

CARE OF HIGH RISK INFANTS IN HAWAII

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FOREWORD

This study on the state of care of high risk infants in Hawaii was undertaken in response to *House Resolution No. 316, H.D. 1*, adopted during the 1989 legislative session.

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Chapter 1

SUMMARY OF BACKGROUND INFORMATION

House Resolution No. 316, H.D. 1, 1989, attached as Appendix A, requests the Legislative Reference Bureau (Bureau) to conduct a study ". . . to determine the state of care in Hawaii for infants who are medically at high risk, to include, but not be limited to, an examination of the types of facilities available to care for these children and the community-based, family-oriented, and other types of services available for them."

This chapter summarizes the relatively more technical background information contained in chapters 2 and 3. The main points of the two chapters summarized are listed below. These points are briefly discussed in the sections following the listings. For a fuller treatment, please refer to the chapters themselves.

Chapter 2 contains a more detailed discussion of the following highlights:

- (1) Infants and the risk factors associated with pregnancies resulting in poor medical outcomes;
- (2) The condition of low birthweight associated with high risk infants; and
- (3) The scope of the study.

Chapter 3 discusses the nature of infant mortality, morbidity, low birthweight, and high risk pregnancies and examines their inter-relationships. Technical details on the following topics are more fully presented in chapter 3:

- (1) Various national and state data, where available, regarding different aspects of infant mortality, morbidity, and low birthweight;
- (2) The appropriateness of examining low birthweight infants as a group to study the problems of high risk infants;
- (3) The differences between neonatal mortality and infant mortality and their implications for low birthweight and high risk infants;
- (4) The relevance of other factors such as:
 - (a) Perinatal mortality, which includes deaths of the fetus before birth;

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- (b) Infant deaths resulting from congenital anomalies and the general occurrence of non-fatal infant congenital anomalies to complement the incidence of low birthweight infant deaths and the general occurrence of low birthweight babies; and
- (c) "Apgar" scores, which predict infant survival, and how Hawaii scores compare with national statistics.

Chapter 2 Summary

Infants and Risk Factors

"Infants" refers to children from birth to twelve months of age. They do not include the unborn fetus. Those at medically high risk are infants who are in danger of dying or suffering from a variety of disabilities or illnesses due to a wide range of causes. These could include infants whose mothers were exposed to alcohol, drugs, or the human immunodeficiency virus, or infants whose families have a history of child abuse and neglect.

The direct causes of death and disabilities in high risk infants are not fully understood. However, various risk profiles identify a range of conditions in the pregnant mother that are associated with negative medical outcomes such as death and disabilities. These risk assessment tools usually identify a broad range of factors covering medical, biological, and environmental conditions. For example, the mother's exposure to cocaine or alcohol, which are environmental risks, affects the unborn fetus. The purpose of using risk assessment tools is to identify, at an early stage, mothers and their newborns that are at high risk of dying or suffering some disability. Hawaii is in the final stages of formalizing an integrated risk assessment tool which encompasses medical, biological, and environmental (including psychosocial) risk factors. In a preventive vein, the extent and quality of early prenatal care has also been identified as a condition that has an important effect on pregnancy outcomes.

Low Birthweight and High Risk

Many high risk infants are also low in birthweight. Those weighing under 2,500 grams or five and one-half pounds are considered low birthweight (LBW). Those weighing under 1,500 grams or three and one-third pounds are considered very low birthweight (VLBW). Low birthweight is a condition that characterizes very many high risk infants. Although not all high risk infants are LBW or VLBW, there is a preponderance of low birthweight babies among those identified as at high risk. Because of this, and because the medical literature does not keep statistics for "high risk infants" as a separate category, the category of low birthweight is

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the appropriate one for analysis for purposes of this study. There is overwhelming evidence in the literature that low birthweight is strongly associated with infant mortality and morbidity.

Scope of the Study

A medical analysis of risk factors would require expertise that is beyond the scope of this study. There is not enough information to order definitive priorities among different target populations. Instead, the study aims to find out how all high risk infants are faring, what facilities and services are available to all, and where the system needs improvement.

The role of prevention will also be discussed. Important as facilities and services are for high risk newborns suffering from congenital disabilities, it is just as important to reduce the number of these high risk infants in the first place. It is generally conceded that preventive strategies are more cost effective although they are not as dramatic and attention-getting as technological solutions such as further advancements in neonatal intensive care management.

Perinatal mortality, which includes deaths of fetuses before birth, are examined only to the extent that this type of mortality reflects the overall risks to high risk infants after birth. Sudden infant death syndrome (SIDS) is an altogether separate phenomenon. SIDS cuts across socioeconomic status and occurs regardless of certain risk factors associated with high risk infants and is not within the scope of this study.

Facilities for high risk infants are available within Hawaii's Regional Perinatal Center (RPC). The State has only one designated Level III RPC which is Kapiolani Medical Center for Women and Children (KMCWC). The regional perinatal system also has lower Level I and II facilities which handle low risk pregnancies. Services are also examined as they are available from the RPC and from various sectors of the health profession. Chief among these is the network of community-based and family-oriented services for high risk infants. Integral to the discussion of facilities and services is the statewide policy of providing services in the least restrictive environment, that is, in a de-institutionalized setting.

Chapter 3 Summary

Infant Mortality, Morbidity, Low Birthweight, and High Risk Pregnancies and Their Inter-relationships

According to the literature and most health professionals, low birthweight is the most useful category for looking at the relationships between various risk conditions and infant mortality and morbidity. LBW is the most reliable predictor of high risk in infants. The lower

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the birthweight, the higher the incidence of *infant mortality and morbidity*, the longer the infant needs to spend in intensive care, and the higher the rate of rehospitalization. Three-fourths of all neonatal deaths--those occurring within the first month of life--are related to low birthweight.

The category of congenital anomalies (CA) is not as appropriate as LBW. Congenital anomalies are malformations that occur at birth which are not genetically inherited but are caused by *certain behavior of the parents, particularly the mother*. Exposing the fetus to toxic substances such as drugs and alcohol is an example of such behavior. Viewing CAs does help to provide a more complete picture, however, since LBW does not represent the entire *universe of high risk infants*.

The infant mortality rate is defined as the number of deaths during the first year of life per 1,000 live births in a defined population. The United States ranks only 19th in the world compared to other industrialized nations in terms of infant mortality. In fact, some newly industrializing countries such as Hong Kong and Singapore have lower infant mortality rates than the United States. However, the national neonatal mortality rate has declined greatly. Most of this improvement has come from dramatic technological advances in neonatal intensive care of high risk infants. However, reductions in post-neonatal infant mortality--deaths from the second month to the end of the first year--have not kept pace. It is the failure in this country to reduce the post-neonatal mortality rate that has most contributed to the poor overall infant mortality rate. Neonatal technology is reaching its limits, however. Further improvements in the overall infant mortality rate must come from improvements elsewhere. Just as post-neonatal mortality has seen little improvement over the years, the percentage of LBW births nationally has also experienced a similar stagnant trend for the past fifteen years. The challenge is to reduce the number of LBW and all high risk births and to reduce the rate of post-neonatal infant mortality.

Hawaii's infant mortality rate has continued to compare very well against those of the other states. Hawaii had the lowest infant mortality rate in the country in 1982 and has since consistently remained among the lowest ten. In fact, if considered a separate nation, Hawaii would have ranked among the countries with the ten lowest infant mortality rates.

Infant morbidity (illness or disability), is often predicted by low birthweight. The most well-known cause of LBW is prematurity. Babies born before they reach full term are popularly referred to as "preemies." An LBW baby can also reach full term but still be small for its gestational age. The United States has only the 16th lowest rate of LBW births among industrialized nations and has shown almost no improvement over many years.

Hawaii ranked solidly in the middle at 23rd in the country in 1985 for LBW births. Because of the particular ethnic mix of the State's population, however, the risk of negative birth outcomes based on the incidence of LBW births may be somewhat overstated. For

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example, many Filipino babies are marginally below 2,500 grams at birth but show no ill effects usually associated with high risk infants. Still, consistently more than half of all infants who died within their first year in Hawaii were low in birthweight.

LBW babies are forty times more likely to die in the neonatal period than normal weight babies. For VLBW babies, the risk is two hundred times greater. In the post-neonatal period, LBW babies are twenty times more likely to die than normal weight babies. Low birth weight is also strongly associated with a wide range of infant morbidity. The most well-known are mental retardation, Down's syndrome, cerebral palsy, respiratory distress syndrome, birth defects, and developmental and learning disabilities. Premature LBW babies are ten times more likely to be mentally retarded than normal infants.

In Hawaii, fewer infants overall have been dying. Babies that are LBW have been surviving at a rate increasingly worse relative to babies that are not LBW. In a sense, this is to be expected because non-LBW babies are inherently at lower risk. It may also mean that neonatal technology may be reaching its limits. Very high risk babies who would not have survived birth were it not for advancing technology, may be surviving just long enough to qualify statistically as LBW infant deaths when they finally succumb. Over the 11-year period from 1977 to 1987, the rate of LBW infant deaths in Hawaii has generally dropped.

Other indications of the state of health of Hawaii's high risk infants come from a brief examination of perinatal mortality, infant deaths due to congenital anomalies, and Apgar scores for newborns. Hawaii's perinatal mortality rate is slightly lower than, but hews closely to the national trend. The incidence of CA deaths occurring during infancy in Hawaii is higher than the national norm by several percentage points. However, when comparing Hawaii CA infant deaths to all live births, the State's figures very closely match national statistics. That is, of all infant deaths, Hawaii has had more due to congenital anomalies than the country as a whole. On the other hand, of all infants born, Hawaii has not had more deaths due to congenital anomalies than the rest of the country. Finally, Apgar scores are predictors of infant survival and are given at one and five minutes after birth. There is very little difference between Hawaii's scores and those for the country as a whole. In a sense, Hawaii should not be complacent anytime the State's statistics conform to the national norm because it is no worse than the rest of the country. It also means that, as the "health State," it is no better.

Chapter 2

INTRODUCTION

Medically High Risk Infants

The term "medically high risk infant" (MHRI) is used in this study to refer to babies from birth to one year of age who are subject to a high probability of sustaining a poor medical outcome such as death, illness, or disability. The "medical" in the term is not intended for the identification of any specific or proximate medical cause of high risk status in infants. Nor is it intended to refer to any specific medical risk factors associated with high risk status. Rather, it refers to the medical nature of the poor outcome that high risk infants are subject to.

"High-risk" refers to the status assigned to an infant resulting from a systematic identification of probable risk for a poor medical outcome. "Probable risk" is determined from the identification of risk factors contained in any number of prenatal risk profile assessment tools in use by various hospitals and perinatal centers.

"Risk factors" consist of the behavior and conditions of, and the events associated with, the parents -- primarily the mother -- before and during the immediate newborn period that have been observed to be closely related to the birth of infants who are at high risk.

Risk factors are commonly classified in the literature into three broad categories:

- (1) Medical;
- (2) Biological (developmental); and
- (3) Environmental (behavioral, socioeconomic, and demographic).

A major difference among risk assessment tools is the comprehensiveness of risk factor profile listings. Other differences appear to reflect the demographic, cost, and other circumstances peculiar to an area. A major research hospital hosting a regional perinatal center may tend to emphasize experimental risk factors over traditional ones. Another may adapt a tool to reduce the cost of administration. In any event, as the classifications below suggest, infants can be assigned high risk status due to a wide variety of risk factors.

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Risk Factors

According to Sarah Brown of the Institute of Medicine, the causes or origins of high risk for infants are not well understood. However, many risk factors, especially "behavioral" or "environmental" factors can be identified before pregnancy so that interventions can be employed. Risk factors tend to cluster in several categories:¹

- (a) Demographic
 - (1) Age (under 17 and over 34);
 - (2) Race;
 - (3) Marital status;
 - (4) Socioeconomic status; and
 - (5) Educational status;

- (b) Maternal
 - (1) Previous pregnancy;
 - (2) Inadequate weight for height;
 - (3) Previous DES exposure;
 - (4) High purity genital anomalies;
 - (5) Previous surgery;
 - (6) Diabetes;
 - (7) Hypertension; and
 - (8) Problematic obstetric history;

- (c) Medical risks in current pregnancy
 - (1) Short interval between pregnancies;
 - (2) Hypo- and hypertension;
 - (3) Preeclampsia toxemia;
 - (4) First or second trimester bleeding;
 - (5) Placental problems;
 - (6) Hyperemesis;
 - (7) Polyhydramnios;
 - (8) Oligohydramnios;
 - (9) Anemia;
 - (10) Multiple pregnancies;
 - (11) Isoimmunization; and
 - (12) Incompetent cervix;

- (d) Behavioral and environmental
 - (1) Poor weight gain;
 - (2) Smoking;
 - (3) Alcohol or substance abuse; and

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- (4) High altitude residence;
- (e) Health care risks
 - (1) Little or no prenatal care; and
 - (2) Iatrogenic prematurity resulting from induction of labor or Caesarean section before adequate fetal maturity; and
- (f) Tentative risk areas
 - (1) Physical, psychological stress;
 - (2) Uterine irritability and contractility;
 - (3) Inadequate expansion of plasma volume;
 - (4) Progesterone deficiency; and
 - (5) Certain infections;

Risk factors cited by the Robert Wood Johnson Foundation which can be identified before or during pregnancy include:²

- (1) Extent and quality of early prenatal care;
- (2) Harmful behavior (smoking, alcohol, drug, or medication use);
- (3) Genetic inheritance, race, health, age, and environmental exposure of both parents;
- (4) Weight and nutritional status of mother before and during pregnancy;
- (5) Previous pregnancy outcomes; and
- (6) Current multiple births.

Guidelines for prenatal risk identification issued by Hawaii's Regional Perinatal Planning Program (RPPP) is attached as Appendix B. The RPPP reports that it has completed an initial validation of one segment of a risk assessment tool to be used in the State's regional perinatal system. It is now being integrated with other components by the staff at the Kapiolani Medical Center for Women and Children, the State's designated regional perinatal center. A variety of risk assessment tools are in use in other states. For example, Louisiana adapted the Hollister Risk Scoring System for its own purposes after finding its administration too expensive³ and Tennessee developed its own list of medical risk factors for identifying high risk pregnancies.⁴

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Hawaii's Regional Perinatal Planning Program, in cooperation with the Department of Health (DOH), incorporates the likelihood of certain treatment and services into its definition of a high-risk infant.⁵

"High Risk Infant" - refers to an infant who, on the basis of a comprehensive infant screen and assessment (which covers medical, developmental, behavioral, nutritional and environmental factors as well as those risk factors identified by the comprehensive maternal screen), is considered likely to require more than standard follow-up services. These medical and psychosocial factors are indicative of potential adverse outcomes with respect to the infant's health and well-being. [Emphasis added.]

The RPPP issued a similar definition a year earlier in 1986 which is closer to the current study's working definition in that a wide variety of risk factors is taken into account, including the mother's, that indicates a high probability of a poor medical outcome for the infant.⁶

"High Risk Infant - refers to an infant who, on the basis of genetic, medical, nutritional, developmental, behavioral, environmental factors and/or mother's comprehensive risk status, prior to birth or during the immediate newborn period can be considered likely to develop a significant, debilitating or life-threatening condition that will require more than standard newborn care.

Low Birthweight

Among MHRIs, there is a disproportionately high number of low birthweight babies. Babies born weighing under 2,500 grams (5.5 pounds) are universally classified "low birthweight" (LBW); those under 1,500 grams (3.3 pounds), "very low birthweight" (VLBW).

Conditions characterizing MHRIs need to be distinguished from risk factors that are predictive of, or associated with, the birth of MHRIs. LBW is a major (but not the only) condition characteristic of MHRIs. That is, not all high risk infants are low in birthweight although there is a preponderance of LBWs among MHRIs. There are also other conditions which have recently been much publicized, including:

- (a) Fetal alcohol syndrome (FAS), a cluster of congenital defects caused by maternal alcohol abuse;

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- (b) Cocaine or crack addiction; and
- (c) Human immuno-deficiency virus (HIV) infection.

In a sense, these conditions can be considered different facets of the general problem of high risk in infants. Conditions often overlap. For example, many infants suffering from FAS or cocaine addiction are low in birthweight. Among the various aspects by which MHRIs can be viewed, the condition of low birthweight appears to be the most useful. Most health statistics cannot be expected to identify the different causes of congenital anomalies in LBWs resulting from different types of parental abusive-addictive behavior. Therefore, using low birthweight as an analytical tool is preferable to using FAS, drug addiction, or other conditions.⁷

Mortality is the most extreme of the poor medical outcomes to which MHRIs are subject. Overwhelming evidence in the literature points to a strong positive correlation between LBW and VLBW babies and infant mortality. The higher the incidence of LBW and VLBW, the higher the incidence of infant mortality, and vice versa. Of course, the same positive correlation also holds for LBW and various illnesses and disabilities to which all MHRIs are subject.

In sum, low birthweight is the one most appropriate condition associated with MHRIs for analysis. "Low birthweight" is defined whereas "medically high risk infants" as a category is not.

Scope of the Study

It is clear that infants can be at high risk due to any one or a combination of risk factors the cause of which is not definitively understood. The scope of this study does not include a medical analysis of risk factors which would require specialized expertise. Neither are data available for a complete analysis that attempts to order priorities for allocation of resources among different target populations. The thrust is more to ascertain how all high risk infants are faring, what facilities and services are available to all, and where the system needs improvement.

Nonetheless, this study will discuss certain risk factors but only insofar as their mitigation can alleviate the burden on facilities and services -- the primary concerns of House Resolution No. 316, H.D. 1. The role of prevention is especially important here. It would be only logical to channel greater preventive effort in terms of, say, increasing the universal availability of and access to quality prenatal care if it can be shown that this will reduce the amount of resources and effort needed for facilities, treatment, and allied services for MHRIs at a later stage.

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The definition of the term "infant" is chronologically restricted to the period between birth and the end of the first year of life. Accordingly, unborn fetuses, including spontaneous abortions, fall outside the scope of this study. In a similar way, perinatal mortality statistics are not directly useful because deaths during this period are defined as either occurring from the 28th week of gestation through the 6th day after birth (perinatal I) or the 20th week of gestation through the 27th day (perinatal II). (See chapter 4 for a third definition of "perinatal.")⁸ Perinatal deaths, then, are examined but only as a general reflection of the overall risks to MHRIs. Finally, victims of sudden infant death syndrome (SIDS) also fall outside the scope of this study although they do occur in the appropriate time frame. By definition, a SIDS death is ". . . unexpected by history and in which a thorough post mortem examination fails to demonstrate an adequate cause of death."⁹ SIDS also cuts across socioeconomic status and occurs regardless of certain risk factors associated with MHRIs such as low birthweight, maternal age, previous fetal death, and the extent and quality of prenatal care and maternal education.¹⁰

Facilities and Services

In terms of facilities, infants at high risk for medically poor outcomes, for the most part, initially require intensive care regardless of the specific risk factors associated with their high risk status. For example, medically high risk infants born to different mothers who were subject to different risk factors could all require essentially similar initial care in a neonatal intensive care unit (NICU). To illustrate, three separate infants born to:

- (1) A hypertensive and diabetic 45-year-old mother;
- (2) A second mother with a history of bleeding in the first two trimesters and having previous placental problems; and
- (3) A third cocaine-taking, 16-year-old mother;

would in all probability start life as low birthweight babies requiring care in an NICU. Because LBW babies tend to suffer from a variety of illnesses, various technologically sophisticated and costly monitoring and therapeutic equipment may be needed even after NICU discharge.

The facilities available to MHRIs, at least initially, are institutional and revolve around the so-called Level III regional perinatal center and its NICU and related facilities. Lower Level I and II facilities of other health providers are also examined to the extent that they are available.

It is in the post NICU-discharge phase that options become available for high risk infants in terms of services and facilities. Specifically, the community-based and family-

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oriented services mentioned in H.R. No. 316, H.D. 1, are examined as alternatives to institutionalization, in accordance with the statewide goal of providing health services in the least restrictive environment. In addition to suffering from congenital abnormalities, LBW babies are also less likely to receive proper care from parents suffering from social dysfunction. For example, crack addiction tends to undermine the maternal instinct, to say the least.¹¹ Infants who are born with handicaps are also more likely to be abused or neglected by parents, at least in part due to the frustration of trying to care for children who are extremely difficult to care for.¹² Although the thrust in the State is placement in the least restrictive environment, that is, return to the family or at least the community rather than life in an institution, this is often not possible. Frequently, the task falls to foster parents. It is here that family-oriented and community-based services become important.

The next chapter discusses the status of infants in Hawaii including infant mortality and morbidity, particularly in relation to low birthweight. Where figures are available, comparison with national statistics are included.

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1. Sarah Brown in Haynes, Pamela, Dick Merritt, and Douglas Reese (eds.) Intergovernmental Options for Reducing Infant Mortality: Proceedings from a Conference (George Washington University: 1985), p. 35, hereafter referred to as Intergovernmental Options.
 2. Robert Wood Johnson Foundation, Special Report: The Perinatal Program: What Has Been Learned, (1985) p. 7, hereafter referred to as The Perinatal Program.
 3. John Olive, "Infant Mortality Reduction: The Arkansas and Louisiana Experiences" in Innovations, The Council of State Governments, (Lexington, Kentucky: 1986) p. 5, hereafter referred to as Innovations.
 4. Tennessee General Assembly, Legislative Council Committee, Study on Infant Mortality 1977 (Nashville: 1977), p. 15.
 - (a) Weight of mother before conception (under 100 or over 200 pounds);
 - (b) Age of mother at conception (under 16 or over 40);
 - (c) Weight of mother before conception (under 100 or over 200 pounds); and
 - (d) Previous pregnancy experience:
 - (1) Parity of 4 or more births;
 - (2) Age under 20 or over 35;
 - (3) 2 fetal losses before 28 weeks;
 - (4) Fetal loss after 28 weeks or a neonatal death;
 - (5) Premature or prolonged labor (more than hours);
 - (6) Poor prenatal care;
 - (7) Improper maternal nutrition;
 - (8) Maternal congenital or rheumatic heart disease;
 - (9) Maternal diabetes;
 - (10) Nicotine, alcohol, drug abuse;
 - (11) German measles;

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- (12) Thyroid disorders;
 - (13) Previous Rh sensitization;
 - (14) Rubella during current pregnancy;
 - (15) Toxemia of past or current pregnancy; and
 - (16) Multiple current pregnancy.
5. Hawaii, Department of Health, Maternal and Child Health Branch and Kapiolani Medical Center for Women and Children Regional Perinatal Program, Provider Guidelines for Perinatal Care: Guidelines for Prenatal Care: Guidelines for Postpartum Care: Guidelines for Infant Care (Honolulu: 1987), p. C-3, hereafter referred to as Provider Guidelines.
 6. Hawaii, Department of Health, Maternal and Child Health Branch and Kapiolani Medical Center for Women and Children Regional Perinatal Program, Hospital Guidelines for Perinatal Care (Honolulu: 1986), p. 3, hereafter referred to as Hospital Guidelines.
 7. Consonant with the proviso that high risk infants and low birthweight are not mutually exclusive categories, LBW data for Hawaii may have to be viewed with a further proviso. Hawaii is home to many ethnic groups for which births lower in birthweight than the "standard" cutoff of 2,500 grams may not be subnormal. In fact, in an interview on August 21, 1989, Jean Stewart, coordinator of the Zero to Three Project, Maternal and Child Health Branch, cautioned that, for example, many Filipino babies born here weighing 2,300 to 2,499 grams may not be at risk at all although officially classified "LBW" because a lower range of birthweights is normal for this ethnic group. Thus, the VLBW group (under 1,500 grams) may be a more accurate indicator of MHRIs. Be that as it may, the LBW category is felt to be satisfactory if only because data is more readily available in this form.
 8. Hawaii, Department of Health, Maternal and Child Health Branch and Kapiolani Medical Center for Women and Children Regional Perinatal Program, Organizing Perinatal Services to Improve the Health of Mothers and Children in Hawaii (Honolulu: 1984), p. 1, hereafter referred to as Organizing Perinatal Services.
 9. Dexter S.Y. Seto & Thomas A. Burch, "The Epidemiology of Sudden Infant Death Syndrome in Hawaii" in Research and Statistics Report (Honolulu: 1984), p. 1.
 10. ibid., p. 4: "Significant risk factors that were identified were: illegitimacy, low birthweight (< 2,500 grams), low gestational age (< = 37 weeks), male, twin births, and teenage mothers. However, these factors were also found to be significant in other causes of infant death." (emphasis added)
 11. Cathy Trost, "Babies of Crack Users Crowd Hospitals, Break Everybody's Heart: Infants' Many Needs Overtax Staff, and Some Stay On For Months as Boarders" in The Wall Street Journal, July 18, 1989, p. A-7, hereafter referred to as "Babies of Crack Users."
 12. Hawaii, Department of Health, Timely Prevention: The Key to Healthy Children (Honolulu: 1989), hereafter referred to as Timely Prevention, reports that developmentally disabled children are particularly open to abuse because of the frustration factor. Also, the National Center for Clinical Infant Programs, Infants Can't Wait: The Numbers (Washington: 1986), p. 8, hereafter referred to as The Numbers: "... handicapped infants and toddlers are more likely to be abused."

Chapter 3

INFANT MORTALITY, MORBIDITY, LOW BIRTHWEIGHT, AND HIGH RISK

"Low birthweight is still the major factor associated with infant death."¹

This chapter presents empirical data regarding infant mortality and morbidity and their relationship to low birthweight infants. However, as the National Center for Clinical Infant Programs aptly states:²

. . . unfortunately, major aspects of the lives of infants and young children are sparsely sampled or ignored altogether in data gathering by the federal government. While research and clinical awareness of the early years of life have expanded tremendously in the past twenty years, infants are still awaiting the attention to their circumstances and needs which can only come from systematic collection of information on a national level. [Emphasis added.]

Infants at high risk who survive are highly likely to suffer various disabilities. However, there appears to be no standard national criteria defining these infant disabilities:³

Ill defined criteria -- No nationwide system reports the incidence of physical disabilities and mental retardation among infants and toddlers. Despite increasing national concern about the well-being of disabled infants and those at risk for developmental problems, no uniform reporting criteria, with standard definitions and measurement tools, exist even for those disabilities and risk conditions which can be identified while the newborn is still in the hospital.

Low Birthweight and High Risk

Because data relating to various poor medical outcomes for infants with certain risk conditions are unavailable, the general category of low birthweight appears to be the most useful tool for examining the status of high risk infants. It is not practical to analyze "high risk infants" if only because records are not kept under such a category. While data are available under the category of congenital anomalies (CA), this category is narrower than that for LBW.⁴ Congenital anomalies are malformations that occur at birth which are not genetically inherited but are caused by exposure of the parents, particularly the mother, to certain toxic environments such as drugs and alcohol. In addition, congenital anomalies are only one of

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many possible poor medical outcomes while LBW is more a condition that is characteristic, and an indicator of, high risk in infants. However, because it is possible for an infant to be born with various congenital anomalies without being an LBW baby, a brief examination of the incidence of CA would provide a more complete look at high risk infants.

There are limitations in using the CA category, however. For example, although it would be useful to link a risk factor such as maternal substance abuse to a poor outcome such as congenital anomalies in infants, CA figures do not attribute outcomes to specific maternal conditions or behavior. To illustrate, although it has been estimated that the prevalence of Fetal Alcohol Syndrome births is similar to that of Down's syndrome and neural tube defects, there are no nationwide statistics on the number of babies born to alcohol addicted mothers.⁵ The same is true in Hawaii although some partial data for some drug abusing mothers may be available informally.⁶

Furthermore, in the opinion of health professionals, LBW serves as the best and most reliable indicator of high risk for infants. With the qualification that LBW and high risk are not mutually exclusive categories (that is, not all high risk infants are low in birthweight and some LBW infants are not at high risk), there is general agreement that LBW, by default, may be the best tool available.⁷ High risk babies require more intensive care and stay longer in the hospital. Babies low in birthweight, especially VLBW babies, almost universally require intensive care in NICUs.⁸ Of surviving high risk infants, babies of normal weight average 3.5 days in NICUs. LBW babies weighing 2,000 to 2,500 grams average seven days and those weighing 1,501 to 2,000 grams average 24 days. It is even longer for VLBW babies: those weighing 1,001 to 1,500 grams average 57 days and those weighing the least at under 1,000 grams average 89 days.⁹ The rate of rehospitalization of high risk infants also measures the disproportionate needs of LBW babies. Of normal weight high risk babies, 8.7% are rehospitalized for a mean stay of 8.9 days compared with 19% of LBW babies who stay an average of 12.5 days. A much higher 40% of VLBW babies are rehospitalized for an average stay of 16 days.¹⁰

Infant Mortality

High risk infants (and LBW babies) suffer disproportionately from mortality and morbidity. In general, measures that reduce infant mortality also tend to reduce infant morbidity.¹¹ The infant mortality rate is defined as the number of deaths during the first year of life per 1,000 live births in a defined population. Infant mortality is generally regarded as the best statistical indicator for the well-being of vulnerable populations.¹²

Our national infant mortality rate, at 10.6 per 1,000 live births in 1985, is among the highest of all industrialized countries. As a nation, we experience more infant deaths than eighteen other industrialized countries including Finland, Japan, Sweden, France, Denmark, Norway, the Netherlands, Switzerland, Australia, Belgium, Canada, Hong Kong, Singapore,

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the German Democratic Republic (East Germany), the Federal Republic of Germany (West Germany), Ireland, Spain, and the United Kingdom.¹³ The United States has made tremendous strides in reducing neonatal mortality -- deaths during the first 28 days. This has been achieved mainly by improving the survival rate of LBW infants through advances in neonatal transport to regional perinatal centers and more specialized technological management in neonatal intensive care units.¹⁴ However, reductions in post-neonatal infant mortality -- deaths from the second month to the end of the first year -- have not kept pace. Nationally, neonatal mortality has declined 58% from 1970 to 1988 while post-neonatal mortality has dropped only 27%. In Hawaii, the decrease in neonatal mortality was slightly higher at 65% from 1970 to 1987 while post-neonatal mortality has not experienced much change.¹⁵ This lack of progress in post-neonatal mortality appears to account in large part for the nation's poor global standing with regard to overall infant mortality.¹⁶ This situation is mirrored by a similar failure to reduce the percentage of LBW births. Nationally, LBW births dropped from 7.1% in 1971 to only 6.8% in 1981 (with almost no improvement in the VLBW group) while infant mortality declined 47% from 1965 to 1981.¹⁷ The percentage of infants born in Hawaii with low birthweight has remained relatively stable for the past 15 years.¹⁸

Hawaii's infant mortality rate continues to compare very well against those of the other states. The State had the lowest infant mortality rate in the nation in 1982 but fell to seventh in 1984.¹⁹ At 8.8 in 1985, Hawaii was tied with Minnesota for the fifth lowest rate in the country. Rhode Island had the least with 8.2 and Delaware, the most with 14.8.²⁰ In fact, Hawaii's 1987 rate of 8.8 infant deaths per 1,000 live births would have ranked the State about 9th lowest against industrialized countries in 1985.²¹

Low Birthweight and Infant Morbidity

The condition of low birthweight has two causes. An LBW baby can be born premature: "preemies" are born after a gestational period of 37 weeks or less. Low birthweight can also be a result of intrauterine growth retardation (IUGR). A baby born as a result of IUGR is often alternatively described as small for gestational age. This means that the infant is not born prematurely but does not reach normal size at delivery.

The Institute of Medicine has concluded that the overwhelming weight of the evidence shows that ". . . low birth weight (under 2,500 grams) is a major determinant of infant mortality in the United States . . ." ²² A high infant mortality rate is directly attributable to a high percentage of low birthweight infants.²³ Three-fourths of all neonatal deaths are related to low birthweight.²⁴

The National Center for Clinical Infant Programs, quoting data published in 1985 by the United Nations Children's Fund, reports that for the period 1979 to 1982, the United

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States ranked behind 16 other nations in percentage of LBW births with 7.4%.²⁵ Similarly, the Children's Defense Fund, in 1982, cites the same ranking but at 6.9%. The 16 countries with lower percentages of low birthweight infants included Norway, Sweden, the Netherlands, Finland, Ireland, Switzerland, France, Japan, the Federal Republic of Germany, Belgium, Austria, Greece, Canada, Denmark, the German Democratic Republic, and Italy.²⁶ There has been almost no change in the percentage of LBW births in the U. S. from 1950 when 7.5% of infants were classified LBW.²⁷ In 1985, Hawaii had the 23rd lowest percentage of low birthweight births in the country, placing it squarely in the middle of the national rankings.²⁸

Various sources cite a range from two-thirds to three-fourths of all infant deaths as neonatal deaths -- those which occur in the first 28 days. The Hawaii Department of Health cites a figure of 42% for all infant deaths occurring during the first day due to LBW and complications of pregnancy and prematurity.²⁹ According to various other sources, LBW infants account for more than 60% of all neonatal deaths and 20% of all post-neonatal deaths up until one year of age. LBW babies are forty times more likely to die in the neonatal period than normal weight babies. For VLBW babies, the risk is 200 times greater. In the post-neonatal period, LBW babies are 20 times more likely to die than normal weight babies. Low birth weight is also strongly associated with infant morbidity, including congenital anomalies such as Down's syndrome, cystic fibrosis, sickle cell anemia, mental retardation, developmental and learning disabilities, cerebral palsy, neurodevelopmental handicaps, respiratory distress syndrome, gastrointestinal disorders, and other handicaps. LBW infants are three times more likely to experience adverse neurologic sequelae -- other pathological conditions resulting from a neurologic disorder. Premature LBW babies are ten times more likely to be mentally retarded than normal infants. LBW infants are more likely to need technologically advanced treatment available only at Level III facilities and have a higher rate of rehospitalization. There is also evidence that LBW and the concomitant birth defects and disabilities subject these infants to a greater risk of child abuse and neglect. Surviving low birthweight babies typically spend weeks and months in neonatal intensive care units. VLBW survivors constitute a new and growing population that probably will have long-term needs beyond those recognized for LBW infants in general.³⁰

According to Sara Rosenbaum:³¹

The leading factor associated with neonatal mortality is low birthweight. Low birthweight babies (those weighing less than 5 1/2 pounds at birth) are 20 times more likely to die as normal weight infants. Low birthweight babies are also far more likely to suffer from abuse and neglect and permanent handicapping conditions including mental retardation, birth defects, growth and developmental problems, visual and hearing defects, delayed speech, autism, cerebral palsy, epilepsy, learning disabilities, and chronic lung problems. Low birthweight not only accounts for

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three-fourths of all infant deaths during the neonatal period, but also for half of the overall infant mortality rate.

Hawaii: Infant Mortality

Compared to other states, Hawaii has had a relatively low infant mortality rate (IMR). The IMR for both the State and the nation has been declining steadily. The State's resident IMR for the 11-year period from 1977 to 1987 is reflected in Table 3-1 and is graphed in Figure 3-1.³² Hawaii's IMR reached a low in 1982 at 0.85%, or 8.5 infant deaths per 1,000 live births. Comparable national IMR data for 1985 and 1986, at 10.6 and 10.4, respectively, reveal that Hawaii fared better, with 8.7 and 9.2, than the country as a whole. While there does not seem to be much difference between 8.7 and 10.6 infant deaths per 1,000 live births in 1985, that difference of 1.9 allowed Hawaii to have the sixth lowest IMR in the country.³³

Table 3-1

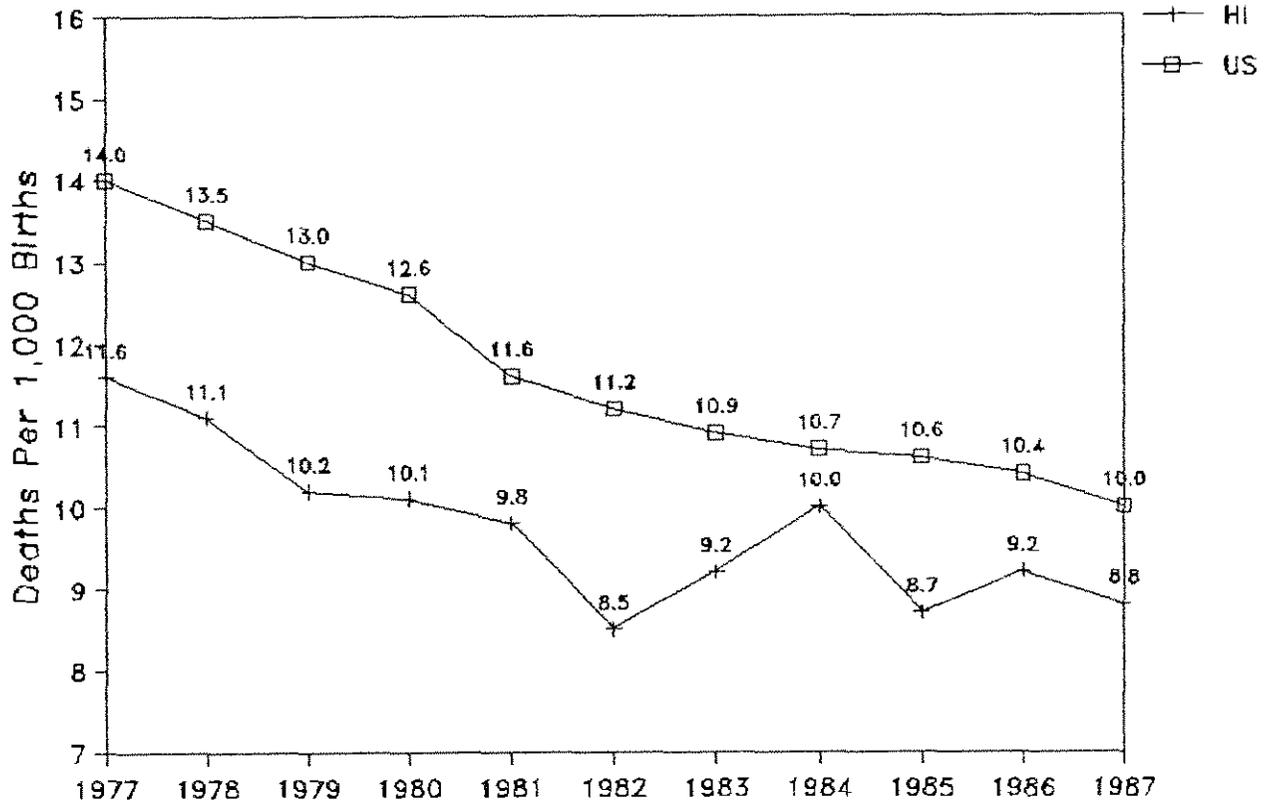
LIVE BIRTHS AND INFANT DEATHS IN HAWAII AND THE UNITED STATES

	Total Live Births		Hawaii Resident Births	Infant Deaths		Infant Deaths As Percent of Live Births	
	HI	U. S.		HI *	U. S.	HI *	U. S.
1987	18,690	---	18,555	164	---	0.88%	1.00%
1986	18,341	3,756,547	18,253	168	38,891	0.92%	1.04%
1985	18,329	3,760,561	18,267	159	40,030	0.87%	1.06%
1984	18,756	---	18,667	186	---	1.00%	1.07%
1983	19,164	---	19,090	175	---	0.92%	1.09%
1982	18,734	---	18,675	158	---	0.85%	1.12%
1981	18,230	---	18,174	178	---	0.98%	1.16%
1980	18,216	---	18,129	183	---	1.01%	1.26%
1979	17,568	---	17,513	179	---	1.02%	1.30%
1978	16,762	---	16,717	186	---	1.11%	1.35%
1977	16,983	---	16,874	196	---	1.16%	1.40%

* = Resident figures only

Figure 3-1

INFANT MORTALITY RATE
Hawaii and the U. S. (1977-1987)



Hawaii: Neonatal Mortality

The neonatal mortality rate is defined as the percentage of deaths which occur in the first 28 days. Various sources cite the percentage of neonatal mortality as between 60% and 75%. For the country as a whole, 65.4% and 64.8% of all infant deaths in 1985 and 1986, respectively, occurred within the first 28 days (Table 3-2 and Figure 3-2). Hawaii's neonatal mortality rate rose steadily from 67.9% in 1977 and peaked in 1981 at 74.2%. It dropped sharply the next year to 66.5% and held steady until 1987 when it registered another sharp decrease to 61.0%, below the averaged national rates for 1985 and 1986.

INFANT MORTALITY, MORBIDITY, LOW BIRTHWEIGHT, AND HIGH RISK

Improvements in the U. S. neonatal mortality rate in recent years have frequently been ascribed to advancements in neonatal technology and management techniques. As more and more very high risk infants survive with the help of sophisticated neonatal intensive care, the overall infant mortality rate has improved. In the case of Hawaii, it is possible that the establishment of the regional perinatal center in 1982 may have had a positive impact. It is generally agreed in the literature, however, that neonatal technology is reaching its limits so that further improvements in the overall infant mortality rate must come from improvements elsewhere in the system.

Table 3-2

NEONATAL DEATHS, HAWAII AND THE UNITED STATES

	Number	Percent of Infant Deaths
(U. S.)		
1986	25,212	64.6%
1985	26,179	65.4%
(Hawaii)		
1987	100	61.0%
1986	116	69.0%
1985	107	67.3%
1984	124	66.7%
1983	116	67.4%
1982	105	66.5%
1981	132	74.2%
1980	128	69.9%
1979	123	68.7%
1978	127	68.3%
1977	133	67.9%

Hawaii: Low Birthweight and Infant Deaths

There seems to be some unintended confusion over the proportion of low birthweight babies in Hawaii. For example, in 1986, the percentage of LBW babies born in the State has frequently been quoted as 6.1%. However, this percentage accounts for only all single live births in the State. If all live births -- single and plural live births -- are considered, the

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percentage rises to 7.0%.³⁴ The use of single live births in computations becomes misleading only if Hawaii LBW figures are compared with national data which are ostensibly computed from all live births. In 1985, the proportion of LBW babies in Hawaii was lower than the national percentage of 6.8% for both single live births and all live births. However, in 1986, Hawaii's LBW percentage was lower than the same U. S. percentage of 6.8% for single live births, but higher for all live births. In fact, the differences are rather small and become relevant only if claims are made that the proportion of Hawaii's LBW babies is lower than the national proportion. Figure 3-3(a) depicts the differences. Note that in Figure 3-3(a) the U. S. percentage is graphed only for convenient comparison with Hawaii figures and does not extend to the entire 11-year period from 1977 to 1987.

Figure 3-2

HAWAII NEONATAL DEATHS (0 - 28 DAYS) Percent of All Infant Deaths *

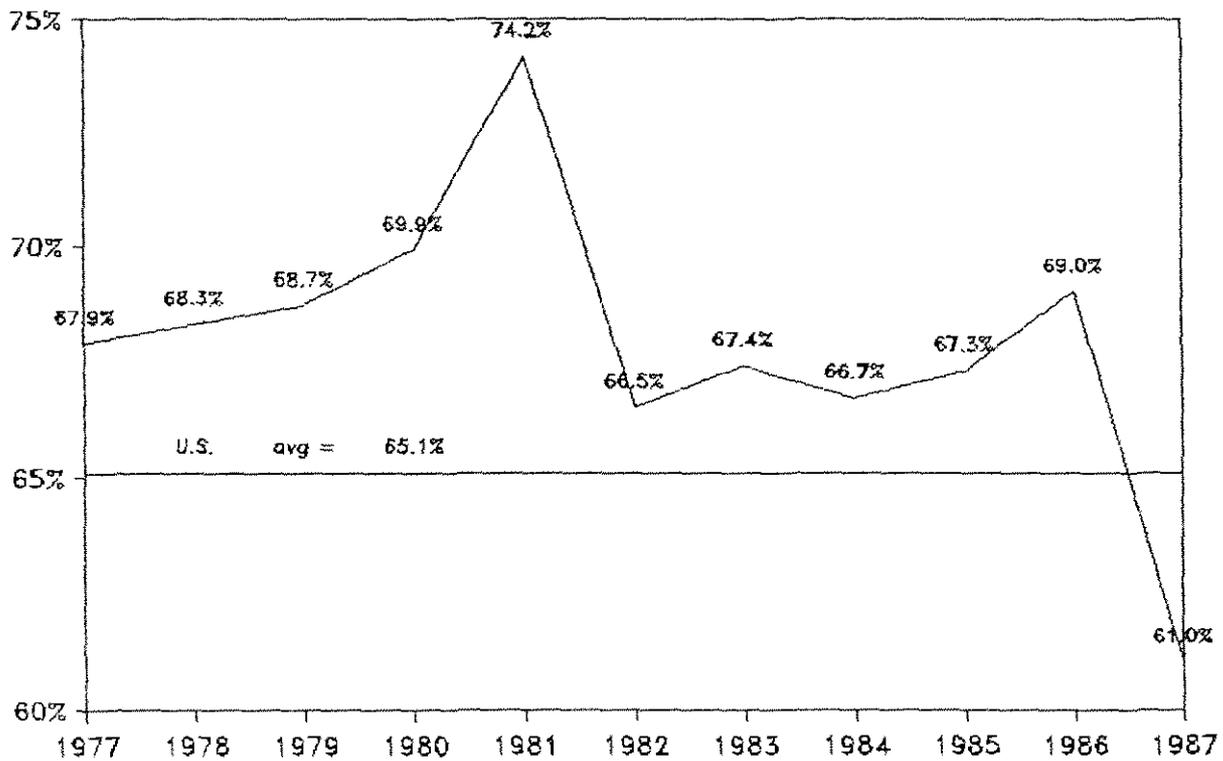
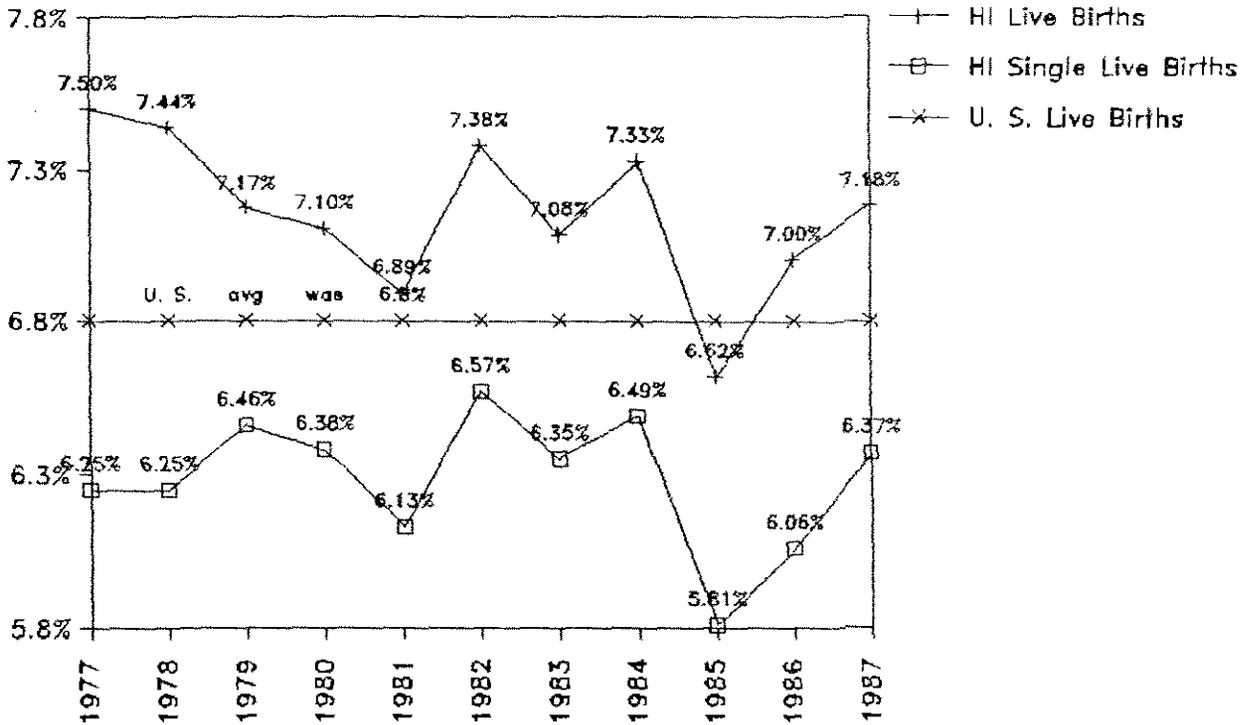


Figure 3-3(a)

HAWAII LOW BIRTHWEIGHT INFANTS
Percent of All Live Births and Single Live Births *



* U. S. data for 1985 and 1986 only: 6.8%

More than any other category, low birthweight is a determinant of infant mortality and is the major condition associated with high risk in infants. Consistently more than half of all infants who died within their first year in Hawaii were low in birthweight. Table 3-3 details the number and percentage of low birthweight infant deaths. LBW infant deaths accounted for an average of 57.2% of all infant deaths over the 11-year period from 1977 to 1987 and is graphically reflected in Figure 3-3(b). Unfortunately, there are no comparable national figures.

Figure 3-3(c) plots a three-year moving average of the percentage of LBW infant deaths in the State against the simple average of 57.2% for the 11-year period from 1977 to 1987.³⁵ There is apparently an upward trend in the proportion of LBW infants deaths to all infant deaths beginning in the 1982 to 1984 period up to the last period from 1985 to 1987. However, for the same 11-year period, the overall infant mortality rate has been declining in Hawaii.

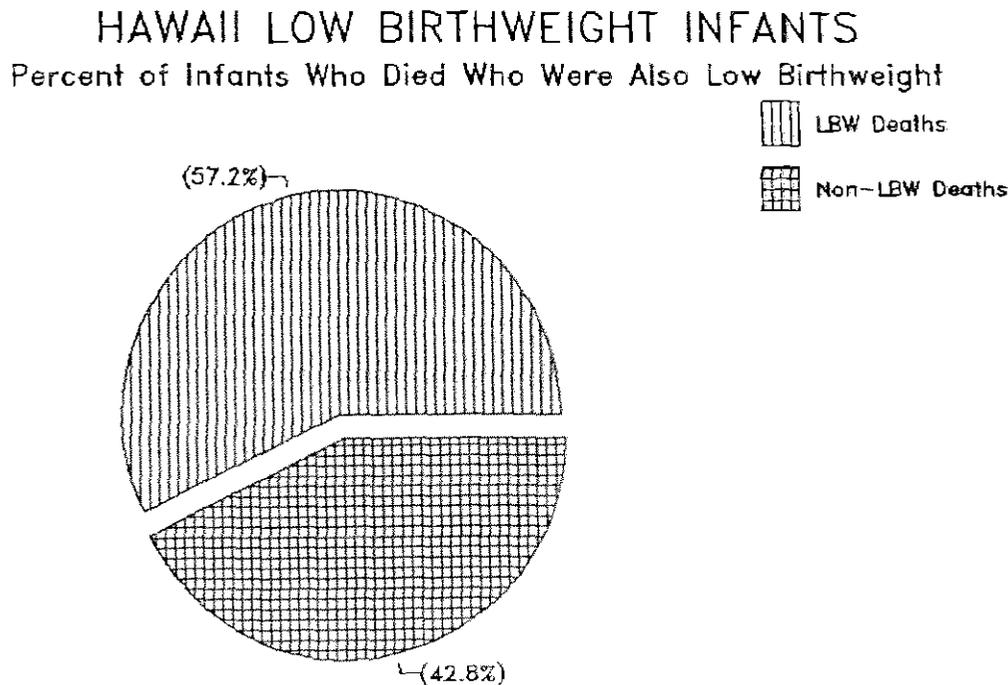
CARE OF HIGH RISK INFANTS IN HAWAII

Table 3-3

RESIDENT LIVE BIRTHS, PERCENT LOW BIRTH WEIGHT (LBW) INFANTS, AND INCIDENCE OF DEATH

Hawaii Resident Live Births & Low Birthweight			U. S.			Percent			HI LBW Infant Deaths			
Single + Plural Births			Single Live Births			LBW			Births : Infant Deaths			
Births	LBW Births	%	Births	LBW Births	%	Births	HI	U. S.	No.	Deaths	% Live Births	
1987	18,555	1,332	7.18%	18,235	1,161	6.37%	--	164	--	94	57.3%	0.507%
1986	18,253	1,278	7.00%	17,895	1,084	6.06%	6.8%	168	38,891	110	65.5%	0.603%
1985	18,267	1,210	6.62%	17,946	1,042	5.81%	6.8%	159	40,030	94	59.1%	0.515%
1984	18,667	1,368	7.33%	18,340	1,191	6.49%	--	186	--	92	49.5%	0.493%
1983	19,090	1,352	7.08%	18,794	1,194	6.35%	--	175	--	101	57.7%	0.529%
1982	18,675	1,378	7.38%	18,343	1,205	6.57%	--	158	--	91	57.6%	0.467%
1981	18,174	1,252	6.89%	17,858	1,095	6.13%	--	178	--	99	55.6%	0.545%
1980	18,129	1,288	7.10%	17,841	1,139	6.38%	--	183	--	99	54.1%	0.546%
1979	17,513	1,256	7.17%	17,241	1,114	6.46%	--	179	--	103	57.5%	0.588%
1978	16,717	1,244	7.44%	16,431	1,027	6.25%	--	186	--	101	54.3%	0.604%
1977	16,874	1,266	7.50%	16,571	1,036	6.25%	--	196	--	119	60.7%	0.705%

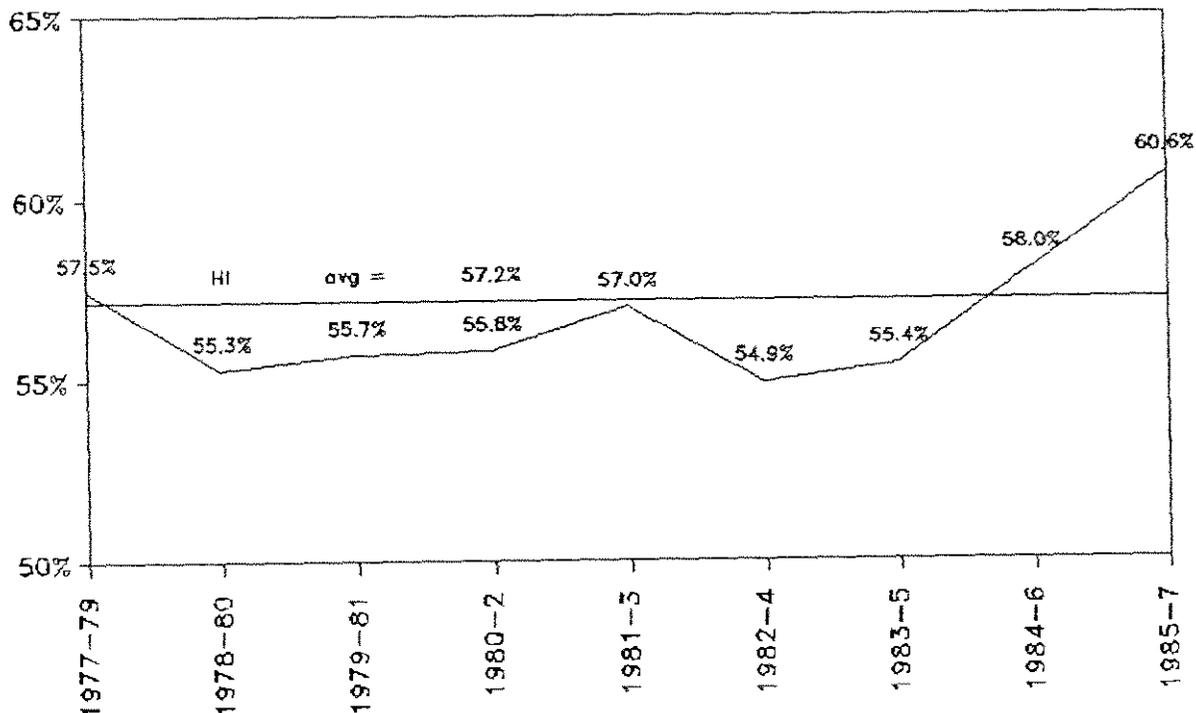
Figure 3-3(b)



Averaged Over the Period 1977 - 1987

Figure 3-3(c)

HAWAII LOW BIRTHWEIGHT INFANTS
LBW Infant Deaths Per All Infant Deaths



3-Year Moving Average for the Period 1977 - 1987

Realistically, it is probably impossible to totally eliminate infant mortality. The goal is to reduce it as much as possible. However, for purposes of illustration, all infants who die can be arbitrarily divided into those who are low in birthweight and those who are not in order to chart progress in each group. It is important to realize, then, that regardless of progress in LBW mortality, there would be no overall gain if overall infant mortality does not drop. That is, decreasing LBW infant mortality would be at the expense of increasing non-LBW infant mortality, and vice versa, in a "robbing-Peter-to-pay-Paul" manner. With this in mind, the two trends of increasing LBW mortality and decreasing overall infant mortality taken together indicate that fewer infants have been dying overall and that non-LBW babies have been surviving at a rate increasingly better relative to that for LBW babies. Ironically, one possible reason why LBW babies have been dying at a higher rate may be due to continuing technological advances. Very high risk babies who would not have survived birth were it not for advancing technology, may be surviving just long enough to qualify statistically as LBW infant deaths when they finally succumb.

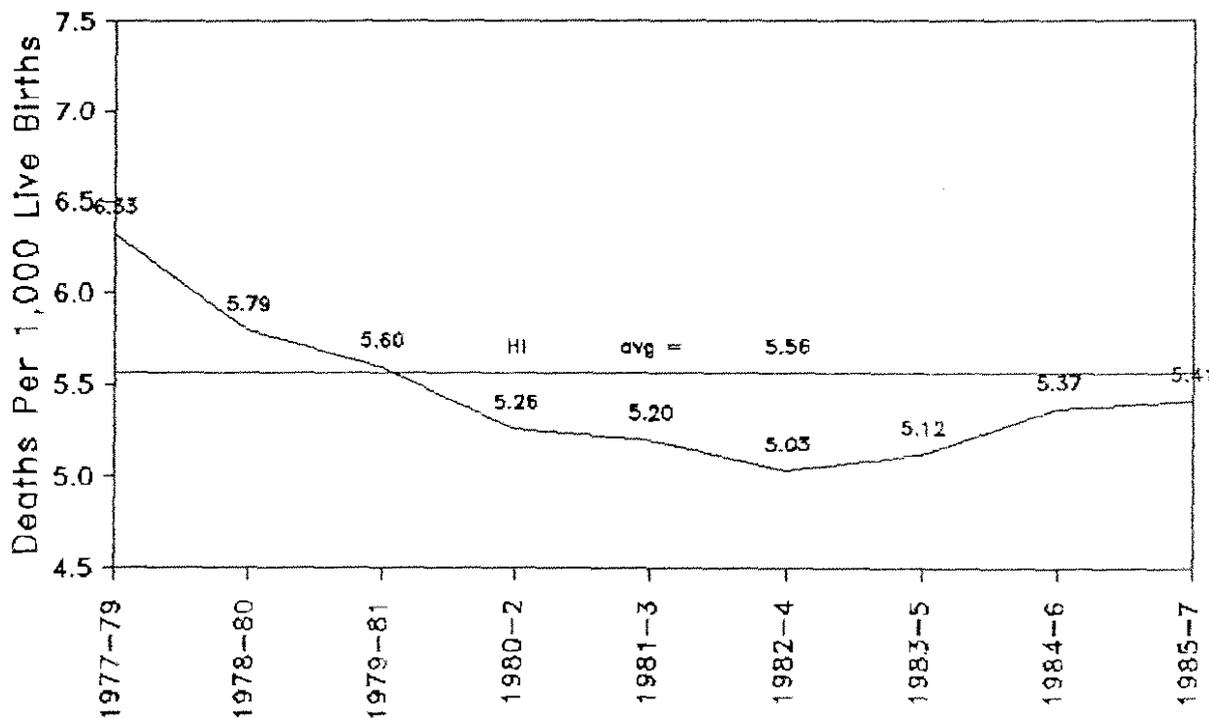
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No one has definitively established the the lower limit for LBW baby survival. No one would wish to impose a limit as long as technological improvements are still possible. For example, at Kapiolani Medical Center for Women and Children, the successful use of an artificial surfactant that coats the lungs of premature babies weighing as little as 700 grams has been shown to improve their survival rate by 34%.³⁶ Although no one wishes to halt advancements in the technological treatment of high risk infants, there is much room for reducing the number of LBW babies, who are inherently at high risk, in the first place. That is, it may be possible to both continue to improve LBW/high risk babies' chances for survival as well as to reduce the number of LBW babies who require that improved chance for survival. It is generally conceded that a strategy to prevent low birthweight babies must supplant the emphasis on a purely after-the-fact technological fix.

A more useful way to view the problem and to track progress would be to aim for a reduction in the proportion of LBW infant deaths to all live births. This ratio would account for movement in both LBW infant mortality and overall infant mortality. Figure 3-3(d) tracks the trend in LBW infant deaths as a *proportion of all live births*, using a three-year moving average, for the period from 1977 to 1987.

Figure 3-3(d)

HAWAII LOW BIRTHWEIGHT INFANTS
LBW Infant Deaths Per Live Births



3-Year Moving Average for the Period 1977 - 1987

INFANT MORTALITY, MORBIDITY, LOW BIRTHWEIGHT, AND HIGH RISK

The relevant percentages in Table 3-3 have been converted to the number of LBW infant deaths per 1,000 live births in Figure 3-3(d). A steady decline began in 1977 to 1979 at 6.33 and ended in 1982 to 1984 at 5.03. From then on up to 1985 to 1987, the last period under study, the trend has reversed. The range of increase is from 5.03 to 5.41. However, the proportion of LBW infant deaths for the period of increase has generally remained below the simple average of 5.56 deaths per 1,000 live births for the entire 11-year period.

Figures 3-3(c) and 3-3(d) indicate that LBW infant deaths have increased in relation to all infant deaths and to all live births in the past few years. However, the more severe increase relative to all infant deaths is tempered by the more moderate increase relative to all live births. This means that there is room for improving the survival rate of LBW babies as opposed to non-LBW babies, but the absolute rate at which LBW babies have been dying has generally declined during the 11-year period, increasing slightly during the more recent years. It also means that non-LBW babies, who are not normally at high risk, are surviving better than LBW babies, which is normal. It may also be an indication that neonatal technology may be approaching its limits.

Hawaii: Perinatal Morality

Although perinatal deaths is a broader category than infant deaths (see chapter 2) it does appear to parallel the narrower category. To that extent, Table 3-4 and Figure 3-4 are included. Hawaii's perinatal death statistics are quite similar to national figures. Hawaii's perinatal deaths as a percentage of all deaths for the ten-year period from 1978 to 1987 averaged 45.6% compared with the U. S. average of 48.1% in 1985 and 47.3% in 1986. For unknown reasons, Hawaii's rate seems to be roughly cyclical, at least for the ten years surveyed.

Hawaii: Congenital Anomalies and Infant Mortality

Another major manifestation of poor medical outcomes for infants is the incidence of congenital anomalies (CA) in newborn. Various types of congenital anomalies are classified in the International Classification of Diseases (ICD) published by the World Health Organization. The ICD classification is also the basis for the reporting of cause of death by the National Center for Health Statistics in the Vital Statistics of the United States, which is the source for U. S. data in this chapter. Table 3-5 and Figures 3-5(a) and 3-5(b) use the current revision (ICD-9) of the classification which translates underlying conditions leading to death into medical codes. The range of codes for congenital anomalies is 740-779.

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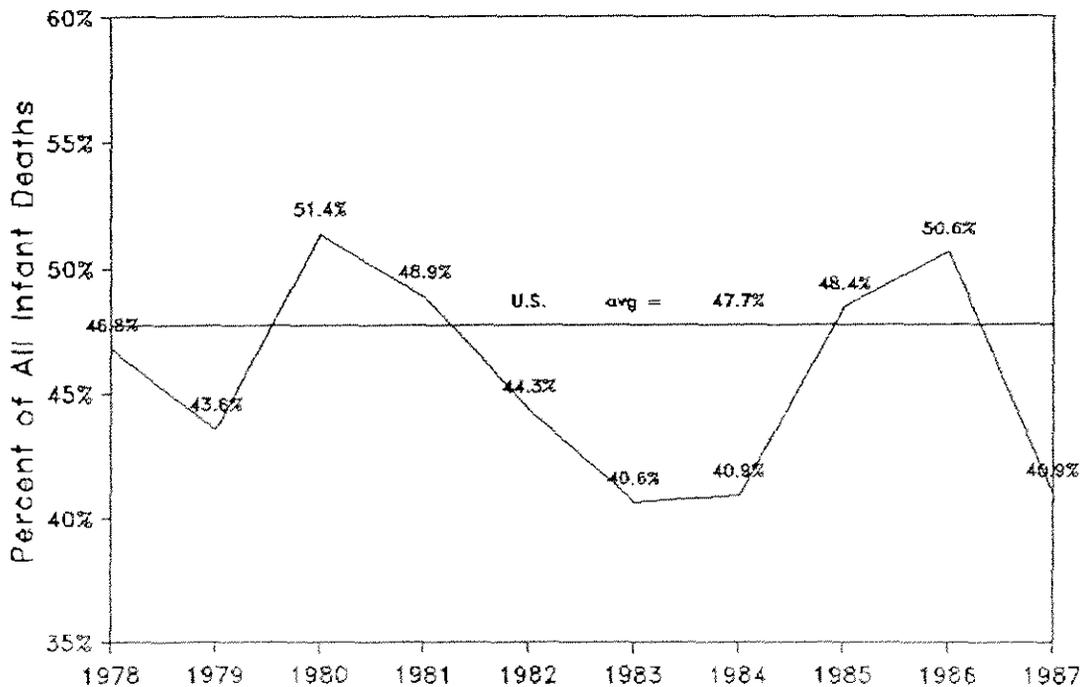
Table 3-4

INFANTS DEATHS CAUSED BY CONDITIONS ORIGINATING
IN THE PERINATAL PERIOD (ICD-9, 760-779)

		(760-779) Deaths		: Per Live Births :			
		HI #	%	US	%	HI #	US
1987	:	67	40.9%	---	--	0.36%	--
1986	:	85	50.6%	18,391	47.3%	0.47%	0.49%
1985	:	77	48.4%	19,246	48.1%	0.42%	0.51%
1984	:	76	40.9%	---	--	0.41%	--
1983	:	71	40.6%	---	--	0.37%	--
1982	:	70	44.3%	---	--	0.37%	--
1981	:	67	48.9%	---	--	0.48%	--
1980	:	94	51.4%	---	--	0.52%	--
1979	:	78	43.6%	---	--	0.45%	--
1978	:	87	46.8%	---	--	0.52%	--

Figure 3-4

HAWAII INFANT DEATHS (ICD-9, 760 - 779)
From Conditions Originating in the Perinatal Period *



* U. S. Data for 1985 = 48.1%; 1986 = 47.3%

INFANT MORTALITY, MORBIDITY, LOW BIRTHWEIGHT, AND HIGH RISK

Table 3-5 presents the percentage of CA infant deaths as a percentage of all infant deaths. Figure 3-5(a) shows Hawaii's proportion for the 11-year period from 1977 to 1987 to be consistently higher than the national average of 21.3% for 1985 and 1986. The figure rose from 21.9% in 1977 to 31.5% in 1981. In 1982, the percentage dropped precipitously to 24.7% but rose again to peak at 36.6% in 1984. It dropped sharply again in 1985, continued down in 1986 to 25% but rose to 27.4% in 1987.

Table 3-5 also lists the percentage of CA infant deaths per all live births and has been converted into the number of deaths per 1,000 live births in Figure 3-5(b). It is important to recall the discussion regarding the "Peter-paying-Paul" situation for low birthweight infant deaths in relation to all infant deaths and to all live births. The percentage of Hawaii's CA infant deaths per all infant deaths is higher than the national average but it is tempered by CA infant death figures per live births that are lower and closer to the national average. In fact, from 1985 to 1987, Hawaii has registered 2.3, 2.3, and 2.4 CA infants deaths per 1,000 live births, respectively, compared with the national average of 2.2 and 2.3 for 1985 and 1986, respectively.

Table 3-5

DEATHS CAUSED BY CONGENITAL ANOMALIES (CA)
FOR INFANTS & ALL AGES IN HAWAII AND THE UNITED STATES AND
CONGENITAL MALFORMATIONS OBSERVED AND SURVIVAL RATES

Live Births		CA Deaths				Infant CA Deaths Per				Congenital Malformations (CM) Observed at Birth (HI only)					
HI	U. S.	HI	U. S.	HI	U. S.	HI	U. S.	HI	U. S.	HI	U. S.	Number CMs	% Deaths	% Survivals	
1987	18,555	---	62	--	45	--	72.6%	--	27.4%	--	0.24%	---	255	17.6%	62.4%
1986	18,253	3,756,547	51	12,638	42	8,244	82.4%	65.2%	25.0%	21.2%	0.23%	0.22%	203	20.7%	79.3%
1985	18,267	3,760,561	55	12,783	42	8,561	76.4%	67.0%	26.4%	21.4%	0.23%	0.23%	189	22.2%	77.6%
1984	18,667	---	85	--	68	--	80.0%	--	36.6%	--	0.36%	--	200	34.0%	66.0%
1983	19,090	---	67	--	58	--	86.6%	--	33.1%	--	0.30%	--	221	26.2%	73.8%
1982	18,675	---	51	--	39	--	76.5%	--	24.7%	--	0.21%	--	147	26.5%	73.5%
1981	18,174	---	80	--	56	--	70.0%	--	31.5%	--	0.31%	--	165	33.9%	66.1%
1980	18,129	---	67	--	55	--	82.1%	--	30.1%	--	0.30%	--	184	29.9%	70.1%
1979	17,513	---	61	--	49	--	80.3%	--	27.4%	--	0.28%	--	179	27.4%	72.6%
1978	16,717	---	56	--	47	--	83.9%	--	25.3%	--	0.28%	--	135	30.3%	69.7%
1977	16,874	---	57	--	43	--	75.4%	--	21.9%	--	0.25%	--	142	30.3%	69.7%

* = Resident figures only

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Figure 3-5(a)

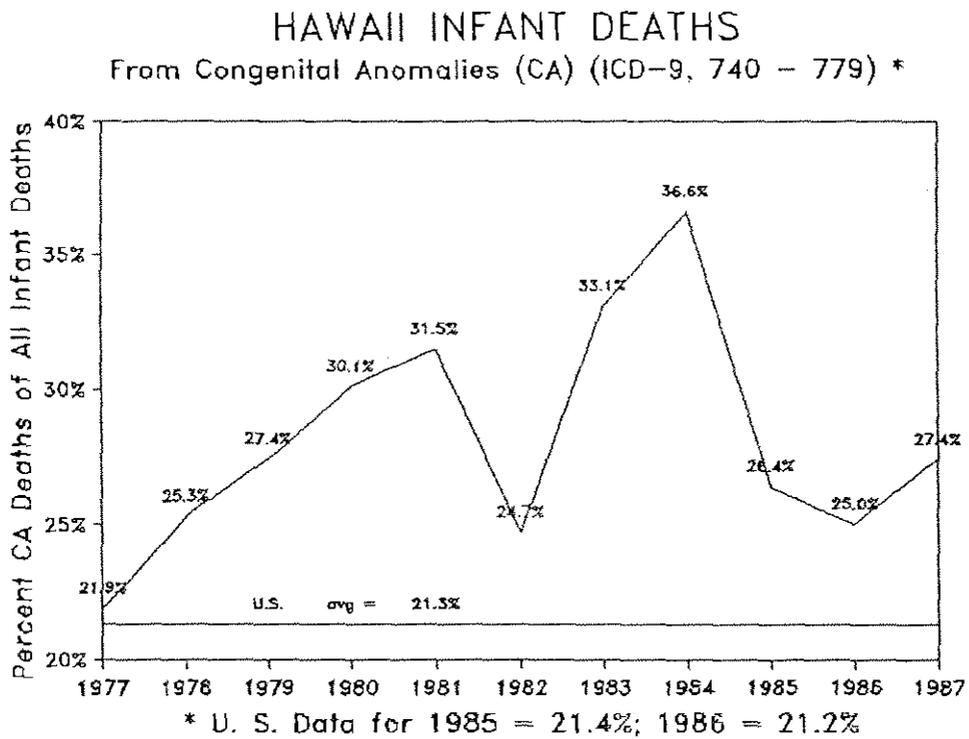
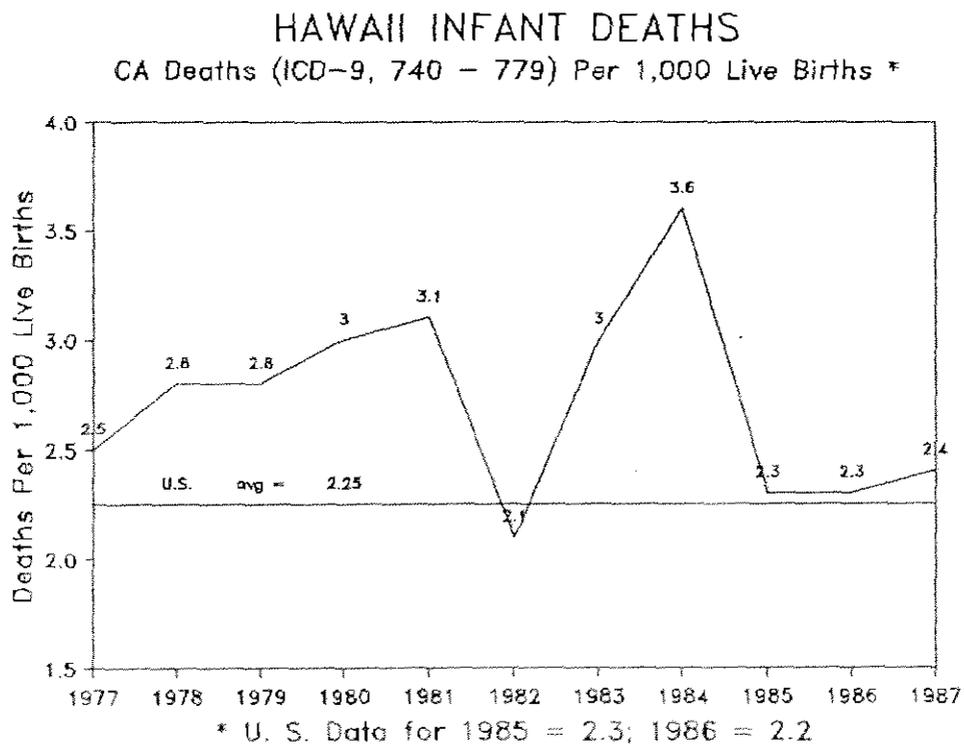


Figure 3-5(b)



INFANT MORTALITY, MORBIDITY, LOW BIRTHWEIGHT, AND HIGH RISK

Although congenital anomalies, as a poor medical outcome, does affect many high risk infants, low birthweight, as a condition, characterizes a greater number of high risk infants. It is apparent that LBW infant deaths -- at around 5 per 1,000 live births -- is somewhat higher than CA infant deaths at around 2 per 1,000 live births. If only for this reason, low birthweight is the more important category for viewing high risk in infants.

It is also interesting to note the survival rate of infants with congenital anomalies. Another point generally conceded is that these babies will require extensive and costly treatment and services later in life, often extending over a lifetime. For the 11-year period from 1977 to 1987, an average of 27.2% of all infants with congenital anomalies died. This means that 72.8% have survived beyond infancy with indeterminate consequences for cost of care in the future.

Table 3-6 details deaths caused by congenital anomalies for each year from 1978 to 1987 for Hawaii in five-year age groups compared with national data for 1986. Across the country, 65.2% of all CA deaths occurred in infants. Hawaii's rate is higher. The most recent figure is 72.6% in 1987 although the ten-year average is 79.1%. Nationally, 72.2% of all CA deaths occurred before the age of five. In Hawaii, the average is 84.7%. In a perverse way, from a purely financial standpoint, Hawaii is "better off" in terms of cost savings due to consistently higher CA mortality in the early years of life. Table 3-7 charts the survival rates for those born with congenital anomalies beyond age five.

Hawaii: Apgar Scores

Finally, Apgar scores are predictors of infant survival and are given at one and five minutes after birth. The Apgar score ". . . is a summary measure of the infant's condition based on heart rate, respiratory effort, muscle tone reflex, irritability and color."³⁷ Scores from 0 - 3 indicate high risk whereas scores of 9 - 10 are given to healthy babies. In general, five-minute scores are higher than one-minute scores as the newborn is given time to adapt to life outside the womb.

Table 3-8 compares both types of scores for Hawaii and the United States. For one-minute scores, in the critical 0 - 3 low-scoring group, Hawaii's 2.4% matched the national average of 2.4% in 1985. In 1986, Hawaii maintained the 2.4% rate while the U. S. rate declined slightly to 2.3%. There was little difference between the Hawaii and the U. S. five-minute 0 - 3 scores. Hawaii had only 0.42% and 0.38% of infants still scoring low after five minutes in 1985 and 1986, respectively, while the national average was 0.54% and 0.57%, respectively. In sum, Hawaii appears to be solidly average in terms of infant risk as predicted by Apgar scores.

INFANT MORTALITY, MORBIDITY, LOW BIRTHWEIGHT, AND HIGH RISK

Table 3-7

INFANTS BORN WITH CONGENITAL ANOMALIES SURVIVING BEYOND AGE 5 FOR THE UNITED STATES AND HAWAII

US		HI		HAWAII											
1986		Average		1987	1986	1985	1984	1983							
No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
3,513	27.8%	9.6	15.3%	11	17.7%	8	15.7%	11	20.0%	13	15.3%	6	9.0%		
				1982	1981	1980	1979	1978							
				No.	%	No.	%	No.	%	No.	%	No.	%		
				11	21.6%	13	16.3%	9	13.4%	8	13.1%	6	10.7%		

Table 3-8

1-MINUTE AND 5-MINUTE APGAR SCORES FOR RESIDENT BIRTHS IN HAWAII AND THE UNITED STATES

1-Minute								5-Minute								
Score = 0 - 3				Score = 9 - 10				Score = 0 - 3				Score = 9 - 10				
HI	US	HI	US	HI	US	HI	US	HI	US	HI	US	HI	US			
No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%			
1987	392	2.1%	---	4,773	25.7%	---	---	81	0.44%	---	---	16,395	88.4%	---	---	
1986	443	2.4%	66,769	2.3%	4,087	22.4%	1,186,826	40.8%	69	0.38%	15,561	0.54%	15,997	87.6%	2,519,860	86.7%
1985	432	2.4%	69,312	2.4%	4,081	22.3%	1,195,903	41.0%	77	0.42%	16,592	0.57%	15,953	87.3%	2,515,610	86.2%
1984	428	2.3%	---	4,545	24.3%	---	---	79	0.42%	---	---	16,278	87.2%	---	---	

Total Apgar scores recorded in 46 states = 2,906,887 in 1986
 = 2,918,691 in 1985

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1. Robert Wood Johnson Foundation, Special Report: The Perinatal Program: What Has Been Learned (1985), p. 7, hereafter referred to as The Perinatal Program.
2. National Center for Clinical Infant Programs, Infants Can't Wait: The Numbers (Washington: 1986), p. 5, hereafter referred to as The Numbers.
3. Ibid., p. 6.
4. However, Loretta Fuddy, Chief of the Maternal and Infant Services Section, Maternal and Child Health Branch, Hawaii Department of Health, indicated in an interview on August 22, 1989 that it may be useful to include the category of congenital anomalies if only to complement the major LBW category.
5. The Numbers, p. 22, and Hawaii Healthy Mothers, Healthy Babies, "Facts and Figures: General," December, 1986. However, Newsweek reported in an article entitled "Alcohol + Pregnancy = Problems" (July 31, 1989) that in 1988, one to three newborns in every one thousand were diagnosed with the more severe FAS (as opposed to the milder Fetal Alcohol Effect, or FAE) and an estimated ten per cent of the infants born to moderate drinkers may have alcohol-related problems.
6. Interview with Dr. Frances Riggs, Hawaii Department of Health, Family Health Services Division Chief, August 14, 1989: as of August, for the fiscal year 1989, there were 68 cases of drug-abusing mothers observed at the Kapiolani regional perinatal center, evenly divided among cocaine, methamphetamine ("crystal meth"), and poly-drug abusers. Dr. Lisa Simpson, Hawaii Department of Health, Family Health Services Division, Maternal and Child Health Branch Chief, testified at a State of Hawaii, House of Representatives joint Committee on Human Services and Committee on Health informational briefing on "Drug Exposed Babies" on September 27, 1989, that 10% to 15% of all pregnancies nationally involved drug addiction and projected 900 drug addicted babies per year in Hawaii if the State had even half the national rate.
7. Interview with Jean A. Evans, Program Director, Regional Perinatal Planning Program, August 10, 1989; interviews with Loretta Fuddy and Jean Stewart, coordinator of the Zero to Three Project, Maternal and Child Health Branch, Hawaii Department of Health. (See chapter 2 footnote regarding LBW Filipino babies.)
8. Interview with May Beck, member of medical team under contract with Department of Human Services, Child Protective Services at KMCWC regional perinatal center, August 14, 1989; interviews with Jean Stewart and Loretta Fuddy.
9. The Numbers, p. 19.
10. Ibid.
11. Hawaii, Department of Health, Maternal and Child Health Branch and Kapiolani Medical Center for Women and Children Regional Perinatal Planning Program, Organizing Perinatal Services to Improve the Health of Mothers and Children in Hawaii 1984, pp. 2, 11: cites studies in 1980, 1982, and 1983 showing reduced neonatal mortality rates resulting from better quality care practices have also resulted in reduced risk of handicaps in surviving infants, hereafter referred to as Organizing Perinatal Services.
12. C. Arden Miller, Maternal Health and Infant Survival (Washington D.C.: National Center for Clinical Infant Programs), 1987, p. 9, hereafter referred to as Infant Survival.
13. Kathleen Sylvester, "Infant Mortality: It's as American as Apple Pie" in Governing, July, 1988, p. 58.

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hereafter referred to as Governing. Incidentally, it is often pointed out that among those countries having lower rates of infant mortality than the United States are some countries that are not even fully industrialized -- the so-called "NICs" or newly industrializing countries such as Hong Kong and Singapore -- where the median income and standard of living are greatly eclipsed by those in America.

14. Henry M. Ichiho and Dana Hughes, The MOMI Program (Medicaid Options for Mothers and Infants): An Analysis of Medicaid Options for Mothers and Infants in the State of Hawaii (Honolulu: 1987), p. 4, hereafter referred to as MOMI; and Intergovernmental Options, p. 34.
15. Jean Evans, "Hawaii Follows U. S. in Infant Mortality Trend" unpublished report, 1989.
16. Martha P. King, Saving Lives and Money: Preventing Low Birthweight (Denver: National Conference of State Legislatures, 1988), p. 3, hereafter referred to as Saving Lives.
17. Intergovernmental Options, pp. 34-5; Hawaii, Department of Health, Maternal and Child Health Branch and Kapiolani Medical Center for Women and Children Regional Perinatal Planning Program, WIN (Women & Infant Numbers) in Hawaii (Honolulu: 1989), p. 11, hereafter referred to as WIN.
18. WIN, p. 11.
19. Hawaii Healthy Mothers, Health Babies, "Facts and Figures: Infant Mortality Rate," December, 1986, p. 2.
20. Governing, p. 50. The Children's Defense Fund, the source for the data, claims that Delaware's standing may be a statistical anomaly and does not reflect its true standing. South Carolina, at 14.2 would then have the highest rate.
21. Finland, Japan, Sweden, France, Denmark, Norway, the Netherlands, and Switzerland would still have had lower rates.
22. Intergovernmental Options, p. 33.
23. MOMI, p. 4.
24. Hawaii Healthy Mothers, Health Babies, "Facts and Figures: Low Birthweight," hereafter referred to as "Low Birthweight," December, 1986, citing the National Association of Community Health Centers, Inc., Primary Care Focus, Spring, 1985.
25. The Numbers, p. 18.
26. Children's Defense Fund, A Call for Action to Make Our Nation Safe for Children: A Briefing Book on the Status of American Children in 1988 (Washington, D.C.: 1988), pp. 21, 27, hereafter referred to as Defense Fund.
27. "Low Birthweight."
28. Defense Fund, p. 21.
29. Hawaii, Department of Health, Timely Prevention: The Key to Healthy Children (Honolulu: 1989), unpagged, hereafter referred to as Timely Prevention.

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30. The Numbers, pp. 16, 18; MOMI, p. 5; Intergovernmental Options, p. 34; The Perinatal Program, No. 3, 1985, p. 7; Hawaii Healthy Mothers, Healthy Babies, "Facts and Figures: Child Abuse and Neglect," December, 1986; Lori Leu, Harvard Legislative Research Bureau, "A Proposal to Strengthen State Measures for the Reduction of Infant Mortality" in 23 Harvard Journal on Legislation 559 (1986), p. 562, hereafter referred to as Harvard Journal; and Organizing Perinatal Services, p. 5.
 31. Sara Rosenbaum, "The Prevention of Infant Mortality: The Unfulfilled Promise of Federal Health Programs For The Poor", 17 Clearinghouse Review, pp. 702-703 (1983), hereafter referred to as Clearinghouse Review.
 32. Unless otherwise indicated, Hawaii and U. S. data for all tables and graphs in this chapter either come, or are derived from, respectively:
 - (1) Hawaii, Department of Health, Statistical Report, years 1977 to 1987; and
 - (2) United States, Department of Health and Human Services, Public Health Service, Centers for Disease Control, National Center for Health Statistics, Washington, D.C. Vital Statistics of the United States, 1985 and 1986.Since only 1985 and 1986 data for the U. S. are available, figures from the 2 years have been averaged for easier comparison with Hawaii data. All graphic figures depicting U. S. data represent only the average of these 2 years -- the difference between the two being extremely small -- and do not extend to the entire 11-year period from 1977 to 1987.
 33. Defense Fund, p. 20-1.
 34. In 1986, there were 1,084 LBW births out of 17,895 single live births (6.06%), but 1,278 LBW births out of 18,253 total live births (7.0%).
 35. A moving average smooths out abnormal aberrations to provide a more accurate look at a relatively long-term trend.
 36. Beverly Creamer, "Breath of hope: new substance saving preemies" in The Honolulu Advertiser, September 7, 1989, p. A-3.
 37. Hawaii, Department of Health, Statistical Report, 1987, p. 4.

Chapter 4

FACILITIES AND SERVICES

The Regional Perinatal Center

The State Health Planning and Development Agency (SHPDA) is responsible for planning for high risk perinatal services in Hawaii. In 1977 and 1978, the SHPDA conducted an assessment of all medical facilities that serve high risk maternity patients and newborns. Based on Hawaii's size and geography, the SHPDA decided that one civilian tertiary (highest level) perinatal facility could be supported. In 1978, it formally recognized a facility then known as the Kapiolani/Children's Medical Center as Hawaii's Regional Perinatal Center (RPC). The facility is now known as Kapiolani Medical Center for Women and Children (KMCWC).¹

The scope of this study is restricted to high risk infants up to one year of age. However, their state of care cannot be restricted only to the period from birth to one year of age. What happens to the mother-to-be during pregnancy materially affects the infant's well-being after birth. The term "perinatal" as used in the regional perinatal health system refers to the entire period of pregnancy up to one year after birth.² An infant is most vulnerable to death and injury during the perinatal period. Because of this, a perinatal health system strives to provide optimal care for both pregnant women and newborns during this period in order to reduce infant mortality and morbidity.

The driving force behind the concept of a regional system is the efficient allocation of scarce health resources within a geographic region. A regional perinatal system aims to optimize the delivery of perinatal care by organizing and coordinating various elements in the system. These elements include community hospitals, academic medical centers, obstetricians, pediatricians, general practitioners, nurses, nurse-midwives, clinics, and laboratories within the region. The system monitors all pregnancies within the region and identifies high risk conditions. According to the SHPDA, not all high risk pregnancies can be anticipated because problems may arise during labor in a normal pregnancy. However, about two-thirds of all high risk newborns can be anticipated through proper evaluation before delivery.³

In a regional perinatal system, certain procedures should be developed for the entire region. These include:

- (1) Standardized risk assessment;⁴
- (2) Telephone or on-site consultation; and

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- (3) Transfer of patients from one facility to another.

That is, in the ideal system, all relevant components in the network of perinatal services would be able to correctly define and diagnose problems, know what other resources are available, and make the appropriate transfers as necessary. All women and newborns should be provided risk screening and appropriate diagnostic and therapeutic care, including transport to a regional perinatal center. A generic model for the organization of a regional perinatal health system, adapted from the American Academy of Pediatrics and the American College of Obstetricians and Gynecologists, is attached as Appendix C. The model is broken down into identifiable activities relating to patient care, education, evaluation, and funding.

A regional system seeks to assure the efficient distribution of resources -- obstetric, gynecological, neonatal, pediatric, and other related services -- to pregnant women and their infants according to their needs. However, not all health facilities are equally equipped to handle the full range of potential perinatal problems. Facilities, then, are classified into three levels of increasing capability.

Three-Tiered Regional Facility System

The SHPDA defines the three facility levels as follows:⁵

Primary (Level I) facilities are small urban or rural hospitals serving maternity patients or pregnant women and newborn infants who have minor or no complications.

Secondary (Level II) facilities are general hospitals with perinatal care units caring for uncomplicated maternity and normal newborns as well as certain high risk maternity patients and certain newborns with complications.

Tertiary (Level III) facilities have a Neonatal Intensive Care Unit (NICU), an Intermediate Newborn Care Unit, a Normal Newborn Care Nursery, as well as intensive care facilities for mothers. It is a referral center for mothers, newborns and infants.

Although classification is not required by statute, according to the Regional Perinatal Planning Program (RPPP), the current classification is as follows:⁶

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Level I: Wahiawa General Hospital, Castle Medical Center, Kahuku Hospital, Kuakini Hospital, Wilcox Memorial, Kauai Veterans, Hana, Honokaa, Kau, Kohala, Kona, Lanai Community, and Molokai General Hospital.

Level II: Queen's Medical Center, Hilo Hospital, and Maui Memorial Hospital.

Level III: Kapiolani Medical Center for Women and Children (designated RPC), Tripler Army Medical Center⁷ -- which is outside the regional perinatal system -- and Kaiser Permanente. Kaiser has a cooperative agreement with the RPC for transferring patients to KMCWC and for their return to Kaiser when a higher level of care is no longer needed.⁸

Facilities which do not handle labor and delivery include Straub Hospital, St. Francis Hospital, Pali Momi, Kula Hospital, Leahi Hospital, Maluhia and Samuel Mahelona.

Components of the Regional Perinatal Center at KMCWC

In 1982, the components of the regional perinatal center was described to include the following:⁹

- (1) Obstetric-Gynecologic Outpatient Department consisting of six examination rooms and six offices for counseling and patient interviews; access to clinical laboratory services and diagnostic and evaluative techniques including x-rays, ultra sound, visualization of the fetus and oxytocin challenge testing;
- (2) Perinatal Nursing Services Department consisting of the:
 - (a) Labor Unit: 15 beds with internal and external electronic fetal monitors; central fetal monitoring capability; and oxytocin induction or augmentation of labor;
 - (b) Delivery Unit: six rooms with infant warmers and resuscitation equipment; and Caesarean capability;
 - (c) Antenatal Fetal Testing Unit (also known as oxytocin challenge testing unit): four beds; and
 - (d) Maternal-fetal Intensive Care: self-contained unit with ten beds with a nursing station; and cardiac and fetal monitors;
- (3) Gynecology Unit consisting of 68 private beds;
- (4) Postpartum Unit consisting of 60 private beds;

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- (5) Nursery consisting of 90 bassinets configured among the following nurseries:
 - (a) Five term nurseries;
 - (b) One admission nursery;
 - (c) One isolation nursery;
 - (d) Two intermediate care nurseries with monitors; and
 - (e) One treatment room equipped for infant transfusions and special procedures; and

- (6) Neonatal intensive care unit consisting of 24 bassinets divided between intensive care and intermediate care (accommodating up to 30 if necessary) with specialty equipment such as ventilators, transcutaneous oxygen monitors, a fiberoptic transilluminator, a blood gas analyzer, a microcomputer-controlled audiometer, and echocardiograph.

Current facility components of the regional perinatal center have not changed significantly since 1982.¹⁰ The number of births at KMCWC has remained stable at about 6,000 for a fairly long time. The current division of nursery bassinets is 36 in intermediate care and 54 for normal newborns.

Special Care Versus Standard Care

According to the SHPDA, a Level III facility provides care for normal maternity and newborn patients and all types of maternal, fetal, and neonatal illnesses and abnormalities. Infants admitted to NICUs who are identified to be at high risk for disabilities ". . . as well as psycho-social factors . . ." are provided special services.¹¹ The SHPDA further describes the NICU as being "designed for the management of critically ill newborns who require respiratory support, continuous cardiopulmonary support, intravenous therapy, major surgery, and treatment of sepsis (infection)."¹² However, no document definitively or comprehensively lists these special services.

The RPPP specifies continuous surveillance and risk assessment throughout the antepartum, labor/delivery, and postpartum periods for both the mother and the infant.¹³ When a patient is identified to be at high risk at any stage, the provider is alerted to the potential need to provide "special perinatal care." However, the program does not define what these special services consist of because:¹⁴

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Guidelines for "special" perinatal care do not lend themselves to documentation due to the wide variety of risk factors that will determine individual service needs. An individualized plan of care is necessary and shall incorporate referrals, interventions and/or consultation at the primary health care provider's discretion. [Emphasis added.]

The great majority of pregnancies and births are normal and not high risk. Therefore, both of the RPPP's guidelines for providers and hospitals are meant to deal with "standard" as opposed to "special" care for mothers and infants. The RPPP's definition of "high risk" is the high likelihood of the need for "more than standard" care or services regardless of whether the risk applies to the pregnant woman or to the infant at various stages during the perinatal period.

Presumably part of this "special care" includes admission to an NICU. KMCWC staff have developed the following NICU admission criteria for infants who:¹⁵

- (1) Weigh below 1,500 grams (VLBW) or are symptomatic pre-term infants (less than 34 weeks);
- (2) Need respiratory assistance including those with respiratory distress syndrome;
- (3) Need continuous physician attendance or a high degree of nursing care; and
- (4) Need "life-threatening" neonatal surgery, especially requiring intensive care after surgery.

For example, this would include infants who need intravenous therapy and treatment for infection. These infants can be admitted under a neonatologist or pediatrician directly from the RPC labor and delivery unit, the regular nursery, or be transferred from lower level facilities. The multidisciplinary NICU team itself consists of a pediatric resident, a neonatologist or patient's private physician, an occupational therapist, a physical therapist, and the NICU social worker or other social worker involved with the patient's family.¹⁶

Infants who need continued hospitalization for observation and growth after receiving intensive care are either moved to the intermediate section of the NICU or are transferred to one of the intermediate nurseries. Occasionally, NICU infants who have been stabilized but need continued hospitalization for growth and observation, may be transported back to the referring hospital. However, this depends on whether that hospital has the necessary facilities.¹⁷

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Newborns who do not need NICU care but require closer observation are admitted to one of the intermediate nurseries. These infants may be admitted directly from the labor and delivery unit. They may also be admitted from the admissions nursery, which provides basic supportive care for temperature stabilization before being moved to a "term," or regular, nursery. They may also be transferred from another facility.

Neonatal Transport

One essential element of a regional perinatal system is the capacity to transport infants requiring Level III care from a facility that does not provide it. In July, 1988, the RPPP, the neonatal transport team management staff, and medical staff involved in maternal transport, published a comprehensive manual providing transport guidelines. The manual is meant as a guide for physicians, nurses, paramedical personnel, and other health care providers regarding procedures, staffing patterns, and equipment for the transport of high risk neonates.¹⁸

The referring physician, usually after applying a high risk assessment tool, and after consultation with the RPC neonatologist on call, is responsible for initiating a transport. A medical director for neonatal transport from the RPC has overall responsibility. All arrangements for transport, including method of transport and selection of personnel are made at the RPC. The transport team is available at all times, seven days a week. An around-the-clock neonatal consultation hotline is also available for physicians referring high risk neonates for transport. The transport team for infants requiring intensive care is specially trained in transport procedures and emergency care of the newborn. The team usually consists of a physician (neonatologist, neonatology fellow, or senior pediatric resident), a neonatal nurse, a neonatal nurse practitioner, and a respiratory therapist.

Guidelines are also provided for:

- (1) Care and stabilization of high risk infants before transport;
- (2) Essential medicines;
- (3) Essential medical and nursing equipment;
- (4) Basic equipment including incubators, monitoring, respiratory, and suctioning equipment;
- (5) Out-of-state transport;
- (6) Non-NICU infant transport;

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- (7) Back transport to the referring facility;
- (8) Mode of transport including ground ambulance, military helicopter, commercial air ambulance, and Coast Guard emergency procedures; and
- (9) Data collection regarding mother and infant demographics, medical status before and during transport and at admission, and transport team evaluation for the purpose of quality assurance.

Neonatal Beds

The SHPDA sets the "neonatal special care units standard" as follows:¹⁹

The total number of neonatal intensive and intermediate care beds should not exceed four per 1,000 live births per year in a defined neonatal service area. An adjustment upward may be justified when the rate of high-risk pregnancies is unusually high, based on analyses by the [Health System Agency] HSA.

A single neonatal special care unit (Level II or III) should contain a minimum of 15 beds. An adjustment downward may be justified for Level II unit when travel time to an alternate unit is a serious hardship due to geographic remoteness, based on a analyses by the [Health System Agency] HSA.

According to the SHPDA, it appears that a Level II neonatal bed means an intermediate care bed and a Level III means a neonatal intensive care bed. A neonatal special care unit appears to encompass both "Level II and Level III" beds.²⁰ In 1983, the SHPDA reviewed the inventory of Level II and Level III neonatal beds. With 19,164 live births in 1983, a maximum of 76 Level II and III bassinets were justified at that time.²¹ The SHPDA found that the State had fewer than the maximum number but there was no indication that this represented a shortage.²² In addition, none of the special care units within the regional perinatal system had the minimum number of 15 beds deemed necessary for economical operation.

Data reported since 1983 have not been reported in a way that makes comparison possible. For example, in 1987, the 18,555 live births justified a maximum of 74 Level II and III bassinets while only 20 neonatal intensive care unit beds were reported by the SHPDA --

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two at Kaiser and 18 at KMCWC.²³ These 20 beds no longer included Tripler's beds and Queen's Medical Center no longer reported any NICU beds.²⁴ Subsequent SHPDA facilities utilization data are provided only under the following categories:

- (1) Medical/surgical;
- (2) Critical care;
- (3) Obstetric;
- (4) Pediatric;
- (5) Neonatal intensive care unit; and
- (6) Psychological.

That is, neonatal data are not broken down for Level I, II, and III beds. The SHPDA indicates that some facilities may also be reporting some Level II neonatal beds under the "pediatric" category.²⁵ There is also some confusion over "10 Perinatal intensive care (PICU)" beds that appear to be reported among the 126 "pediatric" beds in 1987. [Emphasis added.]²⁶ "PICU" beds, however, are also described as "pediatric intensive care unit" beds in another document. [Emphasis added.]²⁷ It should be kept in mind that pediatric beds serve the entire population of children and not just those in the perinatal period. But it is still unclear if these "PICU" beds differ from NICU, or Level III, beds. As a result, direct comparison with data from the 1983 the SHPDA survey is not possible. The most recent data at the time of writing -- the first quarter 1988 -- show no change from that for 1987.

Support Services at the Regional Perinatal Center

Support services at the RPC include:

- (1) Fiscal services;
- (2) Genetic counseling comprising the birth defects program and medical genetics services;
- (3) Health education services;
- (4) Nutritional services;
- (5) Occupational therapy services;

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- (6) Physical therapy services;
- (7) Respiratory therapy services;
- (8) Social work services provided by an Ob-Gyn social worker, an NICU social worker, a patient relations coordinator, and a birth defects social worker; and
- (9) Speech, language, and audiology services.

Fiscal services consist of financial counseling for patients.

The birth defects program offers genetic counseling and follow-up services for the care and management of children with birth defects. Services are provided by a specially trained inter-disciplinary team while infants are still in the hospital or as outpatients in the birth defects clinic. The medical genetic services component accepts referrals and works closely with the Department of Health (DOH). Diagnoses are made for children suspected of having a genetic condition. Clinical services include management of certain inherited metabolic disorders.

KMCWC's department of training and education provides health education services. The content of training classes for postpartum patients include family planning, breast feeding, baby care, nutrition, diapering, and infant bathing.

Nutritional services includes instruction to families of NICU infants requiring special diets after discharge.

Occupational therapy (OT) is available upon referral. The OT department also provides evaluations and treatment (neuromotor, fine motor, sensorimotor, and oral motor) for high risk infants and assists the families to be aware of normal development and how to facilitate it through developmental therapy.

Physical therapy (PT) is also available by referral and to NICU infants, infants with birth defects, neurological or orthopedic conditions, and those at high risk of developmental delays due to prolonged hospitalization.

A respiratory therapist is assigned to each NICU shift. Respiratory services are also available on an as-needed basis. Services include pulmonary evaluations with physicians and administration of, and instruction in, mechanical ventilation, aerosol and intermittent positive pressure breathing treatment, spirometry, chest physiotherapy, oxygen therapy, and cardiopulmonary resuscitation.

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Social work services provided by the Ob-Gyn social worker include social risk screening, assessment, and casework. This person also provides psychosocial assessment and discharge planning for babies in intermediate care or transferees from the NICU. The NICU social worker provides crisis-oriented services, consultation, and discharge planning specifically for NICU infants. The patient relations coordinator investigates patient grievances and complaints. The birth defects social worker provides consultation and casework services to infants with birth defects and their families.

Speech, language, and audiology services are available by referral. Audiology services involves the testing of hearing of infants born at risk of a hearing loss.²⁸

The family centered care project which provided counseling and case management to families of infants in the NICU is no longer in operation. However, elements of this program have been incorporated into other programs.

Non-Institutional Neonatal Services

Other than the usual inpatient and support services provided by the various Level I to III facilities, the SHPDA facilities plan makes note of the following continuing support services including nursing and home follow-up services:²⁹

In the prenatal phase, primary care physicians and their support personnel are important to ensure continuity, as well as State public health nurses who provide generalized nursing services. Honolulu Home Care, Upjohn-Health Care Services, Medical Manpower Pool, Inc., and Straub Clinic and Hospital's Home Health Agencies provide follow-up home health services to patients/families on Oahu while neighbor island home health agencies provide the same service on their respective islands -- Hilo Home Care - Hawaii; Hale Makua - Maui; DOH - PHN - Lanai and Molokai; and Kauai Home Health Service - Kauai.

The Maternal and Child Health Branch [MCHB] of the State Department of Health provides comprehensive health services to eligible pregnant women, newborn infants and children through their Maternity and Infant Care Projects (MIC) in Hilo and Waimanalo and Children and Youth Project (C&Y) in Waimanalo.

The MCHB services include prenatal care, early identification and screening for high risk pregnancies, and family planning. Although its primary orientation is preventive, the MCHB is also planning to start a unit in Kona on the island of Hawaii similar to the ones in

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Waimanalo and Hilo.³⁰ The MCHB is also planning a perinatal substance abuse program containing some of these preventive and intervention strategies which is discussed in a later section.

NICU Follow-up Program

The MCHB also contracts with KMCWC staff to operate an NICU follow-up program. Staff regularly visit certain infants who have been discharged from the regional perinatal center NICU to ensure that they continue to receive the appropriate services. The MCHB directs and coordinates the program and collaborates with participating agencies to:³¹

- (1) Develop and implement standards of care;
- (2) Assure the availability and quality of follow-up services; and
- (3) Assure data collection and evaluation of the follow-up program.

According to the MCHB's FY 1987-88 annual report on the NICU follow-up program, activities include periodic tracking and monitoring of enrolled NICU graduates to age three for medical, developmental, and psychosocial assessment at specified ages. The program began screening for language delays last year. The primary goals of the program are to:

- (1) Identify children with developmental and psychosocial sequelae (other subsequent psychosocial handicapping conditions); and
- (2) Facilitate access to needed services.

However, not all eligible NICU graduates can meet program criteria and not all those who do are enrolled.³² Only NICU graduates at KMCWC are eligible. The criteria for enrollment in the program are:

- (1) Weight under 1,500 grams, or very low birthweight;
- (2) Ventilation for more than 48 hours;
- (3) A twin of an eligible infant; or
- (4) Special referral, for example, infants with suspected neurological or sensorimotor problems; infants of mothers receiving prenatal intensive care.

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Table 4-1 documents the program's target population and enrollment since its inception in 1983. For FY 1987-88, only 28% of eligible infants met program criteria and of these, 64% were enrolled. Of the 481 NICU graduates, 135 met program criteria. Of the 135, 86 were new enrollees. A total of 247 children were seen and assessed and 27 referrals were made. The cumulative total number of children known to the program at the end of FY 1987-88 was 1,179.³³ Of the 27 referrals, the largest number (11) were made to the infant development program. The MCHB also collaborates with the Public Health Nursing Branch (PHNB) to fund a public health nurse coordinator ". . . to systematically provide services to all high risk newborns and others in need of nursing services"³⁴ including coordinating NICU referrals to the PHNB. The MCHB report contends that the number of referrals to PHNB is undercounted (only 1 referral) and does not accurately reflect the larger number referred before or upon discharge. In fact, the annual report states that the MCHB reported 111 referrals to PHNB from the NICU from April 10, 1987 to June 30, 1988 although not all would have been eligible to enroll in the follow-up program.³⁵

Table 4-1

ELIGIBILITY AND SERVICE DATA

Characteristics	FY 82-83	FY 83-84	FY 84-85	FY 85-86	FY 86-87	FY 87-88
Resident Live Births	19,090 (1983)*	18,667 (1984)*	18,267 (1985)*	18,341 (1986)*	18,690 (1987)*	NA
Eligible Population						
1. NICU Graduates KMCWC	380	367	296	271	412	481
Target Population						
1. <1500 gm. BW	148=39%	167=44%	148=50%	132=36%	159=39%	135=28%
2. >48 hrs. vent.		of				
3. Twin of elig. infant		elig.				
Services						
1. Number enrolled of target	120=81%	118=71%	86=58%	104=79%	76=48%	86=64%
2. Follow-up Assessments	259	257	219	234	212	247
3. Referrals	41	54	30	99	70	27

*Calendar Year

Source: Hawaii, Department of Health, Family Health Services Division, Maternal and Child Health Branch, NICU Follow-up Program Annual Report FY 1987-88, 1989.

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Table 4-2 summarizes the incidence of handicaps and subsequent debilitating psychosocial conditions at three and nine months and at three years for the period from 1983 to 1988. Major handicaps include "cerebral palsy, psycho-motor retardation, deafness, blindness, and shunted hydrocephalus."³⁶ Minor handicaps are defined as "developmental delays observed at age three years" when the score on a certain developmental test falls below a certain point.³⁷ The number of developmental delays is very small, according to the report, and falls mostly in the area of language delay (19%) and fine motor development (11%). A total of 25 children, or about 10% of the 247 seen, received assessments in the area of subsequent debilitating psychosocial conditions. For example, the team noted significant psychosocial delay such as foster home placement, placement with relatives, divorce of parents, abuse, and neglect.

Table 4-2

SUMMARY OF RATES FOR DIFFERENT PERIODS
Percentages of Number of Assessments Done

	Project Wide 1983-86 (Includes TAMC)	Only 1985-86 (Includes TAMC)	1986-87	1987-88
<u>HANDICAPS:</u>				
Suspected Handicaps @ 3 months	72/302=24%	NA	18/67=27%	28/95=29%
Major Handicaps @ 9 months	48/248=19%	14/89=16%	10/67=15%	7/81= 9%
Major Handicaps @ 3 years	11/85=13%	9/67=13%	6/49=12%	0
Minor Handicaps @ 3 years	30/85=35%	24/67=36%	17/49=35%	4/27=15%
<u>PSYCHO-SOCIAL SEQUALAE:</u>	47/694=7%	18/234=8%	22/212=10%	25/247=10%
<u>TOTAL REFERRALS:</u>	178/694=26%	NA	72/212=33%	27/247=11%
To Infant Dev. Prog	57/178=32%	24/124=19%	15/72=33%	4/27=41%
To Audiology	59/178=33%	57/124=46%	24/72=33%	3/27=11%
To Headstart	8/178=5%	8/124=7%	9/72=13%	3/27=11%

Source: Hawaii, Department of Health, Family Health Services Division, Maternal and Child Health Branch, NICU Follow-up Program Annual Report FY 1987-88, 1989.

The follow-up clinic is staffed by a multi-disciplinary team consisting of a neonatologist, neurologist, occupational therapist, speech pathologist, pediatric nurse

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practitioner, and social worker. The follow-up program operates clinics located at KMCWC twice weekly. Children attend at the ages of three months, nine months, two years and three years of age corrected for premature birth. Children on other islands are followed with at least ten annual on-site staff visits. Coordination of the clinics is done by the social worker who also identifies and monitors NICU infants before discharge, and assists in making referrals to various community agencies as appropriate.

The MCHB report concludes that the program has been successful in meeting one of its goals -- that of tracking high risk infants through early identification leading to correct diagnosis and treatment including early intervention services. However, it also concludes that the program may not be meeting another goal of collecting data adequately to facilitate informed planning because of the relatively small number of children tracked.

Perinatal Substance Abuse Program Planned

An increasing proportion of high risk infants in Hawaii -- and certainly the most visible -- consists of drug-exposed babies. The Maternal and Child Health Branch has been working to plan a perinatal substance abuse program.³⁸ Infants born to women addicted to drugs or alcohol are frequently afflicted with multiple problems.³⁹ These babies can be both drug-damaged, which is more serious and more long-term, and drug-addicted, which is less serious and shorter-term. Drug-damaged babies can suffer from inadequately developed central nervous systems, physical deformities, and other mental and physical birth defects. Drug-addicted babies need to go through the wrenching experience of withdrawal, just like adults.

The thrust of the program is intended mainly to be preventive to counter the growing incidence of pregnancies involving parental, especially maternal, substance abuse. The components of the planned program include education before conception about the effects of substance abuse on pregnancies and the newborn. However, intervention is also planned to include outreach and early identification of mothers abusing substances. The challenge of the program is to encourage and persuade at an early stage a target population that is inherently difficult to identify and resistant to intervention to receive appropriate treatment and services. There is a fear among this target population that identification may lead to arrest, incarceration, or other undesirable -- from their perspective -- ramifications.

Community-Based Transitional Center

The development of a transitional center located in the community and away from a hospital setting is being worked on by the DHS and the DOH's Developmental Disabilities and Family Health Services Divisions. The idea of such a transitional center has also been discussed fairly widely among other health professionals in the State. For example, KMCWC

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also supports a transitional center to provide the "rooming-in" for mothers and their infants that was once available at KMCWC.⁴⁰ The center would enable mothers and infants with special needs, who have been stabilized and no longer have pressing medical problems, to be together for a period under supervision.⁴¹ During this time, mothers can be trained to provide their infants with the appropriate care at home. When babies require acute care, hospital staff give their undivided attention to the infants' medical condition to the detriment of the infants' and mothers' other needs. For example, attention to follow-up services and proper training for parents are given short shrift when infants are still in acute medical danger. Only when the infant is stabilized are ancillary needs attended to. The argument is that these other needs, such as arranging for substance abuse treatment and psychosocial evaluations and intervention for the mother, are not addressed adequately after discharge. These needs would be taken care of if mothers and their babies could spend time in a transitional "buffer" before the day-to-day care of their infants becomes a reality. The transitional center would take not only substance abuse babies but a multiple population of infants with special needs whatever the causes. Once adequately trained to provide for the long-term management of their special needs infants, caregivers would no longer need to resort to the more costly services that were available only in medical facilities. However, the system would work only if caregivers were properly and adequately trained and if an adequate network of support services were available in the community to provide ongoing support. Examples of support services are discussed in subsequent sections in this chapter dealing with the Zero to Three Project, the planned DHS program, and early intervention services for infants and toddlers with special needs under Act 107, Session Laws of Hawaii, 1989.⁴² Lastly, there has to be an adequate pool of foster parents. The issue of foster parents is also discussed in a later section.

Training could include special techniques such as administration of medication, suctioning,⁴³ and operating oxygen supply and monitoring equipment. The cost of providing this training early while mother and infant are still in the acute care facility is prohibitive. Providing it after mother and infant get home may be too late. There appears to be general agreement among most health professionals that lay caregivers can be adequately trained to provide this special care at home. The Family Health Services Division of the Department of Health (FHSD) believes that infants can be adequately cared for outside the hospital setting regardless of how medically fragile the infants may be as long as they have been stabilized, and proper training and community support services are provided.⁴⁴ It is assumed by some, however that there will always be a very small number of infants who have such major medical problems that they will always need to remain in an institution.⁴⁵ Some estimate that the number of babies whose medical needs continue so that home discharge is not feasible has been very small in the past -- less than one per cent. With the apparent increase in drug-exposed babies recently, the proportion may grow.⁴⁶ The need to involve the family in all decisions, even if it involves the very last resort of institutionalization, remains paramount. It is also understood that although lay caregivers can be trained to provide adequate special care, their understanding and interpretation of various symptoms would be more limited than

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that of health professionals on the whole. The point is to provide better training for lay caregivers.

There is widespread agreement among the State's health professionals, including those responsible for acute care, that infants benefit over the long run in the least restrictive environment. That is, the first priority is to return the infant to the natural home if possible, and to a foster home if necessary. Placing medically stabilized infants in long-term care facilities, which do not exist in Hawaii, is an extremely low priority. The focus, it is commonly agreed, should not be a consideration of the circumstances under which less desirable long-term skilled nursing or intermediate care facilities become valid alternatives. (SNF/ICFs are discussed in a later section in this chapter.) Rather, the focus should be to work toward better alternatives so that Hawaii does not need to resort to SNF/ICFs.

It has also been pointed out that placement into foster homes from a transitional center would be easier than direct placement from an acute facility. Prospective foster parents are often wary of the stigma of lingering "medical" problems. That stigma could be removed by making the placement from the less restrictive setting of a transitional center rather than from a medical facility.⁴⁷

Children With Special Health Needs

One of the agencies to which social workers at the RPC can refer high risk infants upon discharge is the Family Health Services Division's Children With Special Health Needs Branch (CWSHNB) of the DOH.⁴⁸ Historically, the branch has operated in the role of a bill paying agency. The branch receives federal Social Security Act, Title V moneys from the Maternal and Child Health Services block grant as well as some state funding. The CWSHNB provides coverage for patients up to age 20. Although diagnosis is free, payment for treatment is based on a means eligibility test.⁴⁹ Basically, the CWSHNB coordinators work with public health nurses who contact the potential health care provider. The branch then advises whether proposed services are covered and, if appropriate, authorizes payment for those services. However, third-party insurance is used first so that the CWSHNB acts as the payor of last resort. As a result, authorized payments are usually low.

Covered services are based on medical categories. Coverage is restricted due to limited funds and is shaped by historical precedent. Medical categories currently covered include:

- (1) Severe asthma;
- (2) Heart disease;

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- (3) Eye surgery;
- (4) Hearing loss;
- (5) Myelodysplasia;
- (6) Birth defects;
- (7) Seizure disorder;
- (8) Orthopedic problems;
- (9) Cleft lip & palate;
- (10) Metabolic disorders;
- (11) Cerebral palsy; and
- (12) Genetic conditions.

The type of coverage has developed from precedent, beginning with coverage for orthopedic services. As a result of the arbitrary nature of coverage, the branch does not provide comprehensive coverage.⁵⁰ Although the CWSHNB believes that the definition of children with special health needs (formerly crippled children) is a subset of a broader definition of the developmentally disabled, some within the branch have voiced a desire to expand coverage.⁵¹

The CWSHNB also provides limited direct medical services. The branch pays specialists to conduct orthopedic, neurologic, and genetic conditions clinics on all islands. The branch has social worker representation at the RPC but the referral procedure at discharge from the RPC is informal and not systematic.⁵² The social worker, whether employed by the DHS, the DOH, or the RPC itself, essentially decides where an infant is referred to. There appears to be no formal written procedure, for example, for referring certain infants to the DOH's Developmental Disabilities Division, and others to the CWSHNB.

NICU Discharge and Boarder Babies

A common discharge pattern for the high risk infant is transfer from intensive care to an intermediate nursery, and from there either to a regular nursery or out of the facility. It is possible for an infant in an NICU to be moved to an intermediate level of care within the NICU before discharge. (See "Special Care Versus Standard Care" section above.) It is also not

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uncommon for an infant to be discharged directly from the NICU out of the facility.⁵³ Often an LBW infant must be kept in an intermediate nursery to feed and grow to four pounds before the infant can be discharged. These infants are usually those convalescing from surgery or other serious problems and preemies who have not yet reached discharge criteria. In the past, the percentage of infants whose medical needs continue so that home discharge is not feasible has been very small (under 1%). The number of drug babies has made the situation less certain. There have been 68 observed cases of drug addicted mothers for the year ending August, 1989 (see chapter 3) although to date there seems to have been only one AIDS baby born in Hawaii.⁵⁴

NICU discharge is handled by committee. The discharge committee consists of the attending neonatologist or pediatrician, social workers from KMCWC's social services section and the Department of Human Services, a Public Health Nurse, staff from the Department of Health representing the Children with Special Health Needs Branch and the Maternal and Child Health Branch, and therapists. Discharge criteria used are based on medical, social, and psychosocial factors. Referrals are made at discharge, including placement in foster homes. The role of the social worker is crucial at this stage. It appears that referral guidelines are not written. The process of making referrals depends on the collective experience of the committee members and is guided in general by principles of appropriateness and cost savings. For example, referral is made to the PHNB if rural follow-up is required, and to the CWSHNB if an infant qualifies for medical payment coverage.

A pressing problem, however, is that of boarder babies. Sometimes the discharging neonatologist or pediatrician will certify that all medical problems for the infant have been resolved. If there is no more need for acute care the infant can be medically discharged. However, sometimes the baby has no place to go. When an infant has been stabilized and is ready for discharge cannot be returned to the natural family or a foster home, the infant remains institutionalized, to no one's satisfaction or benefit. A transfer to a level below intermediate nursery would theoretically be skilled nursing. However, KMCWC does not have criteria for defining a skilled nursing level. Instead, infants who do not need to, remain on a higher level, incurring higher costs.

Many boarder babies are those born to substance-abusing parents. Returning to a drug-abusing environment directly endangers the infant's welfare. The risk of abuse and neglect is increased not only because of the parent's impaired physical condition but because the excessive irritability exhibited by a drug baby makes it very easy for a caregiver to mistreat the infant out of frustration. Other boarder babies are abandoned for a variety of reasons. Some are born to underaged parents who themselves cannot, or do not have relatives willing and in a position to, care for the babies. Some are simply abandoned.

Whatever the reason, acute care hospitals are subject to the high costs of maintaining boarder babies in their facilities. For example, from June to August, 1988, drug-exposed

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infants at KMCWC incurred costs for extra length of stay amounting to \$15,310 over 73 days or an average of \$210 per infant per day. (See testimony from the DHS in a subsequent section citing a slightly different total of \$15,330.) Each infant suffering from perinatal drug abuse averaged three extra days of hospital stay. Those who returned to the biologic mother stayed an average of 2.2 days with a range of 0 to 4 days. Those who required foster home placement stayed an average of 5.5 days with a range of 0 to 11 days.⁵⁵ It is also possible for an NICU dischargee to be transported back to a Level I or Level II facility as a boarder baby if there is nowhere else for the baby to return. Given the chronic lack of foster parents, this is a constant concern for all facilities. The DHS has just recently instituted a new policy whereby the departmental social worker will not discharge an infant if the baby cannot be adequately placed⁵⁶ -- that is, payments will continue for boarder babies. In fact, the DHS claims that payments have not been cut off in the past for babies who continue to remain in hospitals even after their medical problems have been resolved and acute care is no longer necessary.⁵⁷ However, DHS payments for boarder babies may not entirely cover the cost of maintaining them in hospitals. This does not mean the DHS encourages institutionalization over in-home placement, quite the contrary. The DHS is willing to increase payments to foster caregivers to recruit new, and to retain current, foster parents. It is also willing to provide initial certification and provide ongoing training for foster parents.⁵⁸ The DHS also supports the role of prevention to reduce in the first place the number of boarder babies that need placement.

It has also been contended that the Hawaii Medical Service Association (HMSA) does not pay for intermediate care for infants, thus providing an incentive for hospitals to keep infants longer at the acute care level.⁵⁹ The real issue may be that the DHS will make medicaid payments only if services are covered, if the patient is eligible, and if a physician recommends that the services are medically necessary. However, many community-based, family-centered services are considered by the DHS to be "social" in nature and not medical. The question of whether medical facilities are fully or adequately reimbursed by the DHS through the medicaid program for boarder babies is beyond the scope of this study but is included in the scope of current studies being done by the Legislative Auditor.⁶⁰

Skilled Nursing/Intermediate Care Facility for Infants

It has been suggested that skilled nursing facilities (SNF) or intermediate care facilities (ICF) be established to take in boarder babies. There are none at present. SNFs and ICFs, as the terms are used here, refer to entirely separate facilities and not to the different levels of neonatal nursery care. Infants no longer requiring acute or intensive neonatal care in a hospital setting would be released to SNF/ICFs specially designed for infants. These SNF/ICF facilities would no longer provide expensive acute care. They would provide 24-hour care -- like any nursery -- but on a long-term basis and at a lower level. It is conceivable that SNF/ICFs may be virtually the last stop for a long time for some infants who cannot be

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placed. There is currently no distinct category of SNF/ICF facility for infants.⁶¹ Unless new rules are specifically adopted, these infant SNF/ICFs would be subject to the same rules and licensing requirements as long-term SNF/ICFs populated mainly by the elderly. It would be reasonable to expect similar paraprofessional staffing patterns as now exist for long-term facilities for the elderly.

A major assumption underlying the call for institutionalizing infants in SNF/ICFs is that this is more cost effective than institutionalizing infants in acute care hospitals. Siphoning stabilized infants to SNF/ICFs would also improve utilization of acute care bassinets as they opened up for new admissions who really need acute care. The drawback is that SNF/ICFs are institutional in nature and would provide care in a very restrictive environment when that kind of environment, according to many, is not necessary. Taking the cost argument a step further, at-home or community-based care should be even more cost effective. The issue is: at what point will it be necessary to place boarder babies in SNF/ICFs. One view of why it is not yet necessary to resort to these long-term infant facilities is that Hawaii has not yet been inundated with drug babies to the extent that some other localities such as New York and Washington, D. C. have been.⁶² The lesson and the warning is that if the State does not adequately anticipate the problem and prepare better alternatives, as the number of hard-to-place drug babies increases, the temptation to place them into a long-term facility also increases.

There is also some skepticism over the motivation of potential operators of for-profit SNF/ICFs. Many in the foster care field believe that foster parents are motivated by altruism and not by profit. The potential for abuse in for-profit group homes for infants is heightened if only because of the nature of the target population. Babies are even less able than the elderly to protect themselves from abuse and exploitation. At the least, infants cannot lobby for themselves. As a result, some local health professionals believe that SNF/ICFs have been mentioned as an alternative only as a stopgap measure in response to pressing problems that call for immediate solutions. The fact that they are even considered at all is because the more desirable alternatives are scarce.

Foster Care for High Risk Infants

A major problem is that there are not enough foster parents. At present, the DHS licenses only one kind of foster home for children of all ages and limits the number of children to no more than four if they are under the age of two and if extra help is available. There is no distinct category of foster home for infants.⁶³

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The DHS testified that of its count of 81 drug-exposed infants born at KMCWC from July, 1988 to July, 1989:⁶⁴

" . . . about 60 were or are active recipients of the Department's services. One of these services is foster care where, as of late September, 1989, 32 drug-exposed infants/babies live in 26 foster homes. Twenty of these children are on apnea monitors. The Department is currently without a pool of available placements for children which would enable us to more appropriately select homes and 'match' children with foster families. The need to address placements for drug exposed and other medically fragile children further compounds this problem . . . As a result of the unknown risks faced by these infants and the lack of a pool of specially trained foster families available to care for these babies, each time a placement is needed for an infant, a caregiver must be found, licensed and trained in cardio-pulmonary resuscitation and, for some infants, in monitoring of heart monitors. Currently, the average time between request for placement [in a foster home] and placement is seven work days with the range going from 1 day to 3 weeks. . . In 1988, the Department received less than one request for placement of these infants per month; we are currently receiving an estimated minimum of 3 requests per month and do not expect this to decrease. [Emphasis added.]

At least 21 of these babies did not receive DHS services. At least 32 infants were placed in foster care. However, this represents only about 40% of the 81 drug-exposed infants. Even assuming that it was appropriate to discharge all of the other 60% of drug-exposed infants back to their biological drug-abusing families, it is not clear that all who needed foster care placement actually received it. For a slightly different period (January 1988 to June 1989), KMCWC reported 71 cases of perinatal substance abuse infants in its facility. There were 20 cocaine babies of which 17 required foster care placement.⁶⁵ The extent of the need is hinted at by the amount of time required to place an infant which is reported by the DHS to average seven work days with a range from one day to three weeks. KMCWC reports an average of 5.5 days with a range of 0 to 11 days of extra hospital stay for perinatal substance abuse infants requiring foster home placement.⁶⁶ In addition, the DHS testimony spoke only of infants of substance-abusing mothers. However, high risk in infants results from more than just substance abuse. That is, the need for foster care is not limited only to the population of drug-exposed infants but to the larger population of high risk infants.

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Testimony from KMCWC reinforces the pressing problem of the lack of foster care:⁶⁷

One measure of the current strain on resources is the extended stay of these [drug-exposed] infants in our hospital nurseries beyond medical necessity. From June, 1989 through August, 1989, there were 24 drug-exposed infants in our nurseries for whom CPS [Child Protective Services of the Department of Human Services] made a determination of risk necessitating special arrangements. For this group, there were a total of 73 patient days beyond medical necessity, while alternate placements were [being] sought, caregivers appropriately trained, or evaluations completed. Total cost of nursery days alone: \$15,330. The average stay beyond medical necessity for those entering foster placement was 5.5 days, the average for those going to biological parents 2.22 days.

In 1987, The Department of Human Services testified that about 500 foster care spaces were available for 600 children needing placement. About 100 new foster homes were recruited but about 90 were lost.⁶⁸

Developmentally Disabled Infants

Although most referrals to the DOH's Developmental Disabilities Division (DDD) are adults who are mentally retarded, the DDD does accept infant referrals. Early diagnoses during infancy are difficult to make definitively. However, the aim is to intervene at an early stage so that developmental disabilities can be mitigated or eliminated at a later stage of the child's life. The DDD's Waimano facility is a long-term intermediate care facility for the mentally retarded. The DDD makes every effort not to refer any infants to that institution. There are no infants at Waimano. Most high risk infants are referred to the DHS upon discharge. If there is a suspicion that the infant may be developmentally disabled, the DHS re-refers the infant to the DDD.⁶⁹ It is also possible to have infants referred for DDD services from the infant's home. The DDD then makes a determination and diagnosis for developmental disability. A comprehensive diagnostic evaluation is made by a multidisciplinary team consisting of a pediatrician, social worker, nurse, nutritionist, psychologist, speech pathologist, and occupational, physical, and educational therapists. An individualized plan is worked up to match the infant's needs with available services.

A foster home recruiter then attempts to find an appropriate foster home for the infant. The DDD is permitted by the DHS under agreement to recruit foster homes especially for developmentally disabled children and to give special training for caregivers.⁷⁰ Most foster caregivers have had some experience in cardiopulmonary resuscitation techniques as nurse aides. However, the multidisciplinary team gives training every three months. Licensing of

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the foster homes is standard but the training provided is specially designed for the care of developmentally disabled infants. The DDD has placed only one infant in a foster home in the last year. According to the DDD, this reflects the division's policy of providing care in the least restrictive environment.⁷¹ Placement in the natural home is preferable to one in a foster home. If the infant cannot receive appropriate care in the foster home, the DHS can step in to provide assistance such as nursing services, respite care, chore services, and equipment purchases. If the infant is referred to the DHS's community long-term care project (Nursing Home Without Walls), certain services are then covered by medicaid payments. However, the DDD continues to monitor the placement while the DHS monitors the provision of covered medicaid services.⁷²

If an infant is diagnosed for developmental disability, the infant may receive DDD services in the infant development program. Despite its name, the program is open to children from birth to age three and includes the following services:

- (1) Therapy services that include:
 - (a) Occupational therapy;
 - (b) Speech therapy;
 - (c) Physical therapy;
 - (d) Social work services; and

- (2) Special training for caregivers to care for developmentally disabled children, for example, training on how to handle and cope with infants with motor problems.

Although therapy services are meant to be mainly consultative, therapists are often called upon to administer direct therapy. Consultative services from the nutritionist, psychologist, and pediatrician are also available as necessary.⁷³ Participants meet once weekly and respite services are also available. The DDD has historically provided direct services through its infant development program and is currently serving 403 children up to the age of three on Oahu. A total of about 800 are being served statewide which includes those served by privately contracted providers. Approximately one-third of this number (265) are below the age of one.

Case management is also provided by the DDD. However, the DDD voiced the opinion that too many agencies are emphasizing case management over the actual provision of services. Case management is defined in section 333F-1, Hawaii Revised Statutes, as follows:

"Case management services" means services to persons with developmental disabilities or mental retardation that assist them in gaining access to needed social, medical, legal, educational, and other services, and includes:

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- (1) Follow-along services which assure, through a continuing relationship between an agency or provider and a person with a developmental disability or mental retardation and the person's parent, if the person is a minor, or guardian, if a guardian has been appointed for the purpose, that the changing needs of the person and the family are recognized and appropriately met.
- (2) Coordinating and monitoring services provided to persons with developmental disabilities or mental retardation by two or more persons, organizations, or agencies.
- (3) Providing information to persons with developmental disabilities or mental retardation about availability of services and assisting the persons in obtaining the services."

"Services" is further defined in the same section as:

"Services" means appropriate assistance provided to a person with a developmental disability or mental retardation in the least restrictive, individually appropriate environment to provide for basic living requirements and continuing development of independence or interdependent living skills of the person. These services include, but are not restricted to: case management; residential, developmental, and vocational support; training; habilitation; active treatment; day treatment; day activity; respite care; domestic assistance; attendant care; rehabilitation; speech, physical, occupational and recreational therapy; recreational opportunities; counseling, including counseling to the person's family, guardian, or other appropriate representative; development of language and communications skills; interpretation; transportation; and equipment.

It is apparent that case management is only one small component of services. Case management only aims to ensure that all appropriate services are eventually provided. In other words, there is a danger that case management, which facilitates the process of providing services, is threatening to supplant the actual services themselves. The complaint is: many facilitators, not enough service givers.

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Zero to Three Project

In 1975, the United States Congress passed the Education for All Handicapped Children Act, Public Law 94-142, which requires special education programs for all children aged 6 to 21. In 1986, some of its provisions were amended by Public Law 99-457 to require special education for children under six years of age. However, programs were mandatory only for those aged three to six, and were optional for those up to age three. In fact, all states participate to some extent by providing optional programs.⁷⁴ In Hawaii, the Department of Health was designated in 1987 as the lead agency for implementing the law. Up until FY 1987-88, all funding for the project had come from federal sources. In 1989, the Legislature enacted Act 107, Session Laws of Hawaii 1989, which took effect on July 1, 1989. Act 107 authorizes the DOH to provide a comprehensive program of early intervention for infants and toddlers with special needs and is discussed in detail in the following section.

The Zero to Three project was established in October, 1987 under Public Law 99-457 and is supervised by the DOH.⁷⁵ The project is part of the State's response to the challenge of providing a coordinated system of comprehensive early intervention services for infants and toddlers with special needs and their families. The project's goal is to bring into being a comprehensive network of community-based and family-oriented support services. The project's role is more to plan, coordinate, and encourage the development of this network and to assure that it continues to operate at a high level. It will not actually develop the components of the system. In monitoring the system, the project plans to perform various needs assessments regarding target populations, facilities, and services.

The types of community-based and family-centered services which the project advocates -- some of which do not yet exist -- include:

- (1) Crisis nursery care which is given to the infant when the caregiver family requires emergency assistance in giving nursery care to the infant;
- (2) Respite care in which the caregiver is provided a period of respite from the stress of caregiving responsibilities either by temporarily taking the infant away from the home for care in the community, or by enabling the caregiver to leave the home for a temporary respite;
- (3) Provision of training and support for parents, foster parents, and aides which can include parenting and caregiving techniques as well as specialized training with sophisticated monitoring equipment for routine infant care procedures;
- (4) Health services at the nurse level -- not "medical" services provided by physicians -- including community-based:

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- (a) Occupational therapy;
 - (b) Physical therapy; and
 - (c) Speech therapy;
- (5) Social worker counseling visits;
 - (6) Case management services in which a case manager follows the infant and family to ensure that all appropriate linkages are made and maintained with the support network;
 - (7) Advocacy services in which the infant and family are represented and their rights advocated and protected in various arenas;
 - (8) Transport services for special needs infants and toddlers and their families, for example, to attend special clinics in the community such as the infant development program; and
 - (9) Financial support for the purchase or use of special equipment and supplies over and above those needed for the care of low risk infants and toddlers.

As a general rule, the project does not provide direct services. However, it has recently received funding for 16 case manager positions. The project organizes its case management activities around the Individualized Family Support Plan wherein case managers are assigned to each infant discharged from the regional perinatal center. (See discussion below on Act 107, Session Laws of Hawaii 1989.) Although there is no provision for outreach to other facilities, it is possible at times to handle cases from Kaiser or Tripler.⁷⁶ Another exception to its principal role of coordination and planning is its funding for certain gaps in the system such as that for certain services on the islands of Molokai and Lanai. A final exception is its joint funding with KMCWC for a mobile team of occupational, physical, and speech therapists and social workers who make home visits.

The Department of Human Services is planning to seek supplemental funding for an infant program in fiscal year 1990-1991 along similar lines.⁷⁷ The program would consist of two major elements. First, an intervention team is to follow each infant home to train parents and caregivers and provide supervision and support on a 24-hour emergency basis. Second, specialists are to provide intensive training for parents, foster parents, and other at-home caregivers in techniques traditionally provided by health professionals in institutional settings. By training natural or foster parents in techniques such as heart monitoring, suctioning, physical therapy, and use of respiratory equipment, it becomes increasingly possible for an infant to avoid institutionalization by receiving the proper care at home or in the community. The training must be thorough, however. In addition, there must be sufficient support services in the community such as respite care and visits by home health aides from the DHS

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and from various therapists and social workers.⁷⁸ This type of program would provide treatment and services in the least restrictive environment -- a policy endorsed by the State.

The effects of this planned program would dovetail with the DOH's support for keeping the infant patient in the least restrictive environment -- at home. The benefits of any community-based and family-centered treatment are not limited to cost containment. There are also gains for the infant in terms of improved psychosocial development and reduction in human suffering for the entire family although these are difficult to measure. The Family Health Services Division believes that all babies can be returned to the community as long as the baby's condition has been stabilized. In general, this would mean that an infant would no longer be in an NICU and that medical diagnoses have been completed so that only routine and repetitive care, although sophisticated, need be given.⁷⁹ The RPPP believes that the definition of when an infant is stabilized should be a medical one. However, it does feel that most infants are stabilized when there is no longer any imminent danger and when they can be transported.⁸⁰ Of course, this does not prevent infants who have been stabilized from returning to NICU care nor for critically ill infants to be transported to an NICU in the first place.

Early Intervention for Infants and Toddlers With Special Needs

During the 1989 regular session, the Hawaii State Legislature enacted Act 107, Session Laws of Hawaii 1989, which added a new part to chapter 321, Hawaii Revised Statutes. The new part is entitled "Infants and Toddlers" and authorizes the Department of Health to develop a statewide, coordinated, multidisciplinary program containing a continuum of early intervention services to meet the needs of infants and toddlers with special needs. The law is intended to:

- (1) Enhance the development of infants and toddlers with special needs to minimize their potential for developmental delay;
- (2) Reduce the education costs to our society;
- (3) Minimize the likelihood of institutionalization; and
- (4) Enhance the capacity of families to meet the special needs of these infants and toddlers.

Act 107 also established the Hawaii Early Intervention Coordinating Council.

The target population of infants and toddlers includes those subject to biological and environmental risk. *Biological risk is defined by Act 107 to include prenatal, perinatal,*

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neonatal, or early developmental events suggestive of biological insults to the developing central nervous system which increase the probability of delayed development. Delayed development means a significant delay in one or more of the following areas of development: cognition, speech, language, and physical, motor, vision, hearing, psychosocial, or self-help skills.

Act 107 defines environmental risk as physical, social, or economic factors which may limit development which includes, but is not limited to the following conditions:

- (1) Birthweight between 1,500 and 2,500 grams, in combination with any other environmental risk factor;
- (2) Parental age less than 16;
- (3) Parental age between 16 and 18 and less than a high school education in combination with any other environmental risk factor;
- (4) Any existing physical, developmental, emotional, or psychiatric disability in a primary caregiver;
- (5) Presence of physical, developmental, emotional, or psychiatric disability in a sibling or any other family member in the home in combination with any other environmental risk factor;
- (6) Abuse of any legal or illegal substance by a primary caregiver;
- (7) Child abuse and neglect of target child or siblings;
- (8) Economically disadvantaged family in combination with any other environmental risk factor;
- (9) Single parent in combination with any other environmental risk factor; and
- (10) Incarceration of a primary caregiver in combination with any other environmental risk factor.

Act 107 also defines "infants and toddlers with special needs" to mean infants and toddlers from birth to the age of three with delayed development, biological risk, or environmental risk. This focuses on a narrower range of children than is specified elsewhere

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in the Hawaii Revised Statutes relating to children with special health needs or to those with developmental disabilities.⁸¹

Early intervention services are defined by Act 107 to include services provided under public supervision which are designed to meet the developmental needs of infants and toddlers with special needs. These needs include physical development, cognitive development, and self-help skills. Services are to be provided in conformity with an individualized family support plan which includes:

- (1) Family support, counseling, and home visits;
- (2) Special instruction;
- (3) Speech pathology and audiology;
- (4) Occupational therapy;
- (5) Physical therapy;
- (6) Psychological services;
- (7) Case management services;
- (8) Medical services only for diagnostic or evaluation purposes;
- (9) Early identification, screening, and assessment services; and
- (10) Health services necessary to enable the infant or toddler to benefit from the other early intervention services.

The legislation providing for a network of services has just come into being. It is not possible at this early date to evaluate the success of this initiative. It appears, however, that the transitional center being discussed and planned could be the next most visible step forward.

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1. Hawaii, Department of Health, Maternal and Child Health Branch and Kapiolani/Children's Medical Center, Description of the Regional Perinatal Center (Honolulu: 1982), p. 2, hereafter referred to as Regional Perinatal Center.
 2. Hawaii, Department of Health, Maternal and Child Health Branch and Kapiolani Medical Center for Women and Children Regional Perinatal Planning Program, Organizing Perinatal Services to Improve the Health of Mothers and Children in Hawaii (Honolulu: 1984), p. 1, hereafter referred to as Organizing Perinatal Services. It does not refer to either perinatal I or perinatal II. See chapter 2.

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3. Hawaii, State Health Planning and Development Agency, The Health Services and Facilities Plan for the State of Hawaii 1986 (Honolulu: 1987), p. 7.2, hereafter referred to as Facilities Plan 1986.
4. See Appendix B "High Risk Pregnancy Identification" issued by the Department of Health and Kapiolani/Children's Medical Center in 1982 in Perinatal Regional Center, pp. 36-7. The Regional Perinatal Planning Program has completed validation of the psychosocial component of a comprehensive risk screening tool. The RPC at KMCWC will complete the rest of the tool.
5. Facilities Plan 1986.
6. Interviews with Jean Evans, Program Director, Regional Perinatal Planning Program, August 10 and 21, 1989. There is some uncertainty over the classification of Kaiser Permanente as a Level III facility. Loretta Fuddy, Chief of the Maternal and Infant Services Section, Maternal and Child Health Branch, Department of Health, State of Hawaii, expressed similar reservations in an interview on August 22, 1989 about considering Kaiser as a Level III facility. Jean Evans assigned Level II status to Hilo and Maui Memorial Hospitals, and Level I status to Wilcox, Hana, and Kauai Veterans Hospitals although there is some question whether they were in fact operating up to these levels.
7. Facilities Plan 1986, p. 7.3: the SHPDA also considers Tripler a level III facility.
8. Fuddy interview.
9. Regional Perinatal Center, pp. 4, 12-15.
10. Interview with Dr. Sherry Loo, Kapiolani Medical Center for Women and Children, staff neonatologist, September 29, 1989.
11. Facilities Plan 1986, p. 7.13.
12. Ibid., p. 7.2.
13. Hawaii, Department of Health, Maternal and Child Health Branch and Kapiolani Medical Center for Women and Children Regional Perinatal Planning Program, Hospital Guidelines for Perinatal Care (Honolulu: 1986), p. 23, hereafter referred to as Hospital Guidelines.
14. Ibid.
15. Regional Perinatal Center, p. 42.
16. Ibid., p. 21.
17. Ibid., p. 22.
18. Hawaii, Department of Health, Maternal and Child Health Branch and Kapiolani Medical Center for Women and Children Regional Perinatal Planning Program, Neonatal Transportation/Communication Reference Guide for the State of Hawaii (Honolulu: 1988), hereafter referred to as Neonatal Transport.
19. Facilities Plan, 1986, p. 7.20.

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20. Interview with Linda Lee, Chief, Planning Branch, State Health Planning and Development Agency, State of Hawaii, September 11, 1989.
 21. Facilities Plan, 1986, p. 7.27.
 22. There were only 45 Level II and III bassinets, including 6 Level II beds and 12 Level III beds at KMCWC, 16 Level III beds at Tripler, 5 Level II beds and 1 Level III beds at Kaiser, and 5 Level II beds at Queen's Medical Center.
 23. Hawaii, State Health Planning and Development Agency, State of Hawaii Annual Summary of Acute, Long Term Care and Specialty Hospital Utilization by County, 1987 (Honolulu: 1988), p. 4, hereafter referred to as Utilization Summary 1987.
 24. Data for Tripler could not be verified because Tripler does not operate within the regional perinatal system; Lee interview.
 25. Lee interview.
 26. Utilization Summary 1987, p. 4; Linda Lee of the SHPDA acknowledged that the relevant footnote "b" was not attached to any category it was meant to explain. Presumably it applied to the pediatric category. Two other footnotes "a" and "c" were appropriately attached to their proper categories.
 27. Neonatal Transport, p. 8.
 28. Dr. Alan Taniguchi, Chief, Children With Special Health Needs Branch (CWSHNB), Family Health Services Division, Department of Health, State of Hawaii, expressed a desire to see an expanded early newborn hearing screening program which may reduce payments made by the CWSHNB under the hearing loss medical category when children reach the ages of 4 and 5; interview on August 14, 1989.
 29. Facilities Plan 1986, p. 7.18.
 30. Fuddy interview.
 31. Hawaii, Department of Health, Family Health Services Division, Maternal and Child Health Branch, NICU Follow-up Program Annual Report FY 1987-88 (Honolulu: 1989), p. 1, hereafter referred to as NICU Follow-up.
 32. Lack of funding limits coverage. Fuddy interview.
 33. NICU Follow-up, p. 14.
 34. Ibid., p. 3.
 35. Ibid., p. 6.
 36. Ibid., p. 17.
 37. Ibid., p. 6.

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38. Interview with Dr. Lisa Simpson, Chief, Maternal and Child Health Branch, Department of Health, State of Hawaii, September 21, 1989.
 39. George Washington University, Intergovernmental Health Policy Project, "States Take Aim at Substance Abuse to Reduce Infant Mortality" in State Health Notes, May, 1989, No. 93:1-2.
 40. Loo interview.
 41. According to Dr. Loo, an infant stabilized for discharge would be able to feed by mouth, no longer need incubation to regulate body temperature, and does not have apneabradycardia (have difficulty breathing and evidence a slowing of the heart rate). *Some babies can be stabilized without reaching discharge criteria.*
 42. A sample of case management services provided in community-based facilities comes from a list cited by the Department of Human Services as the "Ross comprehensive level of case management activities" in C. Ross, "Proceedings of the conference on the evaluation of case management programs (March 5-6, 1979)" *Volunteers for Services to Older Persons* (Los Angeles: 1980):
 - (1) Outreach;
 - (2) Client assessment;
 - (3) Case planning;
 - (4) Referral to service providers;
 - (5) Advocacy for clients;
 - (6) Direct casework;
 - (7) Developing natural support systems;
 - (8) Reassessment;
 - (9) *Advocacy for resource development*;
 - (10) Monitoring quality;
 - (11) Public education; and
 - (12) Crisis intervention.
 43. This could involve a bulb syringe or mechanical catheters that suction out secretions in the nose and throat of an infant who is unable to remove these secretions naturally.
 44. Interview with Dr. Frances Riggs, Chief, Family Health Services Division, Department of Health, State of Hawaii, August 14, 1989.
 45. Interview with Lynn Fallin, Director, Governor's Office of Children and Youth, September 29, 1989.
 46. Interview with Jean Stewart, Coordinator of the Zero to Three Project, Maternal and Child Branch, Department of Health, State of Hawaii, August 21, 1989.
 47. Loo interview.
 48. None were referred by the Maternal and Child Health Branch's NICU follow-up program for FY 1987-88, according to the NICU Follow-up Program Annual Report, p. 15.
 49. Taniguchi interview.

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50. Taniguchi interview.
 51. The CWSHNB does not have a council of its own similar to the State Planning Council on Developmental Disabilities. It does have a medical advisory group, some members of which feel that coverage should be expanded.
 52. Jean Stewart agrees with Dr. Taniguchi's observation that the discharge procedure is too informal and hopes that the Zero to Three Project, discussed below, will help to formalize it, especially through its "Individualized Family Support Plan."
 53. Interview with May Beck, Regional Perinatal Center team member, August 14, 1989.
 54. Stewart interview.
 55. Letter from Dr. Loo dated October 5, 1989, and testimony from Willow Morton, KMCWC Social Services director during House of Representatives joint Committee on Human Services and Committee on Health informational briefing on "Drug Exposed Babies," hereafter referred to as "Briefing," on September 27, 1989.
 56. Interviews with Sandra Tangonan, Chief, Foster Home Certification Unit, Department of Human Services, State of Hawaii, August 30, 1989 and Winifred Odo, Assistant Administrator, Department of Human Services, State of Hawaii, August 30, 1989.
 57. Odo interview.
 58. Ibid.
 59. Beck interview.
 60. Act 394, Session Laws of Hawaii 1989, requires the Legislative Auditor, in cooperation with the Office of Children and Youth, to conduct a comprehensive study of the foster care system including out-of-home placements and alternatives to such placement. Both House Resolution No. 275, H.D. 1 (1989), and Senate Concurrent Resolution No. 214, S.D. 1 (1989), request the Legislative Auditor to conduct a study and develop a plan to ensure the most efficient utilization of federal medicaid funds which presumably would include the issue of reimbursement for the cost of boarder babies.
 61. Odo interview.
 62. Loo interview.
 63. Tangonan interview. Also, an organization named Tender Loving Care (TLC) had operated a "group" home for infants for a short period but was no longer licensed as of August, 1989. Attempts were also made to contact TLC but the Bureau's calls were not returned.

According to the DHS, TLC was taking care of up to four infants under two months old at one time who were medically needy but had not admitted any infants since June, 1989. According to Jean Stewart, most of these babies were on ventilators. The home apparently began as an ordinary foster home. Later, the concept of a "group" home was proposed to which the DHS was sympathetic because of the lack of placement options generally. To accommodate, the DHS first applied the rules relating to "child caring institutions" but later determined that TLC could not be licensed as a foster home. TLC also felt that it would take too long to meet

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building and facility requirements and did not pursue the matter. The DHS had no knowledge of TLC's situation after it became unlicensed. There does not appear to be any other organization in Hawaii of a similar nature.

64. "Briefing," testimony from Winona Rubin, Director, Department of Human Services, State of Hawaii.
65. Letter from Dr. Sherry Loo to Peter G. Pan, *Legislative Reference Bureau*, October 5, 1989.
66. Ibid. and "Briefing," testimony from Willow Morton.
67. "Briefing," testimony from Willow Morton.
68. Hawaii, *House of Representatives*, Committee on Human Services informational briefing, November 23, 1987.
69. Information in this section is based on an interview with Ethel Yamane, Chief, *Developmental Disabilities Division*, Department of Health, State of Hawaii, on September 29, 1989 and on a joint interview with Ethel Yamane, Jennifer Lee, Margo Masuda, Sharon Tanaka, and Stanley Yee of the DDD on October 5, 1989.
70. For example, foster parents are currently allowed to carry out heart monitoring. Heart monitoring is not an intrusive procedure where tubes are actually inserted into the baby. Natural parents are permitted to monitor oxygen ventilation, which is considered an intrusive procedure, according to May Beck. According to the *Zero to Three Project*, it has been infrequent but not rare for parents to use monitoring equipment at home.
71. "Least restrictive environment" is defined in section 333F-1, Hawaii Revised Statutes, as: "that environment that represents the least departure from normal patterns of living that can be effective in meeting the individual's needs."
72. The DDD has referred infants to the Convalescent Center of Honolulu, which is a skilled nursing facility for the elderly. There used to be two infant beds at the facility but only one remains. Placement here is definitely not the norm. It appears that the original placement was an extraordinary measure taken due to lack of alternative placement at the time.
73. The DDD has recently lost its psychiatrist to the private sector.
74. Stewart interview.
75. In time, the *Family Health Services Division* hopes to incorporate the substance of the project formally within the Division. Riggs interview.
76. Stewart interview.
77. Odo interview.
78. Riggs interview. Lynn Fallin especially urges respite care.
79. See Dr. Sherry Loo's definition of stabilization in footnote above.

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80. Evans interview.

81. For example, part IV of chapter 321, Hawaii Revised Statutes, entitled "Children With Special Health Needs" designates the Department of Health as the lead agency to administer services for these children. However, the target population of children is not defined. Although the part heading was amended from "Crippled Children" by Act 4, Session Laws of Hawaii 1988, the Children With Special Health Needs Branch deals with more than just crippled children.

Section 350C-2, Hawaii Revised Statutes, defines "child with special needs," but clearly in the inappropriate context of adoption assistance and does not apply to this study. Section 350C-2 defines "Child with special needs" to include, among other things, specific factors or conditions, including but not limited to, ethnic background, age, membership in a minority or sibling group, or physical, emotional or mental handicaps, which make it likely that the child could not be placed with adoptive parents without providing adoption assistance.

Chapter 333F, Hawaii Revised Statutes, is entitled "Services for Persons with Developmental Disabilities or Mental Retardation." Section 333F-1 defines developmental disabilities as follows:

"Developmental disabilities" means a severe, chronic disability of a person which:

- (1) Is attributable to a mental or physical impairment or combination of mental and physical impairments;
- (2) Is manifested before the person attains age twenty-two;
- (3) Is likely to continue indefinitely;
- (4) Results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic sufficiency; and
- (5) Reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated.

Although this definition includes infants, the main application is for older children since infants cannot be expected to have "a capacity for independent living," or "economic sufficiency," or to be able to care for themselves.

Chapter 5

BENEFITS OF PREVENTION AND PRENATAL CARE

"Other than preventing unwanted pregnancies, providing good prenatal care is both the most effective strategy and the best bargain available to state governments to reduce the number of low birthweight babies."¹

Effective Prevention: Prenatal Care

Evidence abounds in the literature regarding the effectiveness of prevention, especially prenatal care, in improving pregnancy outcomes. The view is frequently advanced that resources would be better used for preventive programs rather than for the technological management of high risk infants. Of course, the need for the current regional perinatal system that cares for both high risk and normal pregnancies will always continue and should continue to be supported. However, "For the future, preventive efforts which significantly reduce the occurrence of LBW are likely to have a greater impact on the overall infant mortality rate than are additional investments in medical care designed to save babies who are born too soon or too small."²

The State Health Planning and Development Agency (SHPDA) recognizes several causes for the reduction in infant mortality and morbidity. These include:³

- (1) Research and technological advancement in treatment for pregnant women and newborns;
- (2) Improved prenatal care during the first trimester and early recognition of high risk;
- (3) Transfers to appropriate level of care;
- (4) Family planning; and
- (5) Genetic counseling.

The Institute of Medicine, while participating in a national conference in 1985, stressed the importance of prenatal care:⁴

After careful consideration of the major methodological problems with understanding this issue, we found that the overwhelming weight of the evidence is that prenatal care contributes to a

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reduced risk of low birth weight and is probably most helpful to women who are at highest risk for this poor outcome -- often the same women who get inadequate prenatal care As noted, a major theme of virtually all the studies reviewed is that prenatal care is most effective in reducing the chance of low birth weight among high-risk women, whether the risk derives from medical factors, sociodemographic factors, or both existing data on prenatal care suggest that we can in good conscience make an unequivocal commitment to expanding the availability of prenatal care in the United States.

Access to Prenatal Care

A frequent warning accompanying the recommendation to emphasize preventive prenatal care is that it must be made universally available and accessible. Prenatal care is most effective for the self-selecting group of women who are most likely to seek it. That is, those who tend to avoid prenatal care, such as substance abusers, young mothers, the poor, and the poorly educated, need greater access. For example, nationally only 54% of pregnant women under the age of 20 received prenatal care during the first trimester.⁵ In Hawaii, between January, 1988 and June, 1989, KMCWC had 71 cases of perinatal substance abuse infants. Only one-quarter of these mothers had had prenatal care.⁶

High quality prenatal care must be made available and accessible to all pregnant women. In 1986, the Institute of Medicine reported six barriers to universal accessibility of prenatal care:⁷

- (1) Financial constraints;
- (2) Limited availability of maternity care providers, especially for socially disadvantaged women;
- (3) Insufficient prenatal services, especially at sites used by high-risk women;
- (4) Attitudes and beliefs among women that discourage seeking prenatal care;
- (5) Inadequate transportation and child care services; and
- (6) Inadequate recruitment of hard to reach populations.

Those not receiving early prenatal care are, on the whole, those most likely to require prenatal care to reduce their high risk for poor pregnancy outcomes. For example, pregnant

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teens are less apt to seek prenatal care because they are less informed or more fearful. The same is true for drug-abusing mothers who may be wary of the legal and social consequences of asking for help.

The incidence of LBW births is directly affected by prenatal care in some high risk subpopulations that were studied:⁸

In the case of publicly insured women, the higher incidence of LBW is attributed largely to a lack of adequate prenatal care, rather than to their status as recipients of public programs . . . many Medicaid patients do not receive adequate prenatal care; those who do, have a much lower incidence of LBW infants . . .

In 1988, the United States Congress established a National Commission on Infant Mortality. On July 18, 1989, the Commission urged the establishment of a federal program of sending trained workers to give mothers who are poor or addicted to drugs prenatal counseling in their homes. This type of program would make prenatal care more accessible to women who are high risk yet reluctant to seek help. Although no national law may be enacted soon, according to Senator Bill Bradley, it is possible that at least two dozen home visit demonstration projects may receive funding.

⁹ ". . . [The Commission's] report and recommendations stress the importance of women's access to prenatal care."¹⁰

Early Prenatal Care (First Trimester)

Not only is prenatal care crucial in preventing a high incidence of poor pregnancy outcomes, but prenatal care in the early stage of pregnancy is particularly important.

It has been shown that pregnancy outcome is associated with timing of initiation of prenatal care. The earlier that prenatal is initiated the better the pregnancy outcome. Therefore the indicator of utilization of prenatal care is important in determining outcomes.¹¹

Babies born to mothers not receiving prenatal care in the first trimester are at increased risk for low birthweight, of dying early, and developing chronic illnesses and handicapping conditions.¹² Events that occur during the prenatal period are critical in determining pregnancy outcome and, ultimately, the chances of success for the infant.

To combat low birthweight, in addition to detecting and preventing problems appearing in the third trimester such as toxemia, ". . . additional emphasis should be placed on first and

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second trimester issues such as screening and management of behavioral risks in pregnancy (smoking, for example) and patient education on a variety of topics including the early signs of preterm labor."¹³ National data for 1983 indicate that early prenatal care reduces the number of high risk infants and improves pregnancy outcomes:¹⁴

	<u><1500 g.</u>	<u><1500-2500 g.</u>	<u>>2500 g.</u>
All Births	1%	6%	93%
Care Began			
1st trimester	1%	5%	94%
2nd trimester	1%	7%	92%
3rd trimester	1%	8%	92%
No Care	7%	15%	78%

Fewer LBW and VLBW infants are born when pregnant women are given prenatal care. The earlier the care, the less chance of an LBW or VLBW birth. It is important to realize that even a small percentage gain can make a big difference. This is so because of the high cost of technological neonatal management and multi-disciplinary follow-up services over each survivor's lifetime.

The percentage of pregnant women who begin receiving prenatal care in the first trimester is an indicator of the effective provision of overall prenatal care. The Children's Defense Fund reports that 4,459, or 24.6%, of all births in the State in 1985 involved women who did not receive early prenatal care (in the first trimester). This was the 28th best rate in the nation.¹⁵ Hawaii was ranked 33rd nationally in getting women to early prenatal care in 1986.¹⁶ Currently, the percentage of pregnant women not receiving prenatal care in the first trimester is still about 25%. The State has set a goal of reducing that percentage to 10% by 1990.

Inadequate access to early prenatal care may prevent the State from reaching that goal. The nature of the high risk population again looms large. The aversion to seeking prenatal care characteristic of many high risk women magnifies the risk when that aversion prevents them from receiving prenatal care at an early stage. Even if a high risk woman is identified and begins to receive care, if it is not early enough the fetus may already be damaged. The later the care, the higher the risk of a poor pregnancy outcome.

The Content of Prenatal Care

The precise configuration of elements in any one program of prenatal care varies from locale to locale. What must be stressed is that any program should be comprehensive and

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include those elements that have been identified to be effective in reducing the incidence of high risk pregnancies. Hawaii's Regional Perinatal Planning Program and the regional perinatal center at KMCWC are currently engaged in finalizing a comprehensive risk assessment tool. Logically, the elements of prenatal care should then address the identified risks. Because each region has differing demographic and social patterns, both risk assessment tools and the content of prenatal programs can be subject to some modification to suit regional needs. For example, Hawaii's risk assessment tool and prenatal program may wish to include measures specially designed to counter the apparently frequent use of methamphetamine ("crystal meth") among pregnant women.

The content of "generic" prenatal care itself is often unclear. The Institute of Medicine contends that "In reality, prenatal care as practiced in this country is an ill-defined entity -- we do not know what goes on in most prenatal visits . . ." ¹⁷ In addition to making prenatal care universally available and accessible, prenatal care should focus on factors known to reduce risk. For some health professionals, this has resulted in a shift away from the traditional medical model of prenatal care to a more non-medical model. An example of the latter from the Institute of Medicine would typically include the following: ¹⁸

- (1) Reducing smoking;
- (2) Reducing alcohol other substance abuse;
- (3) Promoting adequate weight gain;
- (4) Providing education regarding the prevention of prematurity;
- (5) Providing nutritional intervention; and
- (6) Reducing stress in pregnancy (for example, advocating work leave before and after pregnancy).

Another program of prenatal care recommends the following: ¹⁹

- (1) The full number of prenatal visits recommended by the American College of Obstetricians and Gynecologists;
- (2) Nutrition services;
- (3) Outreach to increase access;
- (4) Psychosocial services;

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- (5) Case management; and
- (6) Health education.

A relatively comprehensive model of care for the entire period of pregnancy -- not just prenatal care -- lists the following mix of medical and health ("non-medical") services to ensure optimal pregnancy outcomes:²⁰

- (1) Comprehensive prenatal health assessments, including health history, physical examinations, appropriate laboratory tests, screening and counseling for nutritional inadequacy, substance abuse, and other behavior patterns harmful to fetal development;
- (2) Services to manage high-risk pregnancies;
- (3) Regular prenatal examinations;
- (4) Prescription drugs;
- (5) Preventive, restorative, and emergency dental services;
- (6) Mental health services, including outpatient therapy, day treatment, and emergency inpatient services;
- (7) Pregnancy-related hospital admissions;
- (8) Labor and delivery care and services;
- (9) Clinic services;
- (10) Postpartum examinations, including, as appropriate and desired by the beneficiary, family planning services;
- (11) Nutritional services; and
- (12) Transportation assistance to prenatal care and inpatient delivery care for high risk patients.

An effective program of prenatal care for Hawaii must include whatever elements are needed to address the particular needs of the State's population of pregnant women. The elements of this prenatal care should be spelled out in more precise terms than now exist.

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The Care of High Risk Infants: A Continuum

The state of care of high risk infants should not be considered only from the point of view of what facilities and services are available for the first 12 months of an infant's life. Especially because prevention plays such an important role, the state of care of infants should extend to the period before birth and before conception. This is particularly true for certain types of high risk pregnancies such as those resulting from substance abuse. Access to early prenatal care is particularly important. However, it would be even better if a drug-abusing mother can be persuaded to give up drugs before conception. The type of counselling and intervention tactics must fit the risk profile. Family planning is an appropriate intervention when the circumstances call for it, as is also the case for medical and genetic counselling. In sum:

- (1) Prevention is more likely to reduce infant mortality and morbidity than increased emphasis on neonatal technological management after birth;
- (2) High quality prenatal care is a major component in any prevention program to reduce risk pregnancies;
- (3) Prenatal care is most effective when begun early;
- (4) Prenatal care should be made available and accessible to all pregnant women, especially to high risk women reluctant to seek help; and
- (5) Prevention efforts should not be limited only to the period after conception.

An Ounce of Prevention: Cost Savings

The Institute of Medicine concluded that for every \$1 spent for prenatal care for high-risk women, \$3.38 would be saved in the total cost of caring for low birthweight infants requiring expensive care.²¹ This estimate was based on a high risk population for routine prenatal care from the first trimester to delivery, assuming that the national LBW percentage will be reduced from 11.5% in 1985 to the goal of 9% in 1990.

The National Center for Clinical Infant Programs, citing figures from a 1985 Institute of Medicine publication, quotes the following average length of stay in NICU for surviving infants:²²

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<u>Average stay in NICU (days)</u>	<u>Birthweight (grams)</u>
3.5	> 2500
7.0	2001-2500
24	1501-2000
57	< 1500
89	< 1000

Another study reports that infants requiring intensive care spend between eight and eighteen days in NICUs each year and that "It is not uncommon to encounter low-birthweight infants with hospital stays of a month or longer."²³

The Children's Defense Fund reports that ". . . The average cost of intensive care for each low-birth-weight infant is \$10,000 to \$15,000, while the average cost of comprehensive prenatal care is only \$600.²⁴ It would be more cost effective to provide comprehensive prenatal care than expensive NICU management techniques after birth. In fact, it has been estimated that ". . . the cost of care for five high-risk premature infants equals the cost of prenatal care of 149 pregnant women."²⁵ Testimony before the United States Congress cites "The cost of caring for a low-birth-weight infant in a hospital when there are no complications is approximately \$450 each day."²⁶

In 1988, the National Conference of State Legislatures (NCSL) cited a United States Office of Technology Assessment estimate that for every low birthweight birth averted by earlier or more frequent prenatal care, the national health care system saves between \$14,000 and \$30,000 in newborn hospitalization, rehospitalizations in the first year, and long-term health care costs associated with low birthweight (calculated to age 35 only).²⁷ A more global view of cost savings must account for the lifetime costs incurred by very high risk infants which represent about 16% of all low birthweight babies. These medical and social costs range from continuing medical needs to support services such as family counseling, speech training, and screening services, special education, and institutional or foster care. Another source estimates that just \$400 in prenatal care could make the difference between a healthy baby and a baby who might need \$400,000 of help throughout life to overcome difficulties and disabilities that could have been avoided.²⁸

A recent article in The Wall Street Journal describes cocaine babies turning into boarder babies over a six-month period in several Washington D. C. hospitals. Compared to 3 days for a normal infant, drug babies spent an average of 42 days in the hospital although not necessarily all in intensive care.²⁹ The daily cost for a boarder baby in one Washington D. C. hospital was about \$367. At the same hospital, in one week ten boarder babies had incurred a cost of over \$500,000. At another hospital, ". . . one abandoned infant alone ran up a tab topping \$250,000 for a 245-day stay."³⁰ The article further reported a daily cost of \$1,768 to care for severely affected drug-exposed newborns in a Los Angeles hospital.³¹

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Numerous examples of the cost effectiveness of prenatal care abound:³²

- Michigan spent \$52 million in medicaid funds to treat sick newborns in 1987, while spending just \$5 million for prenatal care. Adverse pregnancy outcomes that may have been prevented or reduced with prenatal care accounted for between one-half and two-thirds of the \$52 million.
- In 1986, the average hospital cost per discharge for a normal newborn in Maryland was \$658 while that for a LBW infant was \$5,894.
- A 1985 study of medicaid data in Utah revealed that the average initial hospital cost for babies weighing less than 3.5 pounds was \$63,000. Although only 1.7% of babies born to medicaid mothers in Utah weighed less than 3.5 pounds, they consumed \$2.7 million, or 24% of all medicaid expenditures for initial hospital costs for newborns.
- California realized short-term (up to 12 months) savings from a pilot prenatal care project amounting to \$1.70 to \$2.60 for each \$1 spent on prenatal care.
- Utah saved almost \$3 in delivery and intensive care costs for medicaid recipients for each \$1 spent on prenatal care.
- Alaska predicted that if pregnant women who are now getting fewer than five prenatal visits get fourteen visits, a total of 83 fewer LBW births, 8 fewer deaths, 51 fewer NICU babies, and 1.7 fewer infants requiring long-term institutionalization would result each year.
- According to Senator Lawton Chiles of Florida, chairman of the National Commission to Prevent Infant Mortality: "It costs about \$400 to provide a woman with good prenatal care, while the average hospital stay of a low-birth-weight baby costs \$150,000. We are doing an abominable job of taking care of our pregnant women at the front end."
- In 1985, Dr. Alfred Brann, Jr., speaking at a national conference on intergovernmental options for reducing infant mortality, reported that generally the medical technology is adequate but access to prenatal care and public policy are lacking. "The cost of treating a surviving very low birth weight baby who possibly could have been brought to term, for example, is approximately \$15,000. The cost for a term infant is approximately \$2,100."

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- The *Children's Defense Fund* reports that "Between 1978 and 1990, the nation will have spent \$2.5 billion in first-year costs alone to care for more than 330,000 low-birthweight infants [averaging \$7,576 per LBW infant] whose tragedies could have been averted through adequate prenatal care." The CDF also claims that for the same money, the country could have provided comprehensive prenatal care to 3.5 million women or comprehensive pediatric care for 4.5 million children. The CDF finally claims that "The medicaid investment can save money: comprehensive prenatal care costs \$600 per mother, and can avert the need for neonatal intensive care for a low-birthweight baby that averages more than \$1,000 a day. Medicaid-enrolled children who receive comprehensive preventive care have annual health costs that are 10 percent less than poor children who do not."
- The Institute of Medicine concluded that for every \$1 spent for prenatal care for high-risk women, \$3.38 would be saved in the total cost of caring for low birthweight infants requiring expensive care up to age 35. (See section above.) Studies have shown that the same \$1 also saves \$11 over the lifetime of the child by preventing disabling conditions that require special education, services and institutionalization.
- In California, the net cost for a five-year perinatal program for 1,000 women cost \$750,000. The cost for comparable women not in the program and who did not receive such care was \$4.6 million, representing a \$6.10 savings for each \$1 spent in the program.
- In New Mexico, \$64,000 was spent on maternity care for low income women in Lea county which reduced LBW births by 50% and saved \$310,000, representing a \$5 savings for each \$1 spent.
- The average charge for complete maternity care in Hawaii is estimated to be \$3,800 or 36% of the gross annual income of a family of three with an income equal to the federal poverty level. Other national estimates range from \$3,100 for a normal delivery to \$4,800 for a Caesarean section in 1985.
- Further national estimates project that federal savings of more than \$360 million in current costs for neonatal intensive care and rehospitalization of LBW babies can be realized by providing prenatal and postpartum preventive care to low income women. A cost benefit

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analysis done by the American Academy of Pediatrics shows a \$2 to \$10 dollar savings for every \$1 spent on preventive prenatal care.

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Chapter 6

FINDINGS AND RECOMMENDATIONS

Findings

Infant Mortality: Hawaii and the United States

Hawaii's infant mortality rate has consistently been among the lowest in the country. In 1982, the State had the lowest rate. In 1985, it ranked sixth. Hawaii's current infant mortality rate is already lower than the national goal of 9% set for 1990.¹ The United States itself, however, ranks 19th -- very low -- among other industrialized nations. Compared with these nations, Hawaii, if treated as a separate nation, would rank among the ten lowest. The nation as a whole also ranks only 16th for incidence of low birthweight (LBW) births. Hawaii's percentage of LBW births is close to the national average. The State ranked 23rd in the country in 1985. However, the rich ethnic mix of Hawaii's population may be accounting for a greater number of LBW births that turn out not to be inherently high risk. This may be artificially inflating the size of the high risk infant population.²

The country's overall infant mortality rate has been greatly reduced over the past decade and a half. Much of the reductions can be attributed to dramatic advancements in the technological management of neonates receiving intensive care. As a result, the rate of neonatal mortality has declined substantially over this same period. In fact, improvements in the overall infant mortality rate are due largely to reductions in neonatal mortality. However, neonatal mortality remains a major cause of infant deaths. It has been estimated that between 60% and 75% of all infant deaths occur during the first month of life. The national percentage is about 65%. Hawaii's percentage is roughly the same although in recent years, it has been better than the national average.

Overall infant mortality needs to be reduced but there are limits to technological solutions. There is general consensus that neonatal intensive care techniques are approaching those limits:³

The advances of medical technology alone can no longer yield the great leaps in progress against infant mortality that they did in the 1950s and 60s. Medicine continues to improve in its capacity to care for fragile infant lives, but educational outreach, high-risk care, and communication networking components are necessary before any new progress can be made . . . [however] the mere presence of medical services does not necessarily mean that they are available and will be used by all classes of people. Indeed,

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the primary obstacles for indigent patients are cost and lack of accessibility.

Nationally, neonatal mortality has improved 58% from 1970 to 1988. However, post-neonatal mortality has improved only 27%. In Hawaii, neonatal mortality declined 65% from 1970 to 1987 while post-neonatal mortality has not experienced much change. There is definitely room for improvement in Hawaii, especially during the post-neonatal phase.

In Hawaii as well as the country as a whole, there has also been almost no progress since the 1970s in reducing the percentage of low birthweight infants to all live births. In 1985, the State reached a low of 5.8%. Hawaii will probably not meet its 1990 goal of reducing that percentage to 5%.⁴

It may be that improvements in neonatal technology might be contributing to the seeming lack of progress in reducing the post-neonatal mortality rate. Sophisticated technology enables babies who would otherwise not have survived birth to struggle on into the neonatal period. Subject to tremendous odds, some continue to survive but others do not. Those who eventually die may be artificially keeping post-neonatal mortality figures high. If these infants survive beyond the first month but succumb before age one, their eventual deaths would be recorded as post-neonatal rather than, perhaps, fetal or as spontaneous abortions. Post-neonatal mortality is closely associated with the environment after birth: the quality of an infant's home life, including housing, sanitation, food, access to health care, and other items associated with socioeconomic status.⁵

This reasoning also applies to the lack of progress in reducing LBW deaths. Consistently more than half of all infants who died within their first year in Hawaii were low in birthweight. The fact remains, however, that despite Hawaii's relatively low overall infant mortality rate, the percentage of low birthweight births and the post-neonatal mortality rate need to be targeted for improvement. To accomplish this, rather than relying on continued technological management of high risk infants, efforts should focus on reducing the number of high risk infants who require sophisticated technological management in the first instance. This is the role of prevention.

Facilities and Services

The regional perinatal system in Hawaii has been operating smoothly. The number of high risk births has remained relatively stable for the last decade. The facilities at the Regional Perinatal Center at KMCWC, including transport protocol from Level I and II facilities throughout the State, have been generally adequate for the high risk infant population. At times, there has been some pressure on acute care bassinets for high risk infants. When

FINDINGS AND RECOMMENDATIONS

necessary, KMCWC has been able to temporarily appropriate bassinets from other areas to accommodate an increased demand for NICU bassinets.

A growing number of boarder babies, medically stabilized infants ready for discharge but who cannot be returned to biological or foster parents, has contributed to the overall burden on facilities at all care levels. The lack of foster parents in Hawaii remains a troubling and persistent problem. Recently, there has been an apparent increase in the number of drug-exposed high risk infants, some of whom become boarder babies. This increase may be due in part to recent efforts at data collection.

There is a need for an alternative short-term transitional center in the postpartum period (after birth) for high risk mothers and infants. Natural or foster caregivers need to be trained to properly care for a high risk infant at home before the infant arrives. At present, this training often gets neglected. Training provided in a hospital setting would be costly and put pressure on bassinet utilization for those who really need them. Training provided at home may often be too late. In a transitional center, mothers and infants can spend time together to adapt to each other's needs under the supervision of health care professionals.

This transitional center would not be "institutional." To provide care in the least restrictive environment, high risk infants should not remain institutionalized in either an acute or sub-acute care setting. Rather than establishing a long-term skilled nursing or intermediate care nursing facility for high risk infants, these infants should be returned to their own homes or, if necessary, to a home-like environment such as a foster home.

A transitional center would function best if continuing community-based and family-oriented support services are made available to caregivers and infants. A comprehensive network of supportive services does not yet exist in Hawaii. Federal legislation was enacted in 1987 authorizing the Department of Health as the lead agency in implementing special services to infants and toddlers (see chapter 4). State legislation was also passed in 1989 authorizing the DOH as the lead agency to coordinate federal and state funding to provide a comprehensive system of early intervention for infants and toddlers with special needs (see also chapter 4). The legislation also establishes the Hawaii Early Intervention Coordinating Council.

The DOH's Zero to Three project is coordinating the development of such a system. Other infant services are provided by various divisions of the DOH. The Department of Human Services provides foster care and social work counselling for high risk infants. The Regional Perinatal Center at KMCWC also provides various services. There needs to be much more coordination among service providers to reduce service overlap and to avoid service gaps. The newly established Hawaii Early Intervention Coordinating Council together with the DOH should be given an opportunity to meet this challenge.

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These measures all address needs "after the fact" -- after the birth of high risk infants. It is true that high risk infants should not remain institutionalized and should return home. Biological parents should, if at all possible, be made fit to care for their own high risk infants. In some cases of social dysfunction, they cannot. It is also true that more foster parents should be recruited and trained. However, the number of altruistic foster parents is limited. The best way to approach the problem is to prevent situations where these needs arise.

Recommendations

The State is faced with a choice: fund the high costs of remedial care -- technological solutions and long-term services for high risk infant survivors -- or provide less expensive preventive care that will result in healthier residents.

Prevention is not glamorous. Tracking down, identifying and persuading a resistant population of pregnant mothers to seek early prenatal care is not as visible or dramatic as waging a high-tech battle to save a preemie's life. Prevention, however, is cost effective and works. This is not to say that neonatal technology has not made tremendous contributions. However, the limits of technology are fast being reached. Further gains must come at the front end of the health care system by reducing the numbers of infants who require extraordinary care in the first place.

Health professionals are increasingly able to identify those at high risk for poor pregnancy outcomes. Women at risk make up a diverse population: teenagers who know little about contraception or the risks of young pregnancies, older women pregnant for the first time, women with a history of troubled pregnancies including multiple pregnancies, abusers of alcohol, drugs, and tobacco, women with certain medical conditions such as diabetes and hypertension, women who do not wait between pregnancies, and women who are poor and undereducated who are not disposed to seek adequate prenatal care. Any action taken must address the entire population of high risk mothers.

General Recommendations

- (1) An interagency working committee consisting of staff from the Department of Health, the Department of Human Services, the Regional Perinatal Planning Program, and the Regional Perinatal Center at Kapiolani Medical Center for Women and Children, should be established to carry out tasks (a) through (d) below. It is not necessary for additional legislation to be enacted other than general revenue appropriations for funding and implementation. The interagency working committee should also determine the amount of additional

FINDINGS AND RECOMMENDATIONS

funding required. Rules should be adopted as necessary within each respective department. The working committee should:

- (a) Work out the details of operating a community-based transitional center to receive high risk mothers and their infants upon discharge from acute care, as described above and in chapter 4;
- (b) Plan and implement a strong outreach program to ensure that all pregnant women, especially those at high risk, have improved access to prenatal care and to begin receiving prenatal care early -- that is, in the first three months of pregnancy;
- (c) Promote and advance the development of a comprehensive network of community-based and family-oriented support services as described above and in chapter 4; and
- (d) Establish ongoing communication protocols to improve interagency coordination.

The medical, social, psychosocial, and financial needs of high risk infants do not always fall neatly within any one agency's jurisdiction. Better interagency communication and coordination at all levels is required to minimize service overlaps and service gaps. The advice and assistance of the Hawaii Early Intervention Coordinating Council and the State Planning Council on Developmental Disabilities should also be sought.

- (2) Additional resources should be allotted for the development and strengthening of a wide range of prevention programs within the DOH that are aimed at reducing the number of high risk pregnancies in the State. This includes prevention programs provided before birth, such as prenatal care, as well as programs before conception such as family planning and genetic counselling. The DOH should ensure that prenatal health care programs for pregnant women contain elements that directly address factors, both medical and non-medical, that are known to be associated with high risk pregnancies. The DOH should determine the amount of funding required for implementation.
- (3) The use of medicaid funds should be maximized. The DOH and the DHS should jointly explore the use of medicaid waivers for possible payments to acute facilities for the cost of boarder babies and for the provision of various community-based "non-medical" support services. The two departments should make use of recommendations in the study now being conducted by the Legislative Auditor regarding the most effective use of medicaid funds.

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- (4) The DHS and the DOH should jointly explore ways to increase the pool of foster caregivers for high risk infants, including the drafting of necessary legislation. Although most foster parents are motivated by a desire to help, additional financial support for their services may enable potential foster parents to enter the pool or previous foster parents to return. The two departments should make use of recommendations in the study now being conducted by the Legislative Auditor regarding the foster care system.
- (5) Support for the activities of the Regional Perinatal Center at Kapiolani Medical Center for Women and Children should continue. As the State's RPC, its Level III facilities are crucial for the survival of high risk infants.
- (6) Separate and distinct long-term skilled nursing and intermediate care facilities for high risk infants who have been stabilized should not be established at this time. This type of facility would not provide health care in the least restrictive environment. Other alternatives are preferable.

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 3. John Olive, "Infant Mortality Reduction: The Arkansas and Louisiana Experiences" in Innovations, The Council of State Governments (Lexington, Kentucky: 1986), p. 2, hereafter referred to as Innovations.
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Appendix A

HOUSE OF REPRESENTATIVES
FIFTEENTH LEGISLATURE, 1989
STATE OF HAWAII

H.R. NO.

316
H.D. 1

HOUSE RESOLUTION

REQUESTING A STUDY ON ALTERNATIVES FOR THE CARE OF MEDICALLY
HIGH-RISK INFANTS IN THE STATE OF HAWAII.

WHEREAS, it has often been stated that Hawaii's most precious resource is its children and that children, because they are not able to provide for themselves, deserve special consideration in the services our state provides for its citizens; and

WHEREAS, infants, as a group, are the most defenseless and most helpless of Hawaii's children, and those infants with severe medical problems need the most attention of all; and

WHEREAS, there are in Hawaii an increasing number of infants in the medical high-risk category as a result of HIV infection, AIDS, and the use of cocaine, alcohol, and other drugs by their mothers, resulting in infants who require specialized treatment, often involving technologically sophisticated equipment such as cardiac monitoring devices;

WHEREAS, many other infants throughout the State in medically high-risk situations cannot be provided specialized care by their parents because they come from dysfunctional households with histories of child abuse and neglect, which may have been the original cause of the child's disability, and therefore require special facilities to care for them; and

WHEREAS, the current patchwork of services for these infants falls disproportionately on foster care, resulting in situations where foster families have been assigned as many as four high-risk infants on heart monitors who must all be watched twenty-four hours a day; and

WHEREAS, the Department of Health's statistical report for 1986 indicates that out of 18,341 live births in the State, six percent, or 1,100, were classified as having low birth weights (below 5.5 lbs.), with congenital malformations occurring in 1.1 percent of the babies born that year and 2.4 percent having one-minute Apgar scores of 0-3; and medical literature documents that infants with the above characteristics often develop chronic conditions that may lead to a need for long-term care; and

WHEREAS, unlike other states, Hawaii has no facilities for managing skilled or intermediate nursing needs of children from all the above-mentioned groups, and the need for a medical facility to provide care for these children has been expressed by representatives of the major acute care medical facilities in the State as well as the Departments of Health, Education, and Human Services; and

WHEREAS, the State Planning Council on Developmental Disabilities defines a developmental disability as a mental or physical impairment with onset before age 22, which is likely to continue indefinitely and which causes substantial limitations in areas such as self-care, language, learning, mobility, and the eventual capacity for independent living; and

WHEREAS, a population with developmental disabilities indicates there is a need for individually planned and coordinated packages of special services for this population, who, although usually thought of as mentally retarded, include children with the various types of medical problems described above; and

WHEREAS, the current (1986) Health Services and Facilities Plan states as one of its goals: "An adequate and proper mix of acute and long-term care services will be available to provide comprehensive and accessible quality care with a focus on cost containment;" now, therefore,

BE IT RESOLVED by the House of Representatives of the Fifteenth Legislature of the State of Hawaii, Regular Session of 1989, the Senate concurring, that the Legislative Reference Bureau conduct a study to determine the state of care in Hawaii for infants who are medically at high risk, to include, but not be limited to, an examination of the types of facilities available to care for these children and the community-based, family-oriented, and other types of services available for them; and

BE IT FURTHER RESOLVED that the Legislative Reference Bureau report its findings and recommendations to the Legislature at least twenty days before the convening of the Regular Session of 1990; and

BE IT FURTHER RESOLVED that certified copies of this Resolution be transmitted to the Director of the Legislative Reference Bureau, the Department of Human Services, the Department of Health, and the Office of Children and Youth.

Appendix B

HIGH RISK PREGNANCY IDENTIFICATION

The following list of factors that increase the risk for suboptimal pregnancy outcome should be kept in mind throughout any patient's gestation. Those patients with a score of ≥ 10 are considered at "high risk" and increased neonatal mortality and morbidity may be expected.

PRENATAL FACTORS

<u>I. Cardiovascular & Renal</u>	<u>Score</u>
1. Severe preeclampsia (pregnancy-induced hypertension (PIH))	10
2. Chronic hypertension	10
3. Moderate to severe renal disease	10
4. Severe heart disease - Class II-IV	10
5. History of eclampsia	5
6. History of pyelonephritis	5
7. Class I heart disease	5
8. Mild preeclampsia (PIH)	5
9. Acute pyelonephritis	5
10. History of urinary tract infection (non-specific)	1
11. Acute cystitis	1
12. History of preeclampsia (PIH)	1
<u>II. Metabolic</u>	
1. Diabetes \geq Class B	10
2. Previous endocrine ablation	10
3. Thyroid disease	5
4. Gestational diabetes (Class A)	5
5. Family history of diabetes	1
<u>III. Previous Histories</u>	
1. Previous fetal exchange transfusion for Rh disease	10
2. Previous stillborn	10
3. Post-term (> 42 weeks)	10
4. Previous preterm infant	10
5. Previous neonatal death	10
6. Previous cesarean section	5
7. Habitual abortion	5
8. Infant > 10 lbs. (4,500 gm.)	5
9. Multiparity > 5	5
10. Epilepsy	5
11. Fetal anomalies	1

	<u>Score</u>
IV. <u>Anatomic Abnormalities</u>	
1. Uterine malformation	10
2. Incompetent cervix	10
3. Abnormal fetal position	10
4. Nongynecoid pelvis	5
V. <u>Miscellaneous</u>	
1. Abnormal cervical cytology	10
2. Multiple pregnancy	10
3. Sickle cell disease	10
4. Age ≥ 35 or ≤ 15 years	5
5. Viral disease	5
6. Rh sensitization only	5
7. Positive serology	5
8. Severe anemia (Hgb < 9 gm%)	5
9. Excessive use of drugs	5
10. History of TB or PPD ≥ 10 mm	5
11. Weight < 100 or > 200 pounds	5
12. Pulmonary disease, including asthma	5
13. Flu syndrome (severe)	5
14. Vaginal spotting	5
15. Mild anemia (Hgb 9-10.9 gm%)	1
16. Smoking ≥ 1 pack per day	1
17. Alcohol (moderate)	1
18. Emotional problem	1

INTRAPARTUM FACTORS

I. <u>Maternal Factors</u>	
1. Severe preeclampsia (PIH)	10
2. Polyhydramnios or oligohydramnios	10
3. Amnionitis	10
4. Uterine rupture	10
5. Mild preeclampsia (PIH)	5
6. Premature rupture of membranes > 12 hours	5
7. Primary dysfunctional labor	5
8. Secondary arrest of dilation	5
9. Demerol > 300 mg.	5
10. MgSO ₄ > 25 gm.	5
11. Labor > 20 hours	5
12. Second stage $> 2\frac{1}{2}$ hours	5
13. Clinically small pelvis	5
14. Medical induction	5
15. Precipitous labor < 3 hours	5
16. Primary cesarean section	5
17. Repeat cesarean section	5
18. Elective induction	1
19. Prolonged latent phase	1
20. Uterine tetany	1
21. Oxytocin augmentation	1

II. Placental Factors

1. Placenta previa	10
2. Abruptio placentae	10
3. Post-term (>42 weeks)	10
4. Meconium-stained amniotic fluid (dark)	10
5. Meconium-stained amniotic fluid (light)	5
6. Minimal bleeding (cause not determined)	1

III. Fetal Factors

1. Abnormal presentation	10
2. Multiple pregnancy	10
3. Fetal heart rate <100 for >30 minutes	10
4. Breech delivery, total extraction	10
5. Prolapsed cord	10
6. Fetal weight < 2500 grams	10
7. Fetal acidosis pH \leq 7.25 1st stage	10
8. Fetal heart rate >170 for >30 minutes	10
9. Operative forceps or vacuum extraction	5
10. Breech delivery, spontaneous or assisted	5
11. General anesthesia	5
12. Outlet forceps	1
13. Shoulder dystocia	1

Key to Symbols Used:

- < less than
- \leq less than or equal to
- > greater than
- \geq greater than or equal to

Appendix C

GENERIC REGIONAL PERINATAL HEALTH SYSTEM

- I. Patient Care
 - A. Ambulatory services
 - 1. Maternal-fetal assessment and care
 - 2. Genetic diagnosis and counseling
 - 3. Laboratory evaluation
 - 4. Special procedures (e.g. amniocentesis, ultrasound)
 - 5. Maternal and neonatal follow-up
 - B. Inpatient services
 - 1. Maternal-fetal services, including intensive care and surgery
 - 2. Neonatal services, including intensive care and surgery
 - C. Support services
 - 1. Nutritional services
 - 2. Social services
 - 3. Community agencies services
 - D. Consultation and referral
 - E. Transportation
 - 1. Maternal-fetal transport
 - 2. Neonatal transport
 - 3. Return to hospital of origin or local hospital
- II. Education
 - A. What
 - 1. Community outreach to encourage early entry to perinatal health system
 - 2. Health promotion and risk reduction
 - B. Who
 - 1. Consumers
 - 2. Professionals
 - a. primary care providers
 - b. hospital personnel
 - c. public and private service agency personnel
 - 3. Government
 - a. legislators
 - b. administrators
- III. Evaluation
 - A. How
 - 1. Standard setting
 - 2. Outcome surveillance, including follow-up
 - 3. Uniform information system
 - B. Who
 - 1. Service providers
 - 2. State vital statistics office
 - 3. Maternal and child health bureau
- IV. Funding
 - A. Direct and third party payment
 - B. Government agency subsidies
 - C. Legislative mandates