
PERSPECTIVES

Presidential Address 1997—Benchmarks for the Next Millennium

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The 21st century will begin in less than 1,000 days. Even now, the next millennium lingers in the periphery of our vision, a benign stranger who intrigues us with possibilities of the future. This century bears witness to marvelous achievements, changing forever the ways that we live, work, and learn. In this address I reflect on some of our century's preeminent benchmarks and possible scenarios in the next millennium.

Recently, a reporter from the *Washington Post* suggested that anticipating the future is a gauzy task. If this is true, it is with the realization that such forecasting is slippery and somewhat akin to divining the weather. Rather than prognosticate, I will share with you events that remind us of what is past and give us hope for what may yet be possible.

Benchmarks are used widely in business and industry as reference points for performance. When corporations want to improve production standards, their leaders often choose a preeminent market competitor for comparing with their company. They select a competitor's product or service regarded as the best of its kind, a benchmark of competency to which their corporation must aspire, eclipse with a better offering, and, they hope, a greater market share (Senge, 1990).

Citizens of the 21st century may come to realize that few substantive differences remain among nations' benchmarks as the effects of diminishing resources, demographic shifts, social unrest and environmental pollution converge with lessening regard for geographic boundaries.

Suffice it to say, our profession does not exist in a vacuum. We are citizens of the world. We are members of the global community. Hence, I highlight benchmarks for all people, and particularly, citizens with mental retardation and developmental disabilities. These

benchmarks will continue to influence our profession and this association in the next millennium. Clearly, not all have left a positive effect on humankind. Some exist, not as standards to which people aspired, but as unique social, political, or ideological markers. Some events are historical. Some benchmarks have no clear lifespan. Many incidents are of such life-altering magnitude that their occurrence registers an indelible imprint on the world's consciousness and the history of the global community.

Consider these 20th century milestones:

- Singular achievements in science, medicine, and technology that were unimaginable 100 years ago
- Global wars, countless destructive conflicts, and unspeakable holocausts
- The fall of Soviet communism
- The insidious pestilence of the international drug trade, plaguing our families, our children, and the welfare of future generations
- The microchip and the Information Revolution
- The reformation of the family
- Living and working in space
- Legal and legislative benchmarks that propelled civil, constitutional, and human rights from a hazy focus into sharp resolution
- The evolution in the lives of people with disabilities

In our lifetime, we have witnessed profound changes in society's regard for people with disabilities. To be certain, progress has been achieved over improbable odds. History is marred by degradations of abuse, eugenics, involuntary sterilization, neglect, and segregation. This century also records shameful inhuman practices, among these, euthanasia practiced as a state program of Nazi Germany, resulting in

the deaths of 100,000 people with mental retardation (Hollander, 1990; Smith, 1994).

Advances of the past 30 years have changed society's attitudes about people with disabilities. Our vocabulary mirrors these advances in words such as *empowerment*, *inclusion*, and *self-determination* (Dybwad & Bersani, 1996). We have lived in the formative years of the disability movement. Once expressed by others, individuals with mental retardation now tell society how its perceptions and attitudes impact their lives and expectations (Smith, 1997). People proclaim their desires and needs through the growing advocacy movement. Conceived as a single organization in the early 1970s, this vital process now works through over 500 groups, representing thousands of citizens throughout the United States and other countries (Heath, Schaff, & Talkington, 1978; Longhurst, 1994). Invigorated by citizens, parents, service providers, attorneys, and public officials, the movement coalesced into a revolution that found its voice in civil and legislative benchmarks for millions of Americans and serves as an international expression of human rights.

Early on, the President's Panel on Mental Retardation, individuals, and professional organizations (such as AAMR) acted as important catalysts—creating, stimulating, and energizing people to believe in the possibilities of full access for education, housing, and employment. From such beginnings were borne the realities of legislative benchmarks. Together, activists produced the Developmental Disabilities Act, the Individuals with Disabilities Education Act, the Rehabilitation Act, and the Americans with Disabilities Act, events that stimulated change and progress among all people in our society (Parry, 1996).

As this century concludes, we are part of important changes in our professional practices. States have decreased reliance on large congregate settings as the sole means of meeting the needs of citizens and families. People now choose from a vast array of supports designed to maintain family unity and promote individual independence. More important, people are becoming collaborative partners rather than recipients of services. We are moving from service mechanisms driven by the availability of slots to individually crafted networks that enable people to define quality of life in their own terms (Miller & Keys, 1996).

Developments in policy and practice now

yield greater sensitivity for choice and opportunities. Employment and housing options are expanding (Stark & Goldsburly, 1988). Since 1990, fiscal commitments for the Home and Community-Based Waiver have grown at an annual compound rate of over 30% (Perspectives, 1997).

Even in these times, progress seems sporadic, incremental, and conditional. While we celebrate certain benchmarks as standards of excellence, we must also acknowledge with honesty that change has been painfully slow. We are frustrated when critical course corrections are not charted because of systemic inertia and resistance. Service organizations struggle with severe labor shortages and compete for scarce fiscal resources. Criminal justice statistics still record inequities for people with mental retardation. As a group, they are more likely to be arrested, convicted, sentenced to prison, victimized in prison and are less likely to receive probation or parole (Conley, Luckasson, & Bouthilet, 1992). Acceptance within our communities is not always freely extended. Misperceptions are sometimes only a thin veneer over archaic attitudes of exclusion, indifference, and intolerance.

All people value independence and control of personal circumstances. Together with self-advocates, families, and colleagues, we have learned that empowerment is not bestowed. Empowerment occurs as an individual and dynamic process. It is the responsibility inherent in greater control and influence over one's life and environment. Empowerment is a tacit emancipation that motivates and energizes.

An emancipated life is a rich fabric of diverse experiences. Having a place to call home, a healthy lifestyle with friends, recreation, spiritual contemplation, and personal achievement are woven into a vital tapestry that nurtures and sustains individual growth. Meaningful work is among our most valued life experiences. Someone once suggested that the lack of a gainful vocation is perhaps the true definition of disability. Today, only 1 in 10 individuals with disabilities is employed in a full-time capacity. Seventy percent are without work or working below their capacity, despite declining unemployment rates (National Industries for Individuals with Severe Handicaps, 1996). In spite of legislated mandates, neither the Americans with Disabilities Act nor other employment initiatives have created significant job oppor-

tunities for the broad range of individuals with disabilities. Although a majority of major corporations express support for increased employment, these same entities view job training as the primary responsibility of education or rehabilitation programs (*What's Working*, 1997).

It is a sad reality that despite mandates for transition services in the Individuals with Disabilities Education Act (IDEA), our educational system has not been wholly successful in preparing young people for progression from school to work and community life (Bradley, 1997; Herr, 1997). We have failed to recognize the changing nature of the workplace in balancing academic preparation with occupation skills. Job readiness programs are inadequate and vocational programs are often outmoded, lacking necessary modernizations that enable people to be more competitive in today's automated work environments (*Education of the Handicapped*, 1995). In a world where education is the vehicle for personal achievement, young people need survival skills, self-respect, and the psychological resiliency to excel in the workplace.

Historically, government is viewed as inseparable from a country's prosperity. If that is so, Americans' perception of government may be at variance with its abundance. Disillusionment with our legislative infrastructure is well-documented and reached unprecedented levels in the 1980s and 1990s. We are bombarded with frightening statistics about a seemingly endless array of economic, ideological, and political concerns. Disenchantment now seems to extend to other, lesser institutions, such as our schools, banks, churches, and legal system.

Widespread public vexation, coupled with escalating healthcare costs and the federal budget crisis, likely fueled Congressional realignment of welfare policies last year. On balance, the Act created a dramatic shift of social responsibility to the states, restructuring our 30-year program of health and income supports for Americans who are poor, elderly, or have disabilities.

To be certain, this bitter evolution was slow and gradual. Longer-range consequences are at some distance from us, beyond this century's horizon. This legislation will affect millions of families and children much more rapidly (Gaus, 1995).

Over the past several Congressional sessions, bipartisan discussion about balanced budget initiatives has generated widespread

speculation about radical entitlement reforms. Debate in the 105th Congress now proposes Medicaid caps and increased Medicare premiums. Such measures would drastically reduce health benefits for low income people and jeopardize services for children and aging citizens.

It has been said that contemporary discontent is the rumbling underside of progress (Edsall, 1996). Clearly, we live in an age of paradox. Personal freedoms offer more opportunities. At the same time, that freedom generates fundamental transformations in virtually every aspect of human exchange. Moreover, certain benchmarks hold more ominous predictions for the next millennium.

Twenty-two percent of this country's children live in poverty. Reported cases of childhood abuse and neglect, suicide, and homicide are rising at alarming rates. Worldwide, the well-documented effects of deprivation, malnutrition, and environmental poverty leave their imprint on children and on our ability to meet their future needs (Alexander, 1991).

Infant mortality in the United States remains shockingly high for a First World country. A tremendous number of babies are exposed to drugs in the womb—perhaps as many as 10% of all live births, some 375,000 infants each year. Thousands of newborns suffer from the effects of alcohol use during pregnancy, and HIV-infected babies are among the fastest growing group of children at risk for mental retardation and developmental disabilities.

Changing demographic benchmarks may undermine critical political endorsement for legislation that might ameliorate these statistics. Each year, as the percentage of voters with children declines, support for legislation affecting children erodes further. As our country ages, we should note that people 65 and older have the highest voting rate of any population group. By the year 2030, more than 80% of America's voters will be over the age of 55. With such unprecedented strength, this group can influence significantly any legislative agenda.

We may expect that these voters will be more interested in policies that preserve fiscal resources and resistant to any tax initiatives to introduce or expand needed human or social services. When states exert greater control over funding, as with last year's welfare reform bill, we may see socioeconomic benchmarks define crucial preventive healthcare legislation.

The image of America in the 21st century

is a population that is older, longer-lived, better-educated, and more ethnically diverse, the world's first truly multicultural society. If present trends are indicative, marriage and family relations will continue the radically altered path from that of earlier generations, further shaping the demographic landscape.

We will be a nation rapidly growing older in the next half-century. Between 1995 and 2010, about 39 million Americans will be 65 years of age and older. Between 2010 and 2050, the numbers will swell to about 69 million, as baby boomers march steadily into retirement. Meanwhile, the working percentage of America's population, citizens between the ages of 20 to 59 will remain stable at about 160 million (Preston, 1996). These statistics heighten our concern as the percentage of workers to retirees continues to shrink, decimating our nation's revenue base as well as its future work force for all professions. We are already experiencing the effects of current labor shortages on supports and services.

In the 18- to 34-year-old age group, fewer people are available to enter any profession. In the context of labor shortages, industries that suffer the most are those that rely on a high percentage of young adults, industries that pay the least and demand the most from their work force.

Turnover is too high in any service setting. With a workforce that is predominately female, human service professions now attract fewer women into the industry. We face stiff competition within our own professions, all drawing from a limited number of potential direct service staff. These trends will continue into the next millennium.

As historians study the last half of the 20th century, they will likely record that the reformation of the family was the most significant social movement. More than 60% of American children will spend a portion of their early years with a single parent, in most instances, their mother. People marry later and divorce in record numbers. Fewer women remain at home with children. As their earning potential has increased, women are less reliant on marriage as a precursor to motherhood (Preston, 1996).

Well-documented needs of single-parent families, an aging population, and increased percentage of children in poverty will stress federal and state resources, diverted to address burgeoning social challenges and away from fiscal

supports for people with disabilities. Such substantive change suggests that we broaden our expectations for inclusion as a natural consequence of choosing a neighborhood, purchasing a home, and setting up a residence. These markers also suggest a collective response to broaden our definition of individual supports, insistence on quality regardless of service setting, and more flexible program designs.

Achievements in other arenas, particularly medical science, have been remarkable. As we enter the next millennium, we will enjoy longer, healthier lives. We live in a truly miraculous age, witnesses to the doubling of life expectancy since the Industrial Revolution (Klass, 1996).

During the past 30 years, we have advanced significantly in our ability to prevent many causes of mental retardation. Medical science has also ensured that new lives are freed from the debilitating effects of certain conditions. Every year in this country, we prevent thousands of cases of mental retardation among newborns due to phenylketonuria, hypothyroidism, Rh disease, measles, encephalitis, and rubella.

As recently as a decade ago, thousands of children developed diseases caused by the Hib bacterium, particularly meningitis, one of its most serious complications. Today, this disease has been virtually eliminated and, thanks to the new vaccine, three to four thousand cases of mental retardation can be prevented each year. This single dramatic health improvement has saved millions of health care dollars previously needed for treatment and long-term care costs to victims of this disease. Although such preventive advances seem quite commonplace today, early 20th century citizens would have regarded such medical interventions as miraculous.

In another 50 years, people may regard 21st century genetic technology with the same awe. It has been said that we will recall this century before gene therapy in the same way that we look back on medicine before antibiotics or vaccines. It is now possible to contemplate curing diseases with a single, therapeutic intervention (Hirschhorn, 1997).

As marvelous as these new therapies seem, we do not have definitive answers to the inherent ethical questions that accompany these emerging technologies. Indeed, the very inventors of such miracles are apprehensive about where these interventions are leading us (Klass, 1996). Genetic engineering and diagnostic

technology are racing ahead of our ability to regulate its use, to manage what we learn, educate consumers, or assist people in making informed decisions. In the past year, extraordinary advances have rushed toward us with questions that we are not ready to answer. Only months ago, the world met Dolly and her exact genetic twin, cloned by the Wilmut team at the Roslin Institute in Scotland (Hello Dolly, 1997). Even as we were saying "Hello, Dolly," our reactions to such advances were already shaped in a much more deliberate and measured way by long-held societal and cultural beliefs.

The Human Genome Project plans to map the complete DNA sequence by the year 2005. Medical benchmarks of the next millennium will compel answers to questions that are fraught with complex legal and ethical issues. Today, we face shortages of professionals trained in emerging genetic sciences. Nationwide, we have only 1,200 genetic counselors. Medical geneticists are also scarce; hence, primary health care physicians now assume significant management roles. Yet, research indicates that medical schools' curricula often lack requirements for study in genetics, genetic testing, screening, or counseling. Practicing professionals may be aware of certain aspects of these new fields, but many are less educated about the implications of current research, such as that conducted by the Human Genome Project.

As we enter the biotechnology century, health professional education and allied professions must leap ahead of the learning curve. We now need a national clearinghouse for professional organizations to establish critical benchmarks for the next millennium. Through an organized effort, we may expect better access to accurate information and a cohesive assessment of current training strategies. We also need legislative proposals to ensure privacy, prohibit genetic discrimination, and establish policy on reimbursement issues.

These biomedical breakthroughs will illuminate our social priorities in heretofore unknown ways. As genetics moves beyond deciphering the DNA scramble, this revolutionary science will see its greater work in functional genomics, identifying how particular genes collaborate to imprint their messages.

Today's biotechnology is decades away from artificial gestation; but the human fetus is no longer inaccessible. A new generation of fetal surgeons dream of interventions from organ

transplantation to replacement of misspelled genetic codes. Medical science can now diagnose and repair critical malformations in utero. If we think such neonatological wonders are improbable, we only need to recall that less than 20 years ago, in-vitro fertilization was the stuff of tabloid news.

To date, our use of genetic foreknowledge remains virtually benign. Yet, these discoveries emphasize existing societal prejudices and generate new biases. Twenty-first century benchmarks in neurochemistry and biomedical research will depend not just on what scientists do but on the ways in which social policy is framed to make use of their contributions (Kitcher, 1996).

In speculating on 21st century benchmarks for our profession and people with mental retardation, we first must widen our field of vision. How will our concepts of daily life change during that same time period? How will the environment, the family, society, government, and the economy change? What will have the greatest long-term impact on the way that we live?

William Knoke, president of the Harvard Capital Group, suggests that 20th century society bases its conceptual foundations on the primacy of place, that is, the undergirding infrastructure within which all social exchanges rest and must take place. Our traditional economic, social and political structures, our churches, temples, industries, nations, neighborhoods, schools, and states were founded on this one irrefutable constant. Primacy of place defines the physical constructs within which events occur, families converge, people gather, and nations exist.

Hundreds of years ago, people lived in dot cultures. They were capable of a minimum of social interaction and knew only those individuals within their own small clan. We now live in a world where primacy of place seems less relevant, an Age of Everything-Everywhere (Knoke, 1996). Indeed, perhaps it is society's placelessness that heightens our awareness of the speed at which daily events and circumstances occur. Unhappily, technology's ability to deliver nightly encapsulated news reports heightens our awareness of how slowly global human rights evolve.

In any given 24-hour period, we communicate with colleagues and friends around the globe on the Internet, by telephone and fax. In

most instances, this communication occurs far more regularly than with our families (McRae, 1994). We have long since ceased to marvel at the worldwide transportation of people, products, and services. We now expect daily, almost instantaneous access to those products and services.

The traditional family unit is being steadily replaced by many variations, its members sometimes working and living in different locations. In the Age of Everything—Everywhere, location and structure will become irrelevant, as virtual environments open seemingly limitless markets and opportunities to the global family.

By the year 2100, how will primacy of place, or more exactly, its potential absence, impact our society, particularly families and people with mental retardation? Within our profession, part of our conceptual reference of mental retardation has generally implied this primacy of place, that is, the daily effect of where and how people receive supports. One might say that this present day concept is grounded, in some measure, on the location or structure of supports for people whose identity seems defined in reference to where they live, work, and learn.

Since 1960, new housing benchmarks have altered the primacy of place. We have seen systemic changes in where and how people live. By December 1998, nearly 40% of publicly operated residential centers will have been closed (Lakin, Prouty, Anderson, & Sandlin, 1997). States have replaced these settings with a wide variety of options and supports from smaller neighborhood residences to independently owned homes.

Today, the concept of mental retardation is still captured within intellectual and adaptive scores used with labels, those conveniently recognizable descriptors for funding. Over the course of the next 100 years, the concept of mental retardation will likely be much less defined as a condition of intelligence. Even now, we are moving in that direction (Rowitz, 1992).

During the next millennium, medical and scientific developments will significantly impact the concept of mental retardation as we now know it. As these advances diminish the residual impact of disability over one's life span, the 21st century conceptualization may be altered forever.

Among the human community, we use markers to identify things in the environment, markers of things that are seen, heard, and felt. We visually mark or identify the race and gen-

der of people around us. We auditorily surmise an individual's geographic origins from the intonation, rhythm, and inflections in speech patterns. Likewise, the human community marks its members with disabilities by visual or auditory differences in behavior, mobility, physical form, or speech. Mental retardation exists in the minds of many people whenever they see the tangible impact of cognitive or physical challenges in individuals' lives.

One may posit that dramatic advances in medical technology and its application in our lives will make many 20th century concepts seem medieval by comparison (Tierney, 1996) and so, too, our 20th century concept of mental retardation. I do not imply a naive presumption that prenatal therapies will restore morphological abnormalities; but even now we are witness to advances promised by fetal surgery, human genome research, gene therapies, and developmental neuroscience. In another 100 years, 21st century scientific and medical technology may remove certain genetic markers or diminish any residual impact to the extent that only subtle physical or behavioral remnants will suggest that an individual needs support.

At the close of the 21st century, will gene therapy be as commonplace as organ transplants? Will we understand the blueprint of humanity? How will our concept of mental retardation be defined if we no longer witness the differing effects of disability in people's lives? If the human community can no longer see "mental retardation," will discrimination exist?

In his 1997 inaugural address, President Clinton spoke of the American promised land that must become the land of new promise. He also urged us to revitalize our communities, neighborhoods, and workplaces with a renewed sense of personal responsibility. As global citizens, our preeminent mission is not a guarantee but, rather, a genuine opportunity to build better lives.

As the next millennium draws to a close, concepts of life as known and lived by 20th century people will be as irrelevant as our present conceptualization of mental retardation. Likewise, organizations will experience radical changes in the next millennium (Hesselbein, Goldsmith, & Beckhard, 1997). Today, organizations operate in a dynamic consumer environment that demands an accelerated "real time" responsiveness. In the coming techno-millen-

nium, they will be influenced by virtual markets and an increasing awareness of placelessness in the global community (Hesselbein, Goldsmith, & Beckhard, 1996).

Consumers will assess many life experiences according to these same perceptions, moving through sophisticated systems that achieve rapid access of goods and services in ways that we are only now imagining. They will be attuned more acutely to their status in the global community; and they will endorse services influenced by economic, political, and social benchmarks vastly different from their 20th century counterparts (Ray & Rinzler, 1993). Organizations that prosper in the next millennium will be those that discern the most valued technologies and deploy those tools for maximum effectiveness (Hamel & Prahalad, 1994).

I suggest that our benchmarks for the 21st century may be framed within the broad contexts of automation, affiliation, and communication. We have much work to do. The AAMR of the new millennium, indeed our places of work, business, and industry must accelerate basic service delivery to merge into the rapid pace of consumers' expectations.

We recognize that any organization maintains an inherent speed limit within which it creates, assimilates, and sustains its requisite functions (Heifetz & Laurie, 1997). Our 21st century leadership must become more proficient in anticipating changes in our industry and, hence, automating responses to consumers' expectations. We must move with accuracy, efficiency, and surety.

The AAMR of the new millennium must speak with heightened clarity to its goals, strengthening opportunities for people to affiliate with those principles. Our constituency is widely dispersed, separated by geography, philosophy, and experience. Our motivations and values on key critical issues reflect this diversity. As we begin the next millennium, we must reaffirm founding values and establish vital, new benchmarks in policy, practice, and research. If our Association is to continue its role in establishing preeminent benchmarks for and with people with disabilities, we will need the critical member mass essential to communicating and sustaining our field's strength, vitality, and vision.

In its charter year, the President's Commission on Mental Retardation established the goal

of reducing mental retardation by 50% by the year 2000. Current prevalence statistics suggest that we have fallen far short of achieving this mandate. Yet, in the past decades, we have narrowed the gap to its accomplishment. Unforeseen advances in science, medicine, and technology have accelerated our ability to meet the challenge in the next millennium. Old patterns have given way to fundamental changes in policy and practice, suggesting that benchmarks for the next millennium will be set by individuals rather than institutions and by people over politics.

How will we know that we have achieved our goal? In her book, *The Measure of Our Success*, Marion Wright Edelman (1992) suggested that the results of what we do may not be known for years. We all know, at some level, that our work, though important, will best be appraised by professionals, citizens, and families of the future.

The 21st century will begin in less than 1,000 days. As its inhabitants, we have much to do. As we approach the year 2000, we realize that our goals remain worthy aspirations. Within our goals, lie our mission, direction, and vision.

It is a mission that compels sweeping intolerance of the effects of crime, drug abuse, and poverty. It is a direction that mandates sustained investments in early intervention, research, prevention, and human rights. It is a vision that must transcend 20th century rhetoric or philosophical differences. Ultimately, it is a vision that will be powered by a robust and tenacious commitment to realize opportunity for all people.

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