

The First Year of Life



THE COLLABORATIVE PERINATAL
PROJECT OF THE NATIONAL INSTITUTE
OF NEUROLOGICAL AND COMMUNICATIVE
DISORDERS AND STROKE

JANET B. HARDY, M.D., C.M. / JOSEPH S. DRAGE, M.D. / ESTHER C. JACKSON

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FOREWORD



Many of us who witnessed the early planning and organization of the NINCDS Collaborative Perinatal Project have looked forward to a definitive publication of the findings of that remarkable effort. During the years 1959 to 1966, 58,000 women were registered in the project in the twelve collaborating institutions. Although much of the factual information pertaining to immediate pregnancy outcome has been made available in the 1972 volume *The Women and Their Pregnancies*, the follow-up information for the infants is now presented in this long-awaited report.

The uniqueness of this study is in the size of the population, the prospective nature of many of the observations, and the high success in follow-up with carefully conducted developmental assessments in later childhood. We have been given previews of these observations in a number of publications concerned with the rubella epidemic that occurred during the study, reports on the relationship of hyperbilirubinemia and neurologic sequelae, and papers from some of the participating institutions focused on one or another question answerable from a smaller cohort of patients.

The excitement surrounding this publication surely is based on the extensive tabulation of observations, well organized and labeled, and a relatively brief but lucid text interpreting and highlighting well-selected findings. The authors note that many of the observations reported here have been known for a long time, but some are new, and the large number of systematic findings lends important scientific documentation to conclusions that were often based on less adequate information or only impressions. This publication should remain of historical significance as a description of the outcome of pregnancy and delivery and the relationship of events during the perinatal period on outcome of the first year of life. Extraordinary changes have taken place since this study was conducted. As a result some of the findings are recognizably dated and differ markedly from experiences in the 1970s. For example, we are told that only two of forty-five babies under 1,500 grams birthweight with a diagnosis of respiratory distress syndrome survived. We now know that approximately three-quarters of such babies survive, dramatic evidence that the interventions undertaken in the past decade have been successful. Many of them, especially artificial respiration, intravenous nutrition, attention to thermo-

balance, and the like, came into focus and became a part of routine care of the newborn after most of the infants had been enrolled in the study. Thus, the care of the infant now differs significantly from the 1960s and both mortality and morbidity are dramatically reduced. Indeed, it is paradoxical that perhaps the study itself induced to some extent the change that limits the generality of the conclusions or their relevance to babies born in the 1970s.

One can only reflect that perhaps the perinatal project stimulated an interest in problems of the newborn that was necessary before approaches to their solutions could be undertaken. Certainly many individuals in the collaborating institutions put more time and effort on observations pertinent to intrauterine and postnatal life than had ever been done before. Some of these individuals, first recruited into academic medicine as participants in the Collaborative Project, are now themselves either leaders of neonatal programs or of departments of pediatrics where a significant emphasis on the well being of the newborn is taken for granted.

Finally, it should be repeated that data presented in this volume should be of enduring value: as a description of events in the 1960s; as a source of information about relationships between perinatal, and particularly neonatal conditions, and outcomes during the first year; and, as an index of the frequency of specific congenital malformations and other conditions during the first year. These data should be helpful to anyone concerned with comprehensive planning for health care for mothers and infants. They can serve as a resource for the derivation of research hypotheses for further testing in the 1970s and for further analysis by examination of the information obtained from follow-up of the Collaborative Project children to age seven.

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The Collaborative Perinatal Project of the National Institute of Neurological and Communicative Disorders and Stroke is a large, complex study, extending over a long time span and involving many thousands of people. Without the wholehearted cooperation of the mothers and their children the study could not have been carried out.

The authors wish to acknowledge the contributions of the project staffs at the fourteen collaborating institutions (listed in Table 2-1) and of the staffs of the Developmental Neurology Branch (formerly the Perinatal Research Branch) and of the Office of Biometry and Epidemiology, National Institute of Neurological and Communicative Disorders and Stroke.

Individual acknowledgments to many of these dedicated people were made in the first major monograph from the project (see *The Women and Their Pregnancies*, 1972, K. R. Niswander and M. Gordon, editors, Appendix A).

Special thanks are also expressed to the many individuals who served on the Perinatal Research Committee, ad hoc advisory committees, task forces, and as individual consultants to the project.

We wish to express our thanks to the Directors of the National Institute of Neurological and Communicative Disorders and Stroke (NINCDS), who, over the many years of the project, have supported and promoted its development: Pearce Bailey, M.D., Director, 1951 to 1959; Richard L. Masland, M.D., Director, 1959 to 1968; Edward F. MacNichol, Jr., Ph.D., Director, 1968 to 1972; and Donald B. Tower, M.D., Director, 1972 to the present.

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THE FIRST YEAR OF LIFE

CONTENTS



Foreword	xvii
Acknowledgments	xix
1 Introduction	1
2 The Study Population	6
3 The Data: Collection and Processing	13
4 Data Assessment and Interpretation	22
5 Maternal Characteristics and Perinatal Outcome	25
6 Major Pregnancy Outcome Categories	33
7 Intrauterine Growth	38
8 Neonatal Body Length and Head Circumference	71
9 Apgar Scores	78
10 Neonatal Hematocrits	93
11 Neonatal Serum Bilirubin Levels, Hyperbilirubinemia and Later Neurological Development	101
12 Specific Neonatal Diagnoses	116
13 Developmental Status at Eight Months	214
14 Neurological Status at One Year	252
15 Selected Abnormalities, Disease Conditions, and Events during the First Year	259
16 Comparison of Newborn and Later Diagnoses	290
17 Summary and Conclusions	299
Appendix	305
Glossary	327
Index	329

TABLES



1-1	Disability from Various Neurological Entities Which May Represent in Part a Continuum of Reproductive Wastage	4
2-1	The Collaborating Institutions	7
2-2	Infants Examined, Deaths and Attrition, Through One Year—White	9
2-3	Infants Examined, Deaths and Attrition, Through One Year—Black	9
2-4	Comparison of Characteristics of Gravidas Whose Infants Missed the One-Year Neurological Examination with Those Examined	10
2-5	Comparison of Characteristics of Infants Who Missed the One-Year Neurological Examination with Those Examined	10
2-6	Case Counts for Various Tables	11
3-1	Collaborative Perinatal Study Forms for the First Year of Life	16
3-2	Usual Length of Nursery Stay by Institution by Race	17
5-1	Characteristics and Conditions of Pregnancy	29
5-2	Fetal Outcome by Type of Delivery	31
6-1	Stillbirths by Institution by Race	34
6-2	Neonatal Deaths by Institution by Race	34
7-1	Gestation at Delivery by Race	40
7-2	Mean Gestation at Delivery by Institution by Sex—White	41
7-3	Mean Gestation at Delivery by Institution by Sex—Black	41
7-4	Birthweight by Sex—White	42
7-5	Birthweight by Sex—Black	42
7-6	Birthweights under 2501 gm by Institution by Race	43
7-7	Mean Birthweight by Institution by Sex—White	44
7-8	Mean Birthweight by Institution by Sex—Black	45
7-9	Mean Birthweight by Gestation at Delivery by Race	45
7-10	Selected Percentiles of Birthweight by Gestation at Delivery—White Male	47
7-11	Selected Percentiles of Birthweight by Gestation at Delivery—White Female	48
7-12	Selected Percentiles of Birthweight by Gestation at Delivery—Black Male	49
7-13	Selected Percentiles of Birthweight by Gestation at Delivery—Black Female	50
7-14	Stillbirths by Gestation at Delivery by Race	52
7-15	Stillbirths by Gestation at Delivery by Sex—White	53
7-16	Stillbirths by Gestation at Delivery by Sex—Black	53
7-17	Stillbirths by Birthweight by Race	53
7-18	Stillbirths by Birthweight by Sex—White	54
7-19	Stillbirths by Birthweight by Sex—Black	54

7-20	Neonatal Deaths by Gestation at Delivery by Race	55
7-21	Neonatal Deaths by Gestation at Delivery by Sex—White	56
7-22	Neonatal Deaths by Gestation at Delivery by Sex—Black	56
7-23	Neonatal Deaths by Birthweight by Race	56
7-24	Neonatal Deaths by Birthweight by Sex—White	57
7-25	Neonatal Deaths by Birthweight by Sex—Black	57
7-26	Perinatal Deaths by Birthweight by Gestation at Delivery—White Male	58
7-27	Perinatal Deaths by Birthweight by Gestation at Delivery—White Female	59
7-28	Perinatal Deaths by Birthweight by Gestation at Delivery—Black Male	60
7-29	Perinatal Deaths by Birthweight by Gestation at Delivery—Black Female	61
7-30	Neonatal Deaths by Birthweight by Gestation at Delivery—White	64
7-31	Neonatal Deaths by Birthweight by Gestation at Delivery—Black	65
7-32	Children Neurologically Abnormal at One Year by Birthweight by Gestation at Delivery—White	68
7-33	Children Neurologically Abnormal at One Year by Birthweight by Gestation at Delivery—Black	69
8-1	Body Length of Newborn by Race	71
8-2	Mean Birthweight by Body Length of Newborn by Race	72
8-3	Neonatal Deaths by Body Length of Newborn by Race	74
8-4	Head Circumference of Newborn by Race	74
8-5	Mean Birthweight by Head Circumference of Newborn by Race	76
8-6	Neonatal Deaths by Head Circumference of Newborn by Race	76
8-7	Children Neurologically Abnormal at One Year by Head Circumference of Newborn by Race	76
9-1	One-Minute Apgar Score by Birthweight—White	79
9-2	One-Minute Apgar Score by Birthweight—Black	80
9-3	One-Minute Apgar Scores under 7 by Birthweight by Gestation at Delivery—White	81
9-4	One-Minute Apgar Scores under 7 by Birthweight by Gestation at Delivery—Black	82
9-5	Mean Birthweight by One-Minute Apgar Score by Race	83
9-6	Neonatal Deaths by One-Minute Apgar Score by Birthweight—White	84
9-7	Neonatal Deaths by One-Minute Apgar Score by Birthweight—Black	84
9-8	Children Neurologically Abnormal at One Year by One-Minute Apgar Score by Birthweight—White	85
9-9	Children Neurologically Abnormal at One Year by One-Minute Apgar Score by Birthweight—Black	85
9-10	Five-Minute Apgar Score by Birthweight—White	86
9-11	Five-Minute Apgar Score by Birthweight—Black	87
9-12	Five-Minute Apgar Scores under 7 by Birthweight by Gestation at Delivery—White	88
9-13	Five-Minute Apgar Scores under 7 by Birthweight by Gestation at Delivery—Black	89
9-14	Neonatal Deaths by Five-Minute Apgar Score by Birthweight—White	90
9-15	Neonatal Deaths by Five-Minute Apgar Score by Birthweight—Black	90
9-16	Children Neurologically Abnormal at One Year by Five-Minute Apgar Score by Birthweight—White	91
9-17	Children Neurologically Abnormal at One Year by Five-Minute Apgar Score by Birthweight—Black	91
9-18	Mean Birthweight by Five-Minute Apgar Score by Race	92
10-1	Lowest Hematocrit of Newborn by Birthweight—White	95
10-2	Lowest Hematocrit of Newborn by Birthweight—Black	95

10-3	Mean Birthweight by Lowest Hematocrit of Newborn by Race	96
10-4	Neonatal Deaths by Lowest Hematocrit of Newborn by Birthweight—White	97
10-5	Neonatal Deaths by Lowest Hematocrit of Newborn by Birthweight—Black	97
10-6	Children Neurologically Abnormal at One Year by Lowest Hematocrit of Newborn by Birthweight—White	99
10-7	Children Neurologically Abnormal at One Year by Lowest Hematocrit of Newborn by Birthweight—Black	99
11-1	Highest Total Serum Bilirubin of Newborn by Birthweight—White	104
11-2	Highest Total Serum Bilirubin of Newborn by Birthweight—Black	104
11-3	Highest Total Serum Bilirubin of Newborn by Birthweight (500-gm. Intervals)—White	106
11-4	Highest Total Serum Bilirubin of Newborn by Birthweight (500-gm. Intervals)—Black	107
11-5	Mean Birthweight by Highest Total Serum Bilirubin of Newborn by Race	108
11-6	Highest Total Serum Bilirubin of Newborn by Birthweight by Gestation at Delivery—White	110
11-7	Highest Total Serum Bilirubin of Newborn by Birthweight by Gestation at Delivery—Black	111
11-8	Children Neurologically Abnormal at One Year by Highest Total Serum Bilirubin of Newborn by Birthweight—White	112
11-9	Children Neurologically Abnormal at One Year by Highest Total Serum Bilirubin of Newborn by Birthweight—Black	112
11-10	Erythroblastosis—Rh—Newborn	113
11-11	Direct Coombs' Test—Newborn	114
12-1	Brain Abnormality—Newborn	119
12-2	Seizures—Newborn	120
12-3	Jitteriness—Newborn	121
12-4	Hypertonia—Newborn	122
12-5	Hypotonia—Newborn	123
12-6	Hypoactivity—Newborn	124
12-7	Lethargy—Newborn	125
12-8	Symmetrical but Abnormal Reflexes—Newborn	126
12-9	Abnormal Moro—Newborn	127
12-10	Abnormal Cry—Newborn	128
12-11	Abnormal Suck—Newborn	130
12-12	Ocular Nerve Abnormality—Newborn	131
12-13	Facial Nerve Abnormality—Newborn	132
12-14	Brachial Plexus Abnormality—Newborn	133
12-15	Cephalhematoma—Newborn	134
12-16	Intracranial Hemorrhage—Newborn	135
12-17	Primary Apnea—Newborn	137
12-18	Resuscitation during First 5 Minutes of Life—Newborn	138
12-19	Resuscitation after First 5 Minutes of Life—Newborn	139
12-20	Neonatal Deaths by Resuscitation by Race	140
12-21	Resuscitation by Birthweight—White	141
12-22	Resuscitation by Birthweight—Black	141
12-23	Neonatal Deaths by Resuscitation by Birthweight—White	142
12-24	Neonatal Deaths by Resuscitation by Birthweight—Black	142
12-25	Neonatal Deaths by Resuscitation by Gestation at Delivery—White	143
12-26	Neonatal Deaths by Resuscitation by Gestation at Delivery—Black	143
12-27	Aspiration before or during Delivery—Newborn	144
12-28	Aspiration after Delivery—Newborn	145

12-29	Primary Atelectasis—Newborn	147
12-30	Hyaline Membrane Disease—Newborn	148
12-31	Respiratory Distress by Birthweight by Sex—White	150
12-32	Respiratory Distress by Birthweight by Sex—Black	150
12-33	Respiratory Distress by Gestation at Delivery by Sex—White	151
12-34	Respiratory Distress by Gestation at Delivery by Sex—Black	151
12-35	Respiratory Distress by Birthweight by Gestation at Delivery—White	154
12-36	Respiratory Distress by Birthweight by Gestation at Delivery—Black	154
12-37	Mean Birthweight by Mortality by Respiratory Distress by Gestation at Delivery—White	155
12-38	Mean Birthweight by Mortality by Respiratory Distress by Gestation at Delivery—Black	156
12-39	Neonatal Deaths by Respiratory Distress by Race and by Sex	156
12-40	Neonatal Deaths by Respiratory Distress by Birthweight—White	157
12-41	Neonatal Deaths by Respiratory Distress by Birthweight—Black	157
12-42	Neonatal Deaths by Respiratory Distress by Gestation at Delivery—White	158
12-43	Neonatal Deaths by Respiratory Distress by Gestation at Delivery—Black	158
12-44	Respiratory Distress by Birthweight by Type of Delivery—White	160
12-45	Respiratory Distress by Birthweight by Type of Delivery—Black	161
12-46	Respiratory Distress by Gestation at Delivery by Type of Delivery—White	162
12-47	Respiratory Distress by Gestation at Delivery by Type of Delivery—Black	163
12-48	Respiratory Distress by Birthweight by Gestation at Delivery and by Type of Delivery—White	164
12-49	Respiratory Distress by Birthweight by Gestation at Delivery and by Type of Delivery—Black	165
12-50	Pneumonia—Newborn	166
12-51	Pneumonia by Birthweight by Sex—White	169
12-52	Pneumonia by Birthweight by Sex—Black	169
12-53	Pneumonia by Gestation at Delivery by Sex—White	170
12-54	Pneumonia by Gestation at Delivery by Sex—Black	170
12-55	Pneumonia by Birthweight by Gestation at Delivery by Race	171
12-56	Pneumonia by Birthweight by Type of Delivery—White	172
12-57	Pneumonia by Birthweight by Type of Delivery—Black	173
12-58	Neonatal Deaths by Pneumonia by Birthweight—White	174
12-59	Neonatal Deaths by Pneumonia by Birthweight—Black	174
12-60	Cardiac Conditions—Newborn	175
12-61	Respiratory Abnormality with Central Nervous System Abnormality—Newborn	176
12-62	Newborn Summary Data—Neurologic Abnormalities—White	178
12-63	Newborn Summary Data—Neurologic Abnormalities—Black	179
12-64	Newborn Summary Data—Central Nervous System Malformations and Related Conditions—White	180
12-65	Newborn Summary Data—Central Nervous System Malformations and Related Conditions—Black	181
12-66	Newborn Summary Data—Musculoskeletal Abnormalities—White	182
12-67	Newborn Summary Data—Musculoskeletal Abnormalities—Black	183
12-68	Newborn Summary Data—Eye Conditions—White	184
12-69	Newborn Summary Data—Eye Conditions—Black	185
12-70	Newborn Summary Data—Ear Conditions—White	186
12-71	Newborn Summary Data—Ear Conditions—Black	186

12-72	Newborn Summary Data—Upper Respiratory Tract and Mouth Conditions—White	187
12-73	Newborn Summary Data—Upper Respiratory Tract and Mouth Conditions—Black	188
12-74	Newborn Summary Data—Thoracic Abnormalities—White	189
12-75	Newborn Summary Data—Thoracic Abnormalities—Black	189
12-76	Newborn Summary Data—Respiratory Abnormalities—White	190
12-77	Newborn Summary Data—Respiratory Abnormalities—Black	191
12-78	Newborn Summary Data—Cardiovascular Conditions—White	192
12-79	Newborn Summary Data—Cardiovascular Conditions—Black	193
12-80	Newborn Summary Data—Alimentary Tract Malformations and Other Conditions—White	194
12-81	Newborn Summary Data—Alimentary Tract Malformations and Other Conditions—Black	195
12-82	Newborn Summary Data—Liver, Bile Ducts, and/or Spleen Abnormalities—White	196
12-83	Newborn Summary Data—Liver, Bile Ducts, and/or Spleen Abnormalities—Black	196
12-84	Newborn Summary Data—Genitourinary Conditions—White	197
12-85	Newborn Summary Data—Genitourinary Conditions—Black	198
12-86	Newborn Summary Data—Neoplastic Disease and/or Other Tumors—White	199
12-87	Newborn Summary Data—Neoplastic Disease and/or Other Tumors—Black	199
12-88	Newborn Summary Data—Hematologic Conditions—White	200
12-89	Newborn Summary Data—Hematologic Conditions—Black	201
12-90	Newborn Summary Data—Skin Conditions and Malformations—White	202
12-91	Newborn Summary Data—Skin Conditions and Malformations—Black	203
12-92	Newborn Summary Data—Infections—White	204
12-93	Newborn Summary Data—Infections—Black	205
12-94	Newborn Summary Data—Syndromes—White	206
12-95	Newborn Summary Data—Syndromes—Black	207
12-96	Newborn Summary Data—Other Endocrine or Metabolic Diseases—White	208
12-97	Newborn Summary Data—Other Endocrine or Metabolic Diseases—Black	209
12-98	Newborn Summary Data—Procedures—White	210
12-99	Newborn Summary Data—Procedures—Black	211
13-1	8-Month Motor Score by Race	218
13-2	8-Month Mental Score by Race	219
13-3	8-Month Motor Score by 8-Month Mental Score—White	221
13-4	8-Month Motor Score by 8-Month Mental Score—Black	221
13-5	8-Month Motor Score by Birthweight—White	222
13-6	8-Month Motor Score by Birthweight—Black	223
13-7	8-Month Mental Score by Birthweight—White	224
13-8	8-Month Mental Score by Birthweight—Black	225
13-9	8-Month Motor Score by Birthweight by Gestation at Delivery—White	230
13-10	8-Month Motor Score by Birthweight by Gestation at Delivery—Black	231
13-11	8-Month Mental Score by Birthweight by Gestation at Delivery—White	232
13-12	8-Month Mental Score by Birthweight by Gestation at Delivery—Black	232
13-13	8-Month Motor Score by Age of Gravida by Birthweight—White	236
13-14	8-Month Motor Score by Age of Gravida by Birthweight—Black	237

13-15	8-Month Mental Score by Age of Gravida by Birthweight—White	238
13-16	8-Month Mental Score by Age of Gravida by Birthweight—Black	239
13-17	8-Month Motor Score by Age of Gravida by Parity—White	240
13-18	8-Month Motor Score by Age of Gravida by Parity—Black	241
13-19	8-Month Mental Score by Age of Gravida by Parity—White	242
13-20	8-Month Mental Score by Age of Gravida by Parity—Black	243
13-21	8-Month Motor Score by Years of Schooling Completed by Gravida by Birthweight—White	244
13-22	8-Month Motor Score by Years of Schooling Completed by Gravida by Birthweight—Black	245
13-23	8-Month Mental Score by Years of Schooling Completed by Gravida by Birthweight—White	246
13-24	8-Month Mental Score by Years of Schooling Completed by Gravida by Birthweight—Black	247
14-1	Neurological and Nonneurological Status at One Year by Birthweight by Race	253
14-2	Hand Preference at One Year by Race	255
14-3	Prehensile Grasp at One Year by Birthweight—White	255
14-4	Prehensile Grasp at One Year by Birthweight—Black	256
14-5	Highest Locomotor Development Observed at One Year by Birthweight by Race	256
15-1	Summary Data for First Year—Neurologic Abnormality	262
15-2	Summary Data for First Year—Eye Conditions	268
15-3	Selected Conditions Included in Other Non-Infectious Eye Conditions at One Year by Race	268
15-4	Summary Data for First Year—Ear Conditions	269
15-5	Summary Data for First Year—Other Central Nervous System Conditions	271
15-6	Summary Data for First Year—Atypical Behavior	272
15-7	Summary Data for First Year—Musculoskeletal Abnormality	273
15-8	Summary Data for First Year—Thoracic Conditions	275
15-9	Summary Data for First Year—Upper Respiratory Tract and Mouth Conditions	275
15-10	Summary Data for First Year—Lower Respiratory Tract Abnormality	276
15-11	Summary Data for First Year—Cardiovascular Conditions	276
15-12	Summary Data for First Year—Alimentary Tract Conditions	278
15-13	Summary Data for First Year—Abnormality of Liver, Bile Ducts, and/or Spleen	279
15-14	Summary Data for First Year—Genitourinary Conditions	279
15-15	Summary Data for First Year—Hematologic Conditions	280
15-16	Summary Data for First Year—Skin Conditions and Malformations	281
15-17	Summary Data for First Year—Neoplastic Disease and/or Other Tumors	281
15-18	Summary Data for First Year—Syndromes	283
15-19	Summary Data for First Year—Other Endocrine and Metabolic Diseases	283
15-20	Summary Data for First Year—Infection and Inflammation	284
15-21	Summary Data for First Year—Trauma, Physical Agents, and Intoxication	286
15-22	Summary Data for First Year—Disturbances in Homeostasis	287
15-23	Summary Data for First Year—Procedures	288
16-1	Comparison of Newborn and Later Diagnoses N = 34,642 (White 16,521; Black 18,121)	293

FIGURES



1-1	Infant Mortality by Age, U.S., 1955-1973	3
3-1	Collaborative Perinatal Project Data Collection Time Span— 16 Years (1959-1974)	14
3-2	Flow Chart of Examinations and Observations at Specified Ages	15
5-1	Factors Associated with Birthweight—Multiparas	31
7-1	Gestation at Delivery by Race	40
7-2	Birthweight by Race	43
7-3	Mean Birthweight by Gestation at Delivery by Race	46
7-4	Percentiles of Birthweight by Gestation—White Male	47
7-5	Percentiles of Birthweight by Gestation—White Female	48
7-6	Percentiles of Birthweight by Gestation—Black Male	49
7-7	Percentiles of Birthweight by Gestation—Black Female	50
7-8	Stillbirths by Gestation at Delivery by Race	52
7-9	Stillbirths by Birthweight by Race	52
7-10	Neonatal Deaths by Gestation at Delivery by Race	55
7-11	Neonatal Deaths by Birthweight by Race	55
7-12	Perinatal Death Rate by Birthweight by Gestation at Delivery— White Male	62
7-13	Perinatal Death Rate by Birthweight by Gestation at Delivery— White Female	62
7-14	Perinatal Death Rate by Birthweight by Gestation at Delivery— Black Male	63
7-15	Perinatal Death Rate by Birthweight by Gestation at Delivery— Black Female	63
7-16	Neonatal Death Rate by Birthweight by Gestation at Delivery—White	66
7-17	Neonatal Death Rate by Birthweight by Gestation at Delivery—Black	66
7-18	Neurological Abnormality Rate at One Year by Birthweight by Gestation at Delivery—White	67
7-19	Neurological Abnormality Rate at One Year by Birthweight by Gestation at Delivery—Black	67
8-1	Body Length of Newborn by Race	72
8-2	Mean Birthweight by Body Length of Newborn by Race	72
8-3	Neonatal Deaths by Body Length of Newborn by Race	73
8-4	Head Circumference of Newborn by Race	73
8-5	Mean Birthweight by Head Circumference of Newborn by Race	74

8-6	Neonatal Deaths by Head Circumference of Newborn by Race	75
8-7	Children Neurologically Abnormal at One Year by Head Circumference by Race	75
9-1	Mean Birthweight by One-Minute Apgar Score by Race	81
9-2	Neonatal Deaths by One-Minute Apgar Score by Birthweight—White	83
9-3	Neonatal Deaths by One-Minute Apgar Score by Birthweight—Black	83
9-4	Neonatal Deaths by Five-Minute Apgar Score by Birthweight—White	87
9-5	Neonatal Deaths by Five-Minute Apgar Score by Birthweight—Black	88
9-6	Mean Birthweight by Five-Minute Apgar Score by Race	91
10-1	Lowest Hematocrit of Newborn by Race	94
10-2	Mean Birthweight by Lowest Hematocrit of Newborn by Race	96
10-3	Neonatal Deaths by Lowest Hematocrit of Newborn by Birthweight— White	98
10-4	Neonatal Deaths by Lowest Hematocrit of Newborn by Birthweight— Black	98
10-5	Children Neurologically Abnormal at One Year by Lowest Hematocrit of Newborn by Race	100
11-1	Highest Total Serum Bilirubin of Newborn by Race	103
11-2	Highest Total Serum Bilirubin of Newborn by Birthweight—White	106
11-3	Highest Total Serum Bilirubin of Newborn by Birthweight—Black	107
11-4	Mean Birthweight by Highest Serum Bilirubin of Newborn by Race	108
11-5	Mean Highest Total Serum Bilirubin of Newborn by Birthweight by Gestation at Delivery—White	109
11-6	Mean Highest Total Serum Bilirubin of Newborn by Birthweight by Gestation at Delivery—Black	109
11-7	Highest Total Serum Bilirubin of Newborn over 15 by Birthweight by Gestation at Delivery—White	110
11-8	Highest Total Serum Bilirubin of Newborn over 15 by Birthweight by Gestation at Delivery—Black	111
12-1	Neonatal Deaths by Resuscitation by Race	140
12-2	Respiratory Distress by Birthweight by Sex—White	152
12-3	Respiratory Distress by Birthweight by Sex—Black	152
12-4	Respiratory Distress by Gestation at Delivery by Sex—White	153
12-5	Respiratory Distress by Gestation at Delivery by Sex—Black	153
12-6	Pneumonia by Birthweight by Sex—White	167
12-7	Pneumonia by Birthweight by Sex—Black	167
12-8	Pneumonia by Gestation at Delivery by Sex—White	168
12-9	Pneumonia by Gestation at Delivery by Sex—Black	168
13-1	8-Month Motor Score by Race	218
13-2	8-Month Mental Score by Race	219
13-3	Mean 8-Month Motor Score by Mental Score by Race	220
13-4	Mean 8-Month Mental Score by Motor Score by Race	220
13-5	8-Month Motor Score by Birthweight—White	222
13-6	8-Month Motor Score by Birthweight—Black	223
13-7	8-Month Mental Score by Birthweight—White	224
13-8	8-Month Mental Score by Birthweight—Black	225
13-9	Mean 8-Month Motor Score by Birthweight by Race	226
13-10	Mean 8-Month Mental Score by Birthweight by Race	226
13-11	8-Month Motor Scores under 27 by Birthweight by Race	226
13-12	8-Month Mental Scores under 75 by Birthweight by Race	226
13-13	Mean 8-Month Motor Score by Birthweight by Gestation at Delivery—White	230