

## **NATIONAL INSTITUTE OF CHILD HEALTH AND HUMAN DEVELOPMENT Comprehensive Strategic Plan for Health Disparities Research**

### **NICHD MISSION/VISION STATEMENT**

Since its inception in 1962, the National Institute of Child Health and Human Development (NICHD) has dedicated its research to understanding the dynamic biological, behavioral, and social processes that dictate physical, emotional, and cognitive growth. NICHD research starts early, from before conception through the transitions of infancy, childhood, and adolescence, which set the foundation for conditions, diseases, and behaviors that last a lifetime. The Institute creates the knowledge to understand the complex interplay of processes that transform cells into healthy functioning individuals, free of disease and disabilities. When this goal is not achieved, or achieved unequally by different groups, the NICHD mission is to understand why, and to develop remedies to ensure the healthy functioning of all infants, children, youth, and families. The NICHD mandate also includes addressing the biological, physical, social, individual, and community forces affecting population dynamics and human reproduction, as well as supporting research to help persons with physical disabilities restore, replace, enhance, and prevent decline in function.

### **OVERVIEW OF NICHD STRATEGY FOR ADDRESSING HEALTH DISPARITIES**

To identify the most appropriate scientific areas to address in this plan, the Institute drew from its existing research portfolio aimed at eliminating health disparities. Reflecting the Institute's mission, the unifying concept of the plan is development, starting before conception and continuing throughout the lifespan and across generations. The Institute's long experience investigating the complex biological and environmental interactions that drive developmental processes is invaluable when clarifying the causes of racial, ethnic, and even community-based disparities. By focusing and coordinating research on gestation and the early years of life, including the transitions into and out of adolescence and young adulthood, the NICHD can address not only the development of health disparities, but the critical timing of preventive and therapeutic strategies.

### **INCLUSION OF PUBLIC COMMENTS**

To further refine and organize these concepts, the NICHD solicited a vast array of professional and public input. Within the Institute, a working group that included more than 30 scientific, planning, and policy staff reviewed ongoing planning efforts; recent forums, workshops, conferences, and research findings to develop initial goals and objectives. This information was then consolidated into a draft plan that was shared with executive staff within the NICHD and the National Institutes of Health (NIH). In addition, the draft plan was posted on the NICHD Web site to encourage broad public comment; it was also shared with our Council members and the Friends of the NICHD. At the same time, the Director of the NICHD sought input and guidance from a panel of 10 national experts, representing a broad array of scientific and policy disciplines, as well as individuals who are authorities on, and have personal experience working with, health disparity issues. Panel members not only reviewed the content of the plan but suggested priorities among the many goals and initiatives, noting that the plan builds on the Institute's strengths. This includes targeting research to the two most vulnerable stages of human development: 1) very early development, with a focus on perinatal outcomes and infant mortality, and 2) the transition from adolescence to adulthood, a period where youth may miss important developmental milestones due to a complicated mix of biological, behavioral, and social factors. The members also endorsed the blending of scientific approaches, ranging from those used in biology and clinical medicine to

those used in the behavioral and social sciences. After all comments were consolidated and reviewed, the plan was revised and finalized. Although in printed format, this plan is a flexible blueprint that will guide new and ongoing activities, and one that will be continuously reviewed in light of scientific findings, advances, and resources.

## **NICHD AREAS OF EMPHASIS**

Listed below are nine scientific areas within the NICHD portfolio where persistent disparities exist. Addressing these areas will be a critical part of the Institute's efforts to bridge the gap between racial, ethnic, and socioeconomic groups. The NICHD also supports *overarching* studies that provide the critical foundation for health disparities research. For example, the NICHD is planning an initiative that will help researchers understand the changing concept of race and ethnicity in American society, and how this identity is shaped by social, economic, and demographic forces. These studies can provide useful information on how changing definitions of race will affect federal statistical systems, and ultimately may shape the way investigators conduct research and interpret findings relevant to minority health.

### **I. Infant and Maternal Mortality and Morbidity**

#### Rationale

Eliminating health disparities in infant and maternal health is a critical research area for the Institute and a prime objective of our Nation's public health policy. Despite a 16 percent overall decline in infant mortality over the last decade, the rate among African Americans remains more than twice that of Whites. African American infants are more than twice as likely to be born low birth weight (LBW) and more than three times as likely to be born very low birth weight as White neonates. Moreover, prematurity and LBW are the leading causes of death among African American infants, occurring at five times the rate of Whites and Hispanics. The disparity in maternal mortality rates is equally as startling: although maternal mortality rates have decreased dramatically, maternal death is four times higher among African American women than among White women, and is often preventable.

#### **Objective 1**

Better understand the etiology, pathophysiology, and related social and behavioral factors, specifically leading to preterm births and low birth weight.

#### Action Plan

**(Number in parentheses denotes the fiscal year in which the initiative is scheduled to start)**

Expand the "D.C. Initiative To Reduce Infant Mortality" with new interventions, targeting African American and Hispanic teens, that simultaneously address psychosocial and behavioral risk factors to prevent preterm births and low birth weight. (2001)

Expand the scope of current efforts in the NICHD's intramural Perinatal Research Branch (PRB), allowing the PRB to relocate to an area and institutions that serve significantly large numbers of high-risk and minority patients, while providing opportunities for minority clinical fellowships. (2002)

Identify genetic factors that may predispose women and their infants to preterm birth and low birth weight, targeting racial/ethnic populations. (2002)

Develop and implement clinical trials to prevent preterm births and adverse neonatal outcomes associated with infectious/inflammatory disease processes in minority women. This includes testing different treatment regimens and evaluating different preventive and counseling strategies. (2003)

Increase research training opportunities concerning health disparities in the perinatal period through the Specialized Clinical Investigator Development Award, which is a mentored research program operating in the NICHD clinical networks. (2003)

#### Performance Measures

Issue and fund appropriate solicitations for the projects described above.

#### Outcome Measures

Viable hypotheses concerning the biologic and social underpinnings of preterm birth, and possible design of new research projects based on emerging knowledge. This could be supported by publications, conferences or other means of disseminating information generated under a research grant.

#### NIH Goal

This objective targets NIH goals in the categories of research, research capacity, and community outreach.

### **Objective 2**

Eliminate the disparate prevalence of risk factors in the sleep environment that ultimately influence the significant disparity in SIDS rates between racial and ethnic groups.

#### Action Plan

Continue intensive community-based outreach campaign with minority populations to reduce risks in the infant sleep environment, such as sleeping on the stomach, sleeping on soft mattresses or sofas, and using quilts and pillows. Continue related evaluation activities to assess the impact of the campaign in high-risk communities. (2002, 2003)

Partner with the DELTA Project, a community-based organization serving the Mississippi Delta, to develop communication and education programs aimed at reducing SIDS and infant mortality in that region, where SIDS and infant mortality rates are among the highest in the nation. (2002)

#### Performance Measures

Increase the number of organizations and individuals involved in developing and disseminating appropriate material.

### Outcome Measures

a) Increased awareness by parents and other caregivers about back sleeping and other behaviors to prevent SIDS, along with a change in behavior; and b) a further decrease in SIDS disparities among racial/ethnic groups.

### NIH Goals

This objective targets NIH goals in the category of community outreach.

### **Objective 3**

Create unique research infrastructures to help eliminate the racial/ethnic disparities in the causes of postneonatal mortality/morbidity rates, and conditions of infancy and early childhood associated with less than optimal birth outcomes.

### Action Plan

Initiate pilot studies that can help inform the development of community partnerships to reduce infant mortality. The goal of this effort is to ultimately create a research infrastructure, linked to community-based institutions, that is tailored to the unique health needs of minority communities and that can address poor maternal and neonatal health outcomes from late pregnancy through early childhood. (2003)

Join collaborative effort with NIAAA to examine factors leading to poor fetal and infant outcomes among American Indians and Alaskan Natives, with a particular focus on the relationship between high prevalence of drinking during pregnancy and its possible association with SIDS. (2003)

Expand pilot studies to create a fully-developed, community-based research infrastructure that addresses infant mortality in minority communities. This effort will involve 1) conducting basic research and design multi-disciplinary interventions addressing poor outcomes from late pregnancy through early childhood, 2) providing opportunities for community-based research training, and 3) providing research-based information to the community. The research would simultaneously emphasize how community, family and SES shape the biological processes that govern health and development. (2004)

### Performance Measures

Issue and fund appropriate solicitations for projects described above. Support conferences to enhance collaboration and increase interaction with outside funding organizations to achieve aims noted above.

### Outcome Measures

Viable hypotheses on a) new ways to measure community influence on behaviors that could affect birth outcomes, b) ways to structure and test interaction of biological and social factors. This could be supported by publications or other means of disseminating this knowledge, or by new projects that build on these hypotheses.

### NIH Goals

This objective targets NIH goals in the categories of research, research capacity, and community outreach.

#### **Objective 4**

Target research efforts to reduce the significant disparity in adverse maternal events, including maternal mortality between racial and ethnic groups. Identify factors and design immediate actions.

#### Action Plan

Ectopic pregnancy and preeclampsia are the number one and number two leading causes of maternal mortality and the leading causes of maternal mortality in African American women. Given these statistics, the NICHD plans to support research to better understand the basic physiologic mechanisms leading to ectopic pregnancy and preeclampsia, and use this knowledge, combined with social/cultural data, to design targeted interventions to improve pregnancy outcomes for minority women. (2002)

#### Performance Measures

Issue and fund appropriate solicitations to support the research described above.

#### Outcome Measures

Viable hypotheses concerning the basic physiologic mechanisms leading to ectopic pregnancy and preeclampsia. This could be supported by publications or other means of disseminating this knowledge, or by new projects that build on these hypotheses.

#### NIH Goals

This objective targets NIH goals in the categories of research and community outreach.

## **II. Reproductive Health**

### Rationale

Reproductive health, another area that is key to the NICHD mission, addresses biological and behavioral mechanisms that compromise the reproductive well-being of men and women, including many minority groups. For instance, 12 to 18 million or 20 to 30 percent of all women of reproductive age have leiomyomata uteri, or uterine fibroids, with African American women diagnosed with fibroids up to two to three times more frequently than White women. Uterine fibroids, which can severely limit a woman's reproductive options, remain the number one reason for hysterectomy. Reproductive health also encompasses issues affecting family planning and sexually transmitted disease, which are covered in *Healthy People 2010*, the update of the Nation's health objectives developed by the U.S. Department of Health and Human Services. Although unintended pregnancy rates have declined overall, the rates remain high for some minorities: nearly 1 in 10 African American women and 1 in 14 Hispanic women of reproductive age experience an unintended pregnancy each year. In 1998, the rate of gonorrhea remained 30 times greater for African Americans than for Whites, and 3 times greater for Hispanics. While part of this disparity is due to the fact that African Americans are more likely to seek care in public clinics, which generally are more likely to report STDs than private providers, other important factors contribute to this disparity, including poverty, social networks, and health-promoting behaviors.

## **Objective 1**

Reduce disparities in unwanted pregnancy by understanding and better addressing the barriers to appropriate contraceptive services..

### Action Plan

Continue to support a new phase of the D.C. Initiative, which is developing an intervention program to delay sexual activity, and extend the program to children in the preadolescent years, their parents, and young males. (2001)

Support research to better understand the barriers to effective contraceptive use in minority populations, and design culturally, socially, and age-appropriate interventions to meet these needs. (2002)

### Performance Measures

Issue and fund appropriate solicitations to support the research described above.

### Outcome Measures

a) Viable hypotheses on barriers to appropriate contraceptive services, and b) possibly new interventions based on this knowledge to reduce disparities in unwanted pregnancy. This could be supported by publications or other means of disseminating this knowledge, or by new projects that build on these hypotheses.

### NIH Goals

This objective targets NIH goals in the categories of research, research capacity, and community outreach.

## **Objective 2**

Support major research efforts to address the causes of excess reproductive morbidity among African American women.

### Action Plan

Address the causes of excess reproductive morbidity among African American women by expanding basic science and translational research studies of uterine fibroids. This effort will help clinicians understand the biological reasons for increased incidence in African American women, and to determine whether there is a familial predisposition to this condition. (2003)

Improve the diagnosis and management of uterine fibroids, including the assessment of ways to reduce surgical interventions, through supplements to existing cooperative clinical research networks. (2003)

### Performance Measure

Issue and fund appropriate solicitations to support the research described above.

### Outcome Measure

a) Viable hypotheses concerning the biologic mechanisms leading to uterine fibroids, and b) possible new treatments or preventive approaches based on these hypotheses. This could be

supported by publications or other means of disseminating this knowledge, or by new projects that build on these hypotheses.

#### NIH Goals

This objective targets NIH goals in the categories of research and research capacity.

### **Objective 3**

Improve prevention, screening, and treatment of STDs, addressing the needs of different racial and ethnic populations, and to reduce disparities in reproductive health and in pregnancy outcomes.

#### Action Plan

Expand investigator-initiated research on behaviors related to the prevention and treatment of STDs, emphasizing sociocultural perspectives and beliefs concerning STDs and related barriers to prevention as a critical step in designing interventions. (2002)

Support multi-disciplinary collaborative research on barriers that prevent minority women from being appropriately diagnosed and treated for STDs and then passing it on to infants. Design effective interventions to help reduce preventable cases of congenital syphilis. (2005)

#### Performance Measure

Issue and fund appropriate solicitations to support the research described above.

#### Outcome Measure

Viable hypotheses concerning behaviors and barriers related to the prevention and treatment of STDs, as supported by publications, conferences, or other means of disseminating knowledge, or by new projects that build on these hypotheses.

#### NIH Goals

This objective targets NIH goals in the categories of research, research capacity, and community

### **Objective 4**

Strengthen reproductive research infrastructure at minority institutions.

#### Action Plan

Strengthen reproductive research infrastructure at minority institutions through the Specialized Reproductive Science Research Centers at Minority Institutions Program, which encourages collaborations between scientists at minority institutions and other NICHD-funded programs. (2001)

#### Performance Measure

Issue and fund solicitations to support the research described above.

### Outcome Measure

Formation of partnerships between the reproductive science research community and research-based centers at minority institutions.

### NIH Goals

This objective targets NIH goals in the categories of research, research capacity, and community outreach.

## **III. HIV/AIDS Targeting Women And Teens**

### Rationale

HIV/AIDS is a key NICHD research area from both a biological and behavioral perspective. Despite stabilization of overall incidence rates in the United States, HIV transmission and the incidence of new AIDS cases have increased for such subpopulations as women and youth, particularly those of color. In the United States, by the end of 1998, 57 percent of women with AIDS were African American and 20 percent were Hispanic. Of women newly diagnosed with HIV, 81 percent were African American or Hispanic. In addition, HIV infection rates continue to rise for American youth, with the majority of reported AIDS cases for youth ages 13 to 19 among youth of color.

### **Objective 1**

Expand and intensify HIV prevention efforts, targeting sexual transmission and related high-risk behaviors, in racial/ethnic minority populations.

### Action Plan

Design, implement, and evaluate interventions based on the science of social/sexual networks to help prevent the sexual transmission of HIV, especially in high-risk communities, including minorities and teens. (2001)

Link social and cultural understandings of gender, gender-related beliefs and expectations, and gender dynamics, to account for how these factors may influence HIV risk among different racial, ethnic, and socioeconomic groups. (2001)

Better understand the impact of demographic and social trends (i.e., changes in family structure, marriage, and labor trends) on sexual behaviors related to HIV risk in different racial and ethnic populations. (2001)

Strengthen partnerships with institutions based in racial and ethnic communities, to develop more effective, research-based, HIV intervention programs (particularly targeting high-risk sexual behavior) that are closely linked to community needs, while generating new scientific data. (2002)

Support research to understand how the media differentially targets, represents, and exposes minority populations to messages involving high risk behaviors that can place them at risk for HIV infection. (2002)



#### Performance Measure

Issue and fund appropriate solicitations to support the research described above.

#### Outcome Measure

Viable hypotheses concerning behaviors, beliefs, and barriers related to the prevention and treatment of HIV/AIDS. This could be supported by publications or other means of disseminating this knowledge, or by new projects that build on these hypotheses.

#### NIH Goals

This objective targets NIH goals in the categories of research, research capacity, and community outreach.

### **Objective 2**

Lead research to develop more effective means of preventing and treating HIV in minority youth, using multidisciplinary and developmentally appropriate methodologies and resources.

#### Action Plan

Through the NICHD Adolescent Trials Network, expand efforts to include adolescents in HIV vaccine prevention trials. (FY 2003)

#### Performance Measure

Issue and fund appropriate solicitations to support the research described above.

#### Outcome Measure

Adolescents enrolled in appropriate HIV trials; potential data on the effectiveness of these vaccines in teenagers that can assist in licensure of the vaccine for adolescent populations.

#### NIH Goals

This objective targets NIH goals in the categories of research, research capacity, and community outreach.

## **IV. Early Antecedents of Disparities in Disease and Growth**

### Rationale

This topic area addresses the most important roots of health disparities (e.g., diabetes, heart disease, obesity) that start with prenatal and gestational mechanisms. It also addresses how early nutrition contributes to these differences.

#### *Part I. Understanding the Fetal Mechanisms Leading to Health Disparities*

Scientists believe that inequalities in health start with the earliest prenatal and gestational mechanisms. The early interactions between fetal, maternal, and external factors may explain much of the health disparities seen in adult rates of hypertension, obesity, diabetes mellitus, and coronary artery disease. These interactions may lead to fetal "programming" that contributes to changes that could be transmitted across generations, and perpetuating disparities. For example, fetal conditions such as small-for-gestational-age and intrauterine growth retardation can be

important biomarkers since these conditions are associated with an increased risk of various health conditions that occur disproportionately in African American populations.

### **Objective 1**

Support research to understand the fetal antecedents of and biomarkers for disparities in hypertension, stroke, diabetes, and coronary artery disease. Use findings as a basis for prenatal and early intervention programs targeting special populations.

#### Action Plan

Continue to support research to understand the fetal antecedents of and biomarkers for disparities in hypertension, stroke, diabetes and coronary artery disease. Findings from these studies will be used as a basis for prenatal and early intervention programs targeting special populations. (2001)

Support pilot studies for a major prospective, multi-agency, longitudinal, cohort study to understand the many factors (biological, psychosocial, physical/environmental, behavioral) contributing to differential health outcomes over the lifespan. This will include approximately 100,000 participants and capture events that predate conception. It will also examine critical chronic and episodic events, including environmental exposures, as well as survey and biologic data to relate external events to physiological changes. Researchers will oversample minority and socioeconomically disadvantaged populations to make comparisons across racial and ethnic groups. In addition, special emphasis will be placed on developing and testing hypotheses that deal with health disparities. (2002)

Support research to identify how intrauterine growth retardation and deficient intrauterine environments influence the developing fetus, providing the basis for future chronic disease. Define “normal” fetal growth, and identify other biomarkers as they apply to minority and non-minority groups. Determine if maternal/fetal responses to external stimuli vary between racial/ethnic groups. Examine physiological response to stress; identify biological and genetic factors that account for differences; and identify other factors (e.g., history of small babies) to serve as markers or potential points for intervention. (2004)

#### Performance Measure

Issue and fund appropriate solicitations to support the research described above.

#### Outcome Measure

a) Viable hypotheses concerning the early antecedents of adult disease and health disparities. This could be supported by publications or other means of disseminating this knowledge, or by new projects that build on these hypotheses; b) reliable sample sizes of minority and socioeconomically disadvantaged populations that can be integrated into the full-scale longitudinal study. (for the longitudinal cohort study only)

#### NIH Goals

This objective targets NIH goals in the categories of research, research capacity, and community outreach.

## *Part II. Understanding Disparities in Growth and Development—Obesity and Nutrition*

The disparity in obesity is greatest among low-income teens, where the percentage of obese teens is twice that for middle/upper-income teens. Young African American females (6 to 17 years old) are 50 percent to 60 percent more likely to be overweight than young White females. The increase in obesity rates is fueling an epidemic of Type 2 diabetes appearing in Hispanic and Native American teens.

In the area of nutrition, breastfeeding has been linked to improved health outcomes for infants. However, despite strong recommendations on the importance of breastfeeding, only 43 percent of African American women choose to breastfeed their newborns, compared with 66 percent of Hispanic and 68 percent of White women. This may place African American infants at a disadvantage for a healthy start.

### **Objective 1**

Better understand the interaction between the biology of nutrition and growth with social and cultural forces to help prevent the early onset of health disparities.

#### Action Plan

Expand research to understand the genetic, physiologic, metabolic, and behavioral characteristics leading to the increased risk of obesity among teenaged African-American women, provide training opportunities for minority researchers in these clinical studies. (2002)

Assess factors that influence the calcium intake of different ethnic/racial groups, targeting children and teens, with particular reference to social, cultural, and ethnic influences on food preference. (2005)

Identify how social and cultural factors interact with food availability to influence the development of dietary habits in infancy through adolescence. Assess the impact of these habits on disparities in obesity and other chronic conditions, particularly in Hispanic and Native American teens; include research on biomarkers, dietary supplements, and complementary feeding practices. (2006)

#### Performance Measure

Issue and fund appropriate solicitations to support the research described above.

#### Outcome Measure

Viable hypotheses on a) the underlying biology of nutrition and growth, and b) how these factors interact with cultural and social forces to produce disparities. This information could be supported by publications or other means of disseminating this knowledge, or by new projects that build on these hypotheses.

#### NIH Goals

This objective targets NIH goals in the categories of research, research capacity, and community outreach.

## **Objective 2**

Eliminate the disparity in the percentage of African American women who choose to breastfeed their infants.

### Action Plan

Better understand the social, cultural and behavioral factors that influence the decisions of women of various racial/ethnic sub-populations to breastfeed their infants, and to continue breastfeeding throughout the first year of life. Target barriers that may exist in different racial and ethnic communities; share data to design interventions/education programs. (2004)

### Performance Measure

Issue and fund appropriate solicitations to support the research described above.

### Outcome Measure

Viable hypotheses on the social, cultural and behavioral factors that influence the decisions of women of various racial/ethnic sub-populations to breastfeed their infants. This information could be supported by publications or other means of disseminating this knowledge, or by new projects that build on these hypotheses.

### NIH Goals

This objective targets NIH goals in the categories of research, research capacity, and community outreach.

## **V. Early Antecedents of Child Health and Adverse Behaviors**

### Rationale

There is a disproportionate incidence of injuries and violence in many minority communities, due in part to poverty and other family and community factors. This compromises the health and well-being of our Nation's most vulnerable children. On average, nearly 3 million children are reported as suspected victims of child abuse and neglect, and nearly 1000 die from such maltreatment. A disproportionate number are minority youth. In addition, homicide has reached epidemic proportions for African-American youth: homicide rates for teens aged 10 to 14 are three to four times greater than for Whites; they are eight times greater for older African American adolescent males.

## **Objective 1**

Understand how the relationships between poverty, single-parent families, and related factors affect childhood well-being for minority children. Encourage targeted interventions to strengthen family support systems and sense of connectedness.

### Action Plan

Extend the "Science and Ecology of Early Development" (SEED) program, which is examining the complex interactions of poverty with other factors that influence developmental outcomes and resilience in children and families. Link studies to the evaluation of government intervention programs. Use the initiative to create an ongoing dialogue between researchers, policymakers, and program officials. (2001)

Expand support of the Early Head Start Fathers studies and the Early Childhood Longitudinal Study—Birth Cohort, to determine the antecedents, consequences, and meaning of parental involvement, program intervention, and other social/community factors, for child outcomes including health, social, and cognitive. (2002)

Collaborate with the CDC's Healthy Futures Program, targeting White, African American, and Hispanic youth to determine the developmental path of health risk behaviors and adverse health outcomes. (2002)

As a followup to the NICHD conference on Parenting and the Child's World, encourage researchers to focus on the roles of parents in promoting healthy development, particularly among children of different racial/ethnic backgrounds and sociocultural settings. Examine how parenting interacts with a variety of other factors to influence children's social, moral, emotional, and cognitive development in these different settings. (2003)

#### Performance Measure

Issue and fund appropriate solicitations to support the research described above.

#### Outcome Measure

Viable hypotheses on how poverty, single-parent families, and related factors affect childhood well-being for minority children. This information could be supported by publications or other means of disseminating this knowledge, or by new projects that build on these hypotheses.

#### NIH Goals

This objective targets NIH goals in the categories of research and community outreach.

### **Objective 2**

Identify antecedent and etiologic factors, and understand complex interactions between social, cultural, biological, and developmental processes, which contribute to intentional and unintentional injury, violence, and other adverse health outcomes for minority youth. Use data to design, implement, and evaluate programs that promote healthful and preventive behaviors.

#### Action Plan

Identify social, cultural, biological, and developmental processes that contribute to intentional and unintentional injury, violence, and other adverse health outcomes for minority youth. Use this data to design, implement, and evaluate programs that promote healthful and preventive behaviors. (2001)

Support interagency efforts to encourage research on injury prevention and emergency services for children affected by injuries, disabilities, illness, or violence. Clarify factors that place minority youth at greater risk and develop effective preventive interventions. (2001)

Develop a research definition and taxonomy concerning child neglect, ensuring that the definition considers the impact of social and cultural norms. (2001)

Support a collaborative effort to understand the immediate and long-term impact of domestic violence during pregnancy, and children's exposure to domestic and community violence. Address differential risk factors and impact across racial and ethnic groups. (2003)

Support basic research to examine the social, parental and other antecedents of child neglect and abuse, while also identifying the factors protecting infants and young children from neglect and abuse, with a focus on racial and ethnic differences. Design and evaluate parenting interventions to reduce rates of infant deaths due to such abuse. (2004)

#### Performance Measure

Issue and fund appropriate solicitations to support the research described above.

#### Outcome Measure

Viable hypotheses on the social, cultural, biological, and developmental processes, which contribute to intentional and unintentional injury, violence, and other adverse health outcomes for minority youth. This information could be supported by publications or other means of disseminating this knowledge, or by new projects that build on these hypotheses.

#### NIH Goals

This objective targets NIH goals in the categories of research, research capacity and community outreach.

### **Objective 3**

Train and encourage more minority researchers to address these health disparity issues that affect the long-term well-being of minority families.

#### Action Plan

Create research/training opportunities at Historically Black Colleges and Universities, and universities with strong Hispanic and Native American Indian researchers for minority researchers to examine : 1) ways to strengthen parenting and a sense of connectedness between minority children, parents, families, schools and communities; 2) unintentional injury; and 3) violence prevention. Include special outreach workshops. (2005)

#### Performance Measure

Issue and fund appropriate solicitations to support the research described above.

#### Outcome Measure

None.

#### NIH Goals

This objective targets NIH goals in the categories of research, research capacity, and community outreach.

## **VI. School Readiness, Cognitive And Behavioral Development**

#### Rationale

Children's early cognitive and behavioral development is key to later success in life. Health disparity research in this area will address differences in acquiring basic cognitive and learning skills that keep minority youth from breaking the disparity cycle. Data from 1998 show that African American, Hispanic, and American Indian students in 4th, 8th, and 12<sup>th</sup> grades were nearly twice as likely to perform below basic levels in reading. Similar disparities exist in math and

science. By 2030, Hispanic children will comprise one-fourth of the Nation's total student population; yet, data show that: young Hispanic children lag behind White children in early school-related skills. Many Hispanic American students are below grade level, which contributes to their higher dropout rates. For instance, 28 percent of Hispanic 16- to 24-year-old students dropped out of school, more than double the rate for African Americans (14 percent) and three times that for non-Hispanic Whites (8 percent).

### **Objective**

Identify barriers to school readiness and academic success for minority and low-income children; examine the effect of barriers in language, cognitive, and behavioral development and the subsequent and cumulative effect on school readiness. Design appropriate developmental interventions to ensure optimal development and optimal school readiness for these children.

### Action Plan

Identify, develop and test the effectiveness of programs, settings, and technologies used to motivate and enhance the skills of parents and other family members who are most likely to be in supportive and teaching roles for their children. (2002)

Support efforts to identify, develop, and assess different programs in early childhood settings that integrate reading, writing, and social skills, with those needed to maintain emotional health, to determine which programs are most beneficial and for which children. (2003)

Determine factors that contribute to disparities in mathematics achievement and how best to address them. Address cognitive, developmental, as well social/cultural factors on a child's ability to learn mathematical concepts and information. (2003)

Identify whether linguistic barriers exist for non-English speaking ("language minority") children. Address cognitive, developmental, as well social/cultural factors to design appropriate interventions to ensure school readiness for these children. (2003)

Identify the interactions among biobehavioral, social, environmental, and community stressors leading to minority disparities in academic achievement and drop-out rates among minority adolescents. Develop effective multidisciplinary interventions for reducing these disparities during the critical developmental period of adolescence. (2004)

Investigate the underlying cognitive and neurological mechanisms of bilingualism to enhance the ability of researchers to design appropriate curricula for students that come from multilingual families. (2005)

Identify the unique developmental and linguistic challenges facing children of migrant workers, an often overlooked subset of children living in poverty. Define which aspects of their unique living environment might be advantageous in educating them, and the specific aspects of their living environment and lifestyle that are most likely to lead to disparities in their physical, linguistic, cognitive, and social-emotional development. (2005)

### Performance Measure

Issue and fund appropriate solicitations to support the research described above.

### Outcome Measure

Viable hypotheses on the barriers to school readiness and academic success for minority and low-income children. This information could be supported by publications or other means of disseminating this knowledge, or by new projects that build on these hypotheses.

### NIH Goals

This objective targets NIH goals in the categories of research, research capacity, and community outreach.

## **VII. Restoring Function And Preventing Disabilities**

### Rationale

This emphasis area is a unique, yet overlooked area that recognizes the special needs of minority families in overcoming the burden of physical or developmental disabilities.

#### *Part I. Physical Disabilities*

Minorities suffer a disproportionate incidence of trauma and illnesses, such as stroke, that lead to permanent disabilities. These disabilities add a double social, economic, and health burden to many minority families already at a disadvantage. For instance, minority victims of spinal cord injury are 2.8 times less likely to resume employment after injury than their White counterparts. Patients from minority groups also access and utilize outpatient rehabilitation services less frequently than White patients. While preliminary data indicate that there may be no differential response of minority patients to acute rehabilitation interventions, these findings need further review.

### **Objective**

Acquire basic data and develop appropriate interventions to reduce the double burden of being a racial/ethnic minority individual or family with a permanent disability. Build on newly established programs to identify specific barriers that impede racial and ethnic minorities from returning to work, reintegrating themselves into the community, and returning to school and to other educational opportunities.

### Action Plan

Supplement newly established sites in the Regional Rehabilitation Network to link with minority institutions to address targeted questions concerning minority populations. (2001)  
Supplement new clinical rehabilitation networks targeting pediatric trauma patients to understand how socioeconomic, cultural, and other external factors influence short- and long-term rehabilitation outcomes. (2003)

### Performance Measure

Issue and fund appropriate solicitations to support the research described above.

### Outcome Measure

Viable hypotheses concerning the relationship between sociocultural, economic, and external factors and rehabilitation outcomes. This could be supported by publications or other means of disseminating this knowledge, or by new projects that build on these hypotheses.

### NIH Goals

This objective targets NIH goals in the categories of research capacity.



## *Part II. Developmental Disabilities in Children*

Having children with developmental disabilities puts a disproportionate burden on minority families. Early data from an NICHD-supported study suggest that the divorce rate for families of young children with disabilities may be twice as high among African American families as it is for similar White families. Data suggest that the stigma associated with having a child with a developmental disability varies across racial and ethnic groups. This ultimately influences access to health services and health outcomes.

### **Objective**

Promote stability in racial/ethnic families with disabled children by designing and implementing research-based interventions based on the special needs of these families. Address the father's role in influencing health outcomes of disabled children and understanding various social/cultural factors that may increase the risk for adverse family outcomes.

### Action Plan

Develop a multi-site collaborative program to design and evaluate interventions to promote stability within families of disabled children. Assess data from ongoing studies and acquire range of racial/ethnic data as needed; design interventions with community advice/input; focus on those minority families where children with disabilities do well, to determine what particular factors or interactions of factors contribute to such successes. (2005)

### Performance Measure

Issue and fund appropriate solicitations to support the research described above.

### Outcome Measure

Viable hypotheses on how to design and implement research-based interventions based on the special needs of these families. This information could be supported by publications or other means of disseminating this knowledge, or by new projects that build on these hypotheses.

### NIH Goals

This objective targets NIH goals in the categories of research, research capacity, and community outreach.

## **VIII. Training and Career Development**

### Rationale

Eliminating health disparities demands the same type of talent pool that exists to address our Nation's science and engineering research needs. In particular, researchers are required who understand the needs of the community that this science is meant to serve. Providing the opportunity to network and meet with NIH and NICHD officials is also key to furthering the careers of minority researchers.

### **Objective 1**

Build on the strength of the NICHD's existing Institutional Training Programs (T32s) in the demographic behavioral, reproductive, maternal/child health, and rehabilitation sciences, which already target health disparity research issues. Expand these programs to better link to the minority communities that the NICHD serves.

### Action Plan

Target additional slots (in the short-term) for existing T32s, institutional training programs, to pursue health disparities research, particularly targeting scientific areas outlined in this strategic plan, and encouraging the recruitment of minority researchers. (additional funds as required to make requisite number of slots available). (2002/2003)

Widely publicize the T32 minority recruitment policy on NICHD website and in the NIH Guide to Grants and Contracts. (2002/2003)

Add a third level of NICHD review to substantively evaluate minority recruitment plans prior to making funding decisions for new or re-competing T32 grant applications. Re-rank the applications based on an additional score reflecting the strength of the applicant's minority recruitment plans. Reinforce for those doing well in recruiting minorities (additional funds as required to make requisite number of slots available) (ongoing)

Encourage the development of new institutional programs that target the training of researchers in health disparities. (2003)

### Performance Measure

Publicize and implement guidelines and procedures to enhance minority recruitment plan; Issue and fund appropriate solicitations to support the goals described above.

### Outcome Measure

Improved recruitment plan with inclusion of specific strategies to increase recruitment of minorities in NICHD sponsored research; additional slots for minority trainees in the institutional training program.

### NIH Goals

This objective targets NIH goals in the category of research capacity.

## **Objective 2**

Provide coordinated clinical research opportunities for minority investigators and for persons seeking to conduct research on health disparity issues of importance to the NICHD; build on the strength of the NICHD's existing career development programs in reproductive maternal/child health and the rehabilitation sciences to provide additional opportunities for minorities who are interested in pursuing health disparity research.

### Action Plan

Increase clinical research opportunities for minority investigators and for persons seeking to conduct research on health disparity issues of importance to the NICHD through its existing network sites (additional funds as required to support minority investigations and investigators seeking to do research on health disparities). (ongoing)

Provide slots as they become available in existing K12 Mentored Research Scientist Development Program Awards for researchers to pursue health disparities issues outlined in the NICHD's strategic plan (additional funds as required to make requisite number of slots available). (ongoing)

Support of Scholar positions in the Building Interdisciplinary Research Careers in Women's Health program, where investigators have been asked to address health disparity issues. (ongoing)

Performance Measure

Identify new opportunities to add trainee positions in existing clinical research and career development programs for minority and other researchers wishing to pursue health disparities research.

Outcome Measure

Additional slots made available and clinicians recruited to pursue this research.

NIH Goals

This objective targets NIH goals in the category of research capacity.

**IX. Outreach**

Rationale

Community outreach involves translating scientific findings concerning health disparities into a common language that enables communities to act upon them. It also implies participating, giving back to communities, and encouraging partnerships so that the Nation gets the best return on its research investments. Clinical researchers need adequate numbers of minority groups in clinical studies to enable them to detect and account for the significant differences in health status between racial and ethnic groups where they exist. However, there are a variety of impediments to recruiting minorities into clinical trials including factors such as reduced income, lower educational levels, reduced access to quality health care information and services. Other factors include a lack of awareness of opportunities to participate in clinical trials and a shortage of minority biomedical scientists to recruit and effectively communicate with potential research participants.

**Objective 1**

Increase the enrollment of individuals from various racial and ethnic minority communities in clinical trials. Ensure that the Institute's intramural and extramural investigators understand community characteristics and needs, receive adequate training and guidance, and communicate information about the trials to appropriate health care providers and communities.

Action Plan

Support research and other activities that improve understanding and interactions of researchers with health care and patient representatives from the communities in which new clinical trials or longitudinal surveys are planned. The goal would be to: a) better inform the community of the nature and scope of the research, b) build the community's trust in the research effort, and c) ensure that the trial design or survey instrumentation adequately meets community needs and concerns. Apply appropriate social marketing and outreach techniques to enhance recruitment where necessary (additional funds as needed to support ongoing research, projects, and conferences). (ongoing)

Performance Measure

Support appropriate conferences and research budgets to ensure appropriate outreach and inclusion of minority research subjects.

### Outcome Measure

Increasing numbers of clinical trials and research studies with adequate numbers of minority representation to allow valid hypotheses and findings to be developed.

### NIH Goals

This objective targets NIH goals in the category of research capacity.

## **Objective 2**

Work with socially and economically disadvantaged children to increase interest in science and health careers by improving their basic reading and math skills.

### Action Plan

Enhance the NICHD's pioneering efforts to partner with local schools and educators, and to work with children from disadvantaged and minority backgrounds. (ongoing)

### Performance Measure

Identify opportunities to increase employee voluntary participation in these programs.

### Outcome Measure

Increase level of volunteer participation in outreach program with local elementary school.

### NIH Goals

This objective targets NIH goals in the category of community outreach.

## **Objective 3**

Actively identify and translate NICHD research findings important to various minority communities to help them and their health care providers obtain and use research-based information.

Actively seek the advice of communities in preparing these materials.

### Action Plan

Support the analysis and synthesis of research findings most relevant to minority communities, developing materials useful to providers and members of racial/ethnic communities. Areas in which new targeted materials will be developed in the short-term include: 1) nutrition for pregnant mothers, and for children and teens, 2) reading and related school readiness issues, and 3) increased calcium consumption for youth, and 4) parenting. Also, expand efforts to publicize the NICHD Clearinghouse in minority communities. (ongoing)

Support the development of targeted issue papers, articles, speaker series, and forums to translate the newest NICHD scientific findings and projects addressing health disparities into implications for health care researchers, health care providers, policymakers, and community/advocacy groups. (ongoing)

Expand support for activities that allow the NICHD to participate in local community health activities and functions, particularly those serving minority and economically disadvantaged populations around the country. (ongoing)

Performance Measure

Publish new brochures available on topics of relevance to racial/ethnic communities.

Outcome Measure

Increased requests for materials from a diverse range of institutions.

NIH Goals

This objective targets NIH goals in the category of community outreach.

NICHD Health Disparities Budget  
(Dollars in Millions)

Institute / Center	FY 2002			FY 2003		
	Research	Infrastructure	Outreach	Research	Infrastructure	Outreach
NICHD	\$261.50	\$10.10	\$4.80	\$285.10	\$11.00	\$5.20