



Children's Health Fund

**Chronic Illness and School Performance:
A Literature Review
Focusing on Asthma and Mental Health
Conditions**

A Children's Health Fund Monograph
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ONE: EXECUTIVE SUMMARY

1. Introduction

The relationship between health status and academic achievement is more complex than it would seem at first glance. While there is strong evidence that children whose health care needs are met are less likely to miss school days because of illness and better able to focus on learning in the classroom, school performance is multi-determined. There are multiple diverse and inter-related factors which affect a child's opportunities for successful learning and academic achievement. Some of these factors are amenable to clinical intervention; managing chronic health conditions such as asthma is one such factor. Other factors are not as easily controlled. These include socioeconomic status, neighborhood characteristics, the quality of education resources available (teachers, textbooks, class size), and psychosocial stressors such as exposure to violence, maternal depression, and homelessness.

The stressors that may undermine educational success are also risk factors for early developmental and later psychiatric disorders. These in turn are associated with social and academic problems that together comprise "school problems." The presence of these stressors is greatest among children living in poverty. Opportunities to reduce risk and improve outcomes are also greatest in this population.

In this review we discuss the evidence for the impact that improving health and mental health care access and quality may have on school success. Because of their higher prevalence especially among children in poverty, we focus on asthma as a representative chronic health condition and on mental health problems. We also discuss models of health care delivery that have proven efficacy in improving health, mental health, and opportunities for educational success.

2. The Cumulative Risk Model

There are several models that have been developed to help explain the interaction of multiple factors which together influence developmental, behavioral, social and academic outcomes. These include "social capital," "human capital," and "ecological" or "eco-social" models, all which emphasize the interplay of the individual and the "assets" and "risks" in the community in which he or she lives.

The "cumulative risk model" is a framework to describe the way that risk factors associated with poor outcomes affect the individual, and the way that the individual responds to these risk factors. Evidence for the validity of this model is derived from studies of outcomes such as intelligence test

scores. In this model, outcomes are viewed as being related to interactions among biologic, psychological, social, and environmental factors. Risk factors are cumulative in their impact, and their impact is most powerful when multiple risk factors co-exist.

It is acknowledged in this model that controlling one risk factor will not necessarily produce or prevent a specific outcome, because that outcome may also be influenced by other risk factors which were not, or in some cases, could not be controlled. There is no consistent cause-effect relationship between a specific risk factor (e.g., low birth weight, maternal depression, homelessness, unsafe neighborhood) and poor academic and/or social outcomes. Interventions that alleviate risk factors, for example improving health status for children with chronic conditions, reduce overall risk and improve opportunities for success. Mental health problems typically pose multiple risk factors for the child, often affecting mood, concentration, behavior, and interpersonal relations. Children with unmet mental health needs are at especially high risk of poor academic outcomes. Improving their access to mental health care is predicted to have a dramatic impact on school and life success.

3. Asthma

Asthma is an ambulatory sensitive condition, meaning that its severity and morbidity may be dramatically reduced with access to quality health care services including evidence-based management. In inner city communities, as many as one child in three is diagnosed with asthma. Asthma is associated with higher rates of school absenteeism, particularly among low-income and minority children. There is evidence that appropriate asthma management including the integration of best-practice guidelines in pediatric primary care and the availability of school-based health centers for on-site pediatric care may have the following positive impact on academic performance:

- Good asthma management reduces hospital emergency department (ED) use for acute asthma care, decreasing the number of school days missed because of this chronic condition.
- Children with well controlled asthma have less severe asthma symptoms. This includes improved nocturnal asthma symptoms which interrupt sleep. Inadequate sleep is associated with short attention, hyperactivity, cognitive and speech-language problems, and poor academic outcomes. Improving the child's ability to sleep through the night improves the child's opportunities to learn.
- School-based asthma care allows for on-site treatment of acute asthma exacerbations, if necessary. After school-based treatment, the child returns to class. Without treatment, the child typically stays in the principal's office until picked up by a parent and brought home, or is sent to a hospital ED.

- Reducing the severity of asthma symptoms has a positive impact on the child's quality of life. This in turn may prevent or reduce some of the psychosocial burden often associated with childhood asthma, such as anxiety about possible respiratory problems and inability to exercise or participate in sports and other peer group activities.

Taken together, the evidence suggests effective management of asthma (or any other chronic health condition) removes potential obstacles to academic success. There is no established relationship, however, between improved asthma management (or overall health status) and higher academic achievement.

Asthma and other chronic health conditions increase the risk of emotional or behavioral problems, of having to repeat a grade in school, and of being placed in special education. Quality health care improves health status, which alleviates this risk and increases the child's opportunities for success.

4. Mental Health

The link between unmet mental health problems and compromised academic achievement is well established. Too often mental health problems are identified late if at all. Access to mental health care is especially problematic because there is a protracted shortage of child and adolescent mental health professionals. These professionals are not well distributed relative to need. Inner city and rural poverty communities, where the prevalence of mental health problems is highest, are the least well served.

There is a strong association between early developmental delay and later behavioral, emotional and school problems. Early identification of developmental delay may therefore prevent later mental health and academic problems. Comprehensive preventive services in primary care also include screening for emotional and behavioral problems.

The need for early identification and intervention is clear from the evidence:

- Up to 80% of adults with anxiety disorders, depression disorders, and drug addiction first presented these problems before they were 20 years old.
- Half of adults with a psychiatric diagnosis at 26 could have been diagnosed and treated by the age of 15.
- Nearly three-fourths (72%) of teenagers with conduct disorder showed symptoms before they were 10 years old.

Early identification makes early intervention possible. The benefits of early service delivery are dramatic, as are the consequences of failing to provide needed care:

- Four-year-old children with behavior problems who receive counseling are less likely to be expelled from preschool.
- Elementary school children with learning problems or achievement gaps are often excessively absent from school in the middle grades.
- Continued school failure, whether due to academic or behavior problems, is strongly associated with high school drop-out, with as many as 85% having both academic and behavior problems.
- Rates of psychiatric disorders among adolescents in the juvenile justice system are as high as 70%. More than one-third, 37%, have cognitive and learning disorders that meet eligibility criteria for special education.
- People with a psychiatric disorder earn an average of \$16,306 less than non-diagnosed but otherwise comparable individuals.

5. The Enhanced Medical Home Model

The evidence strongly suggests that the enhanced medical home model – one of continuous, comprehensive, coordinated health care that integrates developmental and psychosocial screening and mental health services for children and youth in need – will effectively identify, potentially prevent and manage problems that interfere with optimal school performance. This model of comprehensive and integrated care may ameliorate risk factors that interfere with academic success. It incorporates evidence-based chronic disease management, a continuum of developmental screening and surveillance, and later mental health screening including adolescent psychosocial risk assessment, and integration of mental health services in the primary care setting.

Timely access to care is an essential element of the medical home model. Community health centers comprise a critical element of the health care safety net especially for children who live in poverty and/or are uninsured. For many high-risk children, alternative health care delivery models are essential to ensure their needs are met. Two key alternate health delivery models are mobile medical clinics (“doctors’ offices on wheels” that bring health care teams into medically underserved communities) and school-based and school-linked health centers (clinics located within schools or care provided near schools through mobile clinics). These models reach high-risk populations (e.g., homeless families and youth) and bridge geographic barriers (transportation restrictions and health professional

shortages). Co-locating and integrating mental health services with primary care greatly improves access so that children are more likely to receive treatment. This is necessary because current data show that only 20% of children needing mental health services receive the care they require.

Comprehensive pediatric care includes the integration of child development and mental health screening, and evidence-based chronic disease management (e.g., for asthma) into pediatric primary care. This model is reliably predicted to improve children's opportunities for educational success.

TWO: INTRODUCTION

A. Health, Education and Income

The relationship between health status and life outcomes, which are generally indicated academic achievement and income, is complex. Much of the relevant literature describes health and income disparities; that is, that people at lower incomes typically have worse health indicators and are lesser levels of academic success (e.g., high school and college graduation). Causal inferences are ambiguous, and it is possible that the relationship is bi-directional (i.e., poor health adversely affects school success and economic opportunities, and lower income adversely affects health through mechanisms involving nutrition, housing and neighborhood conditions, access to health care, etc.). This leads to income-related health disparities. Federal survey data show that inequities in income distribution within individual states negatively affect health status; states with greater inequities have a higher percentage of population reporting fair-poor health compared to good-excellent health.¹ The association between income and health has been attributed to the inter-relationship of employment status, income and health.^{2,3}

Among young adults, those who have completed more formal education report better health status.⁴ Because poor health in childhood may be a factor in educational achievement, and children in poverty are at risk of worse health status, a cycle of disparities between poor and more affluent adults may be perpetuated. It has been suggested that improving the health of children in poverty could reduce later income disparities. In addition to ensuring access, it is also important to improve quality of care including self-management of chronic health conditions.⁵

Effective chronic disease management is an essential element of quality health care. Poverty is also associated with a higher prevalence of chronic conditions. Federal survey data show that an estimated 10.3 million or 14.8% of U.S. children have a chronic health condition. The highest rates of chronic conditions in the U.S. are among school-age children with family incomes below the federal poverty level.⁶ In addition, outcomes for poor children with chronic health conditions are generally worse. They typically have more missed school days, activity limitations, and hospital and emergency department (ED) use.⁷

B. Barriers to Child Health Access

Despite this higher level of need among children and families in poverty, there are often significant barriers to their access to health care services. Children who lack adequate access to a regular

source of health care are considered to be “medically underserved.” The factors included in the federal definition of “medically underserved” are immigrant or non-English speaking family, foster care, family reliance on public assistance, and being uninsured. This definition has been found to be too narrow and has been expanded to include children of the working poor who do not qualify for public benefits but whose families cannot afford out-of-pocket medical expenditures, and children in families with psychosocial issues (often compounded by poverty) such as homelessness, domestic violence, and mental illness.⁸

Two related factors that contribute to children being medically underserved are health professional shortages and transportation. While the increase in the number of pediatric practitioners has been higher than for physicians overall,⁹ there continue to be an estimated 65 million people in the United States living in primary care shortage areas.¹⁰ Especially in rural communities and predominantly rural states, workforce shortages are protracted¹¹ and are likely to get worse as currently practicing health professionals age and retire.¹² Survey data show that pediatric residents entering the health care workforce most often apply for work in communities that already have a high ratio of pediatricians to children.¹³ With fewer physicians available, the distance to travel in order to get care may be insurmountable for poor children and families. Transportation is a powerful barrier to child health access.^{14,15}

These barriers to child health access are clear indicators that, important as health insurance is for all children, it is not sufficient to ensure timely access to health care services.¹⁶ Additional access barriers have especially been noted among children with special health care needs including chronic health conditions. For these children there are often problems accessing specialists and mental health professionals,¹⁷ problems which contribute to protracted and ongoing child health disparities. A prominent example is the higher rate of hospitalization among poor urban children with asthma compared to the general population, which could likely be avoided with timely access to quality care in a primary pediatric setting.¹⁸

Medically underserved children may be viewed as children with special health care needs because of their higher prevalence of health problems, worse health outcomes, and higher need for health care services including specialty care. Indicators that a child may be medically underserved include household income at or near poverty; no or inadequate health insurance; living in low-density rural counties, high-poverty inner-city communities, and/or in federally designated Health Professional Shortage Areas; limited or no access to public transportation; vulnerable population (e.g., homeless, migrant,

immigrant, disabled); and no access to safety net providers. Psychosocial issues associated with this elevated need for health care services include exposure to domestic violence, maternal depression, homelessness, living in areas affected by a disaster, and family issues such as low health literacy and limited English-language proficiency.¹⁹

Federal survey data show that 6.5% (4.4 million) children experience some degree of disability because of chronic health conditions. Disability in this context is defined as limitations in educational participation such as excessive missed school days and/or restricted social functioning such as play. Children in low-income and especially single-parent households showed the highest rates of activity limitations related to chronic health conditions. The most common conditions associated with this definition of disability are asthma and mental health problems.²⁰ For children with asthma, school limitations are noted among those who do not have access to treatment to manage and control their symptoms. This is especially noted among low-income children, who have a higher prevalence of chronic disease and less access to health care services.²¹ Low income children with chronic conditions or other special health care needs are also most likely to also have mental health problems such as attention or behavior problems. These emotional and behavioral problems are often not recognized by parents, especially for young children (2 to 5 years of age).²²

C. The Enhanced Medical Home Model of Care

Medically underserved children with higher rates of chronic conditions and psychosocial risk factors, and vulnerable populations comprise the pediatric patient populations served by the Children's Health Fund (CHF) National Network. The CHF model of care is an innovative application of the "medical home" model first proposed as the standard of care for children with special health care needs by the American Academy of Pediatrics (AAP) decades ago. Briefly, in the medical home, care is comprehensive, continuous, coordinated, family-centered, culturally competent, and compassionate. The model addresses the needs of children with complex medical, psychosocial and developmental problems and sets out a paradigm to coordinate care from health, mental health and other service providers. The result is comprehensive and integrated care that strengthens the child and family, maximizing the opportunities for success.^{23,24}

The quality of available health care is only important if timely access is possible. Care must be available to the children and families who need it, at the time that it is needed. For children without access to community health centers or other safety net providers, care is brought to them through

mobile medical clinics or school-based health centers (pediatric clinics in school buildings). If space is not available to establish a pediatric clinic within the school building, an alternative is to park a mobile clinic near the school for a “school-linked” model of care. CHF has developed Special Initiatives which focus on providing evidence-based care and chronic disease management, including facilitated access to specialists. The CHF enhanced medical home model integrates evidence-based and evidence-informed clinical protocols, health information technology, and on-site access to the specialists most needed by high-risk medically underserved children. To the extent possible, mental health services are co-located and integrated, with the primary care setting. Preventive care includes the comprehensive perceptual, developmental, psychosocial, and oral health screening. The result is comprehensive health care in an enhanced medical home model.²⁵

THREE: THE CUMULATIVE RISK MODEL

The multi-determined nature of academic achievement is such that no one factor, such as access to health care or health status, may be identified as causing or preventing academic success. A more productive conceptual framework is found in the psychology literature for developmental and cognitive risk, both of which are important factors associated with school success. In this model, outcomes are seen as related to interactions among multiple factors: biologic, psychological, social, and environmental. This model acknowledges that controlling one specific factor will not necessarily produce or prevent a specific outcome, because that outcome may also be influenced by other factors which were not or in some cases could not be controlled.²⁶

The risk model helps explain the fact that children who are poor and near-poor frequently have more school absenteeism and worse academic outcomes than their more affluent peers regardless of health status. Because many children who may be considered educationally disadvantaged do not acquire basic skills in the early grades, they fall further behind their peers over time, resulting in more grade retention and possibly school drop-out.²⁷ The risk model is based on considerable evidence that these and similar negative outcomes are associated with the cumulative impact of multiple risk factors and insufficiency of child resilience relative to these factors. This evidence includes studies relating risk factors experienced by the child to variations in measured intelligence (IQ score).²⁸

These risk factors include maternal mental health status, parental attitudes and beliefs, patterns of mother-child interaction, maternal education, socioeconomic status and race-ethnicity, family social support, family size, stressful life events, and the child's cognitive functioning. Low IQ scores (under 85) among children not diagnosed with central nervous system damage or mental retardation with an organic etiology was associated with the presence of multiple risk factors, but not with any single risk factor. This finding indicates that the multiple risk factor model is significantly better at accounting for variance in IQ scores than a single factor model, such as relating intelligence test scores to birth weight, poverty status, maternal depression, or homelessness. It is the confluence of these and other neurobiological and psychosocial factors (and inadequate child resiliency to withstand their impact) that is associated with sub-optimal outcomes.²⁹

In an analysis of data from the National Survey of Early Childhood Health, it was found that children exposed to multiple risk factors had worse health status and developmental outcomes. The risk

factors included household income, health insurance status, parental education and mental health; outcomes included access to health care and developmental functioning by parent report. There was a “dose-response” relationship; that is, outcomes were worse for children exposed to multiple risk factors. The author also found that these children frequently had the greatest problems with health care access.³⁰

The impact of poverty is also cumulative. Based on data from the National Longitudinal Survey of Youth, children exposed to poverty over many consecutive years have about twice the developmental risk of children with a single-year exposure to poverty (controlling for family and health risk factors).³¹ Data from the National Maternal and Infant Survey (and the Longitudinal Follow-up Survey) show that poverty better predicts developmental delay than biomedical risk factors such as preterm birth and chronic illness.³²

While the phrase “health disparities” often refers to different health outcomes based on race-ethnicity, health differences are noted based on family income for all racial-ethnic groups. People in households with an income at or below poverty, whether African-American, Hispanic, or white, are least likely to report being in very good health. These health disparities begin in childhood and may persist throughout life and from one generation to the next.³³ From a life-course perspective, health disparities with respect to chronic diseases may begin with prenatal insults and be compounded by experiences of adversities during critical developmental periods beginning in infancy.³⁴

The negative impact on children of long-term and multiple risk factors associated with poverty has been objectively verified through physiological measures of stress (cortisol levels and cardiovascular function). Among infants and young children, this increased stress level (“toxic stress”) may alter brain development.³⁵ It has an impact on health status³⁶ and may exacerbate asthma symptoms, possibly rendering asthma control medications (inhaled corticosteroids) ineffective.³⁷ Children exposed to multiple environmental and psychosocial risk factors (often children in poor and low-income households) are reported by their parents to be in worse health (including oral health, overweight/obesity, behavior and mental health, and overall health status). Factors in this risk index included maternal mental health status, race-ethnicity, socioeconomic status, household education, neighborhood safety, and adequacy of health insurance.³⁸

The presence of multiple risk factors or stressors is associated with early onset of psychiatric disorders. Multiple stressors were categorized as applying to neighborhood and school (gangs, violence,

noise, etc.), and family (interpersonal and financial strain). In a study using data from a federal survey, Teen Health 2000, investigators established that these stressors are cumulative in their impact. Depression, for example, was associated with from four to six stressors. Anxiety disorders were associated with low social support, high neighborhood and economic stress, and interpersonal relationship problems in the family. Neighborhood stressors were especially noted as contributing to ADHD. Difficulty mastering tasks including schoolwork and problems with family relationships were associated with conduct disorder. Conduct disorder was associated with younger age; depression and other mood disorders with older age. Risk factors for depression include family problems, low self-esteem, and high levels of school, neighborhood and financial stress.³⁹

There are psychosocial factors which affect academic outcomes as well as emotional development. Children who witness violence in their community,⁴⁰ who are exposed to domestic (intimate partner) violence,⁴¹ maternal depression,⁴² exposure to a disaster such as Hurricane Katrina,⁴³ and other stressors are at heightened risk for emotional and behavioral problems and school failure. Children in homeless families experience a high rate of academic failure consistent with the need for special education evaluation and services.⁴⁴ Children in foster care are at high risk of school failure because of their traumatic exposures to maltreatment and loss, and high rates of developmental delay and psychiatric disorders.⁴⁵ There are, however, other mediating factors. Children with stable foster placements are likely to do better in school than children with multiple changes of foster family, and the stress associated with these transitions becomes an additional risk factor associated with sub-optimal outcomes.⁴⁶

Neighborhood characteristics are also factors in school success or failure. Communities in poverty frequently have schools with less well-trained teachers, outdated textbooks, poorly maintained school buildings and overcrowded classrooms, all of which affect the students' opportunities for academic success. The relative degree of assets and risks associated with neighborhood characteristics has been referred to as "social capital." Consistent with the risk model, neighborhoods with better physical conditions, safety, etc. are associated with improved academic outcomes, and these positive attributes have a cumulative positive effect over time.⁴⁷

The "human capital" model is a framework that looks at human development in stages and the social policies that affect the interplay of biological and environmental factors over time. This is a longitudinal model, capturing, for example, the value of interventions for risks or deficits in early childhood in reducing or preventing problems later in life. Similarly, it reflects the benefits of improving a mother's

educational level in terms of value-added for her children (e.g., better educational and social outcomes). This is an “investment” oriented model that builds on the growing body of evidence that early education programs save public sector funds over time.⁴⁸

Another model describing the interaction among child, family, and neighborhood has also been called an “ecological” or “eco-interactive” model. In addition to student characteristics, elements in this model include support from neighbors, behavior of neighborhood youth and neighborhood safety, peer group relationships, family cohesion and support for academics, and school quality. In this model, school success is associated with multiple social-environmental factors.⁴⁹

In sum, there are several conceptual models that explain the interaction of the multiple biological and environmental factors that influence a child’s school success. We found that the cumulative risk model has the best supportive evidence and provides an effective framework for planning interventions to improve outcomes and assessing their impact.

CHAPTER 3: THE CUMULATIVE RISK MODEL SUMMARY

1. Academic achievement is determined by multiple factors.
2. Regardless of their health status, poor children often have worse academic outcomes than non-poor children.
3. Risk factors associated with poverty affect children physiologically and psychologically, with potential long-term medical, dental and mental health consequences.
4. The impact of poverty is cumulative.
5. Poverty better predicts developmental delay than biomedical risk factors such as preterm birth and chronic illness.
6. The presence of multiple risk factors associated with poverty in childhood is associated with early onset of psychiatric disorders.

FOUR: ASTHMA

A. Prevalence and Disparities in High-Risk Children

According to the Centers for Disease Control and Prevention (CDC), 10% of U.S. children had asthma (i.e., had current asthma symptoms) in 2006. This represents approximately 7.4 million children. The lifetime prevalence of pediatric asthma, defined as ever having been diagnosed with asthma by a health care professional, is higher: 14% in 2006 (representing more than 10 million children). In 2006 there were 335,000 asthma hospitalizations (13.6% of all non-newborn pediatric hospitalizations).⁵⁰ It is estimated that there are more than 750,000 annual ED visits for pediatric asthma.⁵¹ Prevalence rates and health care utilization (including hospitalizations and ED use) have consistently been highest for young children and poor and racial-ethnic minority children. African-American children with asthma, for example, had more than three times the hospitalization rate than white children.⁵²

It has been estimated that the cost of medical care per school-age child per year with asthma is \$400, and that the annual cost of medical care for asthma among school-age children exceeds \$1 trillion. When indirect costs are included, the cost per child per asthma per year nearly doubles. Indirect costs include an economic valuation placed on missed school days and missed adult work days attributable to the child's asthma. Because of this economic burden, it has been concluded that there is a public health imperative to better control asthma among school-age children.⁵³ This analysis did not include the cost associated with asthma for preschool-age children, who have a very high asthma prevalence rate. For example, one study of children attending Head Start (which targets three- and four-year-old children in households with income at or below the federal poverty level) found a 35% prevalence rate.⁵⁴

This higher asthma prevalence rate is consistent with many other studies which found rates for high-risk, low income children to be considerably higher than indicated by federal survey data. A Louisiana study found that 39% of inner city school-age children had a lifetime prevalence of wheezing, with 26% reporting wheezing during the preceding 12 months and 24% having been diagnosed with asthma.⁵⁵ Population-based surveillance data at New York City homeless shelters by investigators from the Children's Health Fund revealed peak asthma prevalence among newly homeless children of 40%⁵⁶ which subsequently leveled off at 33%.⁵⁷ This was confirmed on retrospective chart review of homeless patients of CHF's New York Children's Health Project, a mobile health care program for children in homeless family shelters, which found an asthma prevalence rate of 31.5%.⁵⁸ A study of

homeless children between 4 and 7 years of age in Minneapolis, Minnesota found an asthma rate of 27.9%. In this population, asthma was associated higher levels of behavior and attention problems and worse academic performance.⁵⁹

Using a methodology similar to that of CHF, investigators from the Harlem Children's Zone found a prevalence rate of 30% in Central Harlem.⁶⁰ In the Chicago public schools, data show that more than one-third of African-American and Puerto Rican children have asthma.⁶¹ Race-ethnic and socioeconomic disparities are strongly noted among children with asthma in the District of Columbia.⁶² The highest rates and worst outcomes occur in the poor and largely African-American Anacostia community, where data from CHF's DC Children's Health Project shows an asthma prevalence rate of 33%.⁶³

While more attention and study have been allocated to inner city asthma disparities, the problem of higher asthma prevalence rates and powerful barriers to health care access also occur in our rural communities. Rural children may be exposed to pesticides used in farming which may lead to allergic sensitivities associated with asthma, and with acute asthma exacerbations. Asthma is the most common respiratory health condition affecting migrant children. Survey research shows that school nurses in rural settings report more missed school days for children with asthma than do nurses in urban schools.⁶⁴

High childhood asthma prevalence has especially been noted in the Mississippi Delta, where survey data from rural school children found that 33% had a previous physician diagnosis of asthma. Of these children, 79% showed persistent current asthma symptoms and 81% reported asthma-related activity limitations. Half (50%) had used a hospital ED for asthma in the preceding two years.⁶⁵ Emergency department use for asthma among rural children has increased as access to care and effective asthma control through medication has declined.⁶⁶ Children in the Mississippi Delta also have significantly higher rates of asthma hospitalization, including multiple (3 or more annual) hospitalizations, than do children in urban Jackson, Mississippi.⁶⁷

B. Best Practice Asthma Care and Inner City/Rural Asthma Disparities

There is a format for the best-practice management of pediatric asthma. The National Heart, Lung and Blood Institute (NHLBI) Asthma Guidelines were first issued in 1992 and most recently revised in 2007.⁶⁸ The 2007 NHLBI guidelines present treatment recommendations based on age group to accommodate changes in the course of the disease over time and to ensure that appropriate age-relat-

ed measures of severity and risk are applied. Based on asthma assessment, appropriate medication decisions are made to control asthma symptoms. The guidelines also emphasize patient and caregiver education to ensure that medications, once prescribed, are taken consistently, and to facilitate home management of asthma to reduce ED use. The guidelines encourage the delivery of asthma education in diverse community settings including schools.

More than ten years after the NHLBI guidelines were first issued, however, studies continued to show that health care providers serving high-risk and underserved communities such as inner city children did not adequately adhere to these national best practice protocols.⁶⁹ In one cross-sectional study of inner city pediatrician practices, it was found that 73% of children with asthma should have been on a controller medication based on the NHLBI guidelines while only 42% were reported by their doctor as having an appropriate prescription and only 32% of family caregivers were aware of their child having such a prescription.⁷⁰ It has been concluded that many primary care providers may remain unaware of these best-practice protocols despite the fact that delivering care consistent with the guidelines would reduce the degree to which high-risk children with asthma are hospitalized and use the ED.⁷¹ The ED rate for the lowest income, predominantly African-American communities in Washington DC, for example (Anacostia, the southeast section of the District) is 4.6 times higher than the national average and nearly ten times the target for *Healthy People 2010*.⁷²

C. Asthma, School Attendance, and School Performance

Multiple studies have shown an association between being diagnosed with asthma and school absenteeism; however, the nature of this relationship is unclear. This is partly because of issues in the design of these studies. Among the problems found in a comprehensive review of 66 such studies were: failure to distinguish between school days missed for asthma and school days missed by children with asthma for other reasons; inconsistency among the studies in the definition of asthma and the basis of the diagnosis; and lack of control groups. In studies that found higher rates of absenteeism for children with asthma, those with more school days missed were poor and racial-ethnic minority children. Because children living in poverty also are negatively affected by health disparities (higher asthma prevalence, barriers to health care access, and less opportunity to benefit from best practice protocols), these studies would support the conclusion that excessive school absence is associated not with an asthma diagnosis but with poorly controlled asthma. About two-thirds of these studies addressed the question of whether there is a difference in academic achievement between children with asthma and children who have not been diagnosed with asthma. In those studies that found a differ-

ence, the students with asthma who had worse academic outcomes were from families in poverty or lower income than those with better academic performance; that is, children already at an educational disadvantage.^{73,74}

Quantifying the impact of asthma on school attendance is complicated by the frequency with which children with asthma come to school when acutely ill. If their asthma is poorly controlled children may present acute asthma symptoms while at school. According to census data from the National Assembly on School-Based Health Care, 92% of school-based health centers provide asthma care during the school day.⁷⁵ This may include routine asthma management visits for established patients but typically also includes nebulizer treatment to relieve acute asthma symptoms. After treatment the student returns to class and therefore does not have a school absence associated with asthma. Without school-based intervention for asthma exacerbations, children with acute symptoms might be kept in the principal's office until picked up by a parent or sent to a hospital ED. The availability of school-based asthma care has the immediate impact of maintaining the child in class and ready to learn⁷⁶ and is an example of how improved school attendance is associated with effective asthma management.⁷⁷

There is also evidence that good asthma care will reduce barriers to learning. A benefit of guidelines-based asthma care delivered in the primary care setting is the reduction of nocturnal symptoms, which are characteristic of poorly controlled asthma. Nighttime symptoms including cough that awakens the child are associated with greater assessed asthma severity. Effective asthma treatment reduces severity including nocturnal symptoms and leads to the child (and parents) getting a better night's sleep.⁷⁸

Sleep problems during childhood are associated with inattentiveness and hyperactivity.⁷⁹ Even one hour of lost sleep nightly for a young child may undermine school readiness by reducing cognitive and speech-language skills.⁸⁰ Young children with inadequate sleep also show signs of irritability, low frustration tolerance, short attention, and problems regulating emotions (emotional lability).⁸¹ Elementary school-aged children with even mildly sleep-disordered breathing have a high rate of externalizing behavior problems, emotional lability,⁸² impulsivity, hyperactivity, diminished attention, and poor academic performance.⁸³ Children with disordered breathing during sleep often have difficulty following directions and completing tasks.⁸⁴ The lack of alertness associated with inadequate sleep may also affect performance on tasks that require memory.⁸⁵ By adolescence loss of sleep is associ-

ated with grade retention and lower test scores in math and reading.⁸⁶ Data from CHF's Childhood Asthma Initiative show that the application of the NHLBI guidelines reduces nocturnal asthma symptoms including cough that disrupts sleep in children with moderate and severe asthma.⁸⁷ This specific improvement in asthma symptoms due to effective asthma management in primary care improves the child's opportunities for effective learning.⁸⁸

Nonetheless, studies have not consistently found a relationship between effective asthma treatment and improved academic performance. One study, for example, found that participants in a comprehensive school-based asthma program had higher grades in science but not reading, mathematics, or physical education.⁸⁹ Other studies done at inner city schools serving predominantly African-American and/or Hispanic students did not find significant difference in scores on standardized achievement tests⁹⁰ or academic performance⁹¹ between children with or without a diagnosis of asthma. Investigators evaluating a school-based asthma management program in inner city Texas found that children who participated had improved asthma knowledge and self-management skills but not academic performance (reading, math and science grades, and statewide standardized test scores). School attendance had improved over time.⁹² Results of two different interventions studied in Detroit, Michigan were mixed; one program which included asthma education using the Open Airways curriculum was associated with improved grades in a middle school (pre-teen) population.⁹³ A study done in Rochester, Minnesota found that compared to age- and sex-matched peers who were not diagnosed with asthma, children with asthma had significantly more days absent from school but did not differ significantly on achievement test scores, academic grades, or promotion.⁹⁴

The authors of a systematic review of the published literature relating academic achievement to coordinated school health programs concluded that there is some evidence that school-based nutrition, health and mental health programs are effective in meeting their specific goals, but not in improving academic outcomes. A number of methodological problems were found in the studies reviewed including sample size, random assignment for matched controls to assess intervention efficacy, and inadequate follow-up periods to track academic outcomes over time.⁹⁵

These methodological challenges are likely to have contributed to the mixed results that have been found and lack of conclusive evidence that improved asthma management improves academic achievement. These inconsistent findings also underscore the degree to which academic performance is affected by multiple factors, some of which are not amenable to control or moderated by intervention. A roundtable meeting of national health and education specialists, researchers, and private

foundation representatives was convened by the National Assembly on School-Based Health Care in April 2004 to discuss the relationship between school-based health care and academic outcomes.⁹⁶ The group identified four general spheres of influence on educational behaviors and academic outcomes: Health status and risk behavior, including physical illnesses, emotional problems, and substance abuse; individual student characteristics including cognitive/intellectual functioning, learning problems, and resiliency; social and environmental factors such as socioeconomic status, household characteristics, and neighborhood characteristics; and educational or school factors including classroom size, quality of teaching, school discipline policies, and school resources and attitudes towards health issues. After reviewing the available literature (articles in peer reviewed journals and program evaluation reports including those by the federal government) on school-based health centers and academic performance, there was consensus among the meeting participants that:

- The research necessary to establish a relationship between the adequacy of health care delivered in the school and academic achievement has yet to be done;
- Doing this research would be complex because of the multi-factorial nature of academic achievement; and
- This research would best be done in the context of an academic environment in which health care was an integral part.

While efforts to draw a causal connection between asthma or quality of asthma care with academic outcomes are complicated by these confounding variables which are also associated with academic success, the evidence is clear that effective asthma control:

- Reduces acute asthma exacerbations;
- Reduces ED use;
- Increases school participation; and
- Reduces the risk of academic problems associated with poor sleep due to nocturnal asthma symptoms.

D. Asthma as a Risk Factor

Applying the risk model to asthma, we hypothesize that bringing a child's asthma under control through application of best-practice treatment protocols will reduce risk factors associated with poor academic outcomes. The impact is likely to be greatest for high-risk children, who must cope with a range of other family, school, and neighborhood risk factors.

There has been concern that the medications commonly prescribed to control asthma pose psychosocial and academic risk for children with asthma. These concerns influenced provider behavior, making it less likely that asthma control medication would be prescribed especially for children with mild symptoms.⁹⁷ While the most common asthma medication side-effects are cough, hoarseness, and thirst,⁹⁸ there has been concern that inhaled corticosteroids could negatively affect the child's growth resulting in short stature. That problem has rarely been seen in clinical practice.⁹⁹ Concern also has been raised that inhaled corticosteroids may be associated with hyperactivity, anxiety and behavior disorders.¹⁰⁰ A review of the impact of asthma on neuropsychological functioning revealed that there are no data to support the notion that long-term use of inhaled corticosteroids or other asthma control medications affects the central nervous system. Overall, a child's socioeconomic status appeared to have a greater impact on school performance than asthma status or degree of asthma control.¹⁰¹ Hyperactivity, anxiety, and headaches as side effects are more often noted when Theophylline is prescribed as an asthma control medication. Compared to Theophylline, inhaled corticosteroids (and beta2 agonists) have fewer side effects and are now more often prescribed.^{102,103} Their use is recommended in the current NLBI asthma treatment guidelines.¹⁰⁴

Apart from medication side effects, there is evidence that having asthma increases a child's risk of also having psychosocial problems including psychiatric disorders. They may be more withdrawn and show signs of an anxiety disorder ("internalizing symptoms"). It has been suggested that psychosocial issues associated with having asthma have more of an impact on the child's quality of life than do asthma symptoms.¹⁰⁵ Some programs, typically school-based, help alleviate some of the psychosocial burden associated with asthma, such as anxiety that exercise will trigger an asthma attack by developing the skills necessary for asthma self-management. These programs discuss asthma symptoms, appropriate medication use, psychological reactions to asthma attacks, knowing when emergency care is needed, knowing and avoiding asthma triggers, reducing the impact of asthma on daily activities such as exercise, and participation in pediatric care.

Efficacy studies of school-based asthma education programs show participation is valuable in helping children maintain their functioning at grade level, preventing academic decline due to problems associated with asthma.¹⁰⁶ Similarly, a study of children with asthma using standardized measures of behavior and adaptive functioning (the Adaptive Functioning scale of the Teacher Report-Child Behavior Checklist and the School Self-Concept subscale of the Piers-Harris Self-Concept Scale for Children), found that reducing asthma severity through appropriate treatment was associated with maintaining academic performance and school behavior over time.¹⁰⁷

There have been several studies exploring the impact of asthma on child quality of life. These studies have used a variety of quality of life measures, in target populations of differing race-ethnicity and socioeconomic status, and with different approaches to classifying asthma severity. Nonetheless a trend in their results emerged: child quality of life suffered as asthma severity increased. The design of these studies, however, left open the question of whether poor quality of life has the impact of increasing asthma severity. It will take additional studies, using culturally and linguistically appropriate quality of life measures, to better describe the relationship of asthma severity and control on child quality of life.¹⁰⁸

There is an over-representation of children diagnosed with asthma in special education programs including those for learning disability and speech-language impairment. The children with asthma in special education classes, however, were significantly more likely to be from poor and low-income households than children in general education, making socioeconomic status a confounding variable with respect to the possible association of asthma with special education placement.¹⁰⁹

Evidence of a relationship between asthma and attention deficit hyperactivity disorder (ADHD) is also inconclusive. A review of studies exploring co-morbidity of asthma and ADHD diagnoses did not find a link between the two, nor evidence that asthma treatment is associated with symptoms consistent with ADHD.¹¹⁰ A more recent study found that, based on parent report, there may be a higher prevalence of ADHD among children with asthma. It was hypothesized that the observed hyperactivity may be related to hypoxia secondary to respiratory disturbance and/or inadequate sleep due to nocturnal asthma symptoms.¹¹¹ Inadequate sleep for whatever reason is associated, for children, with depressive symptoms and school problems.¹¹² This finding suggests that engaging children with asthma in effective medical care will reduce the chances they will also show signs of ADHD, depression and school problems.

There is evidence among adolescents that being diagnosed with asthma is associated with increased risk of also being diagnosed with a depression or anxiety disorder. This is to some extent attributable to reactions to asthma-related activity limitations. This finding was established in a study which controlled for the overlap of symptoms between asthma and anxiety disorder (e.g., shortness of breath, rapid heart rate) and between asthma and depression (e.g., sleep disturbance, fatigue) by ensuring medical diagnosis of asthma and appropriate diagnosis of psychiatric disorders.¹¹³ Increased incidence of psychiatric disorders may be especially problematic for children and youth with asthma because psychological stress may negatively affect lung function, exacerbating asthma symptoms.¹¹⁴

Overall, it appears that emotional and behavioral conditions secondary to or co-morbid with asthma lead to worse long-term academic and social outcomes than does asthma itself, especially if asthma is well controlled medically.¹¹⁵ The impact on school performance of good asthma management is already evident among preschool children. In a study of school readiness among inner city children entering kindergarten, cognitive and behavioral deficits were noted among children with asthma who had activity limitations but not among children with asthma sufficiently well controlled to prevent activity limitations.¹¹⁶

While this discussion has focused on children with asthma, similar considerations are present for other chronic conditions relative to school problems. Chronic conditions are an additional risk factor for children and youth who already are coping with multiple psychosocial stressors. Among adolescents, for example, there is an association between chronic health conditions and depression and anxiety symptoms; however, also associated were low family income and living in a single parent household. The risk of school failure associated with chronic health conditions is, consistent with the cumulative risk model, most prevalent among children experiencing other risk factors including those associated with poverty. When emotional and behavioral problems ensue, the child is placed at further risk of long-term negative outcomes, in part because access to mental health services is so problematic.¹¹⁷ The relationship of emotional and behavioral problems with school success will be our next areas of focus.

CHAPTER 4: ASTHMA AND SCHOOL PERFORMANCE SUMMARY

1. Low-income children generally have asthma prevalence rates 2-3 times higher than other children.
2. Health care providers serving high-risk children in the United States do not adequately adhere to National Heart, Lung, and Blood Institute (NHLBI) asthma treatment guidelines.
3. While there is an association between being diagnosed with asthma and school absenteeism, the nature of the relationship is unclear.
4. Improved school attendance among children with asthma is associated with school-based asthma care and with effective asthma care at health care maintenance organizations.
5. Evidence to support an association between effective asthma control and improved academic performance is mixed.
6. Effective asthma control generally reduces nocturnal symptoms that might disturb a child's sleep. Improved sleeping patterns are associated with improved school performance.
7. There are no data to support the theory that long-term use of inhaled corticosteroids affects the central nervous system.

FIVE: MENTAL HEALTH AND SCHOOL PERFORMANCE

A. Prevalence of Childhood Psychiatric Disorders and Access to Care

Estimating the prevalence of childhood psychiatric disorders is complex, and the results are at best approximate. Complicating factors in existing studies include differences in: 1) sample size, ranging from under 100 to tens of thousands; 2) criteria used to establish the presence of a psychiatric disorder (verified clinical diagnoses, screening results which identify symptoms consistent with a psychiatric diagnosis, parent report which may comprise the parent's own impression or information from health professionals, and severity of impairment); 3) whether the criterion is "current" diagnosis (symptoms currently present, which is complicated by a range of time frames to define "current") or "lifetime" diagnosis^a (whether the child has ever been diagnosed by a health or mental health professional); and 4) the age of children and adolescents included. If a clinical diagnosis is used as the criterion, results may differ based on the specific diagnostic system being used. In federal survey data, results vary in part because of different definitions employed in the survey design.¹¹⁸

When clinical data are used, there is a significant level of disagreement between results of standardized diagnostic interviews and clinical diagnostic evaluations.¹¹⁹ If a positive screening is used as the criterion, results may differ based on the type of screening instrument (e.g., structured or semi-structured format, psychometric properties). Some child mental health screening forms may be filled out by parent and/or teacher, and the results may vary dramatically based on who fills out the form. One study found that only half of children identified as seriously emotionally disturbed by their teacher were identified as having problems by their parents.¹²⁰

These issues result in a wide range of prevalence estimates of pediatric mental health problems. A review of child and adolescent psychopathology reports published during the course of four decades found an extremely wide range of prevalence rates, from 1% to nearly 51%, with median rates of 8% (preschool-age children), 12% (school-age), 15% (adolescents) and 18% (widest age range inclusion).¹²¹

Federal household surveys are often cited to establish population prevalence for various medical and mental health conditions and related issues such as access to care and insurance status. These surveys include the National Health Interview Survey (NHIS), the National Health and Nutrition Examina-

^aThe usefulness of lifetime diagnosis in psychiatric epidemiology has been called into question because, among other reasons, it is not useful as an indicator of current need for services and for service planning. (DL Streiner, SB Patton, JC Anthony, J Cairney. Has 'lifetime prevalence' reached the end of its life? An examination of the concept. *International Journal of Methods in Psychiatric Research*. 2009;18:221-228)

tion Survey (NHANES), the Behavioral Risk Factor Surveillance System (BRFSS), and the Medical Expenditure Panel Survey (MEPS). When used for mental health surveillance, that is, to establish prevalence of psychiatric disorders, federal household surveys generate different and conflicting data because of differences in their sampling methods, interview protocols, and definition for mental health conditions (criteria for a positive response, whether they are asking about specific conditions like depression or “any mental disorder”), time frame of reference (previous twelve months, current or lifetime), age range (or school grade range) of children and youth described, and severity of the condition if a positive response is registered (e.g., only counting a positive response only if a functional impairment is present).^{122,123} These important differences among federal data sources add to the lack of clarity about the prevalence of child and adolescent mental health conditions.

The most frequently cited prevalence rate for childhood and adolescent psychiatric disorder is 20% or one in five, reported by former Surgeon General David Satcher in his landmark study of mental health in the United States. The report highlighted significant socioeconomic and racial-ethnic disparities, with higher prevalence rates among children who are poor and racial-ethnic minorities. Included in this 20% figure are children and youth experiencing serious functional impairment, estimated at 11% or more than one in ten. An estimated 5% of U.S. children and youth have extreme functional limitations due to psychiatric disorders.¹²⁴

The prevalence rates cited in the Surgeon General’s report are for “current” symptoms, with “current” defined as “within the preceding six-months.” The data are derived from the federal Methodology for Epidemiology of Mental Disorders in Children and Adolescents (MECA) Study which used a structured interview methodology based on diagnostic criteria of the National Institute of Mental Health Diagnostic Interview Schedule for Children (DISC). The MECA study sample only included children and youth aged nine to 17 years and was not fully representative of the U.S. population in terms of race-ethnicity or socio-economic status, with the survey population having a higher median family income.¹²⁵ The nine to 17 year old age group excludes preschool-age and early school-age children and older adolescents.¹²⁶ It represents, however, an age group for which targeted interventions to reduce or prevent school problem behavior have been shown to be effective.^{127,128,129}

The Surgeon General’s data have generally been applied to U.S. Census Bureau 2000 data, indicating that nearly 8.4 million U.S. children aged 9-17 years have a diagnosed mental health condition (psychiatric or substance abuse disorder). This includes:

- 4.3 million children and youth with serious functional limitations in the home, school, and community due to mental health problems; and
- 2 million children and youth with extreme functional limitations due to mental health problems.¹³⁰

Twelve-month prevalence data from NHANES (2001-2004) show that 13.1% of children and youth 8 to 15 years old had one symptom consistent with a psychiatric disorder (other than substance use disorder) using DSM-IV criteria. The most prevalent condition was ADHD. Fourteen percent of children meeting diagnostic criteria for one disorder also showed symptoms of at least one additional psychiatric disorder (conduct, anxiety, eating, or mood disorder).¹³¹ The Great Smoky Mountains Study, a longitudinal study done in three counties in western North Carolina, used the Child and Adolescent Psychiatric Assessment (CAPA) structured interview of parents and children 9 to 13 years old to determine the prevalence of psychiatric symptoms using DSM-IV diagnostic criteria. They found a cumulative prevalence rate across this age range of 24.5% for psychiatric disorders (excluding substance use disorders).¹³² National Comorbidity Survey Replication data show that about half of adults will have met diagnostic criteria for a psychiatric disorder at some point in their lifetime. Generally, initial onset will have occurred during childhood or adolescence.¹³³

These findings underscore the importance of identifying and treating psychiatric disorders as early as possible. For example, adults diagnosed with an addictive disorder and another psychiatric disorder typically were first symptomatic of the psychiatric disorder at age of eleven. Age of onset for addictive disorders was typically 21, ten years later. Up to 80% of adults with anxiety disorders, depression disorders, and drug addiction first presented these problems before they were 20, and nearly three-fourths (72%) of teenagers with conduct disorder were first symptomatic before they were ten years old. One study found that among adults with a psychiatric diagnosis at age 26, half (50%) met diagnostic criteria by 15 years of age.¹³⁴

Another federal survey, The National Survey of Children's Health (NSCH), seeks to establish prevalence by asking parents whether their child has various problems or conditions and whether their children have been so identified by a health professional. We independently analyzed the NSCH data set including only children and youth from nine to 17 years of age, which yielded a sample of more than 50,000 respondents. Our analysis revealed that 5.9% of parents reported that "a doctor or health professional" had ever told them their child had "behavioral or conduct problems." This survey also

asked whether parents were told their child had “depression or anxiety problems” (6.7% positive) and attention deficit disorder or attention deficit hyperactivity disorder (10.1% positive). A substantial percentage of parents who reported one of these child problems reported at least one of the others as well.¹³⁵

These data represent parental report of a problem that had previously been identified by a health care professional. Medicaid claims data also show a smaller percentage of children and adolescents (9% from birth to 21 years) receiving care for a psychiatric disorder than would be expected based on the Surgeon General’s report or in other federal surveys that use interviews based on screening instruments that identify symptoms consistent with a psychiatric diagnosis. There is also considerable variation (from a low of 5% to a high of 17%) among the states, with the lowest mental health utilization in Texas, Louisiana and Florida.¹³⁶ These data suggest considerable under-identification of current psychiatric symptoms by health care professionals, which in turn may reflect poor access to health care and/or under-identification of emotional and behavioral problems by health professionals. The result is missed opportunities for early treatment interventions that could prevent or ameliorate later academic problems.

None of these reported prevalence rates capture the extent to which mental health service needs are presented in high-risk, medically underserved pediatric populations. In a comprehensive study of the health status of children in New York City homeless family shelters by CHF and the New York Children’s Health Project, 30% of elementary school-age children (5-11 years old) and 24% of adolescents (12-19 years old) were diagnosed with a psychiatric disorder on clinical evaluation.¹³⁷ Among children entering foster care, studies have yielded a wide range of prevalence estimates of emotional and behavioral problems, from a low of 22% to a high of 95%.¹³⁸ Foster children are from three to ten times more likely than other children to be diagnosed with a psychiatric disorder and more than seven times as likely to have a psychiatric hospitalization. Their expenditures for mental health services are eleven times higher than those of children who are not in the foster care system.¹³⁹

B. Early Identification and Treatment

As with older children and youth, estimates of the prevalence of early childhood psychopathology vary enormously. One literature review found estimates ranging from less than one percent to 26.4%, with sample sizes on which these estimates were based ranging from 104 to 3,860. The wide range of findings also reflects diverse study settings, different criteria for identifying psychopathology, and

diverse populations at greater or lesser risk of psychiatric disorder. Settings included psychiatric clinics (referred populations), schools and medical clinics (general populations), and Women's Infant and Children Program or "WIC" centers (poverty populations). The highest rates of emotional disturbance were found among young children seen in urban pediatric clinics and among five-year-olds at WIC centers (which provide supplemental nutrition to poor and low-income young children and pregnant women). A wide range of psychiatric disorders were identified, including anxiety and depressive disorders and disruptive behavior disorders (oppositional-defiant disorder, conduct disorder, and ADHD).¹⁴⁰

For children less than five years of age, it is especially difficult to make an appropriate categorical diagnosis. High activity level and short attention span among the most commonly observed symptoms of a possible childhood psychiatric disorder.¹⁴¹ In studies done in Head Start programs, from 10% to 12% were viewed by their teachers as having behavior problems consistent with a diagnosis of ADHD.^{142,143} Other studies of children in community preschool programs found higher rates of problem behavior among boys than girls, with 11% of boys meeting diagnostic criteria for conduct disorder. In longitudinal studies, about half of children with early symptoms of disruptive behavior disorders continued to show behavior problems over time. These children have a high risk of later diagnosis of a psychiatric disorder¹⁴⁴ and of social and learning problems in school¹⁴⁵.

There is concern that the most frequently used diagnostic criteria, the American Psychiatric Association Diagnostic and Statistical Manual (DSM-IV) may not be developmentally appropriate for children, especially for young children. This affects, for example, early diagnosis of mood and anxiety disorders. In young children, depression is often manifested by presentation of externalizing symptoms, possibly consistent with a diagnosis of oppositional defiant disorder. Some psychiatric diagnoses, e.g., bipolar disorder, may not be valid for preschool age children.¹⁴⁶ Nonetheless, some psychiatrists advocate the use of atypical antipsychotic medications (also called neuroleptics) in preschool children while acknowledging that these medications are not approved for young children and that there are potential problems with respect to side effects.¹⁴⁷

There has been a trend towards increasing prescription of psychotropic medication for children, sometimes as young as two years of age. Medicaid and other insurance claims data show that as many as 1.5% of children from two to four years of age are prescribed a psychotropic drug (stimulant, antidepressant, or antipsychotic medication). Most often the prescribed medication is a stimulant to treat ADHD.^{148,149} This is the diagnosis that pediatricians revealed in a study that they felt most

comfortable identifying and treating, as opposed to depression, anxiety, eating and substance abuse disorders. For these other conditions pediatricians felt more comfortable limiting their role to identification and referring to a mental health specialist for treatment. However, pediatricians also cited poor access to mental health providers as a problem in making referrals. Less than 10% reported that mental health services were adequately available in their community.¹⁵⁰

This limited access to community-based mental health services often affects the pediatrician's efforts to identify mental health problems, since it is necessary to refer for treatment patients who screen positive for a problem. The alternative is for the pediatrician to manage the identified mental health problem. One study found that only about one-fourth, 26%, of children diagnosed with ADHD by their primary care provider saw a mental health provider for diagnosis or treatment of ADHD.¹⁵¹

These findings indicate the importance of integrating mental health services with primary pediatric care to ensure coordinated, comprehensive, quality care for children with emotional and behavioral problems. Because children have better access to medical care than mental health services, integrating primary care and mental health services will alleviate some of these access barriers. These findings underscore the need to ensure that the community pediatric workforce is well trained to identify and to some extent manage psychiatric disorders.¹⁵²

Access to mental health professionals is essential to avoid over-diagnosis of ADHD with underlying psychiatric disorders being missed. As previously noted, young children with depression may manifest behavioral symptoms suggestive of ADHD. Lifetime co-morbid prevalence of depression in children with ADHD increased with time, to 45% at age 15 years.¹⁵³

While it is less frequently occurring than ADHD, autism (now classified within "autism spectrum disorders" or ASD) has been steadily increasing. In a report to Congress, the U.S. Government Accountability Office (GAO) found that more than 1.5 million people have autism. This includes 120,000 children and adolescents six to 21 years old who receive special education services and represents an increase of more than 500% from 1993 to 2002. Their cost of education is nearly triple the average cost per pupil. The GAO also noted that evidence for the efficacy of preschool intervention programs for autism has been established in a report by the National Research Council.¹⁵⁴ Federal surveillance data (2006) show an increasing prevalence of ASD, averaging 9.0 cases per 1,000 (or one per 110) children with significant variation among the states, and significantly higher rates among boys than girls.¹⁵⁵

Signs of autism are generally noticeable to parents before the child is three; some signs (e.g., averting eye contact, not responding to familiar faces and voices) may be noted by twelve months of age. Initial parent concerns generally center on limited vocalization, non-responsiveness to spoken communication, and other early signs of poor social communication.¹⁵⁶ Possible hearing loss is suggested by early symptoms. Other early signs include an absence of communicative gestures, atypical developmental patterns (e.g., loss of developmental milestones), stereotypical and self-stimulatory behaviors such as hand flapping, rocking, hitting oneself, and repetitive use of materials (e.g., spinning or lining up toys). Unusual responses to sensory stimuli such as sounds or tactile stimulation are also frequently seen in children with autism. By the time the child is two, 90% of parents have noticed that their autistic child's development is atypical.¹⁵⁷

Because these early signs reliably identify children who may have ASD, screening in pediatric primary care is recommended by the American Academy of Pediatrics. They also emphasize that pediatricians should promote full immunization because there is no valid evidence that autism is caused by the measles-mumps-rubella (MMR) vaccine or any other immunization.¹⁵⁸ In February 2010 the British medical journal *The Lancet* retracted the 1998 paper that purported to establish a link between vaccine and autism.¹⁵⁹

There are racial-ethnic disparities in the identification of young children with autism spectrum disorder. African-American and Latino children with developmental delays are less likely than white children with similar delays to be appropriately identified with ASD, with the diagnostic process stopping with identification of a cognitive (intellectual) delay.¹⁶⁰ This underscores the importance of including autism screening in pediatric primary care, especially for children in poor and low-income families. Brief, accurate screening tools are readily available.¹⁶¹

Early identification of ASD is especially important because families may access services, often at no out-of-pocket cost, through local Early Intervention ("EI") programs. These programs provide evaluation and services to infants and toddlers birth to 36 months of age with developmental delay. A review of preliminary studies of the clinical efficacy of early intervention for children with autism shows that early access to services improves developmental outcomes.¹⁶² Early intervention also provides family support to reduce stress associated with parenting a child with autism, further improving child outcomes.¹⁶³

Early behavioral intervention (“applied behavior analysis” or “ABA”) facilitates the child’s participation and success in mainstream educational settings by increasing attention to a teacher and on a task as are necessary to acquire new skills.¹⁶⁴ Early intensive behavioral intervention for children with autism has produced significant cost savings because of reduced need for special education and related services in school and increased productivity in adulthood.¹⁶⁵ Early identification of autism is especially important because academic and social outcomes for school-age children identified later are generally less favorable. Early identification facilitates education in “mainstream” settings with typically developing peers. Children with autism who entered and remained in self-contained special education classes in elementary school often had lower cognitive achievement and more severe symptoms than children in mainstream classrooms.¹⁶⁶

C. Developmental Delay and Learning Disorders

The term “developmental delay” is generally used when a child does not achieve developmental milestones within age-expectations for a typically developing child. The age at which milestones are typically met has been established through systematic observation of children at various ages to determine normative data on infant and early childhood development.¹⁶⁷ Early development is generally categorized in five developmental domains: motor (gross and fine), adaptive, communication (expressive and receptive language), cognition, and social-emotional (including temperament, behavior and relationships). This is integral to the Individuals with Disabilities Education Act (IDEA), the legal basis for Early Intervention and special education programs.¹⁶⁸ Delays may be noted in each of these domains by comparing the age at which the child demonstrates or fails to demonstrate mastery of developmental tasks such as holding the head steady in infancy, crawling, combining two words, or following simple spoken commands. Alternatively, developmental functioning may be assessed with norm-referenced tests that compare the child’s functioning to norms established for a group of children who were studied to develop and score the test. The child’s test scores are compared to the mean score of the normative group. A common example is intelligence (IQ) testing, where the mean score is 100.¹⁶⁹

Speech-language (or communication) delay is the most commonly diagnosed developmental delay or disability in early and middle childhood. Speech-language delay is also the most common developmental diagnosis in Early Head Start Programs, which provide early stimulation and education primarily for low-income infants and toddlers.¹⁷⁰ Survey data show the prevalence of speech-language delay among Early Head Start children to exceed that of asthma (18.7% vs. 14%), with an additional

9.6% identified with a communication disorder.¹⁷¹ In Head Start Programs, which primarily serve low-income preschool age children and also have slots set aside for children with disabilities, 14% of three- and four year olds (more than 134,000 nationwide in 2004) were identified with a disability. Speech-language delays and communication disorders are the most commonly occurring condition among Head Start children with developmental problems.¹⁷²

There is an association between receptive language delay^b and delayed cognitive functioning.¹⁷³ This underscores the need for early identification and intervention for developmental delays to facilitate academic success. By elementary and middle school, among children receiving special education services, 30% have a primary educational diagnosis of speech impairment and 43% have a diagnosed learning disability.¹⁷⁴

Sociodemographic factors are associated with prevalence of developmental delay. Poverty and poor child care conditions (access to language stimulation, toys and opportunities for play, exposure to domestic violence, etc.) undermine the developing child's mastery of new tasks and increase the risk of developmental delay and later mental health problems.¹⁷⁵ Data from the early childhood Longitudinal Study-Birth Cohort (ECLS-B) show that poverty and social-environmental stressors are associated with cognitive delays which may manifest in the young child by 24 months of age.¹⁷⁶

In a study using U.S. Census Bureau data to explore the relationship between developmental problems and neighborhood characteristics among children 5 to 15 years of age in the state of Rhode Island, investigators classified neighborhoods by degree of "distress" based on rates of child poverty, high school drop-out, male unemployment, and households headed by a single woman. They found that severely distressed neighborhoods were home to 14.5% of that school-age population but accounted for 25% of children with motor disability and 29% of children with adaptive (self-care) disability. Disability rates in moderately distressed neighborhoods were more than triple those in more advantaged neighborhoods.¹⁷⁷

One source used to estimate the prevalence of developmental delay is national and state rates of participation in EI by age-eligible infants and toddlers. Eligibility for EI services may be based on a diagnosis of a condition with a high probability of developmental delay, like Down syndrome, or delayed

^bDelays greater than mild; i.e. more than one standard deviation below the mean on a norm-referenced test of receptive language functioning.

functioning that meets the state's eligibility threshold. Communication delay is the most common reason for infants and toddlers to be found eligible for Early Intervention services (at 41%).¹⁷⁸ Each state is permitted to establish the degree of delay on evaluation (ratio of functional age to chronological age) that establishes eligibility. Some states set an eligibility threshold of mild-moderate (25%-33%) delay. Other states adopt narrow eligibility criteria, requiring a 50% delay. In these states a 24 month old would have to function at or below the 12 month level to qualify for intervention. This is a severe level of delay and excludes many infants and toddler who need developmental services and would be considered eligible in other states.¹⁷⁹ Data from the National Survey for Children with Special Health Care Needs show that fewer than half (45.7%) of these high-risk young children participated in EI, with significant variation based on specific state eligibility criteria. In states with the most stringent eligibility standards, fewer than one child with special health care needs in four, 23.1%, received EI services. Young children living in poverty were significantly less likely to receive early intervention even in states with less restrictive eligibility criteria.¹⁸⁰

Variation in eligibility standards among the states complicates the use of administrative data from state EI programs to determine the prevalence of infant-toddler developmental delay, because a child eligible in one state and counted as delayed may not be eligible and considered delayed in another state. Within this limitation, federal data show that 2.5% of the nation's age-eligible population (birth to 36 months old) received EI services for developmental delay during 2007. Among infants and toddlers in households with incomes at or below the federal poverty level, the rate was 3.0%.¹⁸¹

These data are consistent with data from the National Survey of Children's Health, which show that 2.6% of parents of infants and toddlers birth to three reported that they had been told by a health professional that their child had "any developmental delay or physical impairment."¹⁸² Data from another federal household survey, the National Health Interview Survey on Disability or NHIS-D show that about two-thirds of children age 4 to 59 months with delayed development (based on questions about their ability to perform specific tasks) were not so identified by their parents.¹⁸³

The degree to which developmental delay may be missed by parents and pediatric primary care providers are indicated by other prevalence data. Results of the ECLS-B indicate that approximately 13% of toddlers nine to 24 months of age had delays consistent with EI eligibility criteria.¹⁸⁴ There is consensus from other studies that 15% to 18% of U.S. children have developmental problems.¹⁸⁵ Prevalence of developmental delay is higher in high-risk populations. Among infants and toddlers in

New York City homeless shelters, 19% were eligible for EI services,¹⁸⁶ compared with a citywide rate of 8%.¹⁸⁷

For children in foster care, prevalence estimates vary depending on the methods used. For toddlers, these are as high as 65% for cognitive and speech-language delay and 89% for a reported delay on the Ages and Stages Questionnaire, ASQ. Early serious social-emotional problems is also noted.^{188,189} A generally accepted estimate based on multiple studies is that more than 40% of infants and toddlers with a substantiated child maltreatment case are developmentally delayed.^{190,191}

Because of this high prevalence of developmental problems, federal law now requires that children under three years of age who have a substantiated case of child maltreatment be referred to their local Early Intervention Program for evaluation.^{192,193,194} In part because of the variation in state eligibility requirements, fewer than half (46.5%) of these maltreated infants and toddlers were found eligible for EI services.¹⁹⁵ Nationwide, from 2003 to 2005, there was an overall 22% increase in EI enrollment attributable to mandatory referral of maltreated young children.¹⁹⁶

Despite this additional source of EI-enrolled infants and toddlers, EI participation rates (percent of age-eligible infants and toddlers receiving EI services) remained low based on national and state-level EI data, indicating a continued failure of early identification. This is at least partly attributable to inconsistent use of formal developmental screening instruments and protocols in pediatric primary care. Often providers rely on informal observation which has been found to identify less than 30% of children with developmental delay and less than 50% of children with serious emotional disturbance.¹⁹⁷

Early identification of developmental problems is essential for young children to benefit from early intervention during the first three years of life, when brain plasticity and the likelihood of optimally benefitting from intervention are greatest.^{198,199} There is a substantial body of evidence establishing the value of early developmental stimulation and intervention²⁰⁰ especially for high-risk infants. For those at risk of delay because of neurobiological factors (e.g., very low birth weight),²⁰¹ the social and environmental restrictions associated with poverty^{202,203} tremendously increase their risk of adverse developmental outcomes. It follows that programs that target low-income children for developmental screening and surveillance will be most effective in improving later academic and social outcomes.²⁰⁴

There is a growing body of evidence that demonstrates the value of early intervention services in improving developmental outcomes which in turn is associated with improved opportunities for educa-

tional success. This is consistent with evidence that for the first months and years of life the way that the child's brain develops is in part responsive to experiences and environmental influences. Early experience affects the architecture of the brain: neurons and synapses (neural connections) and even brain size. Early stimulation improves brain growth; lack of stimulation is associated with a smaller and possibly underdeveloped brain.²⁰⁵ These scientific considerations are part of the reason that the EI Program for infants and toddlers with developmental delay was funded, and also why its services are associated with improved developmental outcomes. For example, early intervention for premature low birth weight infants, the medical condition most often associated with Early Intervention Program participation²⁰⁶ is associated with significant gains in IQ scores at eight years of age.²⁰⁷

In addition to developmental gains through early intervention for developmental delay, early intervention services may play a primary preventive role with respect to emotional and behavioral problems. Studies show that developmental delay and social-emotional-behavioral problems are closely associated. The same factors that place a young child at risk for developmental delay, including low birth-weight and other neurobiological factors and poverty, also place the child at risk of behavioral and later psychiatric disorders, an effect that is noted in children as young as two years of age.²⁰⁸

In a study relating speech-language skills and behavior problems in toddlers, it was found that young children with expressive language delays were more likely to also have social-emotional problems, and young children with receptive language delays were more likely to have multiple areas of developmental delay. It was suggested that young children identified with behavior problems should also be evaluated for speech-language delay.²⁰⁹ Three-year-old children with developmental delays are from three to four times more likely than young children without delays to show clinical signs of behavior problems (based on a standardized measure, the Child Behavior Checklist). These behavior problems are more stressful to the parent-child relationship than are the developmental delays, increasing the child's risk of emotional problems.²¹⁰

Low reading achievement in the early grades is a major contributor to school problem behavior consistent with a diagnosis of conduct disorder. This suggests that interventions to strengthen early academic lags may prevent later signs of emotional disturbance and a diagnosed psychiatric disorder while also improving the child's opportunities for academic success.²¹¹

D. Barriers to Access of Mental Health Services – and Their Consequences

As previously noted, mental health services are inadequately available especially to the children who need them most. The National Conference of State Legislators (NCSL) reported that while children comprise 28% of the nation's population, they account for only 7% of mental health expenditures. Of those children in the greatest need of mental health services, less than one in five actually get professional help. This translates to nearly 3.5 million children with significantly compromised daily functioning due to serious emotional disturbance going without treatment each year. The NCSL attributes this problem in part to the fragmented service systems available for children, and recommends collaboration among mental health professionals, pediatricians, and families to facilitate access to care and to reduce stigma that might be associated with seeking mental health services.²¹²

National survey data show that preschool children with mental health needs are especially likely to go unserved. Based on an analysis of National Health Interview Survey data, 8.5% of preschool children needed mental health services. An overwhelming 94% of these young children in need did not receive any mental health care during the preceding year.²¹³

Data from the National Survey of America's Families indicate that geographic mal-distribution of mental health professionals has a strong impact on access to care. States with the highest level of unmet mental health need include Mississippi, Florida, California and Texas. The latter two states have especially high rates of unmet child mental health need, with low income and minority children especially likely to go unserved.²¹⁴

These very low rates of mental health service utilization reflect long-standing problems in the child mental health workforce. Even for children whose treatment consists only of psychotropic medication, the principle provider is likely to be a pediatrician not a psychiatrist. As of 2000, there was an estimated shortage of 30,000 psychiatrists specialized in child and adolescent services to meet demand, and this shortage has worsened over time. Rural states and counties are least well served by mental health professionals. West Virginia, for example, has 1.3 psychiatrists per 100,000 children and youth compared to 17.5 in Massachusetts. For low-income children, the shortage of psychiatrists is exacerbated by low reimbursement rates through public insurance (Medicaid and CHIP). These rates have worsened, and billing requirements have become more time-consuming, as managed care has made greater penetration into Medicaid. Because child psychiatrists are in such short supply, they can opt out of public insurance and provide care only to patients with insurance plans that reimburse at higher

rates and/or those able to pay higher rates out of pocket. This further reduces the availability of mental health services in high-risk, low income communities, where needs are often greatest.^{215, 216}

Provider shortages contribute to protracted delays between identification of a mental health service need and onset of intervention. Data from a federal survey, the National Comorbidity Replication Survey, show that people with a mood disorder such as depression typically began to receive treatment 6 to 8 years after the condition was first noted. Delays were even longer for other psychiatric disorders. These delays beginning mental health treatment contribute to the personal and societal burden associated with psychiatric disorders and underscore the need for systemic changes to facilitate timely access to mental health services when needed.²¹⁷

Problems accessing community-based mental health care have led to the increasing use of hospital EDs for psychiatric care. The rate of increase has been about three times that of ED use for medical care. This trend is attributed to long waits for psychiatric evaluation and treatment at community sites, inadequate supply of mental health resources in the community, insurance and reimbursement issues, and increased numbers of ED referrals directly from schools.

The hospital ED is the least efficient way for children to receive mental health services. The quality of care is less than optimal because the ED staff is not generally well trained in that area, which contributes to recidivism. Psychiatric ED users frequently return within two months of discharge. As is typical for any condition, the cost of ED care is far higher than for other ambulatory settings. There are additional costs for mental health conditions treated in the ED because of the need to use security personnel for patient supervision.²¹⁸

Potentially preventable psychiatric hospitalizations are another consequence of the inadequate availability of community-based mental health services. In 2006, 16.5% (one-sixth) of all hospitalizations of children and youth from one to 17 years of age had a primary or secondary discharge diagnosis of a psychiatric disorder. In 62.9% of these cases, the discharge psychiatric diagnosis was mood disorder such as depression. The percentage of mood disorders among hospitalized patients was higher among children and youth than for any other age group.²¹⁹

E. Impact on Academic Success and Life Consequences

The negative impact of unmet developmental and mental health need on education is already apparent in preschool. Preschool expulsions have been rising; however, four-year-old children with behavior problems who receive counseling are less likely to be expelled.²²⁰ Elementary school children with learning problems or achievement gaps are often excessively absent from school in the middle grades. Continued school failure, whether due to academic or behavior problems, is associated with high school drop-out. One study found that the combination of academic and behavior problems (together comprising “student disengagement”), was associated with 77% to 85% of high school drop-outs.²²¹

In a British study, higher levels of psychological distress as measured on the Strengths and Difficulties Questionnaire were associated with lower school achievement. The Strengths and Difficulties Questionnaire assesses signs of poor attention and emotional or behavioral problems that may not reach the level of a diagnosed psychiatric disorder.²²²

According to the National Institute of Mental Health (NIMH), half of all lifetime cases of diagnosed psychiatric disorders begin by 14 years of age. The NIMH National Comorbidity Study was designed to determine the prevalence of psychiatric disorders (using diagnostic criteria from the American Psychiatric Association) in a nationally representative sample of people 15 to 54 years of age. Data from this survey (conducted from 1990-1992) show that early onset of psychiatric disorders is associated with poor academic outcomes. In this survey 14.2% of high school dropouts had a psychiatric disorder.²²³ By age 12-13, children diagnosed with ADHD had significantly lower reading achievement, significantly higher school absenteeism, were 3 times more likely to be retained in a grade and 2.7 times more likely to drop out of high school than children without this diagnosis.²²⁴

Using longitudinal data from the Family and Community Health Study, investigators compared school outcomes for African-American public school students with and without a psychiatric disorder.²²⁵ Key findings include:

- The most significant antecedent of a psychiatric diagnosis was stressful life events;
- Consistent with a risk model, there was increased risk of a psychiatric disorder as the number of stressful life events increased;

- Psychiatric disorders had a significant negative impact on all aspects of school attitude and functioning including aspirations for higher education, academic performance, and school adjustment;
- Psychiatric disorders emerged as a risk factor which had its greatest impact when added to other factors that potentially undermine school success; and
- Findings from this study are consistent with findings for other race-ethnic populations.

When help is provided for students with poor behavior and academic achievement, it is often in the form of special education referral and placement. Beginning in elementary school, however, special education placement is associated with later poor academic achievement.²²⁶ Federal data for the 2006-2007 school year show that only one-third of students from 14 to 21 years of age receiving special education services who exited school did so with a high school diploma.²²⁷

Emotional disturbance as an educationally related disability condition is generally identified later than other conditions such as learning disability. More than one-third, 38%, of children receiving special education because of emotional disturbance was left back at least once, despite the fact that grade retention is associated with poor academic achievement. Nearly three-fourths were suspended or expelled from school at least once.²²⁸ These outcomes reflect the focus of special education for children classified as emotionally disturbed being on behavior management rather than academics. Underlying communication and learning disorders often go untreated.²²⁹

Adolescents with psychiatric and learning disorders who did not receive appropriate intervention are disproportionately represented in the juvenile justice system. Data show that one-third or more of adolescents in juvenile corrections facilities have an educationally related disability. A national survey incorporating data from the 50 states plus the District of Columbia found that 33.4% had a disability. This is four times higher than the general population. These data, however, may understate prevalence because of issues around identification and classification of disability.²³⁰ A study in Maryland found that nearly one-third, 31%, of incarcerated youth had significant intellectual deficits including diagnosed mental retardation and 37% met eligibility criteria for special education services.²³¹ Data from the Texas Youth Commission show that at an average age of 16 years, the median reading and math achievement levels for newly incarcerated youth was fifth grade (five years behind) and 39% were found eligible for special education.²³²

Psychiatric disorders are the most prevalent conditions in the juvenile justice population. Using criteria from the Diagnostic Interview Schedule for Children Version IV (DISC-IV), a structured interview designed to identify symptoms of more than 30 disorders, an alarmingly high 70.4% meet criteria for at least one psychiatric disorder. Other studies find similarly high rates, from 67.2% to 69.0%. It has been suggested that these high rates reflect the presence of behaviors consistent with a conduct disorder diagnosis as expected in a criminal justice-involved population. About two-thirds (66.3%) of youth in the juvenile justice system meet criteria for at least one psychiatric disorder other than conduct disorder (e.g. a mood or anxiety disorder), and more than half (57%) of those meeting criteria for one disorder have at least one co-morbid psychiatric condition.²³³ Depression and other affective disorders are notable among females in the juvenile justice system, with more than one in five meeting criteria for a major depressive episode.²³⁴

This high prevalence of mental health disorders reflects the fact that the juvenile justice system has become an alternative to community-based mental health care in part because of the protracted shortage of mental health providers. In 47 states, juvenile detention centers, most of which lack adequate mental health services, are sometimes used to house adolescents who are not able to access mental health care, according to a 2004 report of the U.S. House of Representatives. In 33 states, incarceration is substituted for treatment for children and youth without criminal charges filed against them; this affects children as young as seven years old. Each night in the U.S., as many as 2,000 children and youth, or 15,000 during a six month period are in a juvenile detention facility instead of receiving mental health care. The annual cost is approximately \$100 million.²³⁵

The negative impact of psychiatric disorders may persist throughout the individual's life. Data from the National Comorbidity Survey Replication (conducted 2001-2002) show that among individuals 18-64 years of age, having a serious psychiatric diagnosis reduces earning potential by an average of \$16,306 in annual earnings compared to non-diagnosed but otherwise comparable individuals. Using these data, it has been estimated that the cost to society of psychiatric disorders is \$193.2 billion, mostly (75%) attributable to reduced earnings but also reflecting (25%) individuals unable to work.²³⁶

There is also evidence that without access to mental health services, psychiatric disorders such as depression may recur in successive generations. A trajectory leads directly from the child's exposure to stressful and traumatic events within the family to early onset of behavioral and later depressive symptoms which, if untreated, persist into adolescence and adulthood.²³⁷

Mental health problems may persist from one generation to the next. Children of parents with psychiatric disorders, based on data from the National Comorbidity Study, are less likely to finish high school.²³⁸ Children of mothers with depression are at elevated risk for developmental, behavioral and academic problems, which may include later diagnosis of depression.²³⁹

CHAPTER 5: MENTAL HEALTH AND SCHOOL PERFORMANCE SUMMARY

1. Establishing the prevalence of psychiatric disorders among children and youth is complicated and estimates vary widely.
2. The most commonly cited estimate, based on the U.S. Surgeon General's landmark mental health report, is that nearly 8.4 million children and youth aged 9-17 years have a diagnosed mental health condition. Estimates of early childhood prevalence vary widely.
3. Minority children with developmental delays are less likely than non-Hispanic white children to be appropriately identified with Autism Spectrum Disorder (ASD).
4. Distressed neighborhoods were found to have a significantly higher percentage of disabled children when compared to advantaged neighborhoods.
5. Consistent with a risk model, risk of a psychiatric disorder increases with the number of stressful life events a person experiences.
6. Early intervention for children with developmental delay is most effective during the first three years of life, when brain plasticity is greatest.
7. Many pediatricians use observation alone and not formal developmental screening instruments to identify children with developmental delay and emotional disturbance. The result is under-identification of young children in need of intervention.
8. There is a severe shortage of mental health professionals nationwide with rural and low-income communities being the least well served.
9. The lack of mental health providers has led to an increased rate of use of hospital Emergency Departments (ED) for psychiatric care.
10. According to the National Institute of Mental Health (NIMH), half of all lifetime cases of diagnosed psychiatric disorders begin by the age of 14 years.
11. Psychiatric illnesses are associated with lower reading achievement, increased school absenteeism, increased likelihood of grade retention, increased high school drop out rates, increased involvement in the juvenile justice system, and lower earnings.
12. Children of mothers with depression are at elevated risk for developmental, behavioral and academic problems.

A. Community Health Centers

An effective way to deliver health care to poor and other vulnerable populations is through community health centers. This predominantly federally funded initiative began in 1965 with two centers in poverty communities: rural Mississippi and inner city Boston, Massachusetts. Community health centers were founded to comprehensively meet the health care needs of poor, uninsured, high-risk individuals, and to do so in a way that benefits and fully involves the community. These principles are essential to the reduction and eventual elimination of health disparities.²⁴⁰

As of 2007, there were more than 1,000 federally funded community health centers in the United States, up from 550 in 1990. Community health centers provided care to 16.1 million patients in 2007. They are a critically important element of the nation's health care safety net: 92% of community health center patients have annual incomes below 200% of poverty and 40% are uninsured. Nearly one-third of people living in poverty in the U.S. receive care from a community health center.²⁴¹

Community health centers have demonstrated efficacy in improving the health status of their patients and in so doing contributing to the reduction of health disparities. This has been shown in the areas of infant mortality, timely receipt of prenatal care, incidence of tuberculosis, and age-adjusted death rates. Community health centers have successfully improved the diagnosis and management of chronic conditions including diabetes, cardiovascular disease, asthma, depression, cancer, and HIV in their pediatric and adult patient populations.²⁴²

Despite recent increases in the availability of community health center services there are not enough primary care providers to meet the needs of America's medically underserved and vulnerable children. Even before a recession was declared in 2008, increasing numbers of children and adults were falling into poverty and becoming uninsured. This increased demand for care strained resources at community health centers especially for mental health services, oral health care, and specialist care.²⁴³

This increased demand occurs during a time of significant shortages in the health professional workforce available for this population. In November 2009 the National Association of Community Health Centers (NACHC) projected a nationwide shortfall of more than 1,800 primary care providers and

more than 1,300 nurses to meet the demand for services at that time.²⁴⁴ These problems especially affect rural Americans. While community health centers are the source of care to one out of seven people in rural communities,²⁴⁵ there are problems with securing the financial viability of these health centers due to the sparse population density of rural and frontier communities.²⁴⁶

Hospital ambulatory clinics and hospital-affiliated community clinics are also important elements of the safety net and may be especially effective in facilitating access to specialists. However, many communities do not have adequate transportation access to hospital facilities.²⁴⁷ Transient populations like the homeless and children in foster care also are more reliably and efficiently served by alternative modalities to provide pediatric primary care in a medical home model. Two such service delivery models are mobile medical clinics and school-based health centers.

B. Mobile Medical Clinics

Mobile medical clinics are an effective way to bring teams of health professionals to targeted populations in medically underserved areas. The mobile clinic is a 38 to 40 foot long pediatric office on wheels, with several exam rooms, a procedure room, and a small waiting room near the driver's seat. The interior of a mobile clinic may be adapted for mental health work with multiple soundproof treatment rooms that protect patient privacy and confidentiality. While the service delivery modality is different than at a typical fixed site community clinic, the clinical standard of care need not be is not compromised. Mobile clinics are effective ways to bring care to underserved communities in an enhanced medical home model.²⁴⁸

Mobile medical clinics have proven effective in bridging access gaps for high-risk populations, including urban homeless children.²⁴⁹ Elements of a successful mobile clinic program include establishing a regular schedule, using physician-faculty of affiliated medical centers, providing 24 hour/7 day per week coverage, using electronic health records, and facilitating access to specialists. These are essential to ensure comprehensive and coordinated care to high-risk, medically underserved populations including homeless families, homeless youth, low-income children in rural and frontier counties, and inner city poor.²⁵⁰ The mobile clinic model has also proven successful in bridging barriers to access for medical and mental health services and delivering comprehensive pediatric care even in the extreme conditions of the aftermath of a disaster, Hurricane Katrina.²⁵¹

A study of economic benefits of providing comprehensive health care services to medically underserved populations on mobile clinic services explored the cost of care, including annual operating cost

of the mobile van, relative to savings (reduced ED utilization for non-urgent care). The model returns approximately \$36 for each dollar spent.²⁵²

C. School-Based Health Centers

Another way to bring health care to children is through school-based health centers (SBHC), which are pediatric clinics located within school buildings. When space is not available within a school building, an alternative model is to bring care to a site near the school, e.g., by parking a mobile clinic in front of the school. This is generally referred to as a “school-linked” model.

School-based health centers are an acknowledged way to provide the medical home model of care to underserved children²⁵³ and are recommended by the American Academy of Pediatrics.²⁵⁴ The model is especially effective in rural communities, where there are high rates of poverty and uninsured children, and access barriers may include health professional shortages and transportation restrictions.²⁵⁵ Data from West Virginia show higher utilization rates in rural compared to urban SBHCs (although urban sites have more enrolled students, consistent with differences in population for these types of community). Utilization was high for minority and uninsured children, and the model effectively made health care accessible to children with asthma, diabetes, and ADHD.²⁵⁶ The school-linked model, parking a mobile clinic on a regular basis near a school, also effectively alleviates access barriers for rural West Virginia children, including many with asthma and obesity.²⁵⁷

School-based asthma care has been shown to improve health-related quality of life,²⁵⁸ reduce hospitalizations, emergency department utilization, and school absenteeism for asthma.^{259,260,261} In a 2004 study done in Cincinnati, Ohio, it was estimated that school-based asthma care saves up to \$970 per child primarily through prevention of hospital and ED use.²⁶²

The Society for Adolescent Medicine endorses SBHCs as an essential model to deliver health promotion and prevention services to adolescents, bridging barriers to access that might otherwise exclude youth from health care services.²⁶³ School-based health centers have been effective in increasing access to primary care services for adolescents, reducing ED utilization and increasing receipt of preventive services including vaccinations (influenza, tetanus booster, hepatitis B). These improvements in health utilization were especially noted among minority and uninsured youth.²⁶⁴

Health centers in high schools also provide comprehensive medical and mental health services for a wide range of complex issues including asthma, weight management, HIV, depression and suicidal-

ity, eating disorders, and substance abuse.²⁶⁵ Adolescents are significantly more likely to seek mental health care from a SBHC than from a community health center.²⁶⁶

Despite their location within the school building, evidence that participation in SBHCs improves academic outcomes is not consistent. In one study of sixth through twelfth graders, those enrolled in an SBHC were more likely to complete school and graduate.²⁶⁷ A review of the literature on SBHCs and academic performance found some evidence that use of an SBHC was associated with improvements in at least one indicator of better academic performance (absence, tardiness, graduation, disciplinary actions, standardized test scores, grades, and educational aspirations).²⁶⁸ A study of the impact of school-based health center use on academic outcomes conducted at 14 SBHCs in Seattle, Washington between 2005 and 2008 found that attendance (fewer missed school days for illness) increased significantly for users of the SBHC medical services. There was no change in disciplinary actions (suspensions, expulsions) based on SBHC use. In terms of academic success grades improved over time for students who used SBHC mental health services, but not those who used SBHC medical services.²⁶⁹

D. Co-location and Integration of Mental Health and Primary Care Services

Primary care settings have become an entrance point for patients to receive mental health services as well as one of the principal locations for delivery of mental health care. Integrating mental health services in primary care reduces the likelihood that initial mental health appointments will be missed with no intervention taking place following referral. Lack of follow-through at specialty mental health facilities often results in families discontinuing treatment prematurely, including use of prescribed psychotropic medications.²⁷⁰

Facilitating access to mental health care has the potential to save overall health care costs by reducing the higher utilization of health care services by patients with psychiatric disorders. Integrated health care models also encourage screening and identification for psychiatric disorders, reduce the burden for primary care providers to manage them, and reduce the need to make, track and follow up external referrals.²⁷¹ This is important to the primary care provider because, based on a study in more than 200 primary care practices, as many as 16% of pediatric patients 4 to 15 years old present psychosocial issues at primary care visits. Significant barriers to successful referral for mental health services were frequently reported.²⁷²

Three approaches have been identified for integration of pediatric primary care and mental health services: consultation, co-location and collaboration-integration. The consultation model uses face-to-face, telephone or video (telepsychiatry) linkages among primary care and mental health providers and is especially useful in underserved communities. Co-location models have mental health providers present at the primary care site, which facilitates access but not necessarily integration of services. The collaborative-integrative approach links primary care and mental health services together for comprehensive care in the medical home model. Use of a shared electronic health record contributes to service integration.²⁷³

Co-location of mental health and primary care providers is generally a feature of comprehensive school-based health centers. The patient's familiarity with the primary care provider and the service delivery site may reduce the sense of stigma sometimes associated with seeking mental health care. Primary care and mental health providers, using procedures that safeguard patient confidentiality, may share information to ensure seamless, holistic care that comprehensively meets patient needs. Steps are taken to ensure that children entering care for mental health services also receive pediatric care in a medical home model.²⁷⁴

One study of the efficacy of mental health integration in primary care for adults found that co-location and uniform screening for relatively common conditions like depression increased the number of patients properly identified as needing mental health services and improved their access to care. There also was an increase in evidence-based depression treatment for these patients.²⁷⁵ Similar positive results have been reported from a program co-locating mental health services with primary care for inner city adolescents.²⁷⁶

The best evidence for the clinical efficacy of mental health and primary care co-location comes from studies of the comprehensive school-based health center model. The American Academy of Pediatrics (AAP) found that that from 40% to 60% of families who begin psychotherapy in traditional clinical settings terminate care after attending only one or two sessions. As an alternative, the AAP has endorsed school-based mental health care as an effective treatment model.²⁷⁷

Children and youth who receive school-based services are comparable in their exposure to psychosocial stressors and severity of need to children receiving mental health services at community clinics. School-based programs that emphasize prevention may uncover psychopathology comparable to that

seen among patients referred to community-based mental health centers.²⁷⁸ Treatment outcomes are also comparable. A study of the efficacy of school-based mental health services at 36 inner city schools found that the duration of completed treatment at school was shorter than in community clinics. The intensity of services was comparable, however, as was the degree of clinical improvement.²⁷⁹

In April 2009 the AAP Task Force on Mental Health, together with the American Academy of Child and Adolescent Psychiatry Committee on Health Care Access and Economics, published recommendations to improve child access to mental health services by alleviating administrative and financial barriers to child access and interdisciplinary collaboration.²⁸⁰ These recommendations, intended to facilitate access to care and promote the integration of mental health and pediatric primary care in a medical home model, include:

- Use of standardized developmental and mental health screening tools in primary pediatric care to facilitate early identification ;
- Training to improve the pediatrician's ability to identify and initially manage common mental health conditions;
- Development of collaborative interdisciplinary relationships to facilitate referral for more intensive intervention when indicated;
- Improved communication between primary care providers and mental health professionals to ensure integration of care initiated at mental health service sites;
- Use of health information technology including electronic health records and telepsychiatry to improve care coordination; and
- Administrative and fiscal policy changes to support and incentivize integration of mental health care into primary pediatric care.

The Task Force found that barriers to effective service integration include:

- Inadequate reimbursement for identification and management of mental health problems in the pediatric setting, including insurance restrictions on payment to pediatricians who bill for a patient with a primary diagnosis of a psychiatric disorder;
- Lack of a payment mechanism for "collateral" contacts such as consultation with parents of pediatric patients, with teachers, and with early interventionists as are necessary to manage child mental health problems;

- Inadequate or no reimbursement for addressing psychosocial problems that are presented in the primary care setting; and
- Reimbursement restrictions on payment for mental health treatment in the pediatric setting because of the mental health professional's credentials, e.g., social workers, licensed clinical counselors.

E. Integration of Developmental Surveillance and Screening in Primary Care

The AAP recommends that primary care providers integrate regular developmental surveillance and screening into their practice starting at well baby visits. This should include screening for early developmental delays, ASD, and mental health problems.²⁸¹ The use of standardized screening instruments facilitates early identification and referral, and integration of developmental surveillance and screening as part of a comprehensive medical home model.²⁸²

The validity of a screening tool is a composite of different measures of reliability. Two of the principal indicators of reliability are sensitivity, whether the screening tool identifies children who are targeted (few false negatives) and specificity, whether it over-identifies children for assessment and intervention (few false positives). There are two general models for developmental screening instruments, "observation" (administration by the primary care provider or other professional) and "parent report" (forms filled out by the parent/caregiver or by the provider who interviews the parent/caregiver). In some protocols, screening forms are filled out at home and sent back to the provider, with a subsequent visit being scheduled to follow up positive screening results.²⁸³

There are many developmental screening tools available for use in pediatric primary care.²⁸⁴ Some are sufficiently brief to be included in well visits, and others that take 20 minutes or longer may be done at a separate, billable visit. There are now parent report screening tools such as the Parents' Evaluation of Developmental Status (PEDS) and Ages and Stages Questionnaire (ASQ) which have comparable validity as pediatrician-administered screenings.²⁸⁵ These are also effective in detecting behavioral and emotional problems in preschool-age children.²⁸⁶ Comparing results of one parent-report screening with pediatrician observation, it has been established that two-thirds (67.5%) of children who screened positive for developmental delay were not identified by the pediatrician without the use of a screening tool.²⁸⁷ There are also many reliable screening instruments intended for the early identification of behavioral and social-emotional problems.^{288,289}

Primary care pediatric providers may offer mental health screenings for parents. In addition to identifying these adult mental health service needs, interventions for parents with depression and other psychiatric conditions may additionally prevent developmental and mental health problems in their children. Readily available screening tools for maternal depression include a nine item questionnaire which can be shortened further in a validated protocol consisting of only two items.²⁹⁰ The CES-D, a twenty-item screening questionnaire developed by the NIMH, generates numeric scores that identify symptoms consistent depression and symptoms consistent with major depressive disorder. The scoring protocol facilitates tracking patient progress over time through periodic rescreening.²⁹¹ Screening instruments to identify intimate partner violence are also available.²⁹² Interventions may prevent the developmental, mental health and school problems often experienced by children exposed to intimate partner violence.^{293,294}

There should be a continuum of screening in primary care that includes older adolescent patients to identify later onset of developmental, learning and mental health problems. For school-age children, the AAP recommends use of the Pediatric Symptom Checklist (PSC), an open access screening tool that is readily available on-line. This brief psychosocial screening instrument is used to identify children as young as four years of age and adolescents up to age 16 with possible depression, anxiety, and social problems.²⁹⁵

Integrating standardized screening tools into primary care for adolescents improves the quality of preventive services and identifies youth who should be referred for counseling and/or mental health assessment.²⁹⁶ Screening for psychosocial risk factors is essential to adolescent primary care because, according to the Centers for Disease Control and Prevention (CDC), nearly three fourths of deaths of youth 10-24 years old attributable to psychosocial issues: accidental injuries including motor vehicle accidents (45%), homicide (15%) and suicide (12%).²⁹⁷

Two validated psychosocial screening instruments designed for primary care use are the GAPS (Guidelines for Adolescent Preventive Services), a 52-item questionnaire developed by the American Medical Association, and the HEADSS (Home, Education, Alcohol, Drugs, Smoking, Sex), which is somewhat shorter.²⁹⁸ The HEADSS has been effectively used with high-risk adolescents including homeless and runaway youth.²⁹⁹ These instruments are designed to engage the adolescent in conversation about risk-taking behavior and other signs of possible behavioral or emotional problems so

the primary care provider can initiate counseling.³⁰⁰ The adolescent version of the American Academy of Pediatrics Bright Futures Pediatric Symptom Checklist (the PSC-Y) has been successfully used in SBHCs to identify and refer adolescents for mental health services. This intervention has been noted to improve school attendance.³⁰¹ Use of these instruments is also recommended by the Society for Adolescent Medicine.³⁰²

Despite these recommendations and the ready availability of validated screening tools, however, systematic study of screening practices in primary care settings shows that standardized screening is not sufficiently done. As a consequence, serious psychiatric problems may not be identified. Studies show as few as 25% to 33% of adolescents with clinical depression receive the mental health care that they need.³⁰³ Identification in primary care is essential to the treatment and management of adolescent depression and anxiety disorders.^{304,305}

In April 2009, after thorough review of the evidence, the U.S. Preventive Task Force published its recommendation that children and adolescents (seven to 18 years of age) be screened in pediatric primary care for depression. Screening tools for depression include the Patient Health Questionnaire for Adolescents (PHQ-A) and the Beck Depression Inventory-Primary Care Version (BDI-PC). Their use contributes to early detection and treatment of adolescent depression, which in turn is associated with improved clinical outcomes.³⁰⁶ The adoption of this standard by the U.S. Preventive Task Force indicates that the evidence for the validity of the screening protocols and the efficacy of interventions has been well established.

CHAPTER 6: EVIDENCED-BASED INTERVENTIONS THAT WORK

1. Community Health Centers (CHCs) have been shown to effectively reduce health care disparities and improve health outcomes of individuals with chronic health conditions.
2. Mobile Medical Clinics (MMCs) have proven effective in bridging access gaps for high-risk populations and in being cost-effective.
3. School-based asthma care has been shown to improve health-related quality of life, reduce hospitalizations, ED utilization, and asthma-related school absenteeism, leading to significant cost savings.
4. School-Based Health Centers (SBHCs) have been shown to be effective in increasing access to primary care services, reducing ED utilization, and increasing receipt of preventive services including vaccines. School-based mental health care has efficacy comparable to that in community mental health clinics.
5. Integrating mental health services into primary care settings is ideal because it increases the likelihood of early identification and management and that initial and subsequent mental health appointments will be kept.
6. The American Academy of Pediatrics strongly recommends that pediatric primary care providers integrate developmental and mental health screening tools into their practice, using them during Health Care Maintenance (HCM) visits from infancy into young adulthood.

SEVEN: SUMMARY

While multiple factors affect academic success, and many of these factors are not amenable to clinical intervention and control (e.g., neighborhood characteristics and school quality), there is evidence that improving access to high quality comprehensive health care for medically underserved children – children who are also at the highest risk of school failure – reliably improves their health status. Using a risk-based model, we conclude that providing quality health care removes potential barriers to optimal academic performance and improves opportunities for success. Especially for children with chronic conditions such as asthma, improvements may be seen in fewer school days missed because of illness including reduced hospital emergency department use and improved ability to focus attention on learning activities during the school day.

Comprehensive health care services include formal screening to identify developmental delays, which may prevent later behavior and psychiatric disorders. Early identification also allows for early intervention to remediate deficits, which further improves the child’s opportunities for academic success. Bringing mental health services into the primary care setting and integrating these into a seamless system of care improves access to mental health services and may prevent some of the later impact of psychiatric disorders on life outcomes. There is a clear relationship between psychiatric disorders and school problems including high school drop out, and evidence that receiving needed mental health care improves academic outcomes. Learning disorders and mental health problems are disproportionately seen among youth in the juvenile justice system. There is an enormous economic impact to society attributable to persistent psychiatric disorders because of their association with lower wages or inability to work.

When pediatric care is comprehensive, continuous and coordinated, and incorporates evidence-based pediatric practices, facilitates access to specialists, and integrates mental health care, we have an “enhanced medical home” model. This model includes formal developmental and mental health surveillance, screening and referral. Early identification and intervention for developmental and mental health conditions is associated with better social and academic outcomes.

For medically underserved children, federally qualified health centers comprise an important element of the health care safety. However, there are serious shortages of primary care, mental health and oral health providers, leaving many high-risk areas medically underserved. Some communities,

especially in rural counties, are geographically isolated from existing health care resources, with transportation being a serious barrier to health care access. Alternative modes of service delivery are also important components of the health care safety net. These include use of mobile clinics and school-based health centers to bring comprehensive care to children and youth who would otherwise not have adequate access. These alternative models are especially important to increase access for transient and other vulnerable populations (e.g., homeless, foster care), and for children in health professional shortage areas.

While millions of children experience significant barriers to primary pediatric care access, there are still greater barriers to access of mental health and other specialist care. The pediatrician is a gateway to the range of services that children require to develop their full potential and succeed in school and in their adult life – which is why comprehensive, holistic health care in an enhanced medical home model is crucial to the health and well-being of our highest risk children.

APPENDIX A: METHODOLOGY

In this literature review we used multiple data bases to identify literature in the broad range of subjects required to explore the intersection of health and mental health with educational success. In addition to the National Library of Medicine data bases (MEDLINE, PubMed and PubMed Central), several EBSCO data bases were used: Academic Search Premier, CINAHL, Education Research Complete, Professional Development Collection and National Criminal Justice Reference Service Abstracts. Other data bases used were PsychInfo and PsychArticles, ERIC (Educational Resource Information Center), ProQuest, Sage Full Text Collection, Gale Virtual Library, and Highwire Press. Google and Google Scholar searches were done for each topic area. This array of data bases provided access to reports and articles in peer-reviewed journals in the fields of medicine, psychology and psychiatry, education, social work, developmental disabilities and rehabilitation, early childhood education, and health law and policy.

While we focused on articles published since 1998, we did not exclude older articles if relevant. Our principle inclusion criterion was that the article had to be available in full text through one of these data bases or the publisher's website as of May 15, 2010. This led to the exclusion of some relevant earlier articles if the publisher's online full text archive did not extend back to the publication date, and the exclusion of any article which was not available as of our cut-off date.

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