Emerging Technologies and Their Impact on Disability

Paul H. Wise

Summary

Technological innovation is transforming the prevalence and functional impact of child disability, the scale of social disparities in child disability, and perhaps the essential meaning of disability in an increasingly technology-dominated world. In this article, Paul Wise investigates several specific facets of this transformation. He begins by showing how technological change influences the definition of disability, noting that all technology attempts to address some deficiency in human capacity or in the human condition.

Wise then looks at the impact of technology on childhood disabilities. Technical improvements in the physical environment, such as better housing, safer roads, and poison-prevention packaging, have significantly reduced childhood injury and disability. Other technological breakthroughs, such as those that identify genetic disorders that may lead to pregnancy termination, raise difficult moral and ethical issues. Technologies that identify potential health risks are also problematic in the absence of any efficient treatment.

Wise stresses the imbalance in the existing health care delivery system, which is geared toward treating childhood physical illnesses that are declining in prevalence at a time when mental and emotional conditions, many of which are not yet well understood, are on the rise. This mismatch, Wise says, poses complex challenges to caring for disabled children, particularly in providing them with highly coordinated and integrated systems of care.

Technology can also widen social disparities in health care for people, including children with disabilities. As Wise observes, efficacy—the ability of a technology to change health outcomes—is key to understanding the relationship of technology to social disparities. As technological innovation enhances efficacy, access to that technology becomes more important. Health outcomes may improve for those who can afford the technology, for example, but not for others. Hence, as efficacy grows, so too does the burden on society to provide access to technology equitably to all those in need. Without such access, technological innovation will likely expand disparities in child outcomes rather than reduce them.

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Technology has long been recognized as a potential way to help ensure that children with disabilities will have optimal opportunity for a long, healthy, and socially engaged life. Traditionally, technology and other interventions designed for children with disabilities were focused on strategies aimed at correcting a child's specific impairment or deficit. New scholarship and decades of disability advocacy have expanded this purview to include a wide variety of environmental and societal factors that are now recognized to be essential in optimizing health, development, and social engagement for children with disabilities. This more comprehensive understanding emphasizes the dynamic interaction between the physical environment and the technological and social forces that can reshape it.

Today the prevention and treatment of disability in childhood are being recast by unprecedented technological innovation. In essence, the nature and cadence of this innovation are transforming the prevalence and functional impact of child disability, the scale of social disparities in child disability, and perhaps the essential meaning of disability in an increasingly technology-dominated world. This article investigates several specific facets of this transformation: the influence of technological change on the definition of disability, the impact of preventive and therapeutic interventions on disabilities in childhood, and the ability of the current delivery system to afford access to emerging technologies designed to prevent and reduce the impact of disabling conditions in children. The article also discusses the interaction of technical innovation and the social determinants of health in shaping patterns of childhood disability as well as the interaction between the diffusion of science and technology design and disparities in child health. Understanding these issues and interactions is helpful in designing the health care delivery systems, programs, and public policies that will ultimately prove most effective in addressing childhood disabilities in the years to come.

Defining Disability and Assistive Technology

The definition of technology used in this discussion is comprehensive in nature and refers to the application of scientific knowledge for practical, applied purposes, here directed toward improving health and well-being. The definition of disability has undergone dramatic evolution over the years, conforming to evolving analytical frameworks and societal perceptions. For the purposes of this discussion, I use the definition of disability proposed by Neal Halfon and his colleagues in their article in this volume:

> *A disability is an environmentally contextualized health-related limitation in a child's existing or emergent capacity to perform developmentally appropriate activities and participate, as desired, in society.*[1]

In relation to this definition, technology can refer to both preventive and therapeutic interventions and can take on a variety of forms, including vaccines, other pharmaceuticals, engineering, or alterations to the physical or social environment. A primary objective is the maximization of a child's ability to function independently, which is in many ways determined by the ability to perform essential daily tasks, including those involving hygiene, mobility, and social interaction.[2] Another central objective is the minimization of the impact that the child's disability has on caregivers, both in their

provision of direct assistance and more generally as part of day-to-day family life.[3]

A careful examination of the relationship between disability and technology, however, raises important questions related to the definition and societal meaning of disability in the face of rapidly changing technological capabilities. First, a changing technological environment can dramatically alter the functional impact of any given disability. For example, the development of the telephone greatly enhanced communication in general society. At the same time, the central importance of aural communication in a telephone-dominated society made deafness an increasingly debilitating disability. Similarly, the emergence of a computer-dominated society and its text-based reliance on e-mail and cell phone texting has placed new burdens on the blind. Second, the dynamic interaction between disabilities and technology development underscores the rather arbitrary nature of disability definitions. Virtually all technologies attempt to address some deficiency in human capacity or in the human condition. Automobiles address human inability to move quickly over long distances; telephones address their inability to communicate with their voice over long distances; typewriters and their successors compensate for poor and slow penmanship. At some level, therefore, the definition of disability and the role of technology reflect both the prevalence of a lack of a particular capability and the social response to it. The interactions between disability and technology are, therefore, intensely dynamic and generally evade static categorization or definitions. Indeed, these interactions are undergoing such rapid evolution that they have generated a proliferation of philosophical challenges that have transcended the meaning of disability to seek the meaning of being human.

The Impact of Preventive and Therapeutic Technologies on Childhood Disabilities

Technological innovation has dramatically altered the landscape of both preventive and therapeutic approaches to childhood disability. Advanced preventive strategies reflect new capacities to reduce the occurrence of a disabling condition. The development of a broad array of new vaccines has helped prevent a variety of infectious diseases, such as meningitis, which in turn can result in serious disabling sequelae. Technologies have also played an important role in the early diagnosis of potentially disabling conditions, such as phenylketonuria and other genetic disorders; early diagnosis can permit the early implementation of preventive interventions, including dietary alteration. Rapid progress in therapeutic interventions has also in many instances reduced the impact of disability on daily functioning and social engagement.

Preventive Technologies

Technical innovation has had a dramatic impact on a central arena of primary disability prevention: the reduction of serious, disabling injuries in children. The importance of this preventive domain stems not only from the significant contribution that injuries make to disabling conditions in childhood but also from the strong evidence that injuries are highly preventable. Technical improvements in the physical environment of children, including housing, automobile travel, pedestrian and water safety, medication and poison packaging, and playground design, have led to significant reductions in injury-related mortality and disability in children.[4] These examples also highlight the interactions between the legal environment, which has mandated safety improvements, and the development of technologies to meet these standards.

Many of these technical improvements benefit all their users because they are based on general design enhancements such as safer roads and automobiles. Other interventions that prevent injuries to children depend for their effectiveness on financial access (buying a child car seat, for example), parental behaviors (using a child car seat or a child-protective car window lock), or both. Many of these interventions are mandated by law, but persistent social disparities characterize their actual use and, consequently, patterns of serious childhood injury.[5] Technical innovation has also revolutionized the identification of children at risk for childhood disabilities. In large measure, this technology has taken the form of screening initiatives designed to identify and respond to genetic or other indicators of disability risk before a child is conceived, during gestation, or shortly after birth. Genetic screening of prospective parents has dramatically reduced the prevalence of certain relatively rare conditions, such as Tay-Sachs disease.[6] The ability to identify risk-associated genetic profiles or biomarkers in pregnancy, however, has proven to be the most active, and a highly controversial, arena of technical innovation in disability prevention. The ability to identify the presence of genetic disorders such as trisomy 21 and cystic fibrosis in the fetus, as well as biomarkers or anatomical indicators of disabling pediatric conditions, has traditionally been linked to pregnancy termination, raising difficult ethical and moral questions. Technology, however, is also developing new prenatal interventions, including fetal surgery, that may be able to correct conditions likely to produce disabling damage either later in pregnancy or subsequent to birth.

The use of prenatal diagnostic technology is also characterized by significant social disparities, particularly when complex medical procedures or delivery infrastructures are required.[7] Yet, the continued link of prenatal diagnosis to pregnancy termination has made the disparate use of prenatal screening hard to interpret. Social differences in the acceptability of abortion and in access to abortion could also be contributing to observed disparities in the use of prenatal diagnostic procedures.[8] Differences in access to and use of abortion are likely to be important in explaining disparities in the number of children born with fetal conditions that can be identified through widely available screening approaches, such as ultrasound.

Preventive strategies have also been directed at identifying disabling conditions in newborn infants. These strategies have traditionally involved screening programs designed to identify affected children early enough to implement preventive interventions. This approach, in turn, has usually required that the condition be present but not clinically recognizable at birth and that the condition be amenable to early intervention. Newborn screening programs were initiated in the 1960s to identify children with phenylketonuria. This genetic disorder can cause cognitive impairment that can be prevented by the early initiation of a special, phenylalanine-poor diet. Over the subsequent decades, state health agencies have implemented universal newborn screening programs, and tests for a number of other conditions, including sickle cell disease and cystic fibrosis, have been added to screening protocols.[9]

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health conditions, including cardiovascular disorders and Alzheimer's disease, has been directly marketed to consumers even though the strength of these associations may be weak. Therefore, while the technical ability to identify risk continues to grow, so too does the challenge of making sense of this knowledge and using it to craft an efficient, effective, and humane response.[10]

Therapeutic Technologies

In general, children with disabilities rely more heavily than other children on technical interventions, including medications, specialized medical and educational services, and a variety of assistive devices. The term "assistive technology device" was initially documented in federal legislation in the United States as part of the Technology-Related Assistance for Individuals with Disabilities Act of 1988. The proposed definition was "any item, piece of equipment or product system—whether acquired commercially, modified, or customized—that is used to increase, maintain, or improve functional capabilities of individuals with disabilities." Despite changes in the supporting legislation in 1994 and 1998, this definition has remained largely intact and in widespread use.

Between 9 and 15 percent of children in the United States need or use a prescription medication for an ongoing health condition. Indeed, a requirement for prescription medication is the most commonly met criterion for designating a child as having a special health care need.[11]

One study found that approximately 36 percent of children with special health care needs had a reported need for eyeglasses or vision care; 7 percent required hearing aids or care; and 5 percent required mobility aids or devices.[12] Several national studies reported that approximately one in seven children with special health care needs had at least one unmet need for medical, dental, mental, or other health service.[13] Approximately half of all children with special health care needs require assistive or medical devices, with 12 percent requiring communication, mobility, or hearing devices. Fourteen percent of these children were found to have unmet assistive technology needs.[14]

Studies of specific conditions, particularly cerebral palsy, have documented the importance of technologies designed to improve the functional abilities of children with cognitive and motor disorders[15] and to enhance education, social functioning, and lifelong learning among children and youth with intellectual disabilities.[16] A study of disabled children in an urban area of Finland found that 77 percent of surveyed families benefited from assistive devices for feeding, dressing, and hygiene, particularly if the child had significant motor but mild cognitive disabilities.[17]

While access to therapeutic and assistive technology is important, evaluations of the effects of these technologies on child functioning and quality of life remains spotty.

Using classification domains outlined in the World Health Organization's International Classification of Functioning, Disability, and Health,[18] a recent systematic review[19] found that most studies of functioning and quality of life were concerned with technologies designed to enhance communication through new, computer-based modalities[20] and to improve mobility through advanced engineering and robotics.[21] One striking finding was the paucity of assessments of the impact of assistive technology on caregivers and on the children's families.

Overall, this literature suggests that therapeutic and assistive technologies can improve daily functioning primarily through enhancing activity levels and participation in normal activities. However, these published studies reflect a wide variation in the conditions and types of assistive technologies examined, methodological rigor, analytical strategies, and child and family outcomes. Moreover, there may be a significant bias against reporting negative findings because many of these studies evaluated novel or prototypical devices or programs.

The intense interaction of impairment and social context is reflected in significant regional variation in the ways that technology can affect activity levels, participation in normal activities, and the quality of life among disabled children. A recent study of children with cerebral palsy in six European countries documented considerable variation across the eight study regions in the intensity and nature of a child's participation in daily activities and in children's social roles.[22] Another far-reaching study of childhood disability in Europe strongly suggested that a substantial portion of this variation resulted from variation in state policies addressing the use of assistive technologies among children with disabilities.[23] For example, in Denmark, the country with the highest reported levels of participation in daily activities, advocates for disabled children worked closely with the government to facilitate the provision of assistive technologies and the participation of disabled children in a variety of school and after-school activities.[24]

The Impact of New Technologies on the Prevalence of Childhood Disability

Despite a strong record of successful preventive and therapeutic strategies, there remains a powerful undercurrent of concern that technical innovation has also increased the prevalence of disabilities in childhood. The first mechanism by which technical innovation could be increasing the number of children with disabilities is by shifting mortality into chronic morbidity. While this shift can occur for a variety of serious conditions affecting young children, the decline in neonatal mortality among high-risk newborns, particularly those born prematurely, is of special concern.[25] The well-documented reductions in neonatal mortality over the past several decades are attributable primarily to dramatic improvements in the survival of extremely premature infants. While surviving, however, many of these infants go on to suffer from a variety of medical and developmental sequelae, including lung and eye disease, neurologic deficits, and learning disorders.[26] Still, the increase in the survival of premature infants is not large enough to account for a major portion of the observed increases in rates of disability.

The improvements in the care of high-risk newborns that have shifted mortality to morbidity in extremely premature neonates have also reduced long-term morbidity in somewhat less premature newborns who previously would have experienced high rates of serious illness and disability.[27] The

year-to-year reductions in morbidity lag somewhat behind those in mortality, however, a trend that indicates a rising prevalence of serious disabling conditions emerging from the newborn period. Nonetheless, the impact of technical innovation on both the reduction and the generation of disabling childhood conditions is exceedingly dynamic and should be examined with an informed, analytical eye.

A second, more direct mechanism by which technical interventions could increase the prevalence of serious childhood disabilities is through increasing the number of infants born with a high risk for disabilities. A variety of medications, such as anticonvulsants and retinoids, have been associated with congenital anomalies and other childhood disorders when taken during the prenatal period.[28] Assisted reproductive technology, including in vitro fertilization, has been associated with premature birth and low birth weight, in part because of its tendency to result in multiple gestations (twins, triplets, quadruplets). In fact, a significant portion of the increase in the prematurity rate in the United States over the past two decades is estimated to be the result of the growing use of assisted reproductive technology.[29]

Beyond these discrete, well-documented examples, broader misgivings regarding the potential health impacts of new technical interventions can emerge even for highly efficacious interventions, such as immunizations, when the etiology of a major disabling condition, such as autism or asthma, is poorly understood.[30] Although there remains no evidence that immunizations heighten the risk of autism or asthma, these concerns reflect a broader distrust of the professional and regulatory entities responsible for the approval, use, and ongoing evaluation of new health interventions. Significantly, this distrust can be rooted in complex public sentiments or troubled historical experiences and can play an important role in shaping public acceptance and patterns of use of any new health intervention.[31] It is sobering, for example, that although none of the concerns about vaccine use have been supported by research, a significant number of parents still refuse or delay vaccinating their children.

In addition to these broad concerns, actual access to appropriate assistive technologies for disabled children depends heavily upon the health care and education systems, both of which are increasingly vulnerable to political pressure to reduce expenditures on public programs. Beyond this general financial pressure, however, lies a series of specific challenges within pediatrics and the child health care delivery system that must also be confronted if any real improvements in the quality of services provided to children with disabilities are to be made.

Assessing the Capacity of Current Delivery Systems

Any assessment of the delivery mechanisms for new technologies available for children with disabilities must begin with an examination of the capacity of the pediatric community to provide high-quality care for children with chronic conditions. In this respect, there is substantial reason for concern. Without important reforms, the current system of child health care in the United States will prove increasingly incapable of ensuring the dissemination and appropriate use of innovative technologies for children with serious disabling conditions.

Pediatric Capability for Comprehensive Care

Over the past several decades, the threat of serious, acute infection in young children has

fallen dramatically, largely in response to the widespread use of a series of new immunizations. Even as the incidence of serious acute disease has decreased, evidence suggests that the prevalence of serious chronic conditions has steadily risen. This historic shift in the epidemiology of childhood, with chronic conditions accounting for a growing portion of childhood morbidity and mortality, has outpaced current child health care systems, which were developed in the 1950s and 1960s and designed primarily to address the risk of acute, infectious diseases. Changing childhood epidemiology coupled with an archaic system of delivery has created a troubling mismatch between child health care delivery structures and emerging patterns of need. This mismatch is posing several complex challenges to the provision of care to disabled children, particularly in the development of highly coordinated and integrated systems of care.[32]

In pediatrics, the concept of the "medical home" is driving efforts to develop integrated systems of care. Although the parameters of the ideal medical home for children have been subject to some variation,[33] it is generally considered a locus of care that ensures "accessible, continuous, comprehensive, family-centered, coordinated, compassionate and culturally effective care."[34] Despite numerous pronouncements regarding the importance of the medical home in child health care, however, several studies document the great difficulty of actually implementing such integrated care for large populations of children.[35] Moreover, it appears that children who require complex care coordination or assistive technologies may be particularly sensitive to the lack of a high-quality medical home.[36]

The obstacles inherent in implementing highly coordinated care for children with complex medical needs are particularly apparent in the troubled relationship between our current health care and education systems. Since the early 1970s, federal law has required that school systems provide children with disabilities with educational and related supportive services that permit them to function as independently as possible. This requirement was extended to infants and toddlers through a reliance on early intervention programs by a law (Public Law 99-457) enacted in 1986 and later expansions in the Individuals with Disabilities Education Act (IDEA) of 1990. These expansions, clearly recognized by the pediatric community,[37] supported services such as mobility devices; occupational, speech, and physical therapy; and other medical requirements. (See the article by Laudan Aron and Pamela Loprest in this volume.)[38]

The prescribed role of primary care physicians in facilitating and coordinating these services has eluded a clear consensus. IDEA describes the physician's responsibility in terms of clinical diagnosis, evaluation, and consultation. The American Academy of Pediatrics criticized this delineation of responsibility, however, because it failed to recognize the physician's role in the management, supervision, and planning of services for these children, basically denying a central role for the physician in the medical home.[39] Regardless of the specific responsibilities of the primary care physician, however, a highly collaborative team is clearly required to coordinate care effectively across the various domains in which the child functions, including the home, the school, and the larger society.

The public education system can play an important role in facilitating access to assistive technology. IDEA specifies that children

should be provided with the assistive technologies they need to reach the goals identified by an individualized education plan or individualized family services plan. In addition to educational programs, schools can facilitate the engagement of other crucial services, including occcupational, physical, and speech therapy. Often, these service providers are highly knowledgeable in the detailed use of relevant technologies as well as the administrative mechanisms required to facilitate access to them.

Considerable change has occurred in the educational and reimbursement policies supporting the involvement of school-based and nonphysician providers in care teams for children with assistive technology needs, such as wheelchairs, communication devices, and corrective glasses. But so far there has been very little insight into how these changes are affecting the nature or quality of services provided by schools. Moreover, the growing financial pressure on both the child health care and educational systems could undermine local capacities to provide highly coordinated, high-quality services for disabled children.

The Promise and Limits of the Medical Home

No comprehensive assessment has been conducted of why the medical home has been so difficult for the child health care system to implement, but several important concerns may play a role. The availability and affordability of insurance coverage is strongly associated with access to services for children with complex health problems, affecting both out-of-pocket family expenditures and the use of those services.[40] The role reimbursement policies play in shaping physician practice, particularly physicians' willingness to care for children with special health care needs, is less clear, however. Relatively low or inflexible reimbursement levels may be generating strong disincentives for physicians to allot the necessary time and practice infrastructure to coordinate the care of children with complex needs.[41] Current reimbursement policies appear to be placing growing pressure on pediatric practices to increase patient volume, primarily for relatively well children. This pressure is also evident in the increased likelihood that primary care pediatricians are more likely now than they were a decade ago to refer complicated patients to specialists.[42] Although the American Academy of Pediatrics has consistently advocated for a strong pediatric role in the care of children with special health care needs, considerable evidence indicates that the training of pediatricians has been lacking in this regard.[43] Physician comfort with prescribing special therapy and assistive technology may also be problematic.[44]

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Medicaid and Access for Poor Children

Medicaid remains the central publicly funded health insurance program for poor children in the United States. Its reach is wide—it now covers approximately a third of all children in the country and almost half of all births in many states such as California. The

importance of adequate health insurance in generating access to high-quality care is difficult to overstate (see the article by Peter Szilagyi in this volume).[45] Therefore, the prospects for the continued capacity of the Medicaid program to address the needs of poor, disabled children are worthy of special scrutiny.

Unlike the Medicare program, which is a federally funded entitlement providing broad health coverage for all elderly citizens, the Medicaid program is a combined federal- and state-funded program, specifically dedicated to providing coverage for the poor, the disabled, and elderly nursing home patients. State budgets have become increasingly dominated by Medicaid expenditures, largely because of increases in payments for the care of elderly patients. In mid-2011, thirty-seven states were planning significant reductions in their state Medicaid allocations. These reductions most often take the form of reduced payments to providers and hospitals. In the past, such reductions have had the effect of reducing program participation among low-income women and children. In addition, many states are eliminating "optional" expenditures, those not mandated by federal legislation, that often relate to specialized technical interventions or devices.

Recent legislative actions designed to enhance primary care reimbursement for children could provide a basis for expanding access to Medicaid and perhaps for expanding the presence of the medical home in pediatrics. In addition, new managed care structures currently being developed, such as the accountable care organization (ACO), may be adopted by the Medicaid program. An ACO is an organization that seeks to tie provider reimbursements both to measures of the quality of care provided and to reductions in the cost of care provided to groups of patients. Medicaid's adoption of the ACO could provide a financial foundation for improving the quality of care for children with special health care needs. But such structures have not yet shown that they can appreciably reduce expenditures, so their implementation should not be viewed as permitting major reductions in Medicaid funding for children. In addition, these managed care structures use primary care providers not only as facilitators but also as gatekeepers for a range of specialized services and assistive technologies. Without reimbursement and structural reforms that would provide clinicians the opportunity to coordinate the care of disabled children, including providing them with a medical home, the current child health care delivery system will make it difficult for primary care providers to play such a comprehensive role in an informed and constructive manner.[46] Rather, the exploration of new kinds of health financing structures should be seen as a historic opportunity to enhance the ability of the pediatric community to focus its expertise and coordination efforts on children with disabling conditions as part of a more innovative and coherent child health care system.

The Impact of Technical Innovation on the Social Determinants of Health

A full understanding of the relationship between technical innovation and social patterns of health and disease has long been hampered by antagonisms in disciplinary approaches and political ideology. Social disparities in health are rooted in social forces and societal stratification virtually by definition. A World Health Organization Commission on Social Determinants of Health and a televised documentary series on this issue have recently emphasized this point.[47] However, recent decades have also

witnessed unprecedented technological advances in health care driven by a strong belief in the capacity of medical, largely technical, interventions to improve health outcomes. The task of understanding the role of technology in improving the health and well-being of children with disabilities will, therefore, require some reconciliation, if not integration, between these two perspectives and domains of empirical analysis.

A History of Antagonism

Tensions between the social and technical perspectives can be traced to the earliest use of health statistics to support improvements in public health. Victorian reformers, making good use of newly available vital statistics data, drafted a series of public reports calling attention to the distressingly high levels of mortality among children living in poor areas of industrializing Europe.[48] This documentation, particularly the classic *Report on the Sanitary Condition of the Labouring Population of Great Britain* in 1842, brought long overdue public attention to the plight of the urban poor by laying out in cold statistics the unmistakable message that poverty meant more than hardship: it also meant death.[49] While progressives of all types saw these reports as strong justification for reforms, there quickly emerged some very real tensions in the precise role that social and technical approaches should play in any public response. An influential group of reformers, led by Florence Nightingale and Edwin Chadwick, framed the disparities in mortality as the product of poor sanitary conditions, including overcrowded housing, inadequate sewage, and contaminated water. For this group, the focus was on improvements in public engineering, largely technical sanitary reforms, with little direct concern for the social or political claims of the poor.[50] This perspective tended to elevate the technical above the social, hygiene above injustice. Although clearly a call for remedial public action, this call was advocating the eradication of unsanitary exposures rather than of the social forces that shaped them.

Other reformers, however, saw the alarming disparities in health and disease as evidence of inequities in economic relations and political power. For example, Friedrich Engels used tabulations of disparate child mortality to support calls for systematic changes in basic economic structures and political control.[51] Similarly, Rudolf Virchow, a father of modern pathology, recast epidemics and inequalities in health outcomes as the product of social forces and local political conditions.[52]

In many ways, these tensions between technical and social perspectives have continued to characterize analytical approaches to disparate child health outcomes both in the United States and globally.[53] In the early 1900s, the Children's Bureau, the major federal agency concerned with improving maternal and young child health at that time, attempted to link the establishment of technical programs with more basic arguments regarding the social plight of young families in poor urban and rural settings.[54] Later in the century, growing technical capacity and a strengthened medical profession led to a refocusing of federal attention on technical approaches to improving child health.[55] This trend was greatly accelerated by the creation and rapid expansion of the Medicaid program, which dramatically shifted federal funding to frankly medical interventions.

The Interaction between Technical Innovation and the Social Determinants of Health

In some measure, the recent elevation of the social determinants of health in public

discourse is a regulating response to the dominance of the technical world during the past several decades. In addition, strong disciplinary impulses help generate tensions between these two different approaches. For those who elevate social causation as a focus for public response, the utility of a health indicator like the child mortality rate lies in its capacity to reflect the human impact of larger societal forces. In this sense, child mortality acts as a kind of social mirror, serving as a stark, ultimate expression of deep, often complex social influences. For those who embrace clinical or technical strategies, on the other hand, the very purpose of technical intervention in a setting of material deprivation is to uncouple poverty from its implications for health. Here, the intent is to use technical capacity not to alleviate poverty but to reduce or eliminate its power to alter health outcomes. In this manner, the goal of technical intervention is to eradicate child mortality's linkage to social causation; the ultimate goal is to create equity in child mortality regardless of the scale of persistent social stratification. For the clinician, success is defined as eliminating child mortality as a social indicator, thereby challenging the very premise of the disciplines that use child mortality as a reflection of the social determinants of health.

The reality is that technical innovation does not truly undermine the power of social causation; but it can radically transform the mechanisms by which social forces exert their profound influence. At a basic level, adverse social influences on a health outcome elevate risk in a population or reduce access to effective interventions, or both.[56] This "dual currency" approach to the etiology of social differences in health outcomes, while simplistic, can nevertheless help disentangle complex disciplinary discourse and offer an analytical footing that can begin to bridge the perspectives that have traditionally separated the social causation and technical realms. This general approach has also been constructively used to reframe socioeconomic status less as a modifier of a disease pathway than "as a fundamental cause of disease."[57] This formulation has stressed the multiple and often complex means by which social forces can exert their influence on health and the variation by which these influences can act over time.

Of central importance, and what ultimately determines the relative role of risk and access in shaping patterns of outcomes, is the efficacy of the intervention in question. Here, efficacy is defined as the power of an intervention to alter outcomes. Interventions wholly without efficacy are not likely to generate differences in outcomes regardless of whether differences in access exist. When interventions are ineffective, differences in underlying risk status will be the dominant cause of disparities in outcomes. When the efficacy of intervention is high, however, then differences in access to these interventions may be the dominant source of disparities in outcomes. The nature of the intervention, be it preventive or therapeutic, low-tech or high-tech, makes little difference; the crucial issue is its proven efficacy. This pivot on efficacy helps underscore the role that technical innovation can play in shaping disparate patterns of health outcomes.

In a period of unprecedented technical innovation, efficacy must be viewed as being exceedingly dynamic, reshaped and expanded with each new discovery or invention that is shown to alter outcomes or improve function. If technological innovation enhances efficacy, then access to technology will become more important. Hence, as efficacy grows, so too

does the burden on society to provide access to technology equitably to all those in need. In this sense, when equity in health outcomes is an agreed-upon social goal, technical innovation places a burden on delivery systems, making outcomes increasingly sensitive to even small differences in access.

A consequence of this role of efficacy is that in a socially stratified delivery system, technical innovation has the ability to widen disparities in outcomes as well as to reduce them. A growing body of evidence is showing that social disparities in mortality are greater for diseases that are considered preventable, in essence, those that have known, efficacious, technical interventions.[58] Virginia Chang and Diane Lauderdale documented a reversal in social disparities in cholesterol levels after the introduction of statin medications: before statins were introduced, higher social status conveyed an elevated risk for high cholesterol, but after they were introduced, high socioeconomic status was associated with lower risk of high cholesterol.[59] Disparities have also widened after the introduction of some highly efficacious interventions, such as immunizations, cardiac surgery, and antiretroviral therapy. Similarly, if new technologies worsen outcomes or have adverse side effects, then enhanced access to these technologies among socially advantaged groups could reduce observed disparities in outcomes. For example, while assisted fertility therapy has proven highly efficacious in enhancing fertility among women and couples desirous of childbearing, it is also associated with multiple gestations and premature birth. It was not surprising to observe, therefore, that as wealthier populations were able to make greater use of these new fertility therapies and techniques, white prematurity rates rose, reducing the disparity in premature birth rates between white and African American women. Technical innovation, therefore, is inherently neutral in its effect on health disparities; its ultimate impact is determined by its efficacy (including adverse effects) as well as by social patterns of diffusion. Therefore, new or improved technologies for children with disabilities may or may not reduce disparities in disabilities or their impact on the daily lives of affected children. Rather, close examination of the interactions between the technologies, the distribution of need, and access will always be required.

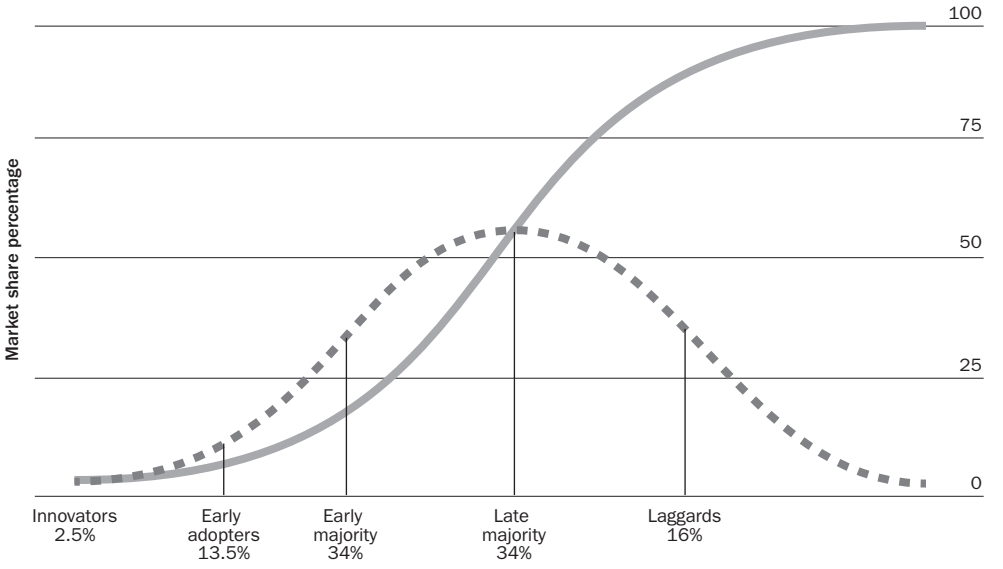
Diffusion Science and Disparity Creation

If technological innovation enhances efficacy, then factors that shape the diffusion of this new technology throughout a delivery system can be of crucial importance to health disparities. The diffusion of technical innovations has been studied since the late nineteenth century, but it became the focus of modern analysis after the publication in 1962 of the *Diffusion of Innovations* by Everett Rogers.[60] Rogers defined diffusion as the process through which an innovation is communicated through certain channels over time among members of a social system, his point being that diffusion occurs through social systems.

The Social Determinants of Technology Diffusion

A variety of studies have demonstrated that diffusion generally occurs in an S-shaped curve over time, depicted as the solid line in figure 1. This shape represents a nonlinear pattern of adoption, reflecting different affinities for adoption in a population. Rogers categorized these different affinity groups as early adopters, majority adopters, and those who are ungenerously labeled laggards. These categories are illustrated in figure 1

Figure 1. Innovation Adoption Pattern in a Social System



Source: Adapted from E. Rogers, *Diffusion of Innovations,* 5th ed. (Free Press: New York, 2003), figures 1-2 and 7-3.
Note: The solid line represents the cumulative percentage of adoption or market share over time. The dotted line represents the distribution of adoption around a mean. Each adopter category is delineated by the multiple of the standard deviation around the mean.

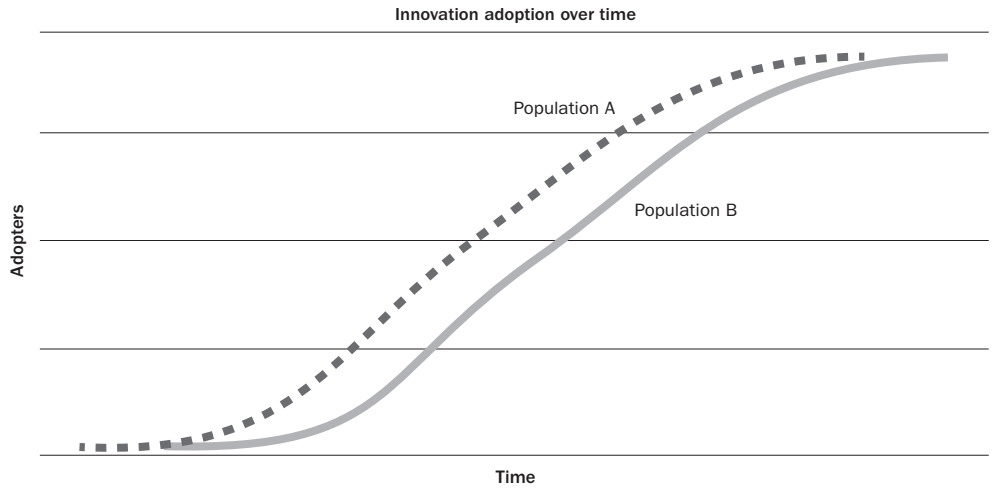
as sections under the dotted line representing the distribution of adopters around the mean. A large body of work now documents the mechanisms that determine diffusion patterns. Not unexpectedly, much of this literature is focused on how best to optimize diffusion either to expand product market share or to alter patterns of practice.

For children with disabilities, the nature of the technical innovation and the practical delivery system are both crucial and highly interactive. The characteristics of innovations likely to move quickly through the S-curve include perceived utility, low cost (not only in dollars but also in ease of use), and good aesthetics. In addition, innovations that depend on a complex infrastructure for use may be more sensitive to the capacity of delivery systems for widespread adoption. For example, amniocentesis for prenatal diagnosis is highly dependent on a fairly sophisticated delivery system for its use. It should not be surprising, therefore, that in a socially stratified delivery system, social disparities in the use of amniocentesis are greater than those for other, less complex, prenatal screening technologies.[61] Systems heavily dependent upon standardized payers, such as insurance plans, may prolong early adopter phases until the payer authorizes expenditures for mainstream adoption. In this manner, the innovation diffusion patterns are sensitive to the interaction of innovation and system characteristics.

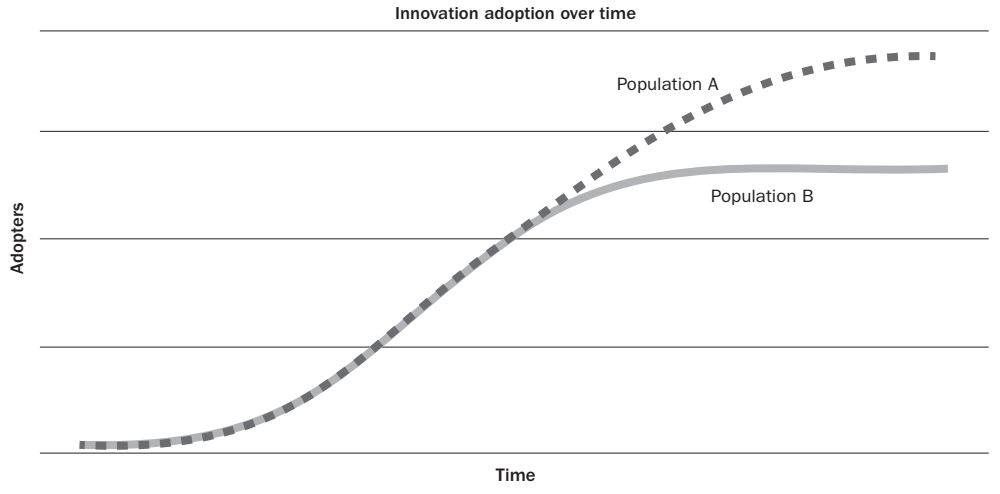
The concern is that these potential interactions may create social differences in the diffusion patterns of highly efficacious innovations. For example, stratified delivery systems can delay adoption and have the effect of shifting the S-curve to the right along the time axis (figure 2A). In this manner, two populations may exhibit the same

Figure 2. Variations in Innovation Adoption over Time-Delayed and Arrested Adoption Curves

A. Delayed adoption curve



B. Arrested adoption curve



Source: See figure 1.
Note: In panel A, the S-shaped curve of adoption occurs first in one population (Pop A) relative to another population (Pop B), and so a disparity in adoption will be observed until the innovation is completely adopted by both groups. In panel B, adoption is similar for both populations until an adoption plateau is reached in one population (Pop B); in this case a disparity in adoption emerges midway through the diffusion process.

adoption pattern but with highly dissimilar time frames, which could create disparities in outcomes for any efficacious intervention for lengthy periods of time. Alternatively, socially disparate characteristics of the delivery system could arrest diffusion at some level of adoption along the S-curve (figure 2B). Adoption could slow, for example, if it required a certain level of base resources (say, for an intensive care unit) that may not be sufficiently available across the whole system serving a socially defined population.

Whenever efficacious interventions exist, differences in the diffusion of and access to these interventions are thus likely to play a major role in shaping disparities in health outcomes. General populations (including adults) show some signs of significant social disparities in access to assistive technologies.[62] These disparities appear to be particularly large for expensive devices, such as powered wheelchairs.[63] Significant variation in coverage policies among private insurance plans and public programs such as Medicaid have made it difficult, however, to fully gauge access disparities to important assistive technologies for children with disabilities.

Technology Design, Markets, and the Burden of Provision

While the inherent interaction between the characteristics of an innovation and the nature of the system dedicated to its functional delivery must be recognized, the forces shaping the design of the technology most relevant to children who are disabled should also be considered. Assistive technology has been generally considered, particularly by the health and human service community, as inherently compensatory or accommodative in nature. Basically, this technology is viewed as being directed at a selected population of disabled users who would benefit from the technology's ability to address a specific functional impairment. Under this approach, assistive technology often represents a specialized adaptation of broader technologies and is distinguished from technology in general on the basis of the rarity of a specific human need. In this setting, one would expect that the design and manufacture of this specialized assistive technology would be dominated by a set of relatively small, niche manufacturers, a phenomenon that traditionally has been very much the case.

An alternative approach perceives the design of technology for the disabled as part of the essential design of any technological innovation. Generally referred to as "universal design," this approach guides "the design of all products and environments to be usable by people of all ages and abilities to the greatest extent possible."[64] This approach does not depend upon the delayed reconfiguration of a general technology to meet the specific requirements of the disabled. Rather, it attempts to design from the start innovations that are accessible to all.

Universal design responds to conceptual frameworks developed to create highly inclusive disability theory and law.[65] It has proven most crucial in influencing the design of new digital technologies, particularly those mediating social communications through the Internet. The reasons have been twofold. First, designing computer software and hardware for universal use should be easier and less costly than designing many other general technologies for such use. Second, and more important, universal design may be most critical in settings of extremely rapid innovation. Adaptive designs, even when developed and implemented relatively rapidly, are not likely to keep up with a highly dynamic technology environment. This lag can lead to the chronic exclusion of disabled people from mainstream technology use. Although relatively little evidence is available regarding the impact of universal design on the activity and participation of children with disabilities, the importance of rapidly advancing digital technologies to the lives of all children, and particularly to disabled children, may underscore the importance of research in this area. In addition, the impact of universal design may prove particularly important in a setting of constrained public financing for health care services. The reduction or elimination of Medicaid support

for the acquisition of assistive or adaptive technologies may only strengthen the utility of universal design strategies.

The potential utility of universal design is also closely related to the concern that small niche markets for adaptive technologies do not provide sufficient financial incentives to support the development of highly innovative products. Drugs or technologies for small markets, often termed "orphan" technologies, may be required to supplement broader, universal approaches.[66] The record on the actual effectiveness and pricing of orphan medications and technologies has been mixed, however, and new strategies may be required to ensure the robust development of new interventions for relatively rare disorders. In addition, universal design may prove more practical for technologies used by large populations of disabled persons, such as the elderly—technologies that may or may not relate directly to the needs of much smaller groups, like disabled children.

An enhanced reliance on universal design, particularly given the persistence of social inequalities in access to computer and Internet-based technology (the well-known digital divide), will nevertheless require specific mechanisms that ensure universal access to the technology in question.[67] This imperative highlights the potential need for specified, focused programs directed at affording access to disabled children and their families even if such programs are concerned with technology designed for and used by a general population. More broadly, rapid innovation in health-related technologies may blur distinctions between universal and orphan interventions. For example, advances in genetic testing technologies have generated hopes for individualized risk assessments and therapeutic plans, a new strategy of "personalized medicine."[68] Such visions transcend traditional boundaries between universal and orphan approaches and underscore just how dynamic the interaction between technologic innovation and systems of dissemination can be.

Conclusion

Childhood disability cannot be fully understood without a clear appreciation for the power and machinery of technical innovation in the modern world. Technical progress in both preventive and therapeutic interventions is constantly reshaping the character and prevalence of childhood disability and therefore its essential challenge to both the health and education communities. Yet technical innovation is also generating remarkable new prospects for enhancing the capacities of affected children and optimizing their quality of life. Indeed, the nature and cadence of technical innovation are likely to set in motion profound changes in the meaning of disability for affected children and their families, particularly as the use of technology becomes more deeply integrated into the common tasks and routines of daily life for everyone.

As technical capacity expands, so too does the burden on society to provide this capacity to all children in need. Here, the essential challenge to practitioners and policy makers is the link between technical innovation and equitable provision, without which technological innovation will likely expand disparities in child outcomes rather than reduce them. While transforming human capability and disability, technical innovation also constantly reshapes our collective commitment to equality and social justice, and, in so doing, to the aspirations and promise of childhood.

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