17.8%) had **White, not Hispanic** mothers, while **10 (9.9%)** had **Hispanic** birth mothers (Figure 15).





*Not, Hispanic

The birth mothers who didn't receive adequate prenatal care during their pregnancies were **mainly between the ages of 20-29 (52.5%).** Nearly **15%** of the mothers in this special population were **teenagers** (Figure 16).





D. PRENATAL CARE IN THE FIRST TRIMESTER

Prenatal care in the first trimester has widely been accepted in the medical community as an important step in preventing low birth weight and infant mortality.* National statistics show that **one out of every 5 women (20.0%)** does not receive care in the first trimester. The children of the mothers in this report show even more discouraging findings. Of the 332 births, only **146** children received care in the first trimester (**44.0%**), while **186** children (**56.0%**) either did not receive first trimester care or their care status was unknown. That is nearly **three times** the national average for children not receiving care in the first trimester. Thirty-four children (**10.2%**) received no prenatal care (Figure 17).

*Source: Preventive Medicine 1994 November, volume 23, issue 6, pages 793-9.

Figure 17. Trimester in which the Birth Mothers of the 332 Children began Prenatal Care



Of those children not receiving care in the first trimester (n=186), the majority of their birth mothers were Black. **One hundred eight** of the 186 children (58.1%) were born to Black mothers. White, not Hispanic mothers totaled 46 in this subgroup and represented 24.7% of the sample (Figure 18).





*Not Hispanic, "Other" and "Unknow n" categories not show n (n=4) $\,$

These mothers were mainly in the **20-29 (53.3%) year age range.** Nearly **12%** were **teenagers** not receiving prenatal care in the first trimester (Figure 19).



Figure 19. Age Groups of the Birth Mothers of the 332 children NOT receiving care in the First Trimester (N=186)

E. AGE GROUPS OF THE 332 CHILDREN'S BIRTH MOTHERS

The birth mothers of these 332 children were largely between the ages of 20-34 (77.1%). Thirty (9.9%) of the mothers were under the age of 20, lower than the State average (13.1%). The youngest of the 332 mothers was only 13 years old. If we look only at the younger teens, those 17 years and younger, 16 (4.8%) gave birth, a percentage exactly the same as the State average (4.8%) for the same age group (Figure 20).

Figure 20. Age Groups of the Birth Mothers of the 332 Children



Age Groups

SPECIAL DEMOGRAPHIC AND HEALTH RISK INFORMATION ON THE HIV POSITIVE PARENTS (N=256)

Accounting for duplicates in the birth registry over the nine year period studied, the HIV positive parents of the **332 children** totaled **256**, **160** (62.5%) mothers and **96** (37.5%) fathers*.

Of these parents, **130** (**48.7%**) had developed AIDS. **Sixty-nine (53.1%)** were mothers, and **61 (46.9%)** were fathers.

1. RACE/ETHNICITY

To the extent that a disease impacts all racial and ethnic groups evenly, we should see a very close correlation between the percentages of the total population comprised by each racial/ethnic group and the percentage of reported cases of disease from each group. For instance if there are 10 Native Americans in a community with 100 people, they make up 10% of the population for that community. If there are 10 Native Americans afflicted with a disease such as AIDS that 20 people total have in that same community, then 50% of the AIDS cases are coming from Native Americans. You would then be able to say that this racial ethnic group was "over represented" among AIDS cases in that community.

Over representation among certain racial/ethnic groups has occurred in our own state of Nevada with regard to HIV infection (Figure 21).



Figure 21. HIV Positive Parents by Race versus 1999 NV population estimates for the different racial/ethnic categories (N=256)

*Because parents could appear multiple times in the birth registry over the time period studied, 76 records were duplicates, and therefore not considered in this analysis of this data.

One hundred fourteen of the matched parents were Black (44.5%), while Blacks made up only 7% of the total population within Nevada (1999 population estimates from the Nevada State Demographer's office). Ninety-nine were White, not Hispanic (38.7%), while Whites made up over three-quarters of the state population at 77%. The former is said to be over represented and the latter, under represented.

Hispanics made up the third largest ethnic background (n=31 or 12.1%), with **Natives and Asians (n=12)** comprising 4.6% of the matched population. The percentage differences between 1999 NV population estimates and HIV positive parents were not as marked with these racial/ethnic groups.

Looking at the mothers and fathers separately, the racial/ethnic backgrounds were largely **Black** for the mothers (**55.0%**) and **White, Not Hispanic** for the fathers (**51.0%**) (Figure 22).





*Not Hispanic

2. AGE GROUPS OF HIV POSITIVE PARENTS AT HIV DIAGNOSIS

The average age at HIV diagnosis for the **HIV positive parents was 29**. The average age for the **mothers and fathers was 27 and 33, respectively**. The age groups of the parents are shown below (Figure 23).

Figure 23. Age at HIV Diagnosis Age Groupings for HIV Positive Mothers (N=160), Fathers (N=96), and Total (N=256)



3. MORTALITY STATUS

Forty-one (16.0%) of the 256 HIV Positive parents had died as of October, 2000. Two **(0.8%)** of the parents' mortality status remained unknown (Figure 24).





4. MODE OF EXPOSURE

The "Mode of Exposure" category describes how a person contracted HIV. Because the modes of exposure exclude women in certain categories (e.g., Men Having Sex with Men or MSM), analyzing modes of exposure for parents was not appropriate. Modes of exposure are presented separately for mothers and fathers below (Figure 25).

A key for these modes of exposure is presented below.

MSM = Men Having Sex with Other Men MSM & IDU = Men Having Sex with Other Men and also an Injecting Drug User IDU = Injecting Drug User Hetsx w/ IDU = Heterosexual sex with an Injecting Drug User Hetsx w/ BiSx Male = Heterosexual sex with a Bisexual Male Sx w/ HIV/AIDS = Sexual Relations with a person infected with HIV/AIDS



Figure 25. Mode of Exposure of HIV Positive Mothers (N=160)

Over half the HIV positive mothers were injecting drug users themselves or had had sex with an injecting drug user **(55.1%)**. A small percentage of the mothers reported having sexual relations with a bisexual male as their mode of exposure **(2.5%)**.

Over 20% (20.6%) reported having sex with someone who had HIV as their mode of exposure, while 21.3% of the mothers did not report a risk of exposure to HIV.

Over a third of the fathers (37.5%) contracted HIV mainly through having sex with other men (MSM). A quarter of the fathers (25.0%) were intravenous drug users (IDU), while a smaller percentage were both MSM and IDUs (9.4%). Unspecified risk reported amongst the fathers was lower than the mothers at 14.6% (Figure 26).

^{*}Transfusion Cases not show n (n=1)



Figure 26. Mode of Exposure of HIV Positive Fathers (N=96)

5. MEDICAL COVERAGE

The primary form of insurance reported by the HIV positive mothers, fathers, and total is presented below (Figures 27, 28, & 29).

Over 10% (13.1%) of the mothers reported they had **no insurance coverage**. The HP 2000 objective is for no one to be without health insurance coverage.

Medicaid was reported as the primary insurance carrier for **30.6%** of the HIV positive mothers, while **21.9%** indicated private coverage as their primary form of health care. Nearly a quarter of the mothers **(23.1%)** did not report any type of insurance coverage and their status remained unknown (Figure 27).

Regarding the HIV positive fathers, a smaller percentage (9.4%) indicated **Medicaid** as their primary form of insurance. **Twenty-five percent (25%)** of the fathers reported private insurance coverage as their primary form of insurance (compare to 22% for the mothers). Nearly a **third of the fathers (27.1%)** did not report any insurance information and their status remained unknown (Figure 28).

Looking at the **HIV positive parents as a whole**, nearly a quarter **(23%)** relied on Medicaid, while **over 10% had no insurance coverage (14%)** (Figure 29).

Figure 27. Reported Insurance Coverage of HIV Positive Mothers (N=160)



Figure 28. Reported Insurance Coverage of HIV Positive Fathers (N=96)





Figure 29. Reported Insurance Coverage of HIV Positive Parents (N=256)

6. GEOGRAPHIC CONSIDERATIONS

The county where HIV positive mothers and fathers currently reside is of importance to future planning efforts to do prenatal and postpartum HIV screening and educational interventions. The map below indicates counties within NV where the parents currently reside according to the information from the HIV/AIDS reporting system (HARS) as of end of January 2001. As the number of parents in certain sparsely populated cities and counties within the state were small, city and county statistics for these areas were combined in a category called "Other Counties within NV". Specific reporting on such small numbers in such small areas could compromise the security and confidentiality of HIV/AIDS surveillance throughout the state.

Clark County, as expected, had the greatest number of resident HIV positive parents at 205 (80.1%). Three mothers (1.2%) currently resided out of state, while just under 4% (3.5%) were residing in other counties within the state. Thirty-nine HIV positive parents (15.2%) did not indicate their current county of residence and were therefore classified as "unknown" (Figure 30).



Figure 30. Current County of Residence of HIV Positive Parents (N=256)

TECHNICAL NOTES

A. SURVEILLANCE OF HIV INFECTION

Through June 30, 2000, 35 areas had laws or regulations requiring confidential reporting by name of all persons with confirmed HIV infection, in addition to reporting of persons with AIDS. Nevada began mandatory HIV infection reporting in 1992. Connecticut required reporting by name of HIV infection only for children less than 13 years of age; and Oregon required reporting for children less than 6 years of age. These states initiated reporting at various times after the development of serum HIV-antibody tests. Before 1991, surveillance of HIV infection was not standardized and reporting of HIV infections was based primarily on passive surveillance. Many cases reported before 1991 do not have complete information. Since 1991, the Centers for Disease Control (CDC) have assisted states in conducting active surveillance of HIV infections using standardized report forms and software. However, collection of demographic and risk information still varies among states.

HIV infection data should be interpreted with caution. HIV surveillance reports may not be representative of all persons infected with HIV since not all infected persons have been tested. Many HIV-reporting states offer **anonymous** HIV testing and home collection HIV test kits are widely available in the United States. **Anonymous test results are not reported to state and local health departments' confidential name based HIV registries.** Therefore, confidential HIV infection reports may not represent all persons testing positive for HIV infection. Furthermore, many factors may influence testing patterns including the extent that testing is targeted or routinely offered to specific groups and the availability of and access to medical care and testing services. These data provide a minimum estimate of the number of persons known to be HIV infected in states with confidential HIV reporting.

A few states use codes in lieu of names to conduct surveillance for HIV infection. These data are not included in the HIV data tables pending evaluations demonstrating acceptable performance under CDC guidelines and the development of methods to report such data to CDC.

For this report, adults, adolescents and children less than or equal to 18 months of age, were classified using the 2000 revised HIV surveillance case definition which incorporates positive results or reports of a detectable quantity of HIV nucleic acid or plasma HIV RNA (MMWR 1999;48[no. RR-13]:29-31). For children <18 months of age, the pediatric HIV reporting criteria reflect diagnostic advances that permit the diagnosis of HIV infection during the first months of life. With HIV nucleic acid detection tests, HIV infection can be detected in nearly all infants aged one month and older. The timing of the HIV serologic and HIV nucleic acid detection tests and the number of HIV nucleic acid detection tests in the definitive and presumptive criteria for HIV infection are based on the recommended practices for diagnosing infection in children aged <18 months and on evaluations of the performance of these tests for

children in this age group. Children aged <18 months born to an HIV infected mother will be categorized as having perinatal exposure to HIV infection if the child does not meet the criteria for HIV infection or the criteria for "not infected with HIV" (MMWR 1999;48[no. RR-13]:29-31) (MMWR 1998;47 [no. RR-4]). Children born before 1994 were considered HIV infected if they met the HIV case definition stated in the 1987 pediatric classification system for HIV infection (MMWR 1987;36:225-30,235).

Over time, persons with HIV infection will be diagnosed and reported with AIDS. HIV infection cases later reported with AIDS are deleted from the HIV infection tables and added to the AIDS tables. Persons with HIV infection may be tested at any point in the clinical spectrum of disease; therefore, the time between diagnosis of HIV infection and AIDS will vary. In addition, because surveillance practices differ, reporting and updating of clinical and vital status of cases vary among states. Completeness of reporting for HIV is estimated to be more than 85% complete (MMWR 1998;47:309-14). CDC estimates approximately 2% of HIV cases are duplicates based on matching of the national coded surveillance database.

(The above information was taken from the annual HIV/AIDS surveillance report put out by the CDC; <u>http://www.cdc.gov/hiv/stats/hasr1201/technote.htm</u>)

B. MATCHING METHODOLOGY

The cross matching was done through a process using Microsoft Access, as well as a manual matching of some birth records to the HARS database.

Birth records prior to 1991 did not have social security number (SSN) information and were not used in the matching process.

Only those records determined to be exact matches with both databases were used in this report. Some records appeared to be matches, but could not be verified for 100% accuracy due to limitations in the initial reporting on the birth certificate or the HARS database. Specific notes on the cross matching are as follows:

- a. Some mothers and fathers in this matched population were parents of twins and some appeared more than once in the birth registry due to multiple births over the nine-year range studied. These records had to be checked for duplication and eliminated from the overall total number of parents matched. Those parents that were found to have multiple births could only be represented once in the final number of matched parents.
- b. In the event that a matched record had multiple entries in multiple years between 1991-1999, the birth record that was the most recent was chosen and all other records were eliminated from the analysis.

- c. In the course of the matching process it was also found that the HARS database contained duplicate records of its own. This duplication is common in large databases such as the HARS where people can move out of the region or state where they originally were tested and have a second or third test done in another region or state. These records also had to be checked for duplication and in the event a duplicate record was encountered, the most recent record in HARS was chosen.
- d. Mothers were matched by first, middle, and last name, age, sex, race and Social Security Number (SSN). Last name, age, race, and SSN variables were used to match the fathers. Fathers information did not include first and last name variables in the birth registry before 1998 and had to be excluded.
- e. Because of the difference in the way the age information was recorded on the birth certificate (age, with no birth dates) versus the HARS database (no age, just birth date), age on the birth certificate was based on the time the record was filled out. No file date was listed in the birth record database, so an arbitrary file date was used to determine the age of the participant based on the birth record year. The arbitrary file date chosen was 7-1-xxxx where xxxx is the year of the birth record. This file date was chosen as it was the midpoint of the year and served to minimize age determination error.

C. ISSUES RELATED TO THE MATCHING METHODOLOGIES

The matching process that was carried out on both databases yielded two main sets of data. One set was the mother and father information from the birth record that matched exactly to the HARS database. The second set was the children born to these mothers and fathers.

Perinatal transmission of HIV is not a certainty when an HIV infected mother gives birth. In fact, with the use of a maternal and neonatal HIV anti retroviral drug known as Zidovudine (ZDV), the transmission rate can drop from 25% to 8% (Source: Centers for Disease Control Website - Perinatal Transmission Grantee Meeting Summary http://www.cdc.gov/hiv/projects/perinatal/materials/summary.pdf).

Nor is it a certainty that if an HIV infected father has sexual intercourse with the mother that the virus will be transmitted to her and then on to the baby. The risk however remains high and it is the goal of this report to present cross-matched data from both mothers and fathers, as well as the respective children of HIV Infected mothers who appeared in the birth records between 1991-1999 and the HARS database.

D. HIV/AIDS REPORTING SYSTEM (HARS)

Much of the statistical information in this report is extracted from the Nevada HIV/AIDS Reporting System (HARS). HARS is a highly confidential computerized database

developed by the Centers for Disease Control and Prevention (CDC). Its purpose is to provide the CDC, HIV prevention and care planners, and resource allocation decision makers with crucial epidemiological information. Statistical data is also provided to educators and others involved in HIV/AIDS awareness efforts so that the public can be apprised of the magnitude of the HIV epidemic in Nevada. The data provided to the CDC and others does not contain information that could identify a specific individual.

Accurate and useful information depends on the consistent and conscientious reporting of HIV and AIDS cases by health care providers, laboratories and others. The HARS database is continually updated and evaluated for accuracy and completeness. Although all reported cases are checked for duplication before they are entered into HARS, not all reporting duplications are initially detected, especially those that are reported in other states. Due to the continual refining of data and the pursuit of missing information, data provided in this report should be considered provisional. As such, the numbers may not always be 100% consistent with previous surveillance reports (The above two paragraphs were taken from the Nevada HIV/AIDS Surveillance Summary, January – December 1998, pages 4&5).

E. KESSNER INDEX

The *Kessner Index* is a multidimensional measure that examines when prenatal care began in terms of the total number of prenatal visits made by the mother as well as the gestational age of the infant. Care is classified as "adequate," "intermediate," or "inadequate." Adequate care is defined as care begun in the first trimester with an appropriate number of prenatal care visits consistent with the length of gestation. Women classified as having inadequate care include all women who began care in the third trimester plus women whose care began earlier but who had four or fewer visits depending on the length of the pregnancy. Intermediate care is the classification for all other combinations of care, visits, and length of gestation (taken from Kotelchuck M. An evaluation of the Kessner Adequacy of Prenatal Care Index and a proposed adequacy of prenatal care utilization index. *Am J Public Health* 1994;84:1414-20).

F. INTERPRETATIONS AND QUALIFICATIONS OF THE DATA

Birth records from the office of Vital Statistics were used in a matching process with the HARS database housed under heightened security in the Bureau of Disease Control and Intervention, State of Nevada. The resulting database was a set of records of women and men (and their respective children) that both appeared in the birth record registry from the years 1991-1999, and also in the HARS database updated as of 10-2000, unless otherwise noted. Data were handled using strict confidentiality.