



MAINE DEVELOPMENTAL DISABILITIES COUNCIL

ADVOCACY, CAPACITY BUILDING, SYSTEMIC CHANGE

DEVELOPMENTAL DISABILITIES PREVENTION COMMISSION:

Preliminary Report

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LD 1364:

*Resolve, Regarding Opportunities to Decrease Occurrence of
Developmental Disabilities and Mental Health Challenges in Children*

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EXECUTIVE SUMMARY

This report is the first phase in a multi-stage program to identify opportunities for the prevention of developmental disabilities. Authorized by the passage of LD 1364, a Resolve, Regarding Opportunities to Decrease Occurrence of Developmental Disabilities and Mental Health Challenges in Children (aka “DD Prevention Commission”), this preliminary report presents a brief synopsis of developmental disabilities and an overview of some factors that may play a role in causing developmental disabilities.

At the most basic level, a developmental disability is one that occurs during the developmental period (childhood) and results in limitations in major life areas. There are a variety of conflicting definitions that fall under the heading of developmental disability. Many focus on “diagnostic medical labels” such as autism, mental retardation, or cerebral palsy. For nearly thirty years medical labels have been recognized as a poor way to define developmental disability. A better way is to assess an individual’s functional ability.

For this report, the Commission chose to use the Federal definition, the most widely used. This definition focuses on the functional impact of a diagnosis, defining developmental disabilities as: attributable to a mental or physical impairment or combination of mental and physical impairments that are manifested before the individual attains age 22, likely to continue indefinitely, and result in substantial functional limitations in 3 or more areas of major life activity. This includes severe mental illness, as long as the symptoms meet the criteria for developmental disabilities.

Preventing developmental disability is both important to society and cost effective. Disabilities impose significant quality of life and monetary costs on individuals, families, and communities. While the monetary savings from prevention are easier to quantify in terms of dollars saved on expensive medical care or increases in productivity, the intangible costs to individual lives are even more significant, though much more difficult to assess. Recognizing the costs associated with developmental disabilities and attempting to minimize them, however, should in no way be seen as a lack of recognition of the contributions made by those individuals, their value, the satisfaction in their lives, and the benefits these individuals bring to their families, communities, and society as a whole.

FACING AN EPIDEMIC?

- Nearly 12 million children (17%) nation-wide suffer from developmental disabilities and 2% have a “severe” developmental disability such as autism, mental retardation, or cerebral palsy¹

¹ Coleen Boyle. *Testimony on the Prevention of Developmental Disabilities*. House Committee on Governmental Reform. 2000. [available on-line] <http://www.bhs.gov/asl/testify/t000406c.html>.

- The incidence of autism may be as high as 2 per 1000 children, with several studies showing the rate increasing²
- 17.7% of all students in Maine received special education services in 2002, up from 10.6% in 1990³
- 21% of U.S. children ages 9-17 have a diagnosable mental or addictive disorder
- A five point decline in the average IQ will result in a 57% increase in the mentally retarded population nation-wide⁴

Only in rare cases are developmental disabilities caused by a single factor, such as a genetic abnormality. In most cases, it is impossible to determine an exact cause because the disability arises through the complex interaction of genetic, environmental, and social factors. Not all developmental disabilities are preventable, but awareness of the potential role of various factors in disability makes elimination of the factors that we can control possible.

IDENTIFYING CAUSES: COMPLEX FACTORS, COMPLEX INTERACTIONS

This report examines factors from four major areas that can play a role in causing developmental disabilities: Public Health, Injury and Abuse, Genetics, and Environmental Toxins. Each section of this report highlights some issues that are currently thought to play a role, sometimes cumulatively, in causing developmental disabilities.

PUBLIC HEALTH

Issues such as tobacco and alcohol use and abuse, immunization, and childhood disease all can play a role in causing developmental disabilities.

- Alcohol abuse can cause fetal alcohol syndrome (FAS), which can cause a range of defects and deficits including craniofacial, limb, and cardiovascular defects associated with growth and developmental delays that can result in a wide variety of clinical manifestations.
- The nicotine in tobacco smoke makes children of smokers much more likely to be born with low birth weight, which puts them at risk for a variety of other birth complications and developmental disabilities.

² Greater Boston Physician's for Social Responsibility, *In Harms Way: Toxic Threats to Child Development*. Cambridge, MA. 2000 p. 10-11. [available on-line] <http://www.igc.org/psr>.

³ Maine Department of Education. Special Education Data. [available on-line] <http://www.state.me.us/education/specedddata/14yeardata.htm>.

⁴ Greater Boston Physician's for Social Responsibility, *In Harms Way: Toxic Threats to Child Development*. Cambridge, MA. 2000 p. 16. [available on-line] <http://www.igc.org/psr>

- Immunizable diseases such as rubella and chickenpox, two very common illnesses, can cause developmental disabilities when the mother contracts the disease during certain periods of pregnancy. For example, congenital varicella syndrome, caused by chickenpox, is a rare syndrome that can result in birth defects including scars, defects of muscle and bone, malformed and paralyzed limbs, a smaller-than-normal head, blindness, seizures, and mental retardation.

INJURY AND ABUSE

Injuries that cause trauma to the brain and child abuse are both substantial causes of developmental disabilities.

- Child abuse can be a substantial factor in causing disability. Data collected in the early 1990s for The National Clearinghouse on Child Abuse and Neglect showed the incidence of disabilities caused or likely to have been caused by maltreatment to be 147 per 1,000 maltreated children.⁵ Near-fatal child maltreatment leaves 18,000 children permanently disabled each year.⁶ Developing a disability then makes a child more likely to be subject to further abuse.
- Near drowning, car accidents resulting in head trauma, airway obstruction, and electrical shocks or lightning strikes can cause accidental brain damage. Brain injury can cause many kinds of physical, cognitive, and behavioral/emotional impairments that may be either temporary or permanent and may range from subtle to severe.

GENETICS

Developmental disabilities caused by gene abnormalities are the most likely to have a specific and identifiable source. Some genetic conditions are inherited, while others are the result of specific mutations that occur during the early part of development.

- Widespread newborn screening programs now identify many infants with rare genetic conditions, the impact of many of which can be effectively mitigated through diet or other specifically targeted interventions.
- Risk factors for certain disabilities have been identified. For example, women over 35 are at a significantly increased risk for carrying a fetus with Down Syndrome. For conditions like cystic fibrosis and Fragile X syndrome, which can cause mental retardation and learning disabilities, genetic testing for the parents may identify if one or both of the parents are carriers of the recessive/dominant genes or mutations that cause these conditions.

⁵ <http://www.ahsc.arizona.edu/acainfo/disabilities.htm>

⁶ United States Department of Health and Human Services, 1995, cited in *Testimony in front of the House Committee on Education and the Workforce Select Education Subcommittee: Child Abuse Prevention and Treatment Act*. [available on-line] http://www.c-c-d.org/testimony_capta.htm.

ENVIRONMENTAL TOXINS

Only in recent years have public health officials and researchers begun to grasp the full range of impact of neurotoxins on child development. Recent progress in understanding the development of the neurological system and an explosion of research into cognitive functions like attention and memory are beginning to create a picture of the impact neurotoxic chemicals commonly present in our environment may have on developmental disabilities. Lead, mercury, dioxins, and PCBs and pesticides are commonly found in our environment and can play a particularly significant role in causing developmental disabilities.

- According to the Environmental Protection Agency's Toxics Release Inventory, in 1997 over 1 billion pounds of known or suspected neurotoxic chemicals (chemicals that interfere with the development of the brain and neurological system) were released into the environment.⁷ Most chemicals, however, have not been evaluated for their toxicity to animals or humans.
- For many chemicals like lead and mercury, recent studies have shown that there is no safe exposure level. Even at currently acceptable levels, children's health may be compromised by exposure.

RECOMMENDATIONS

Maine has many programs that may, both directly and indirectly, help to prevent developmental disabilities. The Commission discovered many resources, including a previously existent developmental disabilities prevention law, Title 22, chapter 962, which requires action on the part of state departments. This preliminary report reflects on the existing programs and law to offer legislative recommendations. As a preliminary report these recommendations are by no means comprehensive. That being said, there are several recommendations that are recognized as prudent at this time:

From this initial phase the Commission has three recommendations:

1. Continue the work of the Commission for at least another year with a second report to the Health and Human Services Committee in January 2005

Continue the work of the Commission for at least another year. This additional time will allow the Commission to hold public forums and comprehensive meetings with interested individuals, advocacy groups, and experts to review and strengthen this report and generate fully informed recommendations for a more comprehensive prevention system.

⁷ Greater Boston Physician's for Social Responsibility, *In Harms Way: Toxic Threats to Child Development*. Cambridge, MA. 2000 p. 5. [available on-line] <http://www.igc.org/psr>.

2. Clarify the definition of developmental disability in Maine statute Title 22 chapter 962 – Prevention of Developmental Disabilities.

The term developmental disability exists in many parts of the Maine code, but is only defined in one section: Title 5, chapter 511, §19503, which uses the federal definition. For clarity, Title 22 chapter 962 should be amended to reflect the definition in Title 5. This will provide a concrete definition to be used by the state departments for their reporting requirements under this chapter.

3. Bring attention to the reporting requirements in Title 22 chapter 962 – Prevention of Developmental Disabilities.

The Commission requests that the Health and Human Services Committee send a letter to the Commissioners of the departments of Education, Health and Human Services, and Behavioral and Developmental Services requesting that they report on the prevention activities they have conducted, as required in Title 22 chapter 962 – Prevention of Developmental Disabilities.

INTRODUCTION

In the first half of the 121st Legislative Session, the Health and Human Services Committee approved LD 1364: Resolve, Regarding Opportunities to Decrease Occurrence of Developmental Disabilities and Mental Health Challenges in Children, and requested that the Maine Developmental Disabilities Council (MDDC) spearhead an effort to meet the goals of this Resolve. To this end the “DD Prevention Commission” was formed.

The principle work of this Commission is to identify opportunities for the State to prevent developmental disabilities and childhood mental health challenges. To streamline its broad topical mandate, MDDC determined to focus the Commission on the following objectives:

- A. Define the term “developmental disability” as it is used in this context, including the relationship between developmental disabilities and mental health issues;
- B. Perform a preliminary survey of current research into the causes of developmental disabilities and mental health issues in order to more narrowly focus future objectives;
- C. Re-examine the 1985 report “Every Child a Healthy Child” created by the Select Committee for the Prevention of Developmental Disabilities, and assess the status of the resulting legislation;
- D. Provide a “snapshot” of Maine’s efforts at prevention in order to assess need; and,
- E. Make recommendations for legislation to the Health and Human Services Committee, with the goal of moving the State closer to best practices in preventing developmental disabilities and childhood mental health challenges.

PROJECT PHASES

As the body of research about causes of developmental disabilities grows, it becomes apparent that many of these disabilities are not caused by a single factor, but rather by complex interactions of overlapping factors such as genetic predisposition, environmental toxins, impoverished social environments, and injury or abuse. The nature of these interactions results

in the need to investigate across disciplines, subject matters, and issues, making the study and prevention of disability complex and multi-faceted.

This preliminary report is a first phase. Its aim is to clarify the term developmental disability, present an initial investigation of the various relevant factors that may cause developmental disabilities, and suggest some initial recommendations for legislation and action.

In the second phase, input will be sought from various participants who have an expertise in the fields of developmental disabilities. These participants will include members of advocacy organizations, providers of services to people with disabilities, medical or other professionals who treat or examine conditions associated with disabilities, caregivers to those with disabilities, and most importantly, people with disabilities who can speak to their experiences and advise on potential prevention solutions.

In the third phase, the results of the input process will lead to further research and evaluation. The initial determining factors will be narrowed and focus will be placed on those factors that seem most likely to create systems change through interventions that can be initiated at the policy level; in other words through legislative action. There may be other programmatic ideas that emerge beyond the scope of legislation. It is hoped and expected that the partnerships developed through the input process will also serve as fertile ground for these sorts of interventions.

The fourth phase may be considered to be a new beginning, where programs are created and implemented as a result of policy interventions.

VALUING PREVENTION

Prevention of developmental disabilities is an important, society-wide effort. Developmental disabilities and the associated secondary conditions they can cause have a profound impact on the individuals and families directly affected, their communities, and society as a whole. This impact can be identified and described in many different ways, each reflecting emphasis on

different variables and factors. Three types of costs will be briefly described in this section: (1) direct costs, or impact on resources; (2) indirect costs, or the impact on productivity; and, (3) intangible costs, or the impact on quality of life.

For the purposes of this report, direct costs are defined as those having a specific measurable financial impact, such as the cost of medical care, assistive devices, and administrative expenses associated with the disability. These direct costs affect individuals and families as well as the providers of medical and related services.

Indirect costs reflect long-term economic consequences, such as sustained un-or-under-employment. These economic factors can lead to life-long economic struggle for individuals and families/caregivers, and can increase the governmental and social services needed to address medical care, poverty, and loss of productivity, which additionally impact the funds available for these services through reduced tax revenues.

Finally, intangible costs, though profoundly real, are harder to quantify as they do not directly impact economic variables. Many cost analyses of the benefits of prevention avoid tackling these difficult consequences because the impact is so difficult to quantify. Nevertheless, the impact of intangible costs such as impact on quality of life and relationships, physical and emotional suffering, and reductions in independence and community participation are no less real or devastating for both families and communities.

Both monetary and quality of life costs need to be considered when assessing the cost/benefit value of prevention efforts and the allocation of resources. Various perspectives and methodologies can be used to calculate the value of prevention, suggesting monetary cost savings that vary based on the type of analysis and the type of disability. However, the final conclusion of most assessments is that prevention of disabilities is very cost effective. Estimated savings for direct medical care costs alone are impressive. One study states that, on average, Americans with disabilities spend more than four times as much on medical care, services, and

equipment as their non-disabled counterparts.⁸ When the costs of decreased productivity and lost income are also factored in, prevention clearly makes good economic sense. This does not begin to cover the benefits of prevention in terms of intangible costs, whose significance cannot be undervalued.

As knowledge of the impact of various factors such as environmental pollutants and social variables grows, it becomes clear that programs targeting these potential causes of developmental disability make good sense. While some of the interventions discussed in this report may have only limited impact on developmental disabilities on their own, the impacts of prevention activities must be looked at cumulatively rather than individually. If each prevention program effected a change of only a few IQ points, just one of many indicators used to classify developmental disabilities, many children might never be labeled as developmentally disabled. It is vitally important to recognize that a five point decline in the average IQ will result in a 57% increase in the mentally retarded population nation-wide.⁹ Given statistics like these, and knowing the costs of disability, we must focus as much energy as possible on all aspects of prevention.

CAVEAT

When discussing prevention and the costs associated with developmental disabilities it is imperative to recognize that this is only one small piece of a full discussion of the lives of people with developmental disabilities. While there are monetary and less tangible costs associated with developmental disabilities, a full discussion of developmental disabilities would view the costs as one of many factors in assessing the lives of those with developmental disabilities and the impact these individuals have on the world around them. Recognizing the costs associated with developmental disabilities and attempting to minimize them should in no way be seen as a lack of recognition of the contributions made by those individuals, their value, the satisfaction in their

⁸ Max, Wendy, Dorothy Rice, and Laura Trupin.. *Disability Statistics Abstract #12*. Department of Education, National Institute on Disability and Rehabilitation Research, 1995.

⁹ Greater Boston Physician's for Social Responsibility, *In Harms Way: Toxic Threats to Child Development*. Cambridge, MA. 2000 p. 16. [available on-line] <http://www.igc.org/psr>

lives, and the benefits these individuals bring to their families, communities, and society as a whole.

DEFINING DEVELOPMENTAL DISABILITY

At the most basic level, a developmental disability is one that occurs during the developmental period (childhood) and results in limitations in major life areas. There are a variety of conflicting definitions that fall under the heading of developmental disability. Many focus on “diagnostic medical labels” such as autism, mental retardation, or cerebral palsy. This is not really a definition in the true sense but rather a laundry list of labels that “qualify” a person to be considered developmentally disabled, the purpose of which is either to identify a person as eligible for some service or program or to exclude. Not only does this set the stage for discrimination, it is impractical, since a medical label does not define actual need nor does it serve as logical rationale for exclusion.

For nearly thirty years it has been recognized that medical label is a poor way to define developmental disability. A better way is to assess an individual’s functional ability. Ironically, despite the decades of knowledge that functional ability is a more accurate and practical way to define developmental disability, few states in the country use a functional definition to identify those who are eligible for services, even though the federal government recognized this more “modern” approach long ago. This lack of enlightenment on the state level often results in inconsistency, frustration, and even discrimination. Further, there is no logical reason to be wedded to a medical criteria since a functional definition can be used to match services with those who have a certain level of functional limitation, in the same way a medical criteria can be used to limit services.

The most widely accepted definition of developmental disability focuses on the impact of the condition, rather than whether its label is included on a list. As stated in the Developmental Disabilities Assistance and Bill of Rights Act (DD Act)¹⁰, a developmental disability includes any condition that leads to:

a severe, chronic disability of an individual that –

- (i) is attributable to a mental or physical impairment or combination of mental and physical impairments;

¹⁰ PL 106-402, October 20, 2000.

- (ii) is manifested before the individual attains age 22;
- (iii) is likely to continue indefinitely
- (iv) results in substantial functional limitations in 3 or more of the following areas of major life activity:
 - (I) Self-care
 - (II) Receptive and expressive language
 - (III) Learning
 - (IV) Mobility
 - (V) Self-direction
 - (VI) Capacity for independent living
 - (VII) Economic self-sufficiency; and
- (v) reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

**** INFANTS AND YOUNG CHILDREN** – An individual from birth to age 9 inclusive, who has a substantial delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting 3 or more of the criteria described above if the individual, without service or supports, has a high probability of meeting those criteria later in life.¹¹

In this report, we will follow the federal definition when referring to developmental disabilities.

MENTAL HEALTH, MENTAL ILLNESS, AND DEVELOPMENTAL DISABILITY

Mental health is fundamental to overall health and an essential component for reaching full developmental potential. “From early childhood until death, mental health is the springboard of thinking and communication skills, learning, emotional growth, resilience, and self-esteem . . .

¹¹PL 106-402 sec. 102 (8).

the ingredients of each individual's successful contribution to community and society".¹² The phrase "mental disorder" refers to health conditions characterized by alterations in thinking, mood, or behavior (or a combination) associated with distress and/or impairment for a specified time period. Mental illness is a term that refers collectively to all diagnosable mental disorders. Mental health problems are signs and symptoms of insufficient intensity or duration to meet the criteria for a diagnosable mental disorder. Mental disorders result from the interaction of biological, psychological, and social factors. Mental health and mental illness are best seen as points on a continuum rather than opposite states.

For many years, mental disorders were not considered illnesses in the same way that cancer or heart disease are. Even today, as the Surgeon General's Report on Mental Health notes, our current language usage "encourages a misperception that mental health or mental illness is unrelated to physical health or physical illness".¹³ This could not be further from the truth. Mental illness is a disease of a specific organ -- the brain -- that has serious and significant impact on peoples' lives, ranking second only to cardiovascular conditions in overall disease burden world wide, as assessed in the Global Burden of Disease Study conducted by World Health Organization, Harvard University and the World Bank¹⁴.

Mental disorders are disabling. When compared with other diseases, mental illness - including depression, bi-polar disorder, and schizophrenia - ranks first in terms of causing disability in the US.¹⁵ When the burden of each disease is calculated, major depression is equivalent to the burden of blindness or paraplegia and active psychosis as seen in schizophrenia is equal in disability burden to quadriplegia.¹⁶ Though perceptions of mental illness are beginning to

12 U.S. Department of Health and Human Services. *Mental Health: A Report of the Surgeon General—Executive Summary*. Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institutes of Health, National Institute of Mental Health, 1999, p. 4-5.

¹² Ibid.

¹³ Ibid.

¹⁴ Ibid. p.4.

¹⁵ The President's New Freedom Commission on Mental Health. *Achieving the Promise: Transforming Mental Health Care in America*. Rockville, MD. 2003. [On-line]. Available: <http://www.mentalhealthcommission.gov/reports/FinalReport/toc.html>

¹⁶ U.S. Department of Health and Human Services. *Mental Health: A Report of the Surgeon General—Executive Summary, Chapters 1&3*. Rockville, MD: U.S. Department of Health and Human Services Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institutes of Health, National

change, the stigma attached to mental disorders continues to make treatment and prevention difficult, and leaves many without help.

There is a looming public crisis in the mental health of infants, children, and adolescents. 21% of U.S. children ages 9-17 have a diagnosable mental or addictive disorder. 11% of children in this age range - or 4 million youth - would meet criteria for significant functional impairments at home, school, or with their peers and 5% could be categorized as having an extreme functional impairment.¹⁷ In a recent study, the World Health Organization found that one in ten young people suffers from mental illness severe enough to cause some level of impairment, yet fewer than one in five receives the needed treatment (World Health Organization pp.36). In the U.S. 70% of children in need of mental health treatment do not receive it.¹⁸

In most cases, once diagnosed, mental illness can be treated effectively. Diagnosis of mental disorders is always complicated, but is even more so when it comes to children. Most diagnostic criteria are created for adults and can be difficult to apply when diagnosing a child as the signs and symptoms of mental disorders are often also the characteristics of normal development in children and symptoms may often wax and wane as children age.

For children with a “serious emotional disturbance” (approximately 5-9 percent of children¹⁹) their mental illness severely disrupts social, academic, and emotional functioning. Like conditions such as autism, cerebral palsy, and mental retardation, when mental illness impacts three or more life areas and is likely to continue indefinitely, or in the case of children up to and including age 9, when the individual without supports and services is likely to meet those criteria later in life, the individual has a developmental disability. In this report, when the phrase developmental disability is used, it includes those whose mental illness meets the criteria outlined above for developmental disability.

Institute of Mental Health, 1999, p. 4. [On-line]. Available:
<http://www.surgeongeneral.gov/library/mentalhealth/home.html>

¹⁷ Ibid p. 124-125.

¹⁸ Ibid, p.180

¹⁹ The President’s New Freedom Commission on Mental Health. *Achieving the Promise: Transforming Mental Health Care in America*. Rockville, MD. 2003. [On-line]. Available:
<http://www.mentalhealthcommission.gov/reports/FinalReport/toc.html>

FACING AN EPIDEMIC: INCREASING RATES OF DEVELOPMENTAL DISABILITIES

- Nearly 12 million children (17%) nation-wide suffer from developmental disabilities and 2% have a “severe” developmental disability such as autism, mental retardation, or cerebral palsy²⁰
- The incidence of autism may be as high as 2 per 1000 children, with several studies showing the rate increasing²¹
- 17.7% of all students in Maine received special education services in 2002, up from 10.6% in 1990²²
- 21% of U.S. children ages 9-17 have a diagnosable mental or addictive disorder

Many scientists now believe that most developmental disabilities arise from complex interactions between genetic and environmental factors rather than from genes alone, while only a small number of developmental disabilities have been shown to be caused exclusively by genetic factors.

IDENTIFYING CAUSES: COMPLEX FACTORS, COMPLEX INTERACTIONS

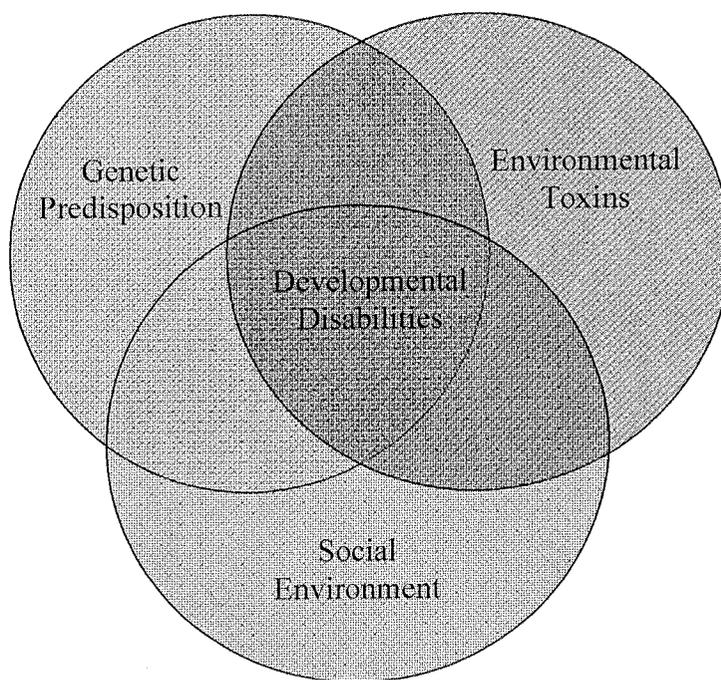
We now know that in the vast majority of cases developmental disabilities develop through complex interactions between a child’s environment and his/her genetic make-up rather than from a single source. Even for those developmental disabilities for which a single cause can be identified, the impact of the disability on the individual’s ability to function in society is highly influenced by that individual’s surrounding environment. This makes establishing an exact cause for a disability, and the abilities that a person with that disability will have, very difficult. It also means that interventions designed to prevent developmental disabilities must involve areas that have not always been seen as related, such as industrial pollution and poverty

²⁰ Coleen Boyle. *Testimony on the Prevention of Developmental Disabilities*. House Committee on Governmental Reform. 2000. [available on-line] <http://www.hhs.gov/asl/testify/t000406c.html>.

²¹ Greater Boston Physician’s for Social Responsibility, *In Harms Way: Toxic Threats to Child Development*. Cambridge, MA. 2000 p. 10-11. [available on-line] <http://www.igc.org/psr>.

²² Maine Department of Education. Special Education Data. [available on-line] <http://www.state.me.us/education/speceddata/14yeardata.htm>.

alleviation as well as best medical practices. Complicating matters further is the process of childhood development itself. As children develop it appears that there are windows of sensitivity to certain types of impacts. This means that something that might not harm a teenager or an adult might cause significant damage to an infant.



In the next section, we will take a broad look at some of the areas now believed to play a significant role in causing and preventing developmental disabilities.

PUBLIC HEALTH

The topics included in this section are in no way meant to be a comprehensive survey of important public health issues, but rather highlight how important some initiatives can be in preventing developmental disabilities. Public health initiatives like drug abuse prevention and immunization can play a significant role in preventing developmental disabilities. For instance, alcohol abuse, smoking, and diseases that can be prevented with immunization can all play a role

in the cause or prevention of developmental disabilities. Additionally, the absence of quality pre and post natal care, routine wellness care, and adequate parenting supports can also lead to disabling conditions or exacerbate existing developmental disabilities, and in the alternative good care can help to prevent disability.

ALCOHOL ABUSE

Alcohol, when excessively consumed, is known to have serious impacts on the developing fetus. Fetal Alcohol Syndrome can cause a range of defects and deficits including craniofacial, limb, and cardiovascular defects associated with growth and developmental delays that can result in a wide variety of clinical manifestations. According to the National Organization on Fetal Alcohol Syndrome, FAS is considered the most common nonhereditary cause of mental retardation, and can cause difficulties with learning, memory, attention, and problem solving as well as problems with mental health and social interactions.²³

High alcohol exposure interferes with the development, function, migration, and survival of nerve cells, and in the embryonic cell layer that develops into the bones and cartilage of the head and face; alcohol exposure at critical stages of development induces premature cell death that is thought to be linked to the FAS facial defects. Alcohol's fetal impact is thought to be related to the peak maternal alcohol level rather than total alcohol consumed, making binge drinking more likely to result in serious injury to the fetus than the same amount of alcohol consumed over a longer time period. Recently however, studies have shown that even in smaller amounts alcohol consumption during pregnancy - as little as one drink a day - can impact the developing fetus, possibly causing impulsive behavior and deficits in memory, IQ, school performance, and social adaptability.²⁴

Unlike many other disability causes, such as environmental pollutants, which are difficult to avoid, and genetic mutations that are nearly impossible to predict, developmental disabilities related to alcohol are entirely preventable. Any actions taken to reduce

²³ National Organization on Fetal Alcohol Syndrome. http://www.nofas.org/main/what_is_FAS.htm.

²⁴ Greater Boston Physician's for Social Responsibility, *In Harms Way: Toxic Threats to Child Development*. Cambridge, MA. 2000 p. 85. [available on-line] <http://www.igc.org/psr>.

alcohol use and abuse to meet other public health goals may have the positive unintended consequence of affecting alcohol related conditions in children; however, that does not minimize the importance of directly raising awareness in the general population about the impact of alcohol consumption during pregnancy.

TOBACCO SMOKE AND NICOTINE

Both active tobacco use and environmental exposure to tobacco smoke - passive smoking - can impact fetal and childhood development. The primary toxin in tobacco smoke is nicotine. Children of smokers are much more likely to be born with low birth weight, which puts them at risk for a variety of other birth complications and developmental disabilities. These children also score significantly lower on postpartum exams such as the Brazelton Neonatal Behavioral Assessment Scales, with hearing particularly affected. The impacts of prenatal smoke exposure extend beyond infancy, with reports of diminished intellectual capacity and achievement into adulthood.²⁵

Environmental exposure to tobacco smoke, or passive smoking, also seems to interfere with brain development. Both maternal and childhood exposure appear to increase attention deficits and cause information processing problems. Children who were exposed to passive smoke in-utero performed better on intelligence tests than those of mothers who smoked, but not as well as those who were never exposed to any form of smoke.²⁶

While nicotine is the primary neurotoxic component of tobacco smoke, the other components in tobacco smoke may also contribute to low oxygen levels and impaired nutrient transfer across the placenta leading to generally retarded fetal growth. Given the impacts tobacco smoke can have on child development, preventing exposure to tobacco smoke in public spaces may have the additional benefit of preventing some developmental disabilities.

²⁵ Ibid. p. 73-74.

²⁶ Ibid. p. 74.

IMMUNIZATION AND CHILDHOOD DISEASES

Several preventable diseases are known to put developing fetuses and children at risk for developmental disabilities. For example, Rubella and Chickenpox, two very common illnesses, can cause developmental disabilities when the mother contracts the disease during certain periods of pregnancy. Congenital varicella syndrome, caused by chickenpox, is a rare syndrome that can result in birth defects including scars, defects of muscle and bone, malformed and paralyzed limbs, a smaller-than-normal head, blindness, seizures, and mental retardation.²⁷

Rubella, or German Measles, poses a serious risk to developing fetuses. About 25 percent of babies whose mothers contract rubella during the first trimester of pregnancy are born with one or more birth defects, which, together, are referred to as congenital rubella syndrome. This can cause potentially disabling conditions including mental retardation, eye defects (resulting in vision loss or blindness), hearing loss, heart defects, and, less frequently, movement disorders. Fortunately, if the mother is immune to the disease, these consequences are avoidable, making vaccination against these diseases an important factor in disabilities prevention.

Childhood infections can also cause developmental disabilities. Group B Strep infections are not dangerous to adults, but can be deadly for newborns. The infection is caused by bacteria that may be present in the mother's body and are passed to the baby at birth. The danger with the infection comes from the development of meningitis, an infection of the membranes around the brain. This can lead to lasting neurological damage in the form of cerebral palsy, sight and hearing loss, and/or mental retardation.

Other very rare diseases like polio can be important causes of disabilities as well. In most cases the infected person has only mild symptoms, however in rare cases, the virus attacks nerves inside the spine that send messages to muscles in arms, legs, and other areas. This can result in partial or complete paralysis. If the virus gets into the brainstem

²⁷ For more information on the impact of these and the other infectious diseases listed here please see the March of Dimes web site at http://www.marchofdimes.com/professionals/681_1116.asp.

(bulbar polio), muscles needed for breathing, swallowing, and other vital functions become paralyzed, possibly leading to death. Vaccination of US children has led to the near eradication of the disease in the West, but in many developing countries it still poses a risk and is easily communicable.

INJURY AND ABUSE

Childhood injury and abuse can cause, exacerbate, and create additional developmental disabilities. One of the most significant causes of developmental disability from injury is brain injury. Brain injury can be caused by a variety of factors such as: direct impact to the head that breaks the skull - a traumatic injury impacting a specific area of the brain, and damage to brain cells from oxygen or blood deprivation - an acquired injury taking place at the cellular level. Near drowning, car accidents resulting in head trauma, airway obstruction, and electrical shocks or lightning strikes can cause accidental brain damage. Even a serious bike or other sports accident can do damage to a child's brain. Brain injury can cause many kinds of physical, cognitive, and behavioral/emotional impairments that may be either temporary or permanent and may range from subtle to severe.

Child abuse can also cause brain injury. For example, when a baby is shaken violently, the rapid movement of the head back and forth pulls apart nerve fibers, damaging brain tissue. Known as shaken baby syndrome, this destruction of brain tissue can cause serious brain damage and even death. Similarly, other sorts of battering and abuse that cause damage to a child's head can result in brain injury. It is difficult to say, however, what impact a given injury will have. The effects of a brain injury are complex and can vary greatly from person to person, depending on such factors as the cause, location, and severity of the injury.

Child abuse can be a substantial factor in causing disability in other ways as well. Sadly, abuse comes in many forms, including emotional abuse and neglect. As with all disabilities, including mental illness, it is very difficult to establish the cause of the disability. There is no universal pattern in the way abuse affects individuals. However, the emotional and physical trauma of abusive situations cannot be discounted as a significant factor leading to developmental

disabilities. Data collected in the early 1990s for The National Clearinghouse on Child Abuse and Neglect showed the incidence of disabilities caused or likely to have been caused by maltreatment to be 147 per 1,000 maltreated children.²⁸ Near-fatal child maltreatment leaves 18,000 children permanently disabled each year.²⁹ Developing a disability then makes a child more likely to be subject to further abuse.

Children with disabilities, including but not limited to those with developmental disabilities, are at a greater risk of all types of abuse throughout their lives. Children with disabilities are, on average, 3.4 times more likely to be maltreated than those without disabilities.³⁰ In addition to its clear inhumanity, this abuse can exacerbate existing disabilities and create secondary conditions that may also be disabling. These children may be at additional risk because of institutionalized beliefs, practices, and policies that "devalue" children with disabilities, as well as the same sorts of risk factors that apply to all children.

Child abuse is an extremely serious and traumatic issue that deserves a much more complex treatment than provided in this brief summary. The impact of abuse is unique to the individual, based on the specific constellation of personal, genetic, and environmental resources and/or deficits present. A discussion of the full impact and spectrum of child abuse is beyond the scope of this paper; however, it is extremely important and necessary to fully consider the impact of child abuse in any discussion of the causation of developmental disabilities. While specific outcomes in any abusive situation may vary, the kinds of interventions and public programs that help prevent abuse have much broader impact, making them a valuable tool for prevention.

²⁸ <http://www.ahsc.arizona.edu/acainfo/disabilities.htm>

²⁹ United States Department of Health and Human Services, 1995, cited in *Testimony in front of the House Committee on Education and the Workforce Select Education Subcommittee: Child Abuse Prevention and Treatment Act*. [available on-line] http://www.c-c-d.org/testimony_capta.htm.

³⁰ Consortium for Citizens with Disabilities Task Force on Child Abuse and Neglect. *Testimony in front of the House Committee on Education and the Workforce Select Education Subcommittee: Child Abuse Prevention and Treatment Act*. August 2, 2001 [available on-line] http://www.c-c-d.org/testimony_capta.htm.

GENETICS

For a limited number of developmental disabilities a genetic root has been identified. Some genetic conditions are inherited, while others are the result of specific mutations. These conditions range from Down Syndrome, where for unknown reasons a child has an additional chromosome, PKU (phenylketonuria) where the absence of the enzyme phenylalanine hydroxylase causes a build up of the amino acid phenylalanine, causing damage to the nervous system and potentially mental retardation, and blood disorders like sickle cell disease.

As the tools and techniques of genetic research advance, many more conditions like PKU are diagnosable. Tandem mass spectrometry, a process by which a blood sample taken from a newborn is broken into compounds and then analyzed for variations in the amount of specific compounds, has played an essential role in the identification of many of these genetic links. While mass spectrometry cannot replace all screening methods as there are certain conditions it cannot screen for, it has greatly expanded the number of identifiable conditions.

The mass spectrometer weighs the amounts of compounds present in the child's blood, revealing any deviations from the norm in specific compounds. Mass spectrometry is relatively inexpensive and can fairly accurately be used to identify between 20 and 30 genetic disorders based on the composition of the blood sample. Mass spectrometry can also be used to diagnose blood disorders, like sickle cell disease, and endocrine disorders like congenital hypothyroidism in addition to enzyme deficiencies like PKU. These three groups of disorders account for approximately 3,000 new cases of potentially fatal or debilitating disease each year for which outcomes are improved with early identification and treatment.³¹

While advances like mass spectrometry have made diagnosis of these types of conditions easier and more accurate, not all diagnosable conditions can be treated, and not all states screen for every diagnosable condition. The national average is 8 conditions, with programs varying from 4 to 36 disorders. Many states base their decisions on which conditions to screen for on several

³¹ Centers for Disease Control. *Using Tandem Mass Spectrometry for Metabolic Disease Screening Among Newborns: A Report of a Work Group*. Posted on line May, 2001. [accessed on line on 12/17/03] <http://www.cdc.gov/mmwr/preview/mmwrhtml/tr5003a1.htm>.

criteria, including how often the condition occurs in the general population, the effectiveness and cost of the screening test, and whether treatment for the condition exists.³²

For the treatable conditions identified through screening, early intervention is an important aspect to disability prevention. A child with PKU, for example, must follow a special diet to avoid the build up of phenylalanine in the system which causes the resulting brain damage or mental retardation. Knowing that the condition exists before symptoms occur, impossible without these sorts of testing, makes it possible to avert some or all of the most serious consequences. However, the tests are not fool proof, do not include all genetic developmental disabilities, and may or may not identify conditions that are relatively rare.

For some developmental disabilities with genetic roots, risk factors have been identified. For example, the risk of having as child with Down Syndrome increases with the age of the mother, especially over age 35. For conditions like cystic fibrosis and Fragile X syndrome, which can cause mental retardation and learning disabilities, genetic testing for the parents may identify if one or both of the parents are carriers of the recessive/dominant genes or mutations that cause these conditions. For carriers considering pregnancy, genetic counseling is often advised so that the parents can understand the likelihood of a potential disability occurring. However, the presence of these and other genetic traits does not ensure that a child will have or be a carrier of the disease, nor does it determine the severity of impact the condition may have.

For other genetic conditions, the defect causing the condition can be identified, but there is no identifiable cause for the initial abnormality. Some conditions result from a chromosomal anomaly, generally from a change occurring during egg or sperm cell development. These errors can include extra chromosomes (as is the case with Down Syndrome) missing chromosomes, or errors in chromosome duplication as the fetus develops. Because the cause of these chromosomal changes has not been identified, there is little that can be done to prevent these

³² United States General Accounting Office. *Newborn Screening: The Characteristics of State Programs*. March 2003, p. 2. [available on line] www.gao.gov/cgi-bin/getrpt?GAO-03-449.

conditions. However, these conditions are relatively rare, and in most cases, the risk of having another baby with a chromosomal abnormality is low.³³

ENVIRONMENTAL TOXINS

Only in recent years have public health officials and researchers begun to grasp the full range of impact on child development caused by toxins like lead, mercury, dioxins, and other chemicals present in the environment from a variety of sources. Recent progress in understanding the development of the neurological system and an explosion of research into cognitive functions like attention and memory are beginning to create a picture - supported by laboratory, clinical, and epidemiological research - of the role neurotoxic chemicals may play in developmental disabilities.

Neurotoxic chemicals are chemicals that are toxic to the developing brain, including the metals lead, mercury, cadmium, and manganese; nicotine; commonly used pesticides; dioxins and PCBs; and solvents including alcohol and others used in cleaning products, paints, and glues.³⁴ These chemicals may be toxic to cells and/or interfere with brain function and development through hormone and neurotransmitter disruption or disruption of other growth factors. Some of these toxins, such as lead and mercury, are well-known pollutants whose impacts on development at high doses are acknowledged and cause substantial disabilities including mental retardation and aggression. Attempts have been made to set a threshold of harm for these toxins, and regulations put in place to prevent child exposure above these levels. However, recent research has shown that even low level exposure to these toxins also impacts development in significant ways.

Even more sinister, the impacts of these chemicals are assessed individually, rather than in terms of their cumulative impact. One small change in IQ or other area of function may not make a significant impact on its own. But small changes in IQ, if they cumulatively add up to an

³³ For more information on a wide variety of genetic and other birth defects please see the March of Dimes web site at http://www.marchofdimes.com/professionals/681_1116.asp.

³⁴ for a brief summary of the impact of each of these neurotoxins please see: Greater Boston Physician's for Social Responsibility, *In Harms Way: Toxic Threats to Child Development*. Cambridge, MA. 2000 p. 2-3. [available on-line] <http://www.igc.org/psr>.

average change of 5 points, will result a 50% increase in the number of children who are functionally disabled.

In 1997 over 1 billion pounds of known or suspected neurotoxic chemicals were released into the environment according to the Environmental Protection Agency's Toxics Release Inventory, and use of some of these chemicals is increasing with lead use in manufacturing in Massachusetts rising 77% between 1990-1997.³⁵ Most chemicals, however, have not been evaluated for their toxicity to animals or humans. For those that have been evaluated, and for which regulations exist, the harm caused by the interaction of chemicals is not considered. Ultimately, the risks caused by exposure to these toxins are avoidable, but preventing them would require massive changes to our current regulatory system.

A complete description of the risk posed by all neurotoxic chemicals is beyond the scope of this report. However, the significance of these toxins as causes of developmental disabilities cannot be overestimated. What follows is a brief summary of the impacts of two of the most widely recognized toxic metals – lead and mercury; and three other potent neurotoxins – dioxins and PCBs, and pesticides.

LEAD

Lead interferes with normal brain development and can result in lowered intelligence, hyperactivity, learning and attention disorders, and changes in behavior.³⁶ Most lead exposure in the United States now comes from lead paint and lead in dust and drinking water. Lead tends to be stored in bones and during pregnancy the lead can be mobilized leading to higher blood lead levels in the mother. Lead easily crosses the placenta and enters the fetal brain, where it interferes with normal development affecting both cellular structure and brain chemistry.³⁷

³⁵ Greater Boston Physician's for Social Responsibility, *In Harms Way: Toxic Threats to Child Development*. Cambridge, MA. 2000 p. 5. [available on-line] <http://www.igc.org/psr>.

³⁶ *Ibid.* p. 60.

³⁷ *Ibid.* p. 61.

As awareness of the toxicity of lead and its impact on development has grown, the “safe threshold” for lead has been consistently revised downward, from 60 microgram/dl in 1960 to 10 microgram/dl in 1990. The downward adjustments need to continue. The most recent studies show that there are impacts at even the lowest levels of exposure, meaning that there is no “safe” threshold. At the current 10 microgram/dl level, 1 million children are currently impacted; revising the threshold downward would mean the recognition of millions more at risk of harm from lead.

MERCURY

Mercury can have a devastating impact on fetal brain development. Large exposures can cause mental retardation, gait, and visual disturbances, and even small exposures can cause impairment in language, memory, and attention. The US EPA estimates that 160 tons of mercury are emitted annually, with the majority of releases coming from coal fired power plants and medical waste incinerators.³⁸ Once airborne, mercury can travel long distances before it settles to the ground. Once it is deposited, bacteria convert it into methylmercury, which bioaccumulates as it moves up the food chain, meaning that with each successive step up the food chain, the methylmercury consumed at the previous level is condensed until the levels become high enough to cause damage when consumed. When people consume fresh water fish or large predatory ocean fish, they expose themselves to all the mercury that that fish has accumulated. When fish contaminated with mercury (which includes swordfish and some tuna, as well as fresh water fish from 40 states including Maine) form a substantial part of the diet, women of childbearing age can put their future children at risk for a range of developmental disabilities.

Women who have become contaminated enough with mercury to cause substantial harm to a developing fetus may not themselves have, or show signs of, mercury poisoning. This is because the developing brain is especially sensitive to the effects of mercury, where its presence can cause significant disruption to a variety of processes including cellular function, protein synthesis, cell division, and cellular migration.³⁹

³⁸ Ibid, p. 61.

³⁹ Ibid p. 67.

The impact of high doses of mercury has been documented since the 1950's, but several recent studies reveal the impact of much lower levels of exposure. These studies showed potential correlations between mercury and impairment in language, attention, and memory at maternal mercury levels of 3-20 ppm. These studies led the EPA to set a minimum risk dose at .1 microgram/kg/day, or 1 part billion. EPA estimates that 7% of women consume mercury in excess of this "safe" dose. For a 132 lb woman, this works out to about 7 ounces of fish with a contamination level of .2 ppm, per week. However, the FDA's actionable level, established in 1979, for mercury is 1 part per million, or 1 microgram/kg/day.⁴⁰ This guideline is not protective of those most at risk.

Finally, recent studies have shown that methylmercury in combination with polychlorinated biphenyls (PCBs) act synergistically, raising questions about the impact of mercury in combination with other neurotoxins at very low levels.⁴¹ Many water systems in the US are contaminated with a variety of toxins including PCBs and other neurotoxicants, raising questions about analyses and alerts based solely on a single toxin.

DIOXINS AND PCBS

Dioxins and PCBs share a similar chemical structure but are produced through different processes. PCBs are chemicals that were produced and used for a variety of purposes because of their inflammability. In most countries PCBs are no longer produced, but their presence in the environment and in hazardous sites and electrical transformers mean they continue to pose a health risk. Though production has ceased, it is estimated that two-thirds of the total amount produced has not yet been released into the environment.⁴² Dioxins are produced through industrial processes such as chlorine based paper bleaching and municipal and medical waste incineration.

Like mercury, dioxins and PCBs often travel far from their emission source before they settle to land or water and enter the food chain. Both chemicals bioaccumulate,

⁴⁰ Ibid, p. 67.

⁴¹ Ibid, p. 67

⁴² Ibid., p. 77.

concentrating in animal fat and fatty substances like breast milk. When foods containing high concentrations are consumed, the amount of exposure increases. Breast milk contains some of the highest concentrations of these chemicals of all body tissues because of its fat content, meaning that a nursing infant is exposed to a large portion of their total lifetime dose in the first months of life. (This does not mean, however, that breast-feeding should be discouraged; breast feeding brings other advantages that are not considered here). Following ATSDR (Agency for Toxic Substances and Disease Registry) advised guidelines for chronic exposure, a breast-feeding infant exceeds the advised daily limit for chronic dioxin exposure by a factor of 34-54⁴³.

Exposure to large amounts of PCBs has been shown to cause numerous abnormalities including low birth-weight and mental retardation, with delays and IQ deficits persisting long after the end of the exposure.⁴⁴ These impacts were seen at toxic levels due to food contamination, but significant impacts were also seen at normal exposure levels. Long-term studies of children whose mothers regularly consumed normal amounts of food containing PCBs correlate PCB/dioxin exposure with delayed or reduced psychomotor development, poorer memory test results, and lower IQ scores.⁴⁵ Other studies showed PCB/dioxin levels to be associated with slower reaction times and more signs of hyperactivity.⁴⁶ These studies indicate that current ambient levels of PCBs/dioxins can adversely impact child development in permanent and potentially substantial ways.

PESTICIDES

Many pesticides kill insects because they are neurotoxic. There are many different types of pesticides, including pyrethroids, organochlorines such as DDT, and organophosphates. While exposure to these chemicals as adults does not appear to create harm at low levels, exposure during specific stages of fetal and childhood development have been shown to cause a range of adverse impacts on neurological functions, including stamina,

⁴³ Ibid. p. 75.

⁴⁴ Ibid. p. 78.

⁴⁵ Ibid p. 78.

⁴⁶ Ibid. p. 79.

coordination, memory, and ability to conceptualize and draw.⁴⁷ Most of the limited studies of pesticide toxicity have been conducted on animals, unlike the chemicals mentioned above for which there is a larger body of evidence as to human impact. While the US EPA has the authority to require testing of pesticides for neurological impact, it rarely exercises this authority.

Most commercial users of pesticides are not required to report releases, complicating efforts to assess its impact on childhood development. Children come into contact with these chemicals in a variety of ways. One of the most common pathways is through food consumption. There are currently 37 pesticides registered for use on foods that are neurotoxic organophosphates, which are chemically related to nerve warfare agents.⁴⁸ Several studies have indicated that more than 80% of the general population have detectable levels of these pesticides in their urine. Pesticides are also used in residential areas such as homes, lawns, and playgrounds. While many of these compounds quickly biodegrade when exposed to sunlight, water, and microorganisms, without these aids, as is the case in a rug or carpet, they remain for a much longer time. As mentioned above, few studies, both human and animal, have been conducted on the impacts of these chemicals. However, those that have show significant deficits in children with regular exposure to pesticides, and indicate the need for further investigation, if not cause for alarm.

PREVENTING DEVELOPMENTAL DISABILITIES IN MAINE

Society pays an extremely high price when children are born with a developmental disability or acquire a disability during childhood. Families face inordinate challenges and frustrations when their child has a disability. The cost of medical and habilitative treatment programs, of special education programs, and of day care or residential care, are staggering. Maine's Blue Cross/Blue Shield has reimbursed hospitals up to \$118,000 for one infant's intensive care. In excess of \$41 million was spent last year on special education in Maine . . . The costs for rehabilitation programs, adult day care programs, and life-long residential care for severely handicapped

⁴⁷ Ibid. p. 85.

⁴⁸ Ibid. p.106.

persons are enormous. We citizens bear most of these costs through insurance premiums and local, state, and federal taxes.

From the 1985 Report of the Select Committee for the Prevention of Developmental Disabilities report: *Every Child a Healthy Child*.

Recognition of the costs incurred by individuals with developmental disabilities, their families, and communities is not a recent phenomenon, nor is a focus on developmental disability prevention new. In fact, in 1985 Commissioner Concannon (then commissioner of the Department of Mental Health and Mental Retardation) challenged the recently created Select Committee for the Prevention of Developmental Disabilities to create a plan that would further Maine's efforts at reducing the number of children born with, or acquiring, developmental disabilities. This report, *Every Child a Healthy Child*, proposed 15 targeted recommendations, resulting in the passage of LD 1385 – An Act to Prevent Developmental Disabilities in Maine (Title 22, c. 962).

While scientific understanding of the causes of developmental disabilities has evolved and expanded significantly in the 23 years since the report was drafted, the actions called for in this bill are as important as ever. Chapter 962 directs the Departments of Health and Human services (DHS), Behavioral and Developmental Services (BDS), and Education (DOE) to perform activities related to developmental disabilities prevention.

Specifically, it directs DHS to serve as the principal agency for the primary prevention of developmental disabilities and requires the provision of services for pregnant women and new mothers to minimize the likelihood of their having a developmentally disabled child. These prevention activities are to include professional education to assure that the best available prevention techniques are utilized by health care professionals and assurance of access to prenatal services for all women of childbearing age in the State.

BDS is required to institute programs of family counseling and support services for families with developmentally disabled children aged 0 to 5 years, to increase the family's understanding of the child's special needs and to enhance family members' abilities to cope with the physical and emotional strains experienced by families with disabled children.

DOE is directed to create preschool coordination projects to assure the provision of comprehensive developmental services, including physical therapy, speech and language therapy, and occupational therapy to preschool children with disabilities or other delays. It is also required to make comprehensive health educational programs available in public schools and that teacher training programs in Maine provide guidance on how to present health educational programs.

In all of these actions, the departments are asked to work cooperatively with private agencies so as to not duplicate resources existing in the community, and more rapidly achieve the goal of preventing developmental disabilities in Maine. Further, all three departments are asked to submit a joint report to the Health and Human Services Committee regarding the prevention activities conducted over the past fiscal year, plans for the following year, and a report on the incidence rate of births of developmentally disabled children in the State.⁴⁹

These requirements, and subsequent programs which have been implemented addressing causes of developmental disabilities, are important steps toward preventing disability. However, for a variety of reasons it is difficult to generate an accurate assessment of Maine's progress and success at prevention, or even gauge the success of this law. While Maine has attempted a variety of interventions, the complexity and inter-related nature of the potential causal factors for these disabilities demonstrates that even when outcome measures are available, they often do not show the entire picture. In many cases, data is lacking, interventions and programs targeting the same or similar issues are not coordinated, and comprehensive evaluation of the impact made by the program is unavailable. It is difficult to even establish to what extent, if at all, the reporting requirements under chapter 962 have ever be met. There are no reference documents available at the state library archives or the legislative committee of record speaking of these required reports.

⁴⁹ For the full text of this statute, please see appendix A.

THE IMPORTANCE OF DATA AVAILABILITY

Precise data on the prevalence of developmental disabilities, both nationally and on the state level, is not readily available. Data on disabilities in general has not traditionally been collected in any systematic or consistent manner. Even the phrase “developmental disability,” regularly used term in Maine statute, is not consistently defined and is often left unclear or undefined entirely. Thus, systematizing existing data to look at issues of prevalence, causation, and prevention of developmental disabilities is extremely challenging. The lack of standardization makes it particularly difficult to compare information across data sources and to track changes over time.

In recent years more attention has been focused on disability issues in general, and the importance of having accurate, reliable, and available data has become increasingly recognized, although accurate data is not yet widely available. In 2000, the US Census included questions on disability status for the first time, resulting in a current national estimate of as many as 1 in 5 persons (20%) with a disability. But this is the tip of the data iceberg.

The inclusion of questions around disability in general in the Census is a step forward in recognizing the significance and impact of disability in this country. However, the particular questions asked are not very helpful in assessing developmental disabilities as they do not include enough specificity to generate accurate figures for the numbers of individuals with developmental disabilities, even on a national level. Improved monitoring of incidence and prevalence of developmental and all other disabilities, as well as evaluation of prevention strategies, is vitally important so that, among other things, programs and practices can be assessed for best practices and effectiveness, and gaps in service identified.

CURRENT PROGRAMS

Though more data is necessary to draw any conclusions, there are many programs in Maine that attempt to deal with potential causes of developmental disabilities. While a comprehensive assessment of Maine's efforts in these areas is beyond the scope of this preliminary report, this section will provide some highlights of efforts currently underway in the State. This section is not intended to fully assess the impact of these programs, but does provide some examples of ways the State is working to prevent developmental disabilities.

As noted in the discussion of causes, many of the causative factors do not fit neatly into categories due to the complexity of their impact. The same is true for the programs that address them. The programs highlighted below are listed following the categories in the previous causes section, with the exception of genetics. While genetic conditions have a different genesis from public health concerns, interventions targeting them are often similar in nature. Therefore, the genetics program highlighted below – newborn screening – will be covered in the public health section. All discussion of these programs is preliminary. Further phases of this project will include more comprehensive assessments of these and other programs, their outcomes, and effectiveness.

PUBLIC HEALTH

Maine has a number of public health programs designed to promote health and well being through the prevention of disease, injury, or behaviors that can lead to disabling conditions. In recent years, more empirical evidence of causal relationships and contributing factors has led to improved methods and recognized “best practices” to address prevention of disabilities or successful mitigation of the impact of disabilities. Subsequently, more targeted strategies including better education and information dissemination among the general public has been used successfully to reduce exposure to many identified risk factors.

IMMUNIZATION

The development of effective vaccines during the last half of the twentieth century has significantly reduced the incidence of death and disability resulting from infectious diseases. Achieving and maintaining high immunization rates is quite difficult given that children are now recommended to receive as many as 20 shots to protect against 11 serious diseases before the age of two years. However, according to the National Immunization Survey, a large proportion of Maine's two year olds are age appropriately immunized. Furthermore, there has not been a report of a child dying in Maine from a vaccine preventable disease in over a decade.

Strategies such as free vaccines, education efforts, and the development of new technological tools have helped to make Maine a leading state in vaccination. Through the Bureau of Health, all necessary childhood vaccines are provided free to all licensed providers. Educational campaigns, directed at both parents and providers stress the benefits of vaccines as well as ways to increase rates. Additionally, Maine was the first state in the country to develop a web-based immunization registry, an important tool for achieving and maintaining high immunization rates, especially for mobile families. In spite of these successful efforts, many children in Maine remain unprotected from vaccine preventable diseases and the disabilities they can cause. Continued work and vigilance are needed to not only maintain current immunization rates but raise these levels even further.

PRENATAL AND INFANT CARE

Maine seems to make considerable effort to address issues of prenatal and reproductive health. There are various programs to help ensure the health and well-being of a child once it is born. A number of methods have been employed with considerable success. These strategies range from school health education, nutritional supplements, and promotion of folic acid, to universal home visits and screening programs. For example, the Women, Infants and Children (WIC) program and other initiatives like food stamps, Healthy Maine Partnerships, and the university extension

system provide critical nutritional support and education to pregnant or nursing women and young children.

These programs are a valuable resource to help ensure proper nutrition for this vulnerable population. For instance, it is particularly important that women of child bearing age receive adequate amounts of folic acid (recommended 400 micrograms) since this substantially reduces the rates of neural tube defects such as spina bifida. An example of another valuable strategy used is home visits following the birth of a newborn (referred to as the perinatal period). Although traditionally focused on “high risk families,” the program has been expanded to include almost all newborns of first time parents.

ALCOHOL AND TOBACCO USE

Maine has invested significant resources in preventing and reducing alcohol and tobacco abuse. Efforts to reduce the use of tobacco have included prohibiting smoking in public restaurants and bars, stricter enforcement of laws on illegal sales to minors, increased resources to help people quit, more targeted educational outreach, and increased taxes on the sale of tobacco products. The Office of Substance Abuse has implemented several different programs aimed at limiting alcohol access by minors, improving the infrastructure of prevention activities, changing cultural attitudes, and developing appropriate monitoring methods. These efforts reflect a focus on collaboration and partnerships with federal organizations, educational institutions, other state agencies, and community coalitions. While few of these programs are designed to prevent developmental disabilities, it is likely that any program that reduces tobacco or alcohol abuse as a whole will also reduce the numbers of children who may be impacted by their abuse during pregnancy and childhood.

Data from Healthy Maine 2010 indicates that substantial progress has been made in some, but not all, aspects of tobacco and alcohol abuse prevention. For example, the overall proportion of Maine women who did not smoke during the last 3 months of pregnancy increased from 75.7 in 1990 to 82.5 in 2000. While this statistic shows important progress, others highlight disparities in impact between genders and income

levels, including a significantly higher rate of women on Medicaid smoking during the last months of pregnancy. These disparities indicate that more still needs to be done in these areas.

NEWBORN SCREENING

Maine has what may be considered a comprehensive newborn screening program. According to the Maine Newborn Screening Program, each newborn receives the nine newborn screening tests (including hearing) that are recommended by the March of Dimes, and nearly all receive an important array of optional screenings (28 in all) designed to detect less common conditions. In addition, Maine has recently developed a surveillance system for identifying and monitoring birth defects. A central registry will be maintained identifying cases of selected major birth defects. The system, which was implemented in the spring of 2003, will help to clarify the extent and type of birth defects that are occurring, develop effective prevention strategies, give assistance with referrals for services, and provide critical information for resource planning.

INJURY AND ABUSE

Injury is the leading cause of death and disability among children and young adults in Maine, as it is in the nation. However, most serious injuries are predictable and preventable.

SEATBELTS AND CARSEATS

Traffic crashes, violence, and falls are the leading causes of traumatic brain and spinal cord injuries, which are two of the most severely disabling conditions caused by injury (CDC). Effective intervention strategies include legal requirements for: (1) mandatory child safety restraints, (2) use of seatbelts by adults in vehicles, and (3) the use of helmets by motorcycle and bicycle riders. Maine does have mandatory seatbelt laws for both children and adults. Additionally, children from birth to age 4 are required to be in a car seat, and those ages 5 to 7 are required to be in a booster seat. The State does not currently require the use of helmets by riders of motorcycles or bicycles.

While passage of laws is important, it is only part of the solution. Compliance with those laws is also critical, requiring public understanding and acceptance as well as strict enforcement. Educational efforts aimed at increasing understanding and awareness can help change attitudes and achieve public buy-in.

SHAKEN BABY SYNDROME

Each year about 30 children in Maine suffer injuries associated with shaken baby syndrome (SBS), resulting in extremely high medical costs (as high as \$300,000 for the first 5 years of life). As is true for all forms of child abuse, DHS operates a phone line for reporting allegations of abuse, including shaken baby syndrome. The Maine Injury Prevention Program, through the Bureau of Health, provides valuable information and education programs on shaken baby syndrome to raise awareness of the damage that can be caused by shaking a child. Information on SBS is provided to all parents before they leave the hospital with their baby. Additionally, in 2000 the legislature amended the criminal statutes to allow consideration of the age of the child when determining sentencing for child homicide cases. Known as “Jake’s Law,” it allows judges to impose steeper sentences to individuals convicted of child manslaughter. While penalties like this may provide more severe punishment, it is unlikely that they do much to prevent the abuse. Comprehensive parent education is much more likely to have a positive impact on prevention.

ENVIRONMENTAL

Both lead and mercury are dangerous toxins that pose serious health risks to citizens of Maine. As mentioned previously, exposure to these and other neurotoxins can cause damage to the brain and central nervous system resulting in mental retardation, and impaired memory, attention span, language, and motor skills, among others things. Developing fetuses and young children are particularly sensitive to these toxins, though at high levels they are toxic for all.

LEAD

Our state has one of the nation’s oldest housing stocks. Before being banned as a paint additive in 1978, lead was a very common ingredient in paint. Before 1950 the lead

content in paint was often 50% or more. In Maine, 41 % of all residences were built before 1950. The Maine State Housing Authority (MSHA) has been working to abate lead hazards in homes and improve the infrastructure to deal with the lead problem. During the past five years, two large federal grants, plus matching funds, have been used by MSHA to make hundreds of homes lead safe, increase public awareness of lead paint hazards, and provide specific training to lead paint inspectors, abatement design consultants, abatement supervisors, Head Start professionals, and others in lead safe work practices.

About 550 children in the state of Maine are identified as lead-poisoned each year (a blood lead level of 10mcg/dl or greater). Screening children can be an effective tool for preventing the full impact lead consumption can have, since once identified and removed from the child's environment, lead levels will lessen in that child. Often, the children most at risk for lead poisoning are those living in older, frequently less expensive housing stock. These children may be more likely to receive Medicaid, though it is important to note that any older home that has not been abated is likely to contain lead paint, regardless of value.

Children between the ages of 1 and 2 are at highest risk for lead poisoning because they are most likely to ingest paint chips, dust, and other substances that can contain lead. Maine legislation passed in 2001 (Title 22:Chapter 252,§1317-D), required the testing of blood lead levels of all one and two year old children covered by Medicaid, consistent with federal law. The same legislation required the testing of one and two year old children not covered by Medicaid unless in the judgment of the primary care provider using a risk assessment tool (developed by the Department of Human Services) the child's risk level does not warrant a blood test. After declining for several years, statewide blood lead level screening rates of children in Maine are now increasing according the Maine Childhood Lead Poisoning Prevention Program. Although rates vary by county, the overall state blood screening rate for one year olds in 2002 reached 45 percent; while the rate for two year olds trailed at 22 percent. (Data on the breakdown

of blood lead screening rates among Medicaid children versus non-Medicaid children was not readily available for this report.)

MERCURY

Maine has undertaken efforts to prevent mercury pollution and public exposure. The legislature has been active in restricting mercury disposal, passing four laws restricting its disposal in the last three years. One law, passed in 2000, requires labeling and recycling of mercury products and bans their disposal in trash. Another, in 2001, prohibits the sale of mercury fever thermometers and requires disclosure of the mercury content of products sold to hospitals. In 2002, Maine passed a “first in the nation” law requiring the removal of mercury containing switches in automobiles before they are crushed. During the same legislative session, another law was passed that phases out the sale of mercury thermostats for use in residential or commercial buildings, having a full effect January 1, 2006. Also in 2002, over 5,000 mercury thermometers as well as other mercury containing products were collected for appropriate recycling.

Fish in many Maine lakes, rivers, and streams have mercury levels that pose a risk to human health. As a result, the Maine Bureau of Health issues fish consumption advisories about the risks of eating mercury-containing fish from inland lakes and rivers. These and other efforts helped Maine receive a “B” on the New England Zero Mercury Campaign’s 2002 Report Card.

CONCLUSION

These programs create a snapshot of the some steps Maine has taken that may impact developmental disabilities. As mentioned before, a comprehensive review of all programs that could impact developmental disabilities is necessary to accurately and adequately begin to gauge how well Maine is doing in its attempts to prevent developmental disabilities. However, these programs do indicate that the State recognizes the importance of many factors that can cause developmental disabilities and is taking some steps to improve in those areas.

RECOMMENDATIONS

As a preliminary report these recommendations are by no means comprehensive. That being said, there are several recommendations that are recognized as prudent at this time:

1. The Prevention Commission continues its work for at least another year, presenting an updated report to the Health and Human Services Committee in the 122nd legislative session. This additional time will allow the Commission to hold public forums and comprehensive meetings with interested individuals, advocacy groups, and experts to review and strengthen this report and generate fully informed recommendations for a more comprehensive prevention system.
2. The Health and Human Services Committee presents a bill to clarify the definition of developmental disability in Maine statute Title 22 chapter 962, using the “federal definition” discussed earlier in this report. Since each of the state departments required to report under this chapter use different concepts to articulate developmental disability, it is important to provide a definition broad enough to encompass these variations, to assure full reporting. While the term developmental disability occurs in many places in the Maine code, it is only defined in one section: Title 5, chapter 511, §19503. Here the federal definition is used, which is the most widely used and supported nationally. For clarity, Title 22 chapter 962 should be amended to reflect the federal definition. This will provide a concrete definition to be used by the state departments for their reporting requirements under this chapter and can be used in the future, if desired, as a starting point to begin to systemize, unify, and improve programming, data collection, and reporting. It is important to note that insertion of the federal definition into Title 22 chapter 962 only serves to clarify the definition of developmental disabilities for the purpose of this specific section and does not impact or cause any changes to other Maine laws or any state department, agencies, or programs.
3. The Health and Human Services Committee reiterates its request that the departments of Education, Health and Human Services, and Behavioral and Developmental Services report on the prevention activities they have conducted, as required in Title 22 chapter 962.

APPENDIX A: TITLE 22, CHAPTER 962: PREVENTION OF DEVELOPMENTAL DISABILITIES

§3571. Prevention of developmental disabilities

1. Prevention of developmental disabilities; Department of Human Services. The Department of Human Services shall serve as the principal agency for the primary prevention of developmental disabilities in the State and shall provide services for pregnant women and new mothers to minimize the likelihood of their having a developmentally disabled child. In particular, the department shall conduct professional education to assure that the best available prevention techniques are utilized by health care professionals in the State and shall assure that access to prenatal services exists for all women of childbearing age in the State. [1985, c. 484 (new).]

2. Counseling and support services; Department of Behavioral and Developmental Services. The Department of Behavioral and Developmental Services shall institute programs of family counseling and support services for families with developmentally disabled children aged 0 to 5 years. The purpose of these counseling and support services shall be to increase the family's understanding of the child's special needs and to enhance family members' abilities to cope with the physical and emotional strains experienced by families with handicapped children. [1985, c. 484 (new); 1995, c. 560, Pt. K, §82 (amd); §83 (aff); 2001, c. 354, §3 (amd).]

3. Preschool coordination projects; Department of Education. The Department of Education through the preschool coordination projects shall assure the provision of comprehensive developmental services, including physical therapy, speech and language therapy and occupational therapy to preschool handicapped or delayed children. To the maximum extent possible, these programs shall make use of existing 3rd party payors and coordinate services with local resources. In instances where needed services are not available, the department shall use authorized funds to enable preschool coordination projects to work with local providers, including public and private agencies and school units to develop new or expand existing service to meet these needs.

In addition, the Department of Education shall ensure that comprehensive health educational programs are available in state schools and that teacher training programs in the State include preparation in conduct of health educational programs. [1989, c. 700, Pt. A, §81 (amd).]

§3572. Use of private agencies to deliver services

Private agencies shall be used as appropriate to carry out the implementation of initiatives to prevent developmental disabilities in cooperation with the respective departments so that State Government agencies do not duplicate existing resources in the community and so that all available resources are used effectively to rapidly achieve the goal of preventing developmental disabilities in the State. [1985, c. 484 (new).]

§3573. Reporting

The Department of Human Services, Department of Behavioral and Developmental Services and Department of Education shall by January of each year submit a joint report to the joint standing committee of the Legislature having jurisdiction over human resources regarding the prevention activities conducted over the past fiscal year, plans for the succeeding year and a report on the incidence rate of births of developmentally disabled children in the State. [1989, c. 700, Pt. A, §82 (amd); 1995, c. 560, Pt. K, §82 (amd); §83 (aff); 2001, c. 354, §3 (amd).]

**APPENDIX B: PROPOSED AMENDMENT TO TITLE 22, CHAPTER 962 –
PREVENTION OF DEVELOPMENTAL DISABILITIES**

An amendment to clarify the definition of developmental disability

Draft outline of amendment language:

Purpose:

The purpose of this amendment is to clarify the definition of developmental disability in chapter 962: Prevention of Developmental Disabilities.

Outline:

Enact a definitions section in chapter 962 that would define “developmental disability” and “mental and physical impairments”:

1) Developmental Disability, using the federal definition as stated in Title 5 § 19503

5 § 19503. Definitions

3. Developmental disability. "Developmental disability" means a disability attributable to a *mental or physical impairment* or combination of mental and physical impairments that:

A. Is manifested before the person reaches 22 years of age;
B. Is likely to continue indefinitely;
C. Results in substantial functional limitations in 3 or more of the following areas of major life activity:

- (1) Self care;
- (2) Receptive and expressive language;
- (3) Learning;
- (4) Mobility;
- (5) Self direction;
- (6) Capacity for independent living; and
- (7) Economic self-sufficiency.

A person from birth through 9 years of age who has a substantial developmental delay or specific congenital or acquired condition may be considered to have a developmental disability without meeting 3 of the criteria stated in this subsection if there is a high probability that the person will meet those criteria later in life if services and supports are not provided to the person; and

D. Reflects the person's need for a combination and sequence of special, interdisciplinary or generic care, treatment or other services that are of a lifelong or extended duration and are individually planned and coordinated.

2) Mental and Physical Impairments:

For the purposes of chapter 962, mental and physical impairments include, but are not limited to, conditions such as: Mental Retardation, Autism, Cerebral Palsy, Aspergers Syndrome, Serious Mental Illness, Praeder Willi Syndrome, and Epilepsy.

Explanatory note to readers: These conditions only qualify as developmental disabilities when they also meet the full criteria for developmental disabilities as defined above.

Justification:

1) Defining developmental disability

Adding a definition of developmental disability clarifies the reporting requirement for the departments. Each department provides services to a wide variety of children, and each uses its own definitions to decide who receives services. Clarifying the definition will instruct the departments which information they should report to the Committee. The federal definition is the most appropriate for two reasons:

- 1) It is the most accepted and used definition.
- 2) It is the only definition that currently exists in Maine statute. Adding the same definition here is consistent with other parts of the code.

2) Defining mental and physical impairment

Mental and physical impairment is a term used in the definition of developmental disability. We believe that including a list of mental and physical impairments will:

- 1) Help to clarify the scope of programs on which the Departments are required to report in their annual update.
- 2) Specifically relate the language in this chapter to the charge given to the Commission in LD 1364, to examine developmental disabilities and mental health challenges.

As background, in its debates on defining developmental disabilities in the 1970s, Congress considered the merits of continuing with a categorical list, as was the case before 1978 in federal law, or moving to a functional definition. There was strong feeling that including a list of conditions that could qualify as developmental disabilities could help individuals less familiar with the term understand the types of mental and physical impairments indicated by the law.

APPENDIX C: PROPOSED PREVENTION COMMISSION WORK TIMELINE TO CARRY OUT RECOMMENDATION ONE

Phase 1: Preliminary Report

July - January 2004

- Preliminary written report finalized and presented to the HHS Committee. Report provides an overview of current science around causes of developmental disabilities and updates a report written in 1985 when a similar commission was formed by the legislature.
- One recommendation for legislation this session: clarification of the definition of developmental disabilities in existing prevention statute and enforcement of reporting requirements.
- Request that HHS Committee continue Commission for additional year.

Phase 2: Stakeholder Forums

February - August 2004

- Report sent to interested parties.
- Input sought from various participants who have an expertise in the fields of developmental disabilities. These may include: advocacy organizations, providers, medical or other professionals who treat or examine conditions associated with disabilities, caregivers, and, most importantly, people with disabilities who can speak to their experiences and offer insights into patterns and trends, and advise on potential prevention solutions.
- Generate possible recommendations for next legislative session or other programs.

Phase 3: Evaluation and Research into Forum Results

September - December 2004

- Initial determining factors narrowed and focus placed on those factors most likely to result in systems change and requiring legislation.
- Revised recommendations and report drafted.
- Programmatic ideas beyond the scope of legislation referred to interested partners

Phase 4: Second Report

Legislative session January 2005

- Results from forum process reported back to HHS Committee including recommendations for legislation.