Impact of Specific Medical Interventions on Reducing the Prevalence of Mental Retardation

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Objective: To explore the impact of medical interventions on reducing the prevalence of mental retardation (MR) in the United States over the last 50 years.

Design: We reviewed the medical literature and other data from 1950 to 2000 to construct estimates of the general and condition-specific prevalence of MR in the United States over time. We further explored the existing literature to document historically important influences on condition-specific prevalence, including the year that an effective intervention was introduced, the likelihood of success of the intervention, and the availability of such interventions nationwide. Specific conditions included congenital syphilis, Rh hemolytic disease of the newborn, measles, Haemophilus influenzae type B meningitis, congenital hypothyroidism, phenylketonuria, and congenital rubella syndrome.

Setting: Twentieth-century North America.

Participants: Children with MR or 1 of the 7 specific conditions listed earlier.

Main Outcome Measures: Case-specific and general prevalence of MR from 1950 to 2000.

Results: The prevalence of MR caused by a number of specific medical conditions has decreased sharply over the last 50 years. However, the incidence of each of these conditions is relatively low, and cases of MR due to these conditions represent, at most, 16.5% of the total number of cases of MR in 1950.

Conclusion: Although specific medical interventions have prevented thousands of cases of MR, their contribution to the overall prevalence of MR is relatively small.

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In 1962, President John F. Kennedy announced a bold new initiative: the federal government would conduct "a comprehensive and coordinated attack on the problem of mental retardation [MR]." Kennedy was inspired by his sister Rose, who had a developmental disability, and counseled by his sister Eunice Shriver, a dynamic and forceful advocate for persons with MR. He convened an expert panel that recommended investing in scientific research, improving health care, and training a special education workforce. Unlike the work of many similar governmental task forces, most of their recommendations were implemented—largely through the efforts of Eunice Shriver, her spouse R. Sargent Shriver, and pediatrician Robert Cooke, MD. Since 1960, the number of federal programs for persons with developmental disabilities has grown from 15 to more than 50, with overall spending topping $40 billion per year. The Kennedy administration was not the first US governmental body to use scientific medicine to try to reduce the burden of MR, although it was the first large-scale federal investment in MR. In the early 1800s, state governments began opening institutions where persons with MR could live if their families were unable to care for them. Based on expert medical opinion, hundreds of these large institutions were built in the 19th century with the hope that MR could be alleviated with the proper environmental treatment. Simple cures were elusive, however, and with chronic underfunding, most of these institutions became warehouses where persons unable to care for themselves were neglected and maltreated. Descriptions of deplorable conditions in large state-funded institutions began to appear in the 1880s and continued through the 1970s, although most of these institutions have since closed.

In the early 20th century, eugenics provided hope that science could eliminate the need for large state institutions. Although today the word eugenics brings horrific images of science and policy gone mad, at one stage in US history it was promoted by respectable scientists and lead-
ers across the political spectrum. By combining Darwin’s theory of evolution with an emerging understanding of genetics, advocates of eugenics hoped to eliminate pain from disease and inequity in US society in a single generation. They understood human behavior in simple genetic terms: characteristics such as intelligence, honesty, and sobriety were passed on according to mendelian genetics. The future therefore lay in encouraging “fit” couples to marry and discouraging others from parenthood. Because persons with MR could not be trusted to understand the wisdom of eugenics, many states passed laws that led to the involuntary sterilization of adults with MR. Although rarely explicit in their eugenic beliefs, physicians routinely withheld care from children with MR, such as infants born with Down syndrome, to reduce the burden to families and society.

The Kennedy panel’s recommendations departed sharply from the science of eugenics, but they continued the historical trend of increasing government commitment to biomedical research. Through the 1930s and especially during World War II, Americans began to accept a larger role for the federal government in national affairs, and the birth of the National Institutes of Health, Bethesda, Md, in the 1940s is 1 small example. Although not specifically related to the newly opened National Institutes of Health, the spectacular success of the Salk and Sabin vaccines in the 1950s seemed to confirm that faith in biomedical research was well placed. It seemed only natural for the Kennedy panel to call for expanded biomedical research as a key to reducing the burden of MR. Indeed, the National Institute for Child Health and Human Development, Rockville, Md, was established in 1962 in part to stimulate research on MR.

The Kennedy panel’s focus on applying knowledge gained from the laboratory to the individual doctor-patient interaction characterizes 20th-century medicine in the United States. Although there have been successful public health programs that have reduced the burden of MR, such as lead abatement and infant nutrition, modern medicine has grown increasingly focused on applying technological solutions to individual patient problems. As part of a larger study on the epidemiology of MR, this study focuses on a single question: what has been the impact of our federal government’s commitment to biomedical solutions to prevent new cases of MR? We hypothesized that, contrary to policymaker expectations, specific medical interventions have had a relatively small impact on the prevalence of MR in the United States over the last 50 years. To test this hypothesis, we identified selected conditions with successful medical interventions that once routinely caused MR. We then compared the prevalence of the selected conditions with the overall prevalence of MR in the United States.

## METHODS

We used existing epidemiologic data to create a 50-year, retrospective description of the general and condition-specific prevalence of MR in the United States. To collect this data, we reviewed the medical literature and other existing data from 1900 to 2000, with a focus on the last 50 years. Our search included the electronic databases MEDLINE (1967 to present), Hstline, and CALLCAT (the database associated with Calder Library, University of Miami, Miami, Fla), as well as relevant Web sites such as those of the Centers for Disease Control and Prevention (CDC) (keywords are available on request). We also searched reference lists from each of these sources to locate other articles, books, and historical works that were not present in electronic databases.

### SPECIFIC MEDICAL CONDITIONS

Our previous research had identified more than a dozen medical conditions for which specific medical intervention can prevent MR, including newborn screening programs, vaccines, and advances in nutritional and pharmacologic treatments (Table 1). Not all of these interventions had their origins in federal research funding, but all of them benefited from the national decision to focus on biomedical research as the primary means of reducing the burden of MR.

We selected 7 conditions to study in detail: congenital syphilis (CS), Rh hemolytic disease of the newborn (Rh disease), measles, *Haemophilus influenzae* type b (Hib) meningitis, congenital hypothyroidism (CH), phenylketonuria (PKU), and congenital rubella syndrome (CRS). We chose these 7 conditions for several reasons: (1) all of them were recognized in the 1950s as specific causes of MR with a high probability of finding or implementing a cure; (2) they account for all of the relatively high-incidence conditions noted in Table 1; (3) they are the commonly discussed “success” stories in the prevention of MR; and (4) interventions for these conditions depend largely on care provided through the individual doctor-patient relationship, ie, they exemplify the traditional biomedic approach to preventing disease or complications in each individual patient.

### CONDITION-SPECIFIC PREVALENCE OF MR

We used a common set of variables to construct estimates of the condition-specific prevalence of MR over the last 50 years: (1) the incidence of the condition; (2) the number of cases of MR likely to arise from that condition (natural history); (3) the efficacy of the intervention to cure the condition; and (4) the population-wide availability of the intervention.

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### Table 1. Causes of Mental Retardation With Specific Medical Interventions

<table>
<thead>
<tr>
<th>Cause</th>
<th>Medical Intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Congenital syphilis</td>
<td>Screening and antimicrobial therapy</td>
</tr>
<tr>
<td>Measles encephalitis</td>
<td>Vaccination</td>
</tr>
<tr>
<td>Kernicterus</td>
<td>Maternal treatment for Rh incompatibility</td>
</tr>
<tr>
<td>Bacterial meningitis</td>
<td>Vaccination or antibiotics</td>
</tr>
<tr>
<td>Congenital hypothyroidism</td>
<td>Newborn screening and treatment</td>
</tr>
<tr>
<td>Phenylketonuria</td>
<td>Newborn screening and treatment</td>
</tr>
<tr>
<td>Congenital rubella syndrome</td>
<td>Vaccination</td>
</tr>
<tr>
<td>Congenital rubella syndrome</td>
<td>Newborn screening and treatment</td>
</tr>
<tr>
<td>Tuberculosis meningitis</td>
<td>Nutrition and antibiotics</td>
</tr>
<tr>
<td>Whooping cough</td>
<td>Vaccination</td>
</tr>
<tr>
<td>Fetal hydantoin syndrome</td>
<td>No phenytoin during pregnancy</td>
</tr>
<tr>
<td>Pelvic irradiation</td>
<td>Limited x-ray exposure during pregnancy</td>
</tr>
<tr>
<td>HIV encephalitis</td>
<td>Reduced perinatal transmission</td>
</tr>
<tr>
<td>Stroke in sickle cell disease</td>
<td>Transfusion therapy</td>
</tr>
<tr>
<td>Brain tumors</td>
<td>Reduced radiation therapy</td>
</tr>
<tr>
<td>Metabolic disorders</td>
<td>Transplantation or gene therapy</td>
</tr>
</tbody>
</table>

Abbreviation: HIV, human immunodeficiency virus.
In an effort to bias toward the null hypothesis, we chose assumptions that would maximize the efficacy and availability of each specific medical intervention. For the 2 genetic conditions, we estimated the incidence as birth prevalence; for the 5 other conditions, we used the prevalence estimates from longitudinal studies. For all 7 of the conditions, we calculated the number of cases of MR likely to arise from the condition by using published reports of the natural history of the condition, ie, the likelihood that a condition would lead to MR before age 10 years. For each condition, we then used the randomized studies of specific interventions to estimate the efficacy of preventing MR. For the 2 genetic conditions, we assumed that population-wide availability of the intervention occurred as universal screening was available for that condition. This was estimated by noting the year in which screening programs were introduced state by state, and we generally assumed 100% sensitivity and 100% specificity. For the other 5 conditions, we noted the date that effective interventions were available and assumed that the reductions in prevalence were related to the newly introduced interventions.

**GENERAL PREVALENCE OF MR**

Because the diagnosis of MR is usually not made before age 5 years, we searched for estimates of the general prevalence of MR in persons who were school-aged and older. When prevalence was reported by age, we chose the cohort closest to age 10 years.

**RESULTS**

**CONDITION-SPECIFIC PREVALENCE OF MR**

Regarding data sources, we were unable to locate research programs that tracked condition-specific prevalence of MR over time in the United States. However, there were longitudinal studies of the prevalence of 5 of the 7 specific conditions. For the other 2 conditions (CH and PKU), we assumed that the incidence has been relatively constant over the last 50 years, and we used the reported incidence from a recent large study, the 2000 National Newborn Screening Report.

We recognize that this reported incidence does not take into account fetal loss, but it does provide a good estimate of the number of births with each condition per 1 million live births (birth prevalence). Furthermore, published studies of the natural history, efficacy of treatment, and availability of treatment for the 7 conditions led to the following condition-specific estimates of the impact of specific medical interventions (Figure 1).

**Congenital Syphilis**

We calculated the incidence of CS by dividing the number of reported CS cases by the total number of births in that year; the incidence ranged from 1 case of CS per 272 births in 1950 to 1 case of CS per 13,000 births in 1980. In general, the epidemiology of CS has followed the pattern of syphilis more generally. Dramatic decreases in CS followed public health efforts to screen and treat the general population in the late 1940s and 1950s. Rates reached a low in the 1950s and have since become cyclic with a generally increasing trend. A rise in the number of cases in the late 1980s and the peak in 1991 have many causes, including the epidemic of crack/cocaine use and changes in the public health approach to syphilis. In 1988, the CDC adopted a new case definition of CS that included stillbirths and asymptomatic infants of untreated or inadequately treated mothers. Since 1991, rates of CS in the general population have continued to decrease amid continuing preventive efforts, such as the CDC’s National Syphilis Elimination Plan.

With regard to the natural history, CS is the result of placental transmission of *Treponema pallidum* from an infected mother to the fetus, causing multiple organ system damage. Mental retardation is associated with approximately 25% of CS cases that are detected clinically. We assumed that MR occurs in the same percentage of cases under the revised 1988 definition (25%), although we did exclude a presumed 5% of cases that represent stillbirths and 1% that result in neonatal death.

Efforts to eradicate CS have focused on elimination of adult disease as well as screening pregnant women. Prenatal detection and treatment with antibiotics prevent clinical CS in 98% of cases. Penicillin has been widely available since the late 1940s. Public health efforts to reach all of the affected persons have varied as described earlier.

**Rh Disease**

Before 1970, Rh disease of the newborn, or erythroblastosis fetalis, was a relatively common occurrence in approximately 10% of the mothers who did not have the blood group antigen rhesus (Rh). Rh disease has declined over the last 3 decades and is relatively rare today, but there are no longitudinal studies of the incidence of Rh disease in the United States. We assumed that the incidence in the United States would have followed roughly the same pattern as that in Canada over the last 50 years.

In 1950, Gerver and Day found that 9% of children who were treated with transfusion and recovered from Rh disease had IQ scores in the range of 61 to 80; among...
healthy controls, only 3% had IQ scores in that range. Using an IQ score of 70 as the criterion for MR and assuming that scores were evenly distributed between 61 and 80, we calculated that Rh disease would lead to excess cases of MR in 3% of children who required transfusion.

In the late 1960s, a group of investigators demonstrated that human anti-D globulin could eliminate potentially antigenic fetal cells in a mother who was Rh negative and could thus prevent severe hemolysis for subsequent babies who were Rh positive. Treatment with RhoGAM reduces the risk of initial sensitization from 20% to less than 1%. By the 1980s, the number of cases of Rh disease decreased dramatically owing to the use of anti-Rh immunoglobulin and to changing family fertility patterns.

**Measles**

As part of the National Immunization Program, the CDC posts the number of reported cases of measles from 1950 through 1998. However, widespread underreporting was likely before 1963, when nearly every child in the United States had contracted measles. Therefore, we assumed that every child in the birth cohorts of 1950 and 1960 had measles before age 10 years, for 1970 through 1998, we used the CDC reports of the incidence of measles.

Approximately 1 in 1000 children with clinical measles develops encephalitis. Although most children with encephalitis recover without sequelae, approximately 15% die and 25% of survivors develop complications such as MR. We assumed that approximately 1 in 5000 cases of measles leads to MR.

Several effective vaccines against measles were licensed in 1963, and by 1968, the Moraten strain emerged as the live-attenuated vaccine of choice. The vaccines were widely available almost immediately after licensing in 1963, and reported cases of measles dropped 10-fold within 5 years. Measles continued its downward trend when the CDC organized a nationwide measles eradication campaign from 1967 to 1969. A resurgence of measles in the 1990s was associated with decreased vaccination rates in children younger than 2 years and with primary vaccine failure leading to waning immunity in adolescents.

**Hib Meningitis**

Between 1980 and 1990, the incidence of invasive Hib meningitis in the United States was 40 to 100 cases per 100,000 children for children younger than 5 years in the United States. With routine use of the Hib conjugate vaccine, the incidence of invasive Hib meningitis decreased to 1 case per 100,000 children in the last several years. We assumed that the incidence from 1950 to 1980 was approximately 70 cases per 100,000 children.

With regard to natural history, Hib meningitis was once the leading cause of acquired MR in the United States. Slightly more than half of the Hib meningitis invasive cases presented as meningitis, and one third of children with Hib meningitis went on to have MR. Approximately 1 in 10 children died from Hib meningitis.

Effective conjugate vaccines were licensed for use in the United States for children aged at least 18 months in December 1987 and for infants aged at least 2 months in October 1990. Widespread use of each vaccine quickly followed licensure, and by 1993, there was evidence of a dramatic decrease in the number of cases of Hib meningitis.

**Congenital Hypothyroidism**

The reported incidence of CH has varied little in different populations over the last 50 years. We used the incidence as determined by the 2000 National Newborn Screening Report and adjusted for a 25% false-positive rate and 27 false negatives per million cases screened to arrive at an incidence of 1 case per 2700 live births as the basis for our estimates over the past 50 years.

In the United States, most cases of CH result from thyroid dysgenesis, inborn errors of thyroxine synthesis, and transplacental maternal thyrotropin receptor–blocking antibody. In 1972, Klein et al found that 48% of children clinically diagnosed with hypothyroidism had childhood IQs of less than 70.

Sporadic hypothyroidism was described as early as the middle of the 19th century, and the efficacy of thyroid replacement therapy was described by Osler in the 1890s. Although recipients of replacement therapy often returned to normal skeletal growth patterns, they retained the central nervous system abnormalities associated with the condition, including MR. In contrast, children detected by neonatal screening and treated early tend to have much higher IQs, with only about 4% having scores under 70. Indeed, as early as 1957, Smith et al noted that infants treated before age 6 months had improved intellectual outcomes.

Unfortunately, clinical signs of CH are often not obvious until a later age; therefore, very few children were treated early enough to prevent MR. Early detection through infant screening programs began with pilot studies in Quebec in 1972, and a universal screening program was in place by 1974 in that province. Universal screening and treatment of CH began in Pittsburgh, Pa, New England, and Oregon soon after, and by 1996, all of the US states required universal infant screening and treatment.

We assumed that from 1950 through 1970, clinical diagnosis rarely resulted in treatment early enough to improve IQ outcomes and that 48% of cases thus developed MR. Based on the number of state screening programs at the beginning of each decade and the effectiveness of newborn screening in detecting CH, we estimated that by 1980, almost 20% of infants in the United States would have been detected by neonatal screening and adequately treated. As of 2000, we calculated that there were approximately 27 cases of MR caused by CH in the United States, half as a result of missed cases.

**Phenylketonuria**

According to the 2000 National Newborn Screening Report, the incidence of PKU is approximately 1 case per 15 500 live births.
Phenylalanine hydroxylase deficiency results in toxic levels of serum phenylalanine and is the metabolic cause of classic PKU. About 94% of untreated or late-treated cases of classic PKU are associated with IQ scores of less than 70.51

It was postulated in 1953 that restricting the phenylalanine intake of affected individuals could prevent the severe MR that almost always accompanies the condition.52 When treatment of the disorder is initiated in the first weeks of life after detection by neonatal screening, virtually no children score below 70 on standard measures of IQ.51,53-55

Before 1963, early phenylalanine testing was only feasible in younger siblings of affected individuals. However, the introduction in 1963 of the Guthrie Test, a semiquantitative phenylalanine assay that could be applied to a drop of dried blood, made universal infant screening practical.56 Most US states quickly adopted the test, and today, all of the states have mandatory universal screening programs. We assumed that 94% of false-negative cases result in MR and that 3% of screened and treated cases will result in MR.

**Congenital Rubella Syndrome**

In the United States, epidemics of rubella occurred every 8 to 11 years through the 20th century. The last major epidemic was in 1964 to 1965, when there were approximately 20,000 cases of CRS.57 For the period between 1969 and 2004, we used the estimated incidence of CRS as reported by the CDC.58

Infection with the rubella virus during pregnancy may lead to CRS. The association between maternal infection and fetal disease was first detected by Gregg59 in 1941, and 2 years later, Swan et al60 confirmed the occurrence of central nervous system abnormalities in affected infants. When maternal infection occurs during the first month of pregnancy, 50% of children will later be diagnosed with MR; overall, 10% of all of the cases of CRS result in MR.61 Because neonatal mortality in CRS is approximately 10%,62 we assumed that 9% of children born with CRS would later be diagnosed with MR.

The rubella virus was isolated in 1960, and an effective vaccine was soon developed.63-65 In 1969, a vaccination program concentrating on young children began in the United States. The maturation of this cohort and efforts beginning in 1977 to inoculate postpubertal females led to dramatic decreases in CRS by the 1980s. Although epidemics of rubella have not recurred, rubella has not been eradicated. In response to an increase in cases in 1990 and 1991, the Childhood Immunization Initiative in 1993 intensified efforts to ensure a universally immunized population.56 Rubella and CRS now occur exclusively among immigrant populations from countries without vaccination programs.57,67

**PREVALENCE OF MR BY SELECTED CAUSES**

For each condition, we estimated the number of cases of MR likely to arise by age 10 years for each decade from 1950 to 2000 (Figure 1). Over this time period, CS and Rh disease were the most significant acquired causes of MR. Although the trends for CS, measles, and CRS have been cyclical, the prevalence of MR due to these infections has fallen dramatically over the past 50 years. The peak number of cases of MR due to CRS was 450 cases per million persons in the epidemic years of 1964 to 1965. Also, Rh disease, Hib meningitis, CH, and PKU cause much fewer cases of MR than they did in the 1950s. The net effect of medical interventions in these 7 conditions is a significant decrease in the number of cases of MR.

**PREVALENCE OF MR BY ALL OF THE CAUSES**

There have been no longitudinal studies of the prevalence of MR in the United States, and cross-sectional estimates of prevalence have varied dramatically over the last 100 years.11,18,21,66-71 Table 2 includes representative estimates for each decade since 1940. Although the variation is partly owing to differences in case ascertainment and the population studied, changes in case definition are, by far, the most important factor.51 For example, the 1961 definition proposed by the American Association on Mental Retardation79 considered MR likely in anyone with general intellectual functioning 1 SD below the mean, which implies that as many as 16% of the population would qualify. By 1973, the criterion was changed to 2 SDs below the mean, or approximately 3% of the general population.79 Based on more recent definitions, estimates of the prevalence of MR in the 1990s have ranged between 1% and 3% for the US school-aged population.71,77,78

To gauge the impact of medical interventions on the prevalence of MR over the last 50 years, we compared the combined prevalence of the 7 condition-specific causes of MR with the estimates of the general prevalence of MR (Figure 2). Using the lowest estimated prevalence of MR, 1.2%, the condition-specific causes of MR accounted for approximately 16.5% of the total number of cases of MR in 1950 and for 0.005% of the total number of cases of MR in 2000.

### Table 2. Estimated Prevalence of Mental Retardation by All Causes

<table>
<thead>
<tr>
<th>Year</th>
<th>Cases of MR per 1 Million Children, No.</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>1942</td>
<td>12 000</td>
<td>Lemkau et al62</td>
</tr>
<tr>
<td>1956</td>
<td>34 000</td>
<td>Goodman et al63</td>
</tr>
<tr>
<td>1957</td>
<td>20 000</td>
<td>Jastak and Whiteman64</td>
</tr>
<tr>
<td>1969</td>
<td>74 000</td>
<td>Lemkau and Imre65</td>
</tr>
<tr>
<td>1980</td>
<td>37 000</td>
<td>McDermott66</td>
</tr>
<tr>
<td>1991</td>
<td>12 000</td>
<td>Boyle et al67</td>
</tr>
<tr>
<td>1995</td>
<td>20 000</td>
<td>Larson et al68</td>
</tr>
</tbody>
</table>


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specific prevalence of MR due to 7 specific medical conditions in the last 50 years, but there are limitations inherent in historical epidemiology. Data from an ongoing surveillance program do not exist, as the only such program in the United States began too recently to reflect trends that began 4 or 5 decades ago. In using cross-sectional data, we tried to err on the side of proving the null hypothesis. For example, we compared the reduction in MR cases from specific causes with the lowest estimate of the general prevalence of MR. If we had chosen 3% as the point of comparison, the condition-specific causes of MR would have accounted for only 7% of the total number of cases of MR in 1950. Furthermore, to maximize our estimates of the effectiveness of medical interventions, we did not account for factors that likely would have lowered the effectiveness of screening and treatment (eg, local variations from standard medical practice, poor adherence to treatment, screening tests for genetic conditions with sensitivity less than 100%). Lastly, we attributed the entire decrease in cases of MR to specific medical interventions, although other factors may have been important.

Despite such limitations in our analysis, there is ample evidence that the number of cases of MR due to these specific conditions has decreased over the last 50 years. Our figures represent 1 estimate of that decline, and we suggest that although different assumptions may change the shape of the graphs documenting the decline, the overall trend would persist.

These case-specific rates can be combined to provide 1 estimate of the impact of medical interventions on the prevalence of MR. At first glance, the impact seems to be small but significant. There are more factors to be investigated, however, before reaching conclusions about the general impact of medical interventions. As suggested by Table 1, there are other conditions that cause MR that may be approached through specific medical interventions. These remaining conditions have such a low incidence, however, that they are unlikely to substantially alter our finding. In this study, we also did not consider causes of MR for which prenatal or preconceptional screening is available (Table 3). Down syndrome, for example, accounts for approximately 5% of all of the cases of MR, and widespread screening and termination of pregnancy might have some impact on the overall prevalence of MR. We chose not to consider conditions such as Down syndrome in this initial study in part because there is a difference between the unambiguous good of a medical intervention that prevents MR in an otherwise healthy individual and the more controversial intervention that prevents the birth of an individual likely to have MR. Furthermore, our initial data review did not suggest substantial changes in the incidence of Down syndrome over the last 50 years.

Medical interventions over the last 50 years may also have contributed to a rise in the prevalence of MR. The increased life span of persons with MR, for example, increases the prevalence of MR: children with Down syndrome now live well into adulthood. Furthermore, the clinical success of neonatologists and cardiothoracic surgeons, among other clinicians, means that many children who would have died in infancy 1 or 2 generations ago now survive to be school-aged and are frequently diagnosed with MR and other neurodevelopmental disabilities. Our ongoing research will help quantify more precisely whether modern medicine has contributed significantly to the prevalence of MR.

Our study’s focus was to test the assumptions of the 1963 Kennedy panel’s primary prevention approach to MR, which proposed biomedical models to treat specific conditions that cause MR. Although the panel’s approach was successful for a number of conditions, our data suggest that the overall impact has been relatively small because specific medical conditions account for a relatively small fraction of the total cases of MR. This is not to say that the nation’s optimism in science was misplaced—thousands of lives have been saved because of specific medical interventions, and the astonishing complexity of neurodevelopment is slowly being revealed. It is only through understanding the causes of MR and other conditions that appropriate prevention and treatment can be implemented.

Future research may reveal, however, that broad-based public health interventions may have had a larger impact on the prevalence of MR than specific medical interventions (Table 4). For example, lead poisoning leading to encephalitis caused relatively few cases of MR, but the vast numbers of subclinical cases of lead poisoning likely shifted the mean IQ to the left, thus resulting in diagnoses of MR among children who would otherwise have had low-average cognitive functioning. Whereas the Kennedy panel’s approach to lead poisoning might have


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Table 4. Causes of Mental Retardation With Potential Public Health Interventions

<table>
<thead>
<tr>
<th>Cause</th>
<th>Potential Public Health Intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child abuse or neglect</td>
<td>Public education and intervention</td>
</tr>
<tr>
<td>Fetal alcohol effects</td>
<td>Public health education</td>
</tr>
<tr>
<td>Iron-deficiency anemia</td>
<td>Nutrition programs</td>
</tr>
<tr>
<td>Lead intoxication</td>
<td>Environmental intervention</td>
</tr>
<tr>
<td>Malnutrition</td>
<td>Nutrition programs</td>
</tr>
<tr>
<td>Neural tube abnormalities</td>
<td>Folic acid before pregnancy</td>
</tr>
<tr>
<td>Traumatic brain injury</td>
<td>Child restraint systems</td>
</tr>
<tr>
<td>Near-drowning</td>
<td>Water safety instruction and pool enclosures</td>
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</tbody>
</table>

This study does not consider the effectiveness, and indeed the greater importance, of other nonmedical approaches to improving the lives of persons with disabilities. Although it may be difficult to measure the cognitive impact of deinstitutionalization and special education programs, individuals with disabilities and their advocates have convinced the nation of the fundamental soundness of the disability rights movement. The late 20th century is characterized by a spectacular change in attitudes toward persons with disabilities, and surely this is the most salient feature in understanding MR in the United States over the last 50 years.

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