BREAK THE CYCLE II
Exploring the Relationship between Disadvantage and Disability

A Monograph of

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Editors

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The mission of the **Institute for the Study of Disadvantage and Disability (ISDD)** is to address health disparities for children living in situations of social and economic disadvantage, particularly those who have developmental disabilities, through:

- Developing a better understanding of the relationship between social and economic disadvantage and the prevalence and severity of developmental disabilities and other chronic medical conditions
- Supporting and developing programs that improve the situation for the identified population
- Supporting and coordinating research in prevention of disabilities and chronic medical conditions related to environmental circumstances and factors, and
- Influencing health care practices, training of health care professionals, and public policy

Since incorporation as a nonprofit organization in 2004, ISDD has strong support from metro Atlanta’s health professionals, the disability community, universities, and private and public agencies. ISDD has its base in clinical services and programs for children with developmental disabilities at the Hughes Spalding Children’s Hospital and also works collaboratively with Emory University Department of Pediatrics on a national program focused on children’s environmental health. ISDD has a unique program in Georgia, Project GRANDD, which is under the auspices of the Atlanta Regional Commission, Area Agency for the Aging. Project GRANDD provides intensive supports and interventions to grandparents who are raising grandchildren with developmental disabilities. In addition, ISDD has successfully engaged a number of projects, including the Adult Down Syndrome Program as part of a multi-center international project on Down syndrome and aging.

ISDD has an executive team with a vast and varied knowledge base in developmental disabilities, health care through the life span with families in need, diagnosis and treatment.

Visit us on our website at:

[www.isdd-home.org](http://www.isdd-home.org)

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**This Monograph is dedicated to all children – may they grow up with love and support and the necessary food, shelter, appropriate medical care and education to make them healthy and successful adults in a just society.**
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We appreciate the support of our funder

Healthcare Georgia Foundation
**ii. Preface**

This Monograph represents the collection of presentations given by the students and varies with the nature of the specific project and the expectations of the supervising faculty. It represents the diversity of styles and approaches of the different disciplines that are critical in serving children who through no fault of theirs are born into circumstances of social and economic disadvantage. The presentations and their representations in this monograph should provide for the reader some insights into the topic areas and also new ideas from which to develop new projects.

We are grateful to Healthcare Georgia Foundation for their funding of the project, particularly Dr. Gary Nelson for his encouragement and ongoing support. We are also grateful to the faculty and students who participated, and, finally, to all the children and families who were part of any of these studies.

All five projects were varied with students and faculty working collaboratively to present an outstanding workshop on March 26, 2008. The meeting was held in partnership with Morehouse School of Medicine and were honored and inspired to have Dr. David Satcher deliver our keynote address. Ms. Lucy Hall-Gainer of Mary Hall Freedom House also addressed the participants.

We feel the implications of the work done by the students have far reaching implications. Since this project, two of the students graduated law school and are practicing attorneys and one student received her MPH and one of the research projects is still in process. Some of the written abstracts have been submitted to a scientific peer-reviewed journal and will be published in early 2009.

ISDD looks forward to our next Break the Cycle IV project in the spring of 2009. Our goal is to develop the knowledge, raise awareness, cultivate future leaders and make sure that in the future this subject will be a study of the past.
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Introduction

1.1 Background and Overview:

In 1998 Children’s Medical Services (CMS) of Georgia discontinued providing direct clinical services to children with Cerebral Palsy (CP) and their families. In response to the anticipated loss of services for the families, an interdisciplinary Cerebral Palsy Program was developed at the Hughes Spalding Children’s Hospital. This clinic was originally held one weekday per month and served an average of 15 children and their families each clinic day. The clinic was attended by a Developmental Pediatrician, Orthopedic Surgeon, Physical Therapist, Occupational Therapist, Speech Therapist, Audiologist, Nutritionist, Orthotist and wheelchair specialist. In addition the CMS Nurse Coordinators were present from Fulton, DeKalb, Clayton and Cobb Counties as needed, as well as volunteer services from Parent Educating Parents and Professionals (PEPP) to help families with school related problems. The clinic has grown, the numbers of children seen has grown, more programs of this design have been established to provide services for children with other types of developmental disabilities and we continue to develop meaningful collaborative partners in the process.

In 2002 we received funds from the Ward Family Foundation and set about reviewing the information we had gathered over the nearly 4 years since starting the clinic. We used a questionnaire developed by the CDC and employed a student to do some of the data extraction and a graduate of the Rollins School of Public Health at Emory to review and analyze the data.

The findings informed us that we had seen almost 250 children in that time, slightly more boys than girls and with a wide age range but predominantly in the school age. There were additional findings on the types of CP, nature of additional impairment, presence of medical and surgical complications, etc. Most of the information was relatively familiar to professionals who know about CP. However, the most striking findings were in the realm of the demographics and psychosocial factors. We found that most of the infants were born prematurely and that they tended to have more severe medical and developmental problems. There was a disturbingly high prevalence of prenatal substance abuse and a strikingly clear inverse relationship between maternal substance abuse and birth weight – the more likely the mother abused substances during pregnancy the more likely the infant would be premature, and the more premature the infant would be and the more severe the medical and developmental
complications. We also found that most children were living in single parent families with mothers and that a significant number of children (about 20%) were living in foster homes most often with their grandmothers or other relatives but also in unrelated foster homes.

These findings forced us to look more deeply into the literature on the relationship between social and economic disadvantage and the prevalence and severity of childhood disability. Indeed the literature was replete with research information and commentaries on the subject of poorer outcomes for children who grew up in less advantageous circumstances and information was strong that the benefits of early intervention to the children and their families and educational support for the children would improve the outcome for the children. Although information on educational and social outcomes of children was plentiful, information on specific disabilities was not as rich.

As a result of our findings and supportive evidence from the literature we decided to form an Institute that would be dedicated to exploring the relationship between social and economic disadvantage and childhood disability and to help to develop strategies of prevention and intervention that would serve to reduce the likelihood that children would have adverse physical, medical, developmental, educational, behavioral and social consequences. In addition, it appeared that there was a cycle of disadvantage and disability that perpetuated the problems in successive generations and that, although the pattern appeared to be grim, there were clearly ways in which the cycle could be interrupted and a positive outcome assured. It was up to us to develop strategies to make this happen.

After much research and planning the Institute for the Study of Disadvantage and Disability, Inc. was formed in May 2004. The first priority of the institute was to promote the concept of “breaking the cycle” and beginning to develop strategies and to inspire and encourage future leaders. We conceptualized and project wherein we would work with major academic institutions and reach as many departments and disciplines as possible who were involved in any way in the promotion of physical, emotional and social well-being for children and their families and also those involved in education and community support.

We were received funding from the Governor’s Council on Disabilities through their Innovative Programs Grant for our first Break the Cycle project in 2005 and collaborated with academic leaders at the 3 major Universities in Atlanta – Morehouse School of Medicine, Emory University and
Georgia State University – in such areas as health, education and law. We were very pleasantly surprised by the enthusiastic response of the faculty and of the energy and intellect of the students who threw themselves into their projects and gave us a prize that we need to treasure; hence this monograph.

The success of this project has led to additional Break the Cycle projects; with Break the Cycle II funded by Georgia Healthcare Foundation. We have worked with the Environmental Protection Agency on a Break the Cycle III project that focuses on the environmental health of vulnerable children.

1.2 Premise:
Children who are born into, and grow up in circumstances of social and economic disadvantage are more likely to have developmental disabilities than their more advantaged counterparts in our society, and are less likely to have access to appropriate services to meet their needs. This situation sets up a cycle of disadvantage and disability that can affect generations to come. The Institute is dedicated to improve the quality of life for children who have developmental disabilities and who live in circumstances of social and economic disadvantage.

1.3 Mission:
The mission of the Institute is to address the health disparities for children living in situations of social and economic disadvantage particularly those who have developmental disabilities. The Institute proposes to accomplish the Mission by:

♦ Developing a better understanding of the relationship between social and economic disadvantage and prevalence and severity of developmental disabilities and other chronic medical conditions

♦ Supporting and developing programs that will improve the situation for children with developmental disabilities and other chronic medical conditions and their families.

♦ Supporting and coordinating research in prevention of disabilities and chronic medical conditions related to environmental circumstances and factors

♦ Assess the cost of the disabilities, in human terms and the dollar cost of health care, to the families and state and other agencies who provide medical and other care arising out of these disabilities and examine the relative benefits in financial terms of programs of prevention

♦ Influencing health care practices, training of health care professionals and Public Policy
1.4 Background of Developmental Disabilities (DD) and Significance for the Atlanta: A. Etiological and Conceptual Underpinnings

Children with DD have, *a priori*, a chronic condition which requires health and related services well beyond those needed by children in general. Developmental Disabilities are neurologically based conditions that have origins in early life, identified by delays or significant differences in an infant or child’s development involving functions across one or more domains that require timely identification, appropriate intervention, and medical, therapeutic, and psycho-social support to assure optimal function for the child and family in the community. Four categories of major Developmental disabilities are: 1) neuromotor-based conditions--cerebral palsy and spina bifida; 2) neuro-cognitive conditions--mental intellectual disabilities syndromes; 3) neuro-behavioral conditions--autism and related disorders; and 4) sensory impairments--visual and hearing. Other related Developmental disabilities include high prevalence, low severity conditions such as learning disabilities and attention deficit disorders, with or without hyperactivity, as well as environmentally driven conditions resulting from toxic exposures, family dysfunction, intentional and unintentional injuries, and living conditions often associated with poverty.

Understanding the particular etiologies related to this broad range of conditions assists in the evaluation of functioning capability and potential, and anticipation and prevention of complications and secondary conditions for the individual and family. Appreciating the epidemiology of these patterns allows for the construction of population-based primary, secondary, and tertiary prevention strategies. The etiologies are specific to three time periods in a child’s development, prenatal, perinatal, and postnatal.

1. *Prenatal* etiologies include genetic disorders that are chromosomal and non-chromosomal, intrauterine infections, and a large group of conditions related to the overall health status of the mother compounded by specific risk behaviors such as smoking, alcohol consumption, and substance abuse.

2. *Perinatal* etiologies fall into two major groups, birth trauma and asphyxia, usually of full-term infants, and the complications of prematurity and low-birth weight. In this latter group, the status of the newborn may be attributed to maternal prenatal factors highlighted above.

3. *Postnatal* etiologies represent the broadest range of factors which include head injuries, intracranial infections, lead and other toxic exposures with the most prevalent cause being psycho-
social circumstances related to the child’s family and community environment.

1. More Complex and Multiple Etiologies.
Although described separately, the etiologies are often interrelated and mutually confounding and complicating. More particularly, maternal factors that contribute to adverse perinatal circumstances are reinforced by the infant’s postnatal family and community situation resulting in a further compromise of the child’s longer range outcome. In this regard, poverty and low academic attainment have been shown to be the most significant correlates of DD and functional outcome.

Particular demographic and risk variables emerge in examination of the burden of DD disability. In a Centers for Disease Control and Prevention (CDC) study (Mervis, 1995) mothers of case children with intellectual disabilities were more likely to have fewer years of education than mothers of normal control children; 55% of mothers of children with mild intellectual disabilities and 40% of mothers of children with severe intellectual disabilities had not finished high school at the time of their child’s birth contrasted with 28% of mothers of control children. These results crossed racial and ethnic boundaries and were not confined to teenage mothers. Also, 60% of children with intellectual disabilities were male and mothers of children with intellectual disabilities were more likely to be black. Particular pregnancy-related risk variables were also demonstrated. The risk for intellectual disabilities increased as birth weight decreased, with risk for severe intellectual disabilities two-and-a-half times higher than for mild MR. In utero exposure to tobacco was also associated with occurrence of intellectual disabilities with data suggesting a 50% increase in the likelihood that a child will have intellectual disabilities. (Drews et al, 1996) A separate CDC report on the epidemiology of mental intellectual disabilities in children (Murphy et al, 1998) revealed a prevalence of Fetal Alcohol Syndrome of between 0.2-1.0/1,000 live births. Prenatal alcohol consumption of two or more drinks per day has been associated with an average decline of 7 IQ points in children, age 7 years. Other investigators have cautioned that part of this cognitive decline may be due to the unstable family environmental often accompanying alcohol-abusing parents. Thus, approaches to addressing individual diagnoses and subsequent needs require engagement at the community and systems level.

2. The Interdisciplinary Imperative.
The complexity and confounding variables in the life of any child with DD requires an interdisciplinary approach that includes specialized/enhanced medical and nursing, therapeutic, and family support services as well as supplies and equipment, education and related enabling services.
such as transportation. (McPherson et al, 1998). By extension, at the population level children with DD require that multiple systems be integrated and configured to address needs. These include health service delivery, public health, legislation, and financing.


Children with DD represent a sizable population that requires attention at an individual level as well as a systemic approach to integrate resources and make them available and relevant. In evaluating results from a 1994 survey, Newacheck et al (1998) estimated that 18% of US children under age 18, 12.6 million children, had a chronic physical, developmental, behavioral or emotional condition and required health and related services greater than those generally required by children. Based on the CDC data from their metropolitan Atlanta study (Boyle et al, 1996), the overall prevalence of mental intellectual disabilities was 8.7/1,000 children ages 3-10; cerebral palsy was 2.4/1,000; hearing impairment was 1.1/1,000; and vision impairment was 0.8/1,000. (Figure 6 below.) MADDSP, a national administrative review study relies on five-county Atlanta data, and shows a pattern consistent with other studies of DD prevalence.

| Disability Status of Noninstitutionalized Children in Georgia Ages 5 to 15 in the 2000 Census |
|--------------------------------------------------|--------------------------------------------------|
| Noninstitutionalized children ages 5 to 15 | Number | Percent of Children Ages 5 to 15 |
| Children with no disability | 1,263,916 | 94.3 |
| Children with one disability | 61,804 | 4.6 |
| Sensory disability | 6,809 | 0.5 |
| Physical disability | 4,761 | 0.4 |
| Mental disability | 47,521 | 3.5 |
| Self-care disability | 2,713 | 0.2 |
| Children with two or more disabilities | 15,301 | 1.1 |
| Includes a self-care disability | 9,623 | 0.7 |
| Does not include a self-care disability | 5,678 | 0.4 |

Source: Population Reference Bureau, analysis of data from the U.S. Census Bureau, 2000 Census Summary

4. Estimated Costs.

While it is recognized that children with DD require more services, these services come at a cost. Ireys et al (1997) surveyed Washington looking at expenditures for care of children with chronic illnesses enrolled in Washington State Medicaid Program for FY 1993. They found that 5.9% of all children surveyed had at least one chronic condition (asthma, chronic respiratory Disease, cystic fibrosis, neoplasms, diabetes, cerebral palsy, spina bifida and muscular dystrophy). The mean cost for this group was $3,800 compared to $955 for the total Medicaid population. Mean payments ranged
from 2.5 - 20 times more than payments to all children, and approximately 10% of children accounted for 70% of the payments. For children with Cerebral Palsy, as an example, the mean cost was $9,887 and included costs for Inpatient, Physician, private nursing, out-patient, drugs, durable medical equipment, other providers and services. Given the prevalence of cerebral palsy in the population, the overall annual cost of approximately $9.4 million, ranked 3rd greatest among all the chronic conditions examined. These data offer a perspective of services required and costs for the services by children with this condition. This permits some projection of cost for other DD conditions. The challenge remains to determine the optimal use of the financial resources to improve the health and well being of children with DD and their families, individually as well as collectively, this particularly in the current era with its managed care trend.

A child with DD results in both financial and emotional costs for the child, the family and the community at large. Of these costs, the financial ones are far easier to quantify. The cost of caring for a child with chronic debilitating conditions has been estimated at $500,000 over a lifetime, not including the costs of neonatal intensive care that may reach $3,500 a day. (Brann et al, 1998) Older cost data (1993, 1996) indicates the Georgia IDEA, Part C, Babies Can’t Wait program, spent about $7,747 in direct client costs for service coordination ($1,297); services and family support related to individual family service plan implementation ($5,700); and evaluation and assessment ($750).

B. Georgia and Developmental Disability Risk Factors and Conditions.

1. State Profile.

Georgia, the largest state east of the Mississippi River, is the country’s tenth most populous state. The state is the 7th fastest growing state in the United States and the fastest growing state east of the Rocky Mountains. Overall, Georgia has added more than one million people in the last seven years (15.6% increases from 6,478,000 in 1990 to 7,486,000 in 1997). Three of Georgia’s 159 counties made the U.S. Census top ten lists for fastest growing areas in the country.

Once a rural, largely agrarian state, Georgia’s increasingly diverse economy has a strong service component and is dominated by metropolitan Atlanta. More than one-third of the state’s population resides in the 20 counties comprising the Atlanta metropolitan statistical area. In contrast, 55 counties have fewer than 10,000 residents and 118 counties are classified as rural. More than one-third (37%) of the population lives in rural areas, compared to one-fourth (25%) nationally. About 60% of
Georgia’s population growth has come from people moving into the state. The remainder is accounted for by new births. Population growth has been uneven, concentration in certain areas. Most growth is focused in seven metropolitan areas--Atlanta, Macon, Savannah, Augusta, Columbus, Athens, and northwest Georgia counties in the Chattanooga, Tennessee metro area.

Despite the robust economy, about one in seven Georgians (1,000,000 people), live in poverty. With the current economic crisis, this number will increase. Extreme differences exist between the richest and poorest parts of the state and the wealthiest and most impoverished individuals. Georgia ranks in the bottom ten states, nationally, in terms of children and poverty. One child out of every five (340,000) lives in poverty, with children under age six more likely to be poor than older children. Over half of the children in poverty live with their mother compared to 10% living in married-couple families, African American children are much more likely to suffer poverty than white children. More than 40% of all African American children in Georgia are poor.

According to Douglas Bachtel, a University of Georgia demographer, rural communities have lagged behind urban areas in income, education and employment. Georgia has one of the largest gaps between middle and upper income families in the country, a difference of over $63,000 between the top and third quintile. Only three counties are above the national median income. While ranking 24th in state median income, Georgia ranks 42nd worst in terms of income disparity. The 13 counties with the highest median income are home to more than one-third of all poor Georgians.

![Graph: Selected Key Indicators of Child Well-Being, 1996-2008]

Source: Population Reference Bureau, analysis of data from the U.S. Census Bureau, for The Annie E. Casey Foundation.

2. Population Characteristics

Children up to age 21 comprise 2.3 million of the state’s population; 1.7 million are under the age of 18. Sixty-four percent of Georgia’s children are white, 34% are African American, 2% are Hispanic.
and almost 1% are Asian. Fifty-one percent of children live in the 15 largest counties, while the remainder area dispersed throughout the other 144 counties. Georgia’s child population is projected to increase by 12% (276,000) by 2005.

3. Health Economics

Despite a strong economy, about 1.3 million Georgians lack health insurance coverage, ranking Georgia in the bottom ten states nationally. About 370,000 children in Georgia are uninsured (15.4% of all children), ranking Georgia 39th among all states. Approximately 700,000 children are Medicaid enrolled; 110,000 are Medicaid eligible but not enrolled; and 140,000 are uninsured, living above Medicaid eligibility but below 200% of federal poverty level. Inappropriate use of emergency rooms linked to low levels of insurance is seen in Georgia’s high rate of emergency room visits (437.3/1,000 compared to 370.1 for the US.

4. Children and Families At Risk

Certain risks have been associated with poor birth outcomes which result in DD as well as post-natal conditions which may exacerbate underlying risk at lead to development delays. Many of these risks focus on maternal status and risk behaviors. These risks relate to prematurity and low birth weight as well as family ability to deal with the concomitant financial demands and emotional stress related to parenting a child with DD.

About 115,000 babies are born in Georgia each year. Of these babies, over half (55%) are born to mothers poor enough to qualify for Medicaid under Right from the Start (185% of poverty level). Twenty-six percent of mothers report family income less than $8,000 during the 12 months before delivery; 25% indicate incomes of $8,000 to $19,999; and only 28% have incomes $40,000 or more. (PRAMS, 1998) Further, 23% of women had less than 12 years of education, and 36% had no more than a high school education. Low income women were more likely to not start prenatal care in the first trimester; one-fourth of all mothers did not start care by the 12th week of pregnancy. In 1996, 35% of all mothers were unmarried at the time of delivery. Of all births, 59% are white, non-Hispanic; 34% are Black, non-Hispanic; and 5% are Hispanic. Georgia ranked 44th among states in teen birth rates. In 1996, 17,992 Georgia teens gave birth; 42% of these births were to girls 17 years old or younger.
A relatively constant percentage of all Georgia births, 8.5% (9,736 in 1996), are low birth weight (LBW), under 2500g with 1.7% (1,923 in 1996) of these births under 1500g, very low birth weight (VLBW). The corresponding percentages for the US, in 1996, were 7.4% and 1.4% respectively. A relatively constant 75% of these LBW infants are born in tertiary care centers, where ideally all such births should occur. A significant gap exists between whites and blacks with black babies twice as likely to be LBW. Infants with VLBW are at increased risk for morbidity. The CDC MADDSP study of infants with VLBW born in metro Atlanta in 1986-88 with follow-up at 3-5 years showed nearly one in ten had a major developmental disability (cerebral palsy, mental intellectual disabilities, hearing deficit, vision deficit). The rate with longer term follow-up can be expected to be significantly higher as a large proportion of disability is not determined until after school entry. The overall rate of cerebral palsy (CP) has remained relatively constant, 2.1 to 2.2 cases per 1,000 live births comparing infants born in 1975-77 and 1985-87, however, a significant increase in the percent of CP occurring in VLBW infants has been shown with these infants accounting for 32% of all CP cases compared to 21% a decade earlier. Since that time further advances in medical care has increased survival of these infants and may have resulted in an even higher rate of CP among an increasingly large number of surviving VLBW infants.

Maternal risk behaviors have been shown to play a role in low birth weight and prematurity. Two studies of such behaviors have been conducted in Georgia, PRAMS done on a random sample of birthing women each year and a more in-depth Women’s Health Survey done in 1995. Infants born to women who smoke during pregnancy weigh, on the average, 200g less than infants born to comparable women who do not smoke. Both PRAMS and the Women’s Health Survey indicated about 20% of Georgia women smoke during pregnancy with higher percentages reported by women with a high school education or less and low incomes. A decline in drinking both before and during pregnancy has been evidenced; between 1994 and 1998, the rate declined 54% in drinking during the last trimester and 15% in drinking prior to pregnancy. However, according to the Women’s Health Survey, 8% of all women reported one episode of binge drinking during pregnancy and approximately 1% reported more frequent episodes. Folic acid use to prevent neural tube defects has been recommended since 1992. Yet, the Women’s Health Survey indicated that only 20% of women took a multivitamin containing adequate folic acid daily and, based on Georgia family planning clinic data, less than 10% of women attending these clinics are taking adequate folic acid. PRAMS reports that about one in twelve women (8%) were involved in a physical fight in the 12 months before they
delivered their baby and 5% of women were physically hurt by their husband or partner in the months before delivery.

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<td>Infant mortality</td>
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<td>Female adolescent has newborn out of</td>
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5. Children with Developmental Disabilities

Based on national estimates, 30% of all Georgia children have a chronic illness (345,000 children) or are severely chronically ill (173,000 children). Data are available from several administrative sources that provide more insight into these children. Babies Can’t Wait (IDEA, Part C), served 6,672 youngsters with an established mental or physical condition known to result in developmental delay or a diagnosed developmental delay, age 0-3. in the FY1997. Infants and toddlers have an individualized family service plan developed by a multidisciplinary team and receive the full range of early intervention services described in IDEA. The most frequently received services are special instruction (18% of all services), physical therapy (16%), speech therapy (16%), occupational therapy (13%), transportation (11%), and respite (9%). In the 1996 school year, 127,000 students, age 6-21, with disabilities were enrolled in Georgia public schools. These students represented 10% of total school age enrollment and have increased by almost 57% since 1987. Of these children, the primary diagnoses were learning disability (32%), intellectual disability (22%), speech (22%), emotional behavioral disorder (17%), and other (7%). Data from the CDC MADDSP, discussed previously, are relevant in examining prevalence of DD, particularly in the core Atlanta area where over 25% of the Georgia’s children reside.

C. Social and Economic Disadvantage

Children who are born into and who grow up in circumstances of social and economic disadvantage are more likely to have developmental disabilities that include the spectrum of severity and complexity. In a Centers for Disease Control and Prevention (CDC) study (Mervis, 1995) mothers of children with mental intellectual disabilities were more likely to have fewer years of education than mothers of control children; 55% of mothers of children with mild intellectual disabilities and 40% of mothers of children with severe intellectual disabilities had not finished high school at the time of their child’s birth contrasted with 28% of mothers of control children. These results crossed racial and ethnic boundaries and were not confined to teenage mothers. Particular pregnancy-related risk
variables were also demonstrated. The risk for intellectual disabilities increased as birth weight decreased, with risk for severe intellectual disabilities two-and-a-half times higher than for mild MR. In utero exposure to tobacco was also associated with occurrence of intellectual disabilities with data suggesting a 50% increase in the likelihood that a child will have intellectual disabilities. (Drews et al, 1996) Prematurity and low birth weight exacerbates underlying risks that lead to development delays. Many of these risks focus on maternal status and risk behaviors such as smoking, drinking alcohol and attending prenatal clinics. These risks relate also to the family’s ability to deal with the concomitant financial demands and emotional stress related to parenting a child with developmental disabilities.

![Emotional and Behavioral Problems by Family Income](chart.png)

**TABLE 1. Cognitive and Educational Effects of Poverty on Children**

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<tbody>
<tr>
<td>Developmental delay</td>
<td>5.0%</td>
<td>3.8%</td>
<td>1.3</td>
</tr>
<tr>
<td>Learning disability</td>
<td>8.3%</td>
<td>6.1%</td>
<td>1.4</td>
</tr>
<tr>
<td>Grade retention</td>
<td>28.8%</td>
<td>14.1%</td>
<td>2.0</td>
</tr>
<tr>
<td>Ever expelled or suspended</td>
<td>12.1%</td>
<td>6.1%</td>
<td>2.0</td>
</tr>
<tr>
<td>High school dropout rate in 1994</td>
<td>21.0%</td>
<td>9.6%</td>
<td>2.2</td>
</tr>
<tr>
<td>Not employed or in school at 24</td>
<td>15.9%</td>
<td>8.3%</td>
<td>1.9</td>
</tr>
</tbody>
</table>

**TABLE 2. Impact of Poverty on the Physical Health of Children**

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Children Who Are Poor</th>
<th>Children Who Are Not Poor</th>
<th>Ratio Poor/Nonpoor</th>
</tr>
</thead>
<tbody>
<tr>
<td>In fair or poor health</td>
<td>11.7%</td>
<td>6.5%</td>
<td>1.8</td>
</tr>
<tr>
<td>In excellent health</td>
<td>37.4%</td>
<td>55.2%</td>
<td>0.7</td>
</tr>
<tr>
<td>Days spent in bed in past year</td>
<td>5.3</td>
<td>3.8</td>
<td>1.4</td>
</tr>
<tr>
<td>Number of short-stay hospital episodes/year/1000 children</td>
<td>81.3</td>
<td>41.2</td>
<td>2.0</td>
</tr>
<tr>
<td>Deaths during 0 to 14 years of age</td>
<td>1.2%</td>
<td>0.8%</td>
<td>1.5</td>
</tr>
<tr>
<td>% with blood lead levels ≥10 μg/dL†</td>
<td>16.3%</td>
<td>4.7%</td>
<td>3.5</td>
</tr>
</tbody>
</table>

*Adapted from Dawson,¹⁴ ¹³ Third National Health and Nutrition Examination Survey (NHANES III), 1988–1991
Children:
Poverty & Vulnerability

<table>
<thead>
<tr>
<th>Child Outcomes</th>
<th>Risk for poor relative to non-poor children</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child abuse and neglect</td>
<td>6.8</td>
</tr>
<tr>
<td>Lead Poisoning</td>
<td>3.5</td>
</tr>
<tr>
<td>Birth to unmarried teenager</td>
<td>3.1</td>
</tr>
<tr>
<td>depression</td>
<td>2.3</td>
</tr>
<tr>
<td>Experiencing violent crimes</td>
<td>2.2</td>
</tr>
<tr>
<td>Short-stay hospital episode</td>
<td>2.0</td>
</tr>
<tr>
<td>Grade repetition and high school dropout</td>
<td>2.0</td>
</tr>
<tr>
<td>Substance abuse</td>
<td>1.9</td>
</tr>
<tr>
<td>Low birth weight</td>
<td>1.7</td>
</tr>
<tr>
<td>Mortality</td>
<td>1.7</td>
</tr>
<tr>
<td>Learning disability</td>
<td>1.4</td>
</tr>
<tr>
<td>Parent report of emotional or behavior problem that lasted 3 months or more</td>
<td>1.3</td>
</tr>
</tbody>
</table>

**Cycle of Disadvantage and Disability**

The most challenging issues in dealing with prematurity, its causes, and its consequences are the sum of factors that are associated with circumstances of social and economic disadvantage. The causes of prematurity, such as young age, smoking, alcohol and other drugs, and risk for intrauterine infections are highly correlated with lower socioeconomic status and adverse social and environmental factors. Likewise, the long-term outcome of prematurity is associated with elements that prevail in families of lower socioeconomic status living in more stressed environments.

This case is particularly true for infants born to mothers who smoked and drank alcohol during pregnancy. The infants are likely to not only be premature but also to have consequences of intrauterine exposure to alcohol, a neurotoxin. The infants are likely to be more irritable (in association with the possibility of withdrawal symptoms as well as the neurobehavioral deregulation), which adds to the mothers’ stress. In trying to cope with the stress, mothers may resort to drugs or alcohol, lose control, and inflict serious physical harm on the infants.

The abuse not only then can take its toll on the central nervous system from head injury or shaken baby syndrome, but also in the emotional consequences of neglect and abuse and the likelihood that
the infant will be removed from the mother by the Department of Social Services. Infants and children who grow up in these circumstances are likely to have limited emotional and social stability, limited education, and limited social and vocational opportunities. Therefore, they more likely to engage in substance abuse and gratification through casual and promiscuous sexual activities, resulting in an increased likelihood of sexually transmitted diseases and pregnancies that subject the fetus to an intrauterine environment that is hazardous to its embryonic and fetal health and development. The cycle then is repeated (see Figure 1).

For this group of infants and mothers, identifying risks as early as possible, providing strong early intervention programs, and offering programs that provide the mothers with rehabilitation and educational opportunities are critical. Because mothers who have had premature infants are likely to become pregnant again and are more likely to have additional premature infants, they need support on delaying further pregnancies. Mothers need to feel more secure in their role as parents and to appreciate the importance of caring for their infants. They need to know that someone cares about them and is encouraging their success.

Therefore,

- There are a significant number of children with developmental disabilities living in Georgia and by extension, in metropolitan Atlanta
- The prevalence of disabilities as well as severity and complexity is higher for children living in circumstances of social and economic disadvantage
- Maternal behavior before and during pregnancy significantly contributes to the likelihood of prematurity and low birth weight, both of which are significantly associated with a greater risk for developmental disabilities
- Adverse social and economic circumstances put pressure on families that reduces the likelihood that they will be able to invest time and energy on their children particularly if the children have increased needs associated with developmental disabilities and chronic medical conditions
- There is a paucity of support services available to these families and their children thus reducing the likelihood that the children will have the necessary and appropriate developmental, educational and social services to enable them to grow into their full potential
These children then grow into young adults who are likely to remain in the adverse circumstances and go on to become pregnant in their teenage years and thus repeat the cycle.

Figure 1. The Cycle of Disadvantage and Disability

**Cycle of Disadvantage and Disability**

- **Potential Outcomes**
  - neurodevelopmental disabilities
  - child abuse
  - foster care placement

- **Risk Factors**
  - infant with increased needs
    - medical needs
    - developmental needs
    - increased irritability
  - mother under stress
    - increased demands
    - lack of supports
    - substance abuse

- **Environment**
  - poverty
  - poor community supports
  - poor health services
  - inadequate academic services

- **Self Worth**
  - despair
  - substance abuse
  - promiscuity

- **Pregnancy**
  - poor prenatal care
  - tobacco, alcohol, and drug exposure
  - risk of STDs/HIV

- **Newborn Infant**
  - prematurity/LBW
  - FAS
1.6 References:


6. Spencer NJ. Poverty and child Health 2nd Ed. Abingdon, United Kingdom: Radcliffe Medical 2000


Break the Cycle II
Exploring the Relationship Between Disadvantage and Disability

2.1. Background:
Children who are born into, and grow up in circumstances of social and economic disadvantage are more likely to have developmental disabilities than their more advantaged counterparts in our society, and are less likely to have access to appropriate services to meet their needs. Our goal is to raise awareness among community, professional, and academic leaders by encouraging the development of innovative and creative ways of overcoming barriers and developing services and supports for children and families at risk in their communities.

2.2. Main Objectives:
The main objective of this project was to examine ways in which we could “Break the Cycle” of disadvantage and disability. We chose to work with universities because of the pursuit of knowledge through rigorous focused study and the spirit of search for new knowledge towards a better understanding of the world around us and on how to use that knowledge to change things for the better. We also felt that working with faculty-supervised students on short term projects was the best way to invest limited resources and gain the greatest benefit. We also chose to include a diverse set of departments and disciplines in order to get as broad a sweep of perspectives as possible.

We therefore worked with faculty from three Atlanta Universities – the Morehouse School of Medicine, Georgia State University and Emory University in the fields of human services to develop projects that would address the circumstances of children with developmental disabilities living in situations of social and economic disadvantage. We were fortunate to be able to collaborate with a spectrum of disciplines that included: maternal and child health, community health, urban studies in education and psychology and law. Each participating faculty member would work with students to develop projects that would look at aspects of ‘breaking the cycle’.

When we looked at what we wanted to gain from the project, we realized that there would be more than one gain. Obviously the goal of developing ways of improving the outcome for all children but the real treasure was in the participants and the process. A small amount of funds and small projects may not do much but the opportunity to inspire and cultivate future leaders of our society to look at these issues and then to capture their work to advance the concepts through advocacy would be the ultimate gain.
2.3 Long-term Outcomes:

- **For the participating students:** The students’ awareness of important social issues will be increased and enhanced. Students will be afforded the opportunity to present their findings in a public forum. Participation in the project may influence career choice.

- **For the University faculty:** The impact on the faculty will also be enhanced. We plan to promote future collaborations and promote curriculum development in the areas of disadvantage and disability.

- **For the community:** Through this project and the conference there will be increased awareness of the need to develop more services and supports for children growing up in situations of social and economic disadvantage. The primary goal is to make existing services more available and accessible and to develop more services and supports.

- **For outreach education:** The conference and monograph will provide a platform from which a knowledge base, further activities and opportunities are planned, and future research and community collaborations are made available.

- **For the Institute for the Study of Disadvantage and Disability:** This project was a stepping-stone to future programs and development that will assist a population in need of services and supports, expand awareness, educate professionals in human services and influence public policy.

2.4 Accessibility and Outreach

This project was designed to focus on the needs of children with developmental disabilities and their families that include health, educational and social aspects. In that, there was a strong incentive and encouragement to the students involved in the projects to get to know families and learn about them and their needs. In addition, as it also focused on the needs of families who are living in circumstances of social and economic disadvantage it will necessarily address the needs of ethnic minorities and other underserved groups.
3. Collaborators

Emory University, Rollins School of Public Health

- **Women’s & Children’s Center**
  
  *Professor:*
  
  Carol J. Rowland Hogue, PhD, MPH
  
  Terry Professor of Maternal and Child Health
  
  Professor of Epidemiology
  
  *Student:*
  
  Kathryn L. Schmidt, MPH, CHES

Morehouse School of Medicine

- **Community Health and Preventive Medicine**

  *Professors:*
  
  Daniel Blumenthal, M.D., FACPM
  
  Professor and Chair, Department of Community Health & Preventive Medicine
  
  Jacqueline Davis, M.P.H.
  
  Research Projects Manager for the Jane Fonda Center
  
  Department of Gynecology and Obstetrics, Emory University School of Medicine
  
  *Student:*
  
  Rasaan Jones, B.A.

Georgia State University

- **Center for Law, Health and Society**

  *Professor*
  
  Charity Scott, J.D.
  
  Director of the Center for Law, Health & Society
  
  *Students*
  
  Brian Basinger, J.D.
  
  Kathryn Lemmond, J.D.

- **Educational Psychology and Special Education**

  *Professors:*
  
  Peggy Gallagher, PhD
  
  Professor and Chair of the Department of Educational Psychology and Special Education
  
  Cheryl Rhodes, M.S., LMFT
  
  Associate Director of Project Georgia SCEIs
  
  Karen Kresak, M.A., M.Ed., student
Figure 2. Student Projects on Breaking the Cycle Diagram

Cycle of Disadvantage and Disability

Uninsured Children

Low-Income and Minority Children with Asthma

Newborn Infant
- prematurity/LBW
- FAS

Factors Influencing Family Planning
- poor prenatal care
- tobacco, alcohol, and drug exposure
- risk of STDs/HIV

Pregnancy
- poor prenatal care
- substance abuse
- promiscuity

Self Worth
- despair
- substance abuse
- promiscuity

Grandparent Caregiver Issues

Risk Factors
- infant with increased needs
  - medical needs
  - developmental needs
  - increased irritability
- mother under stress
  - increased demands
  - lack of supports
  - substance abuse

Potential Outcomes
- neurodevelopmental disabilities
- child abuse
- foster care placement

Environment
- poverty
- poor community supports
- poor health services
- inadequate academic services

Combating the Mass Media’s Influence on teens

Environment
- poverty
- poor community supports
- poor health services
- inadequate academic services

Break the Cycle II Monograph
A Project of ISDD
September 2008
Some of the student projects are in process of submission to a peer reviewed scientific journal. Therefore we are providing the visual presentations made by the students at the workshop on March 26, 2008 in place of the full text of their papers.

THE IMPACT OF MULTI-LEVEL FACTORS ON FAMILY PLANNING USE AMONG MAYAN-QUICHÉ COUPLES IN THE RURAL HIGHLANDS OF GUATEMALA

Student Author: Kathryn L. Schmidt, MPH, CHES¹

Supervising Professors: Carol J. Hogue, PhD, MPH², Karen L. Andes, PhD³

¹Rollins School of Public Health, Emory University, Department of Epidemiology; ²Rollins School of Public Health, Emory University, Women’s and Children’s Center; ³Rollins School of Public Health, Emory University, Hubert Department of Global Health

Introduction: Guatemala has the highest number of maternal deaths in Central America, and indigenous women living in rural regions face even higher risk. Because family planning (FP) can improve maternal health, research was conducted in Totonicapán, a remote, indigenous village in the Highlands, to understand the factors that drive the use or non-use of FP and the possible unmet FP need to space and limit births. The objective was to gain contextual information on factors influencing communication and decision-making in FP issues (CDFP) and to assess the extent to which factors influence the use of FP methods among Totonicapán couples. Focus-group discussions and in-depth interviews were conducted in Totonicapán followed by a secondary data analysis of the Guatemala Reproductive Health Survey (2002). Cultural and social factors such as gender roles, religion, FP knowledge, pregnancy intentionality, and negotiation are influential components to the CDFP. Partner negotiation/communication and FP knowledge were significant positive predictors of ever using a FP method. To improve maternal health, interventions such as community forums and collaborating with valued community members (midwives) should be implemented to dispel inaccurate perceptions about family planning and to encourage couple involvement in FP.
Maternal Health in Guatemala -Statistics-

- Guatemala is among the poorest Latin American countries in terms of health
- High maternal and infant mortality and morbidity
- Women’s lifetime chance of dying from maternal causes (Population Reference Bureau)
  - Guatemala: 1 in 74
  - Nicaragua: 1 in 88
  - El Salvador: 1 in 180
Maternal Health in Guatemala
-S tatistics -

- Total Fertility Rate: 4.4 (Highest in Latin America) [UNICEF, 2005]
  - Totonicapán mean fertility rate: 4.2 (30% have 6+)

- Contraceptive Prevalence: 43% among women in union, ages 15 – 49 [US AID]
  - Second lowest in the hemisphere after Haiti
  - 9% among the Totonicapán population

- ½ Guatemalan women have had a child before 19 [US AID]
  - Age 18: 20% of women have 2+ children
  - Early 30’s: many have given birth to 7 or 8 children

Cycle of Disadvantage
-Influential Factors to Poor Maternal Health in Totonicapán-

- Rural areas present more risk to maternal health
- Family planning naturally plays a role in maternal health
  - Is not a developed concept in the rural regions of Guatemala
- Husbands play important role in family planning use
  - 18% of women married or in a union in Totonicapán have to ask husband for permission to use a FP method

Cycle of Disadvantage
-S ignificance of Research -

- Important to understand the males perspective
- But much research is based on women’s perspectives of husbands roles in family planning issues
- This research obtains perspectives from men and women
  - Which in turn will guide behavioral change and educational interventions
Research Aims

• Obtain contextual information of the factors that influence communication and joint decision-making in FP issues among couples in Totonicapán

• Assess the extent to which certain factors influence the use of family planning methods

Research Aims -Family Planning-

• Definition of Family Planning
  – Voluntary and deliberated communication and decision making to plan ahead of time:
    • Fertility (desired number of children)
    • Birth-spacing
    • Timing of births
    • Contraceptive decision-making and family planning method selection

Methods

• Mixed-method qualitative research in Totonicapán
  • Six focus group discussions (8-10 in each group)
  • 12 in-depth interviews

• Secondary Data Analysis
  • Guatemala Reproductive Health Survey (2002)
    • Descriptive statistics
    • Modeling techniques to achieve models with best fit
    • Various logistic regressions ran
**Study Population**

- **Qualitative research**
  - Men and women recruited from community and National Hospital of Totonicapán
  - 18-40 years of age, married/union, had one child

- **Secondary Data Analysis: Guatemala Reproductive Health Survey (RHS)**
  - Extracted data at the departmental level (Department of Totonicapán)
  - Men and women, married or in a union
  - 15-49 years of age

**Findings: Conceptual Diagram**

**Findings: Regression Models**

- **Factors used to predict family planning use**
  - *Negotiation* (agree with FP, want same number of children, presence of communication)
  - *Social influence* (hear FP being discussed on the radio)
  - *Gender role* (wife has to ask permission to use a FP method)
  - *FP knowledge* (know if there are days easier to get pregnant)
  - *FP resources* (know where to go to obtain FP method)
  - *Pregnancy intentionality* (ideal number of children)
  - *Religion* (Catholic/Evangelical)
Findings: Regression Models

Factors that significantly predict ever using FP among the female sample population

<table>
<thead>
<tr>
<th>Parameter</th>
<th>Odds Ratio Point Estimate</th>
<th>Pr &gt; ChiSq</th>
</tr>
</thead>
<tbody>
<tr>
<td>Negotiation</td>
<td>30.530</td>
<td>0.0002</td>
</tr>
<tr>
<td>FP Knowledge</td>
<td>7.601</td>
<td>0.0001</td>
</tr>
</tbody>
</table>

Findings: Regression Models

Factors that significantly predict ever using FP among the male sample population

<table>
<thead>
<tr>
<th>Parameter</th>
<th>Odds Ratio Point Estimate</th>
<th>Pr &gt; ChiSq</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication</td>
<td>30.3243</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>Social Influence</td>
<td>0.229</td>
<td>0.0139</td>
</tr>
<tr>
<td>FP Knowledge</td>
<td>20.433</td>
<td>&lt;.0001</td>
</tr>
</tbody>
</table>

Discussion

• Religion: confounder in male/female models

• Degree to which factors influence family planning method use varies by gender
  – Negotiation: stronger influence on FP use among women
  – Social influences/FP knowledge: more influential among the male sample population
Discussion

• Marital situation may have a strong impact on family planning method choice

• Research participants explained natural family planning methods (i.e. Rhythm) are more appropriate for couples who communicate about family planning issues

Next Steps

• Collaborating with Guatemala Ministry of Health and Calidad en Salud

• Recommendations
  – Educational family planning community forums
  – Work closely with midwives in the community
    • Midwives are still common in the culture and remain a trusted source for many couples
    • Interventions will receive more respect and trust when working closely with valued community members

References


Overview
Break the Cycle explores the relationship between disadvantage and disability. Our research focused on grandparents who were either raising or heavily involved in child care for their grandchild with a disability. Many of these grandparents are in traditionally "disadvantaged" groups. While common concerns for many grandparents raising grandchildren are increased instances of depression and health issues, many often express high levels of satisfaction with the caregiving relationship (O’Brien, Massat, & Gleeson, 2001; Osby, 1999). In our study of grandparents raising grandchildren ages 3-12, of which at least one had a developmental delay, we looked at how grandparents were involved in the grandchild’s IEP meeting, as well as information and resources that grandparents needed. We hope to publish the final results in a future article.
Relation to Break the Cycle

- BTC explores relationship between disadvantage and disability
- Our research focuses on grandparents raising or heavily involved in child care for their grandchild with a disability
- Many of these grandparents are in traditionally “disadvantaged” groups

Kinship Care

- Type of care provided by grandparents
  - Commonly defined as “full-time care, nurturing, and protection of children by relatives or other adults who have a family relationship to a child”
  - (Kinship Legal Research Center, 2007)

Kinship Care

- Has increased over last 30 years
  - Approximately 4.7 million children are living in households headed by grandparents
  - Approximately 1 million of these households have no biological parent present (U.S. Bureau of the Census, 2006)
  - More than 164,000 children live in grandparent-headed households in GA
  - Almost 100,000 are living without either parent present (Grandfacts, 2007)
Reasons for Increase
- Most dramatic and immediate causal factor is drug use
- Other attributing factors include:
  - Increased reporting of abuse and neglect
  - Increased levels of poverty
  - More children affected by HIV/AIDS
  - Family violence and parental incarceration
  - Parents struggling with physical and mental health
  - Parental death
  - Decline in availability of traditional foster homes
  - Federal law requires preference given to an adult relative when determining placement due to circumstances as outlined above (Child Welfare, 2007)

Characteristics of Grandparent Caregivers
- Cuts across all ethnic groups and socioeconomic backgrounds
- U.S. Bureau of the Census (2006) reports:
  - 52.5% are White
  - 35.1% are African American
  - 13.4% are Hispanic
  - 0.9% are Asian

Characteristics of Grandparents
- Median family income - $30,246
- 33.9% living below poverty level
- Usually grandmothers
- Usually without a spouse
- Minority grandparents are 2-3 times more likely to assume parenting role
Positive Outcomes

- Relief at being able to “keep family together”
- Gratification in fulfilling role as surrogate parent
- Renewed sense of purpose in life
- Getting second chance to do a better job
- Meeting needs of their grandchildren

Grandparent Concerns

- Responsibility increases with amount of care needed
- Face possibility that grandchild could be disabled or dysfunctional due to consequences of parents’ behaviors
- Problems of children often confounded by premature birth, poor nutrition, and inadequate stimulation

Grandparent Concerns

- Often have little information about child’s disability
- Limited understanding of difficulties and strategies for dealing with problems
- Unsure of what to do or expect from grandchild
- Want to be better informed and have some idea of grandchild’s potential
Rationale for Study
- Generic interventions will not address needs of grandparents of children with disabilities
- Specific needs and experiences should be considered and addressed
- Important for agencies to be aware of grandparents raising grandchildren with disabilities and their specific needs

Purpose of Study
- To help understand concerns of custodial grandparents
- To target community or school-based services to those in greatest need of help and support

Study Population
- Grandparent caregivers in GA with grandchild with disability between ages 3-12
- Involved 10 grandparents caring for at least 1 child with a developmental delay or disability
- Recruited during Project GRANDD meetings
Characteristics of Grandparents

- 100% were female
- Ranged in age from 41 to over 61 years
- 70% were African American and 30% were Caucasian
- Educational levels ranged from 10th grade to high school graduate to high school plus some college or technical school
- 90% involved in planning and/or implementation of grandchild’s IEP
  - Length of time child working on an IEP ranged from 1 month to 6 years (m=3.1)

Characteristics of Grandchildren

- 80% male; 20% female
- 60% had siblings living in same household
- Ranged in age from 3-12 (mean age=6.6)
- 30% of grandmothers reported multiple disability categories for their grandchild
- Diagnosed disabilities
  - Autism-60%
  - Cerebral palsy-10%
  - Fetal alcohol syndrome-10%
  - Shaken baby syndrome-10%
  - Mildly intellectually disabled-10%

Methodology

- Signed consent after Project GRANDD meeting
- Sent packet containing cover letter and copy of survey
- Surveys completed via telephone
- Responses recorded by hand by co-investigators
- Qualitative data transcribed by question and analyzed using qualitative methodology
Results to Date

- Involved in planning/implementation of IEP
  - 80% attended IEP meeting and helped write goals for grandchild
- Greatest need for grandchild with disabilities
  - Help with behavior issues
  - Help with getting child to talk
  - Issues of independence
  - Consistency between home and school
  - Help in obtaining resources (e.g., tutoring, computer for the grandchild)

Results to Date

- Information or resources needed by grandparents
  - Respite care
  - Child’s progress in therapy
  - Accessing insurance and other funding sources
  - Information on behavioral issues

Results to Date

- Questions or concerns regarding grandchild with disabilities
  - Need for respite care during year and summer
  - Help with behavioral issues
  - Problems with schools and/or getting therapy
  - Concern over grandchild being easily misled
Results to Date

- Additional comments they would like to make on raising grandchild with disabilities
  - How hard and challenging it is
  - How tired and worn out they were
  - How difficult it is
  - Embarrassment at child’s "meltdowns" in public
  - Things got easier once they understood what to do
  - Had seen improvements for the child
  - "Wouldn’t trade it for the world”

Discussion

- Project confirmed that grandparents raising grandchildren with disabilities have unique needs
- May be helpful for school systems to have training on how to work with grandparents at IEP meetings and how to provide particular strategies for grandparents to use

Discussion

- Agencies should try to link grandparents to necessary support systems
- Grandparents might need information on sibling relationships if also raising typical grandchildren
- Need to be linked to broader community of grandparents raising grandchildren
Conclusions

- Very hard to connect with grandparents raising grandchildren with disabilities
- Intend to continue adding grandparents to participant pool
- Wonder if there are differences in survey results depending on gender and/or race/culture of grandparent
- Wonder about broader policy implications for grandchildren with disabilities living in kinship care as well as uninvolved parents

Georgia Resources for Grandparent Caregivers

- Project GRANDD
  - [http://www.isdd-home.org/PDFS/GRANDD.pdf](http://www.isdd-home.org/PDFS/GRANDD.pdf)
  - Provides needed services and supports to grandparents who are raising grandchildren with chronic health conditions, developmental disabilities, learning and behavior disorders with focus on the added stress of rearing grandchildren with special needs.
- Project Healthy Grandparents (PHG)
  - [http://www2.gsu.edu/~wwwalh/](http://www2.gsu.edu/~wwwalh/)
  - Description: strengthen grandparent-headed families by providing social work and health services, support groups and parenting education classes, legal assistance referrals, improved access to community resources, and early intervention services for children age 0 - 5 years.

Resources for Grandparents

- Atlanta Legal Aid Society
  - Grandparent/Relative Caregiver Project
    - [http://www.atlantalegalaid.org/ar.pdf#page=13](http://www.atlantalegalaid.org/ar.pdf#page=13)
    - Project seeks to stabilize the legal relationship between the relative and the child through adoption or custody and to maximize the financial and medical resources available to assist the relative in caring for the child.
- Atlanta Regional Commission, Area Agency on Aging
  - [www.agewiseconnection.com](http://www.agewiseconnection.com)
    - Kinship Care and Caregiver consultation and networking programs;
    - Grandparents Raising Grandchildren Resource Guide for the Atlanta Region
**A Media Reflection:** Combating Mass Media’s Influence on the Cycle of Disadvantage and Disability  

Student Author: Rasaan Jones, MPH Student  
Supervising Professors: Daniel Blumenthal, MD and Jacqueline Davis, MPH

**Introduction:** In an attempt to help break the cycle of disadvantage and disability, a media project was conducted with the assistance of the Jane Fonda Center at Emory University. Under the guidance and internship of the center, the following research and intervention was accomplished using various methods of public health disciplines. The project was developed using the Media Madness/ Getting the Rap on the Media model and a conceptual framework developed by the Jane Fonda Center. The purpose of the media project is to provide an educational program to reduce the influence of the media on the sexual attitudes and behaviors of youth. The project and intervention is an enhancement of a media curriculum, focused on the subject of teen dating violence, self-worth, and the Cycle of Disadvantage and Disability (CDD) model.

This project has three components:  
1. Research on teen dating violence.  
2. Exploration of the relationship between the CDD, self-worth, teen dating violence, and the media.  
3. Educating, engaging, and helping adolescents to develop healthy relationships will be essential in breaking the break the cycle of disadvantage and disability.
Introduction & Rationale

Self Worth can be affected by teen dating violence and risky sexual behavior

Teen violence in dating relationships can mean not being respectful, engaging in verbal, mental and emotional abuse, engaging in harmful physical acts.

Risky sexual behavior can mean not remaining abstinent (having sex) and not protecting self (not using condoms against STDs/HIV) or not using females methods of contraceptives to prevent teen pregnancy.

Intern Project
At the Jane Fonda Center of Emory University

Help teens learn to resist harmful media messages about teen dating violence and nonuse of methods of protection against pregnancy and disease.
**Intern Project**

At the Jane Fonda Center of Emory University

**Develop Knowledge**
- Literature review regarding the two areas
  - Media and Use of Protection
  - Media and Teen Dating Violence
- Two literature review manuals with attached annotated bibliographies

**Develop Practical Application of Knowledge**
- Teen Dating Violence section for media focused project

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**Conceptual Framework for Media Madness Enhancement**

**INPUTS**

- Literature Review/Research on Lack of Contraception Use in the Mass Media
- Literature Review/Research on the Media’s Influence on Teen Dating Violence and Abuse
- Conceptualization and Testing of Dating Abuse and Violence Segment to Enhance Media Curriculum

**ACTIVITIES**

- Information (lecture)
- Activity: (Agree or Disagree)
- Activity: Creating A Dating Bill of Rights
- Questions (Discussion Starters)
- Summary

**POTENTIAL OUTPUTS**

- Will Young people will be able to:
  - Identify one way viewing media violence can affect teen dating behaviors
  - Give an example of emotional abuse & an example of physical abuse that frequently occurs in dating relationships
  - State that teens can reject media messages that are harmful to healthy teen dating relationships
  - List two important rights teens have in a dating relationship
  - Name at least one way to handle feelings that could lead to abuse or violence in a teen dating relationship

**OUTCOMES**

- Young people will have been helped to:
  - Know what teen dating violence and abuse is
  - Identify Media Messages Affecting Teen Dating Violence & Abuse
  - Understand the consequences of teen dating violence and abuse
  - Resist media messages contributing to dating violence
  - Develop alternatives to being abusive or violent in their relationships

**BROAD PURPOSE**

- To break the cycle of dis-advan-age & disability
- Young people will be less influenced by the media to commit dating violence
- Dating Violence and Abuse will have been included in a Media Curriculum being distributed throughout Georgia
Methodology

What topics searched?

- Conduct Literature search on teen dating violence and any associations with the media
- Conduct literature search on the lack of methods of protection shown by the media and any effects thereof

Methodology

Teen Dating Violence

What sources used?

- Facts, Findings, and Resources (internet web based)
  - Dating Violence Resource Center
  - Center for Media literacy
  - Centers for Disease Control and Prevention (CDC): National Center for Injury Prevention and Control
  - National, State, and local coalition web sites

Methodology

Teen Dating Violence

What sources used? cont...

- Research Articles (Databases & Journals)
  - American Medical Association
  - American Journal of Public Health
  - American Academy of Pediatrics
  - The Journal of Sex Research
  - National Association of Social Workers
  - Applied Research Forum
  - Teen Relationship Project
  - Culture and Medicine
  - Blue Corn Comics
Some Selected Findings...

Health Concerns

Adolescent girls who report abuse from dating partners are more likely to:

- Use alcohol, tobacco, cocaine, or other types of substances
- Engage in unhealthy weight control
- Engage in risky sexual behavior
- Get pregnant
- Consider or attempt suicide

Silverman et al., Journal of the American Medical Association, 2001

Some Selected Findings...

Self-Worth Concerns

- The anger and stress that dating violence victims feel may lead to eating disorders and depression
  (Silverman, 2001)

- Studies show that people who abuse their dating partner are more depressed, have lower self-esteem, and are more aggressive than peers.

Centers for Disease Control and Prevention (CDC), Understanding Teen Dating Violence Fact Sheet, 2006

Some Selected Findings...

Teen Dating Violence

- Teen Dating violence impacts females more than males
- Female youth suffer more from relationship violence than males
- Dating abuse can be emotional and physical
- Violence can lead to very low self-esteem and self-worth
- Abuse from dating partners can significantly elevate risk for a broad range of serious public health concerns

National Youth Violence Prevention Resource Center, 2007
Studies show a relationship between media violence and behaviors of children and young people. However, despite plenty of teen dating violence information, and research, the direct link between media influences and teen dating violence has not been fully established.

Break up violence (definition) is becoming an important aspect of teen dating violence that has not yet made its way into the literature.

Parents or role models can decrease the negative influence of the media on youth.

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**Underlying Theories**

*Gerbner’s Cultivation Theory*

Focuses primarily on television as the dominant cultural story teller of the age.

Predicts that viewers who watch a great deal of sex on television are more likely to accept the view of sex most frequently depicted on TV.

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*Social Learning Theory, and Social Cognitive Theory*

Consumers of media (music, magazines, video games, TV, movies, etc.) will be more likely to assimilate and perhaps imitate negative behaviors that they see frequently portrayed by characters who are rewarded and not punished.

Imitation is more likely if the media consumer thinks the portrayal is realistic and identifies with or desires to be like the media character.
PRACTICAL APPLICATION OF KNOWLEDGE

The Real Dating Game

Curriculum Section Development

Purpose

• To provide information on teen dating violence
• To increase teens awareness of sexual and violent messages on male to female relationships in the media
• To help teens understand that violence in dating relationships can be influenced by media messages
• To discuss the causes of dating violence and the consequences of violence in a relationship
• To help teens explore alternatives to being abusive or violent
• To establish a teen dating bill of rights

Next Steps (Evaluation)

Were activities age appropriate for middle school students?
Were students actively engaged?
Were the activities effective in increasing knowledge in promoting healthy attitudes and intended behaviors?
Evaluation needed of measurable potential Objectives(?)
Conclusion

- Engaging, educating, and empowering youth to break the cycle of violent unhealthy relationships will assist in breaking cycle of disadvantage and disability.

- More research on “Break up Violence”

- Learn to resist unhealthy media messages and embrace positive sources of information on reproductive health.

- Role Models, Mentors, and Parents

References


2. Institute for the Study of Disadvantage and Disability. Break the Cycle II, 2005


This project examines the extent of the problem of children who lack health insurance, the consequences to them of being uninsured, Congressional proposals for improving children’s health insurance, and programs currently in place to increase insurance coverage with the goal of increasing understanding of the issue of children’s health care as it exists today and highlighting the need for attention in addressing this important issue.
Roadmap

1. Statistics of the uninsured
2. Problems caused by being uninsured
3. Basics of Public Programs
4. Reasons for being uninsured
5. Solutions to being uninsured

Uninsured Children

- 8.7 million in the United States
- More than 300,000 in Georgia (13%)
  - 6th highest rate in the US

Demographic Statistics

- Ethnic Background
  - Latinos are the least insured
  - Whites are the most insured

- Socioeconomic Background
  - Below FPL: 22% US, 35% GA
  - Between FPL and twice FPL: 17% US, 38% GA
The Problem?

Access to Care: And it begins even before birth

- Fewer Caesarian sections for risky birth
- Lower infant survival without prenatal care
- Uninsured newborns receive less care than insured newborns despite having more medical problems

Consequences of Being Uninsured

- Lower access to medical care
- Use prescription medicine 2/3 as much as insured
- Children uninsured for a year or more at a time are in worse overall health than children with insurance
- Absenteeism due to poor health

Why aren’t children insured?

- Ineligible for public programs
- Eligible for public programs but not enrolled
PeachCare for Kids

- Georgia’s State Children’s Health Insurance Program (SCHIP)
- Children with family incomes up to 235% of the Federal Poverty Level ($49,820 for a family of 4)
- No cost to family for children under 6
- Monthly payments over 6 that vary with income

Medicaid

Different from PeachCare in that:

- Eligibility level varies depending on age
- Under one year: 200% FPL ($42,400)
- 1 to 6: 133% FPL ($28,196)
- 6 to 18: FPL ($21,200)

200,000 children are eligible for, but not enrolled in, a public insurance program—Why?
**Reasons:**
Why eligible children are not enrolled

- Insufficient Funding
- Administrative barriers
- Unstable enrollment (Churning)

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**Reasons:**
Insufficient Funding

- Lack of money available
- Structure of SCHIP program
  - Extensive outreach in early years
  - Use of money returned to general fund

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**Reasons:**
Administrative Barriers

- No passive enrollment
- Medicaid-PeachCare Catch 22
  - Not just one application process
- DFCS
  - Inconsistency of information
  - Inefficient policies
**Reasons:**

- *Churning* is the term used to describe movement on and off public insurance

- **Factors:**
  - Unstable income
  - Key Birthdays: different eligibility ceilings based on age
  - 6-Month Waiting Period

**Solutions**

- Managed Care
- Administrative
- Expand Public Programs

**Solutions:**

**Managed Care**

- Medicaid and PeachCare switched to manage care providers in 2006

- However, one study found that with the switch to managed care children have less access to care
Solutions:
Administrative

- Combining Medicaid and PeachCare
  - Pro
    - Lower administrative burden through streamlining
    - Children in states with separate programs are 45% more likely to drop public coverage
  - Con
    - Stigma associated with Medicaid
    - Studies showed decrease in satisfaction

Solutions:
Administrative

- Passive Enrollment/Renewal
  - Pro
    - More children remain enrolled
  - Con
    - Potentially ineligible children remain enrolled

Solutions:
Federal Expansion

- Federal
  - Senate and House both passed SCHIP reauthorization bills in Oct. 2007 that would increase SCHIP budget by $35 billion by 2012
    - Projected reduction in uninsured:
      - 4 million US; 171,000 GA
  - Bush’s veto
    - Concerns of Crowd-out
Conclusion

The problems that result when children are uninsured are serious and affect the country as a whole. By taking the time to carefully examine the issue of uninsured children, we are better equipped to make decisions that can move the country toward an ideal of access to health care for all of our children. When people are aware of the adverse effects of being uninsured, the barriers preventing children from being insured and the ideas that are currently being implemented and discussed to remedy the problem, they can make the best decisions about children’s health care. Education about the current state of affairs in children’s health care serves the purpose of drawing attention to a serious issue. The more we focus on children’s health care, the better our chances for improving the health of our nation’s most valuable resource.
Georgia State University, College of Law

Breaking the Cycle of Disadvantage and Disability for Low-Income & Minority Children with Asthma
Pragmatic Solutions for Easier Breathing

Student Author: Brian Basinger, J.D.
Supervising Professor: Charity Scott, J.D.

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The author would like to acknowledge Professor Charity Scott, Director of the Center for Law, Health, & Society at the Georgia State University College of Law in Atlanta. Without her guidance and passion for health-care equality and justice, none of this work would be possible.

Breaking the Cycle:
Low-Income & Minority Children with Asthma

by Brian Basinger
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Graduate Research Assistant
Center for Law, Health, & Society

Kellen Edwin Bolden
Diagnosed with asthma at 4-months-old.
Loved sports.
Severe attack on way to school bus.
Local school policy in 2001 banned inhalers.
Dead at 10.
What could have been different that day?

Potential Legal Solutions to Asthma – Many Forms!

- Practical Solutions/Policy Shifts
- Statewide and Local Laws
- Budgets/Research Funding
- Administrative Laws
- Pro Bono Work
- Community Activism

The Legal Community has a role to play in improving the health outcomes of asthmatic children.

- Changes in science.
- Disproportionate impact on identified populations.
- Tools of change easily accessible.
Changes in Science: Shift in Focus on Asthma:

- NIH guidelines of 2007 show shift in asthma management.
- Must manage *day-to-day* exposure.
- Flare-ups, severe attacks not the first sign of trouble.
- **Asthma not controlled if you wake up at night gasping for air, or avoid exercise altogether.**

Disproportionate Impact seen among Identified Populations

- Highest rates of asthma among those children whose families earn the least.

![Graph showing disproportionate impact of asthma among identified populations by family income.](image)

Why is it important to know this?

- These families are eligible for health-focused legal aid in many places.
- Government programs can be tailored/created to address specific communities.
Disproportionate Impact by Race: Mortality Ratio

- In 2004, for every one white child killed by asthma, 6.3 black children also died.

What does this mean to the legal community?

- Legal solutions, such as education and intervention efforts, can be tailored and targeted for communities most in need.
- Scarce resources allocated efficiently.

It’s time for the Legal Community to act by using tools of change.
Policy Solutions: Changing the focus.

- Day-to-day management of symptoms.
- Not just emergency treatment.
- Applies to nationwide laws to local school board rules.

Policy Shift Needed for Lawmakers and Leaders:

- Some policymakers “are still with the mindset that asthma is a mind over matter kind of thing.”

  - Carolyn Williams, Georgia Dept. of Human Resources Asthma Program Manager. [Interview, Aug. 28, 2007].

Legislative Solutions

- Asthma Management plans
- Bus idling laws
- School Locations
- Inhaler access
- Nurse funding
- Ban smoking in cars w/kids
- Chemical bans
Administrative Solutions

- State Dept. of Education
- School Boards
- State Dept. of Environmental Protection
- EPA’s Clean School Bus Program (retrofitting grant)

Pro Bono Work/Legal Aid

- Firm policy on pro bono.
- Health Law Partnership
  - Targets children at/below 200% FPL.

Community Activism

- Lobby for change
- Testify before decision-makers
- Organize local efforts
Budgeting/Research

- Federal and State Budgets
- Projects have shown success in reducing asthma trigger exposure.
- Research funding

Good News!

- Extra Money in 2008
- Master Settlement Agreement
- Additional $1 billion infusion to states.

What legal interventions could have made a difference?

Inhaler
Asthma action plan
Chemicals
School location
Bus idling
Nurse training
Teacher training
Smoking Bans
Legal changes can improve health outcomes for asthmatics

- Legal community must recognize its role.
- Work with medical and education professionals to develop comprehensive approach.
- Tools are here.
- We only need the will to act.
Monograph Contributors

Editors
Institute for the Study of Disadvantage and Disability

Leslie Rubin, MD

Leslie Rubin MD, President and Founder of the Institute for the Study of Disadvantage and Disability, is visiting Scholar in the Department of Pediatrics at Morehouse School of Medicine in Atlanta, Georgia, Medical Director of TEAM Centers in Chattanooga Tennessee; Medical Director of Adult Down Syndrome Program and Co-director of the Southeast Pediatric Environmental Health Unit at Emory University, Department of Pediatrics, Atlanta, Georgia.

Dr. Rubin is originally from South Africa where he trained in Pediatrics and came to the USA to specialize in Neonatology and then in Developmental Pediatrics. He was initially at the Hospitals of the Case Western Reserve University in Cleveland Ohio from 1976-1980 and then he moved to The Children’s Hospital in Boston and the Harvard Medical School from 1980-1994. In 1978 he became involved in the delivery of health care for children and adults with developmental disabilities and in the appreciation of the interdis-ciplinary process as a vital mechanism for evaluating and providing services for the individuals and their families. He has operated in tertiary care hospitals, as well as a variety of residential and community settings. He has also been constantly involved in undergraduate and post graduate education for health care professionals in formal settings as well as in community settings.

In July 1994 he moved to Atlanta, Georgia as Director of Developmental Pediatrics at Emory University and as Medical Director of the Marcus Institute. At Emory, he developed Residency and Fellowship programs in Developmental Pediatrics and started a project that exposes pediatric residents to families who have children with developmental disabilities and other chronic medical problems. At the Hughes Spalding Children’s Hospital he actively participated in the development of clinical programs in Cerebral Palsy, Autism, children with Sickle Cell Disease who have had strokes, and general child development clinics.

Since 1998 he has been involved with the Southeast Pediatric Environmental Health Specialty Unit at Emory University, where he has integrated his understanding of Developmental Disabilities and applied this to populations of children who had been exposed to adverse environmental circumstances particularly in the city of Anniston Alabama, where he helped form the Vision 2020, a citizens action group focused on promoting optimal health and development for the children of Anniston. In Chattanooga Tennessee he was instrumental in the establishment of the Chattanooga Center for Autism Spectrum Conditions and in establishing a Developmental Pediatrics Program at the University of Tennessee, Chattanooga. Currently he is Medical Director of the TN START program in Tennessee providing crisis intervention and prevention for individuals with Intellectual Disabilities and Mental Health problems.

In May 2004, he founded the Institute for the Study of Disadvantage and Disability, which is dedicated to improving awareness and understanding of the relationship between social and economic disadvantage and disabilities in children. The mission is accomplished by supporting and coordinating research including the Break The Cycle project which focuses on advanced University students addressing children living in situations of social and economic disadvantage, and a research study on senior adults with Down syndrome; conducting clinical and service programs including specialty clinics for children with developmental disabilities, an Adult Down Syndrome Interdisciplinary Program, and Project GRANDD which serves grandparents who are raising grandchildren. In addition ISDD is dedicated to outreach education and training and influencing health care policy and practices.

In September 2004 he left Emory University and Marcus Institute and joined the Morehouse School of Medicine. He is currently on a number of local, regional, national and international committees and projects that address the needs of children and adults with Developmental Disabilities.

Janice Nodvin, BA
Janice Nodvin is Program Director of the Institute for the Study of Disadvantage and Disability and served as Project Director for the Break The Cycle Projects. She has extensive experience as a grants manager, educator and administrator. She works with Dr. Rubin on numerous training, clinical and research projects and is involved in the Aging and Developmental Disabilities and the statewide Kinship Care Program. She serves as Project Administrator to the Southeast Pediatric Environmental Health Specialty Unit at Emory University. With this diversity, she shares insight with parents and professionals alike. She has over twenty five years’ experience in all areas of developmental disabilities and is a parent advocate. Janice sits on several community advisory boards including University Center of Excellence in Developmental Disabilities, DeKalb County Developmental Disability Council, the Marcus Jewish Community Center Developmental Disability Committee, Jewish Family and Career Services, Atlanta Alliance on Developmental Disabilities and Parent-to-Parent of Georgia. She is past President of Down Syndrome Association of Atlanta. She is a certified in Mediation Training.

Faculty and Students

Emory University, Rollins School of Public Health
Women’s and Children’s Center

Carol Hogue, Ph.D., M.P.H.

Carol Hogue, Ph.D., M.P.H. is the Jules and Uldeen Terry Professor of Maternal and Child Health and Professor of Epidemiology in the Rollins School of Public Health at Emory University. Dr. Hogue is the founding Director of the Women’s and Children’s Center, whose mission is to work in partnership with diverse communities to improve the well-being of women and children through multidisciplinary research that advances the body of knowledge about women’s health. Center faculty, staff, and students are committed to creating and disseminating models for collaborative work that educates, supports and empowers the people with whom they work. For a decade before joining the Emory faculty in 1992, she was at the federal Centers for Disease Control, Division of Reproductive Health, where she was chief of the Pregnancy Epidemiology Branch (1982-88) and then Director of the Division (1988-1992). Prior to her government service, she was on the Biometry faculty of Arkansas medical school (1977-82) and the Biostatistics faculty of UNC-CH School of Public Health (1974-77). Dr. Hogue initiated many of the current CDC MCH projects that shape much of MCH Epidemiology practice. Dr. Hogue led the first research on maternal morbidities that was the precursor to the current safe motherhood initiative, and the initial innovative research on racial disparities in preterm delivery that brought about new community research methods for exploring the gap. These efforts have continued at Emory University, in the Women’s and Children’s Center. Among her many honors, Dr. Hogue served as President of the Society for Epidemiologic Research (1988-89), served on the Institute of Medicine Committee on Unintended Pregnancy (1993-1995), was Chair of the Regional Advisory Panel for the Americas of the World Health Organization Human Reproduction Programme (1997-99), is President of the American College of Epidemiology (2002-3), and received the MCH Coalition’s National Effective Practice Award in 2002. She is lead editor of the book, Minority Health in America (Johns Hopkins U. Press, 2000) and of a 2001 supplement to the Journal Paediatric and Perinatal Epidemiology, entitled “New Perspectives on the Stubborn Challenge of Preterm Birth.” Her research interests include the long-term effects of induced abortion, epidemiology of preterm delivery–especially among African American women, and minority health.

Katie Schmidt, CHES

Katie Schmidt holds a dual undergraduate degree, B.A. in Health Education and Spanish (2006) and will obtain her Master Degree in Public Health, Department of Epidemiology in May 2008. Mrs. Schmidt is interested in understanding and targeting the social determinants of health through public health research to improve the well-being of women living in disadvantaged populations. She spent 6 months doing background research and proposal development for the research project and conducted primary research in Guatemala during the summer of 2007. Mrs. Schmidt has completed multiple internships with John Snow, Inc. (JSI) and is a co-publisher of “Safe Injection and Waste Management: A Reference for Logistics Advisors”. She is also a Certified Health Education Specialist (CHES). Mrs. Schmidt plans to pursue a career in social epidemiology where she can combine quantitative and qualitative research methodologies to explore the social determinants of health disparities among women in immigrant populations.
Peggy Gallagher, Ph.D.
Peggy A. Gallagher, Ph.D. is Professor and Chair of the Department of Educational Psychology and Special Education. She received her doctorate in Early Childhood Special Education from the University of NC at Chapel Hill and her undergraduate and master's degrees from the University of Georgia. Gallagher directs Project SCEIs (Skilled Credentialed Early Interventionists), a collaborative of 5 Georgia universities which focus on the training needs of personnel in Georgia's Part C Babies Can't Wait program. She is President Elect of TED, the Teacher Education Division of the Council for Exceptional Children. Her research interests are in inclusion of young children with disabilities, personnel preparation, and families of children with disabilities. She has recently completed the third edition of her book titled Brothers and Sisters: A special part of exceptional families.

Cheryl Rhodes, M.S., L.M.F.T.
Cheryl Rhodes, M.S., L.M.F.T. is Associate Director of Project Georgia SCEIs at Georgia State University and has worked with Georgia’s early intervention program for the past twelve years. She is involved in initiatives for families of children with disabilities at the state and national level serving on the Governance Board of Council for Exceptional Children Division for Early Childhood (DEC) as Chair of the Family Consortium Committee, Institute for the Study of Disadvantage and Disability Board, and Georgia Parent Leadership Coalition Steering Committee. She is a licensed Marriage and Family Therapist and licensed Professional Counselor with expertise in working with families of children with disabilities. She is co-author (with Peggy Gallagher and Tom Powell) of Brothers and Sisters: A special part of exceptional families published by Paul H. Brookes. 3rd Ed. published August, 2006 and several articles published in peer review journals. As a trainer, project director, consultant, and counselor for over 28 years, she has provided counseling, designed programs and conducted workshops and support groups for parents, families, and youth and more recently, siblings of children with disabilities and grandparents rearing grandchildren with disabilities. She is the parent of three, two daughters and a son, ages 23, 21, and 19; her younger daughter has had developmental disabilities since age 13 months.

Karen Kresak, M.A., M.Ed.
Karen Kresak holds her undergraduate: B.A. in Psychology and graduate degrees in Counseling Psychology and M.Ed. in School Psychometry. She was involved in a research study, which looked at the needs of siblings of children with disabilities. Currently, there is minimal research in the area of grandparents raising children with special needs. Ms. Kresak believes this is an area of study that is rich with information. It is also one in which agencies and schools can provide needed resources and support if that information is made available. Previous experiences include her work with children with special needs for 16 years, at times having to interact and include grandparents in the educational process. She did a presentation on circle time in preschool at the GAYC conference. With Dr. Gallagher and Cheryl Rhodes, Ms. Kresak presented a poster session at the DEC conference in the fall of 2008 on a pilot study of grandparents of children with disabilities. Her interest is in fathers and play with children with disabilities. She plans to do her dissertation on this topic.

Charity Scott, J.D.
Charity Scott is Professor of Law with a joint appointment in Georgia State University’s College of Law and J. Mack Robinson College of Business, Institute of Health Administration, and she is the Director of the Center for Law, Health & Society at the College of Law. The Center oversees the law school*s health law program, which is ranked among the top ten health law programs nationally by U.S. News & World Report. Professor Scott is also a Faculty Fellow in Health Law with Emory University*s Center for Ethics. She is a member of the American Law Institute; serves on the American Bar Association*s Special Committee on Bioethics and the Law and Medical-Legal Partnership Working Group; and serves on the Board of Directors of the Public Health Law Association. She is Past Chair of the ABA Health Law Section*s Interest Group on Medical Research, Biotechnology, and Clinical Ethics and Past Chair of the Health Law Section of the State Bar of Georgia. Professor Scott earned her J.D. from Harvard Law School in 1979 (cum laude), and her A.B. with honors from Stanford University in 1973 (Phi Beta Kappa).
Brian Basinger, J.D.
Brian Basinger holds his undergraduate degrees from UGA – one in ABJ in Public Relations (2001) and a BA in Romance Languages (2001). Mr. Basinger will receive his law degree in May 2008. Before law school, he served as a newspaper reporter covering the state government for the papers in Athens, Augusta, and Savannah. He had broad exposure to health-care laws and budgeting. As a result, helped the College of Law's Center for Law, Health & Society by investigating how the legal community can improve the health outcomes of low-income children. Asthma laws were one of the areas he studied. The others included domestic violence, and housing and the physical environment. Brian Basinger will be joining the law firm of King & Spalding this fall.

Kathryn Lemmond, J.D.
Kathryn Lemmond graduated in 2003 from Elon University with a major in Political Science and minor in Business. She has been researching the topic of children's health for the past two years in law school. Ms. Lemmond has a strong passion for children and believes they should be better insured. Ms. Lemmond will receive her J. D. degree on May 9, 2008 and after graduation will travel extensively in South America.

Morehouse School of Medicine, Community Health and Preventive Medicine

Daniel S. Blumenthal, M.D.
Daniel S. Blumenthal is a graduate of Oberlin College and the University of Chicago School of Medicine. He completed his residency in pediatrics at Charity Hospital of New Orleans (Tulane Division) and received his master of public health degree from Emory University. He has served as a VISTA Volunteer physician in Lee County, Arkansas; as an Epidemic Intelligence Service Officer with the Centers for Disease Control in Atlanta; as a medical epidemiologist with the World Health Organization (WHO) Smallpox Eradication Program in India and Somalia; as an assistant professor in the Department of Community Health at the Emory University School of Medicine; as a consultant to WHO in Geneva; and as a Robert Petersdorf Scholar-in-Residence at the Association of American Medical Colleges. He has also served as President of the Association of Teachers of Preventive Medicine and as Chairman of the Medical Care Section and as a member of the Governing Council of the American Public Health Association. He was appointed to his current position as Professor and Chair of the Department of Community Health and Preventive Medicine at Morehouse School of Medicine in 1985. He is a recipient of the Sellers-McCroan Award for outstanding achievement and service to Georgia in public health, the outstanding VISTA volunteer of the 1960s Award, the "Shining Light" Award from the Georgia Association for Primary Health Care, and the Leonard Tow Humanism in Medicine Award.

Jacqueline Davis, M.P.H.
Jacqueline A. Davis, M.P.H., is the Research Projects Manager for the Jane Fonda Center, in the Department of Gynecology and Obstetrics, Emory University School of Medicine. Jackie has worked in the field of adolescent health for over a decade and has managed multiple research projects that focus on the prevention of teen pregnancy and sexually transmitted infections. She is dedicated to empowering youth through research leading to teen-friendly effective health interventions. She is known for her high level of commitment to making a difference in the lives of young people and volunteers in her community and church with youth. Jackie has co-authored several publications and articles on teen sexual education, overcoming online health education disparity, and sexual transmitted infections and pregnancy prevention through the use of technology. Jackie received her BS degree in Mathe-matics/Computer Science from the University of NC at Pembroke and her MPH from the University of SC at Columbia. She is currently completing doctoral work in Public Health, focusing on Community Health Education and Promotion. She and her husband Billy have two sons, a freshman at Georgia Southern University and a 5th grader at Nesbit Elementary.

Rasaan Jones
Rasaan Jones holds his BA degree in History from Hampton University and is currently a first year MPH student. Mr. Jones has a strong interest in adolescent reproductive health and STI prevention in at-risk communities. Prior to his graduate work at MSM, he taught high school English and middle school Social Studies at a special education school in Maryland. Previous presentations include Project Love assignment and the Black Women’s Wellness group project report. Mr. Jones plans to write a grant/proposal on adult capacity building for effective communication on aspects of healthy adolescent reproductive health.
Satcher Health Leadership Institute

David Satcher, M.D., Ph.D.

Dr. David Satcher established The Satcher Health Leadership Institute (SHLI) at Morehouse School of Medicine in 2006 as a natural extension of his experience in improving public health policy for all Americans and his commitment to eliminating health disparities for minorities, poor people and other disadvantaged groups. As a champion of improved health care quality and expanded health care access for minorities, Dr. Satcher found himself drawn to Atlanta and the Atlanta University Center (AUC), the largest association of Historically Black Colleges and Universities in the world, for his next challenge. In an environment with rich history of nurturing minority leaders who engineered the Civil Rights Movement, Dr. Satcher finds both the inspiration and resources to carry out his ambitious mission.

Appointed by President Bill Clinton in 1998 as the 16th Surgeon General of the United States, Dr. Satcher served simultaneously in the positions of Surgeon General and Assistant Secretary of Health at the U.S. Department of Health and Human Services. As such, he held the rare rank of full Admiral in the U.S. Public Health Corps, to reflect his dual offices. During his service as Surgeon General, Dr. Satcher tackled issues that had not previously been addressed at a national level, including mental health, sexual health, and obesity— as well as the disparities that exist in health and health care access and quality for minorities.

His groundbreaking reports, particularly around sexual health and behavior, were often controversial. In 2001, his office released The Call to Action to Promote Sexual Health and Responsible Sexual Behavior. The report provoked both controversy and praise, and was hailed by the chairman of the American Academy of Family Physicians as a long overdue paradigm shift. His initial report on mental health, the first Surgeon General’s Report on this important health topic, asserts that mental illness is a critical public health problem that must be addressed by the nation. This report received such an overwhelming response from policy maker, health professionals, community leaders and individuals, that Dr. Satcher went on to issue three other Surgeon General Reports on the topics. The reports he issues as Surgeon General have triggered nationwide efforts of prevention, heightened awareness of important public health issues, and generated major public health initiatives.

As Surgeon General, director of various government agencies, president of Meharry Medical College in Nashville, Tennessee (1982-1993), and as president of the Morehouse School of Medicine in Atlanta, Georgia (2004-2006), Dr. Satcher has had the opportunity to experience and model effective leadership around health and health policy. Based on his unique set of experiences, his decision to build an institute based on leadership development for minorities is a new and critically necessary approach to addressing our national and global health crises.

Dr. Satcher served as a fellow at the Kaiser Family Foundation and as a Robert Wood Johnson Clinical Scholar and Macy Faculty Fellow. On March 20, 2007, Dr. Satcher received the Research!America 2007 Raymond and Beverly Sacker Award for Sustained National Leadership. In 1995, he received the Breslow Award in Public Health and in 1997 the New York Academy of Medicine Lifetime Achievement Award. In 1999, he received the Benjamin E. Mays Trailblazer Award and the Jimmy and Rosalynn Carter Award for Humanitarian Contributions to the Health of Humankind from the National Foundation for Infectious Diseases.

Mitchell Tepper, Ph.D., M.P.H.

Mitchell Tepper, Ph.D. M.P.H. is Assistant Project Director, The Center of Excellence for Sexual Health and Research Assistant Professor of Pediatrics, Series II at Morehouse School of Medicine, under the Satcher Health Leadership Institute. Dr. Tepper is also the Founder and President of The Sexual Health Network, Inc. and SexualHealth.com. Dr. Tepper is a pioneer in the delivery of sexual health information online and a nationally recognized sexuality educator, researcher, author, and advocate dedicated to ending the silence around issues of sexuality and disability. His years of research at Yale University, Rutgers University, and the University of Pennsylvania have served as the basis for numerous professional, academic, and public presentations, articles, and chapters. Dr. Tepper currently serves on the editorial boards of the Sexuality and Disability and the American Journal of Sexuality Education and on the board of directors of the Institute for the Study of Disadvantage and Disability and The Women’s Sexual Health Foundation. Most recently he has served as Board Member, Chair of Communications Steering Committee, for the American Association of Sexuality Educators, Counselors, and Therapists (AASECT) and was responsible for overseeing Contemporary Sexuality, the monthly membership publication. He has also served as President of the Sexuality Information and Education Council of Connecticut, Chair of Online Services for AASECT, and on the Board of Directors of The Sexuality Information and
Education Council of the United States (SIECUS) and the International Society for the Study of Women's Sexual Health. He was a regular guest lecturer at the Yale University School of Medicine over a five year period and an Adjunct Assistant Professor of Physician Assistant Education at Quinnipiac University. Dr. Tepper has a Master of Public Health from Yale University and a Ph.D. in Human Sexuality Education from the University of Pennsylvania. In addition to academic credentials, Dr. Tepper, who grew up with Crohn's Disease and acquired a spinal cord injury at age 20, brings a lifetime of first-hand experience with chronic conditions and disability to his work.
Conclusions and Recommendations

❖ **For the participating students:** The students’ awareness of important social issues was validated and enhanced.

❖ **For the University faculty:** ISDD solidified a foundation for future collaborations and an incentive to aim for curriculum development in the areas of disadvantage and disability.

❖ **For the community:** Break The Cycle has increased awareness of the need to develop more services and supports for children growing up in situations of social and economic disadvantage.

❖ **For outreach education:** The monograph provided a platform from which a knowledge base, further activities and opportunities are planned, and future research and community collaborations are made available.

❖ **For the Institute for the Study of Disadvantage and Disability:** This project was a stepping-stone to future programs and development that will assist a population in need of services and supports, expand awareness, educate professionals in human services and influence public policy.

❖ **Sustainability of Break The Cycle Project:** Due to the success of this project and interest from institutions of higher learning, ISDD will continue the Break The Cycle Project as a learning experience for interested students and professors. This project has now become a regional project.

❖ **New Partnerships:** ISDD has formed new partnerships since the as a result of the Break The Cycle Project.

- We are working more closely with Children’s Healthcare of Atlanta and Morehouse School of Medicine on the establishment of a children’s continuity clinic that will serve as a Medical Home for children who live in circumstances of social and economic disadvantage.
- We have formed a working collaboration with the Mary Hall Freedom House, a recovery program for mothers of substance abuse and homelessness and their children, in which we are assisting in providing intensive interventions to the children.
- We are collaborating with the Atlanta Regional Commission, Area Agency on Aging on an innovative project of providing interventions to the grandparents who are raising grandchildren with developmental disabilities.
- We are collaborating with the Southeast Pediatric Environmental Health Specialty Unit at Emory University on a Break the Cycle IV project supported by the Environmental Protection Agency, Region IV.