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# PERSPECTIVES

## Presidential Address 1999—Working for Justice: Responsibilities for the Next Millennium

Stanley S. Herr, AAMR President: 1998–1999

### Introduction of Stanley S. Herr for His Presidential Address, May 25, 1999

I knew Stan Herr before he knew me. As a social worker at Forest Haven, the former institution for persons with mental retardation in Washington, DC, fighting to get some sort of education for my clients—even to get them admitted to the school for delinquent kids on the same campus—I read about him in the *Washington Post* as the architect of *Mills v. Board of Education*, the case that first established the right of children with disabilities to a free and appropriate public education. When he left Yale as a young lawyer and those two roads diverged before him, he definitely took the road less traveled by. That road took him to Alabama; New York; California; Washington, DC; Baltimore—criss-crossing the country, blazing a trail of civil rights and justice for persons with mental retardation. How fitting, then, that the title of his address is “Working for Justice”—just what he has been doing over the course of a life that is clearly a mission, not just a career. Stan took the road less traveled and that has made all the difference for him, for those who have shared some part of the journey with him, and for all the people we serve. It is a happy and proud task for me to present to you my professor, my mentor, my friend, my hero, and our president, Stanley Herr.—Patricia Williams, AAMR Board Member

We have come a long way together. Our field emerged from a valley of fear and despair. Now we are steadily climbing a mountain of freedom and justice. As the makers of a humanitarian revolution, we have sometimes battled the shifting winds of public opinion and the chill of our own inner doubts. At the end of the 20th century, it is time to assess the state of our shared quest for justice. So let us take a metaphorical pause on our climb and address not only what we mean by “justice,” but also—and in doing so—ask these four questions:

- Where have we come from?
- Where do we stand now?
- What are our responsibilities and prospects for the next millennium?
- What visions will sustain us on the way?

Before we consider whence we have come, it is fitting to pay tribute to those guides who prepared the way. I dedicate these remarks to Gunnar Dybwad, to Burt Blatt, and to all my mentors during my 27-year association with AAMR. As Isaac Newton (1675) wrote, “If I

have seen further than others, it is by standing upon the shoulders of Giants.” When I called Gunnar recently to wish him a speedy recovery from a grave illness [as he put it, “I was as close to death as I could be”], I asked him what he felt I should share with you. Suddenly, there was the familiar sparkle in his voice, as he became our teacher again. Without hesitation he replied:

Tell them how important it is to have faith and confidence in the people we support, in their capacity. For too long, we as professionals were taught in ways that stressed the negative. Now we know—the self-advocacy movement shows us—that when people are approached from a positive viewpoint, they can really grow.

I will return to Gunnar’s spectacular contributions. But first some preliminaries on the stars by which we navigate and ascend.

### What Do We Mean by “Working for Justice”?

In *Webster’s Dictionary*, one of the meanings of justice is “the principle or ideal of just

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dealing or right action" (Mish et al., 1989). Thus, to work for justice or to *do justice* is not only "to act justly," or "to treat fairly or adequately," but it also means to realize our own powers to do good (i.e., "to acquit in a way worthy of one's powers").

Doing justice is everyone's work. It is not the exclusive province of some profession or the monopoly of the paid public servants we call judges. Each of us is—or can be—a justice worker in our field, community, nation, and throughout the world. In doing so, we must learn from each other, whether our situation is humble or elevated, whether we are supported or a supporter. For, as the Jewish Talmud teaches: "Who is wise? He who learns from every person."

For our purposes, justice must be understood more in its ethical than in its legal sense. For example, the American Catholic Church describes justice as a matter of dedicating oneself daily "to protect human life and dignity and to stand with those who are poor and vulnerable" (Rivera, 1998). As part of a program called Jubilee 2000, its members pledge themselves to work for social justice in the new millennium. Regardless of one's creed or ethical belief system, truly we can all gain by acknowledging our special responsibilities "to welcome the stranger, to combat discrimination, to pursue peace, and to promote the common good." In this field by our welcoming supported people—individuals with disabilities—into the community, increasing their growth and happiness, and combating bias, we are working for justice. By defending their dignity, wherever they live, we are justice workers.

One other starting thought: In fighting for justice the personal and the professional must be interwoven. It is work for the head and the heart, for rational analysis and passionate commitment. So I will try to weave a tapestry not just of larger trends and animating ideas but also of personal stories that give texture and motive to our work.

### Where Have We Come From?

We can count ourselves fortunate that we have the dynamic challenges of working for justice and the means to meet them. It was not always so.

The dark ages in our field are what we can call "the era of exclusion." To surmount this era and get through the 20th century, we have

needed many heroes. The 20th century has had its periods of shame and its many deep lows of despair. For it was during these periods that we perfected monuments of injustice such as life-long involuntary commitment, massive institutions, forced sterilization, and other affronts to freedom and justice.

To see how our predecessors viewed the end of another century and to understand issues of rights, I decided to research the proceedings of the 1899 meeting. As I searched for soaring visions or historic retrospectives, the material was thin. True, a milestone for equality was posted when the Association was led by a woman for the first time. But in her very brief statement, Mary Dunlap dwelt only on the number of states with institutions and the hope that institutionalization would be extended to the rest of the states. Some things, however, do not change as even then the name of the association was questioned. With apologies for the archaic language, here is what our professional ancestors said. To Dr. Dunlap, the name "The Association of Medical Officers of American Institutions for Idiotic and Feeble-minded Persons" seemed, as she delicately put it, "a bit lengthy and cumbersome" (Sloan & Stevens, 1976, p. 44). Well, she got that right but made no recommendation for a substitute. Although there was interest in working with other organizations, such as the American Bar Association, it was for the negative purpose of restricting marriage laws to limit the eligibility of people with disabilities to marry. The now condemned practice of institutional peonage was also endorsed with a paper called "The Self-Supporting Imbecile" in which the author recommended that these unpaid workers live in places called "colonies" and care for the more "disabled inmates." Their living conditions would be severe because, as the author maintained, such a worker would be happiest in "a log hut" not a palace, with plenty of work, "plain food and the simplest and plainest of clothes" (Johnson, 1899, in Sloan & Stevens, 1976, p. 45). But were they ever offered any choice?

By the 1901 meeting, President Polglase decided it was time to look back over the 19th century as "an era . . . [with] an appreciation of the value of human life," when "human freedom was planted in America and a new school of humanitarianism began." But what did all that fine rhetoric mean for our field? The air goes out of the balloon when in the next breath

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he demanded "the adoption of a policy for the segregation and life-long detention of all defectives" (as cited in Sloan & Stevens, 1976, p. 47).

Nor was Polglase alone in this strident call. At the Association's 1903 annual meeting, President J. M. Murdoch urged that "the state segregate all the feeble-minded whose presence in the home and community is a constant source of danger" (Sloan & Stevens, 1976, p. 52). With our leaders acting as "missionaries" for this viewpoint, "particularly [among] our legislators, in matters pertaining to the feeble-minded and the importance of their segregation and control under state supervision," repression was at its zenith. Judges were asked to support this push for permanent institutionalization, and by 1915, magistrates, operating with scant safeguards, were authorized to commit any child "appearing to be feeble-minded" (Herr, 1983, p. 24). In all this, justice failed, fear prevailed.

Other human rights abuses still lay ahead. One of the worst examples of this punitive approach of control over people with intellectual limitations—and certainly its most infamous judicial opinion—was *Buck v. Bell* (1927). In the judgment of scholars, this case was rigged—a collusive "judicial charade"—to have the U.S. Supreme Court uphold the legality of a state's involuntary sterilization law despite dubious facts, flawed legal reasoning, and the absence of a lawyer truly representing the interests of the unfortunate Carrie Buck (Burgdorf & Burgdorf, 1977; Lombardo, 1985, p. 56). In an opinion that the High Court has never expressly overruled, Justice Oliver Wendell Holmes pronounced that "three generations of imbeciles are enough." He asserted that if society could conscript men for military service it could through eugenic sterilization deprive the mentally unfit of their reproductive possibilities. With this judicial imprimatur—albeit based on myths and misleading analogies—eugenic laws mushroomed. At one time as many as 32 states had involuntary sterilization statutes, with 9 states still authorizing such sterilization as late as 1981 (Ross, 1981). Of the eugenic scare, surely it can be said that justice failed, fear prevailed.

These practices in the United States were harbingers of horrors in other parts of the world. In 1933, Germany began its now infamous T-4 operation, which would lead to the killing of 300,000 people with mental retardation and

other disabilities. If the world had stopped this slaughter when it was limited to only German and Austrian nationals, global carnage and conflict might have been averted. Justice wept at the sight of this holocaust of innocents. And in a footnote to history when Nazi Germany's leaders were called to justice in the post-war Nuremberg trials for crimes against humanity, they invoked in their defense the precedent of the forced sterilization law of Virginia and its validation by the *Buck* case. At least in Germany, although after the fact, justice prevailed.

Even after the first stirrings of the international human rights movement in response to these horrors, the mid-20th century was a listless and socially, professionally, and legally apathetic period. The courts were silent. The legal profession was unengaged. The law on mental disability was a backwater, and its tributary on mental retardation was a stagnant pond. The large state institution was the emblem of our field, and exclusion from schools and community activities was the order of the day. Sadly, the period from 1950 to 1968 saw the fastest rate of expansion of those institutions in American history (Trent, 1994). Mental retardation professionals were in more or less a status quo mode, waiting for a better day to dawn.

Despite a civil rights movement for racial justice in the 1960s, that decade saw precious little activity to achieve justice in the disabilities arena. The one exception was *Heryford v. Parker* (1968), a federal appellate decision upholding the right to legal counsel for persons committed to mental retardation institutions. But though the state of Wyoming feared this case would lead to "wholesale release of inmates" around the country, the case—unfortunately for those who might have gained freedom—had no such direct effect (Herr, 1998).

The revolution for the rights of people with mental retardation was finally sparked in 1972. In that year, landmark right-to-education cases in Washington, DC (*Mills v. Board of Education*, 1972) and in Pennsylvania (*Pennsylvania Association for Retarded Children v. Commonwealth*, 1972) declared that children with mental retardation and other disabilities were guaranteed an education appropriate to their needs under the constitutional rights of equal protection and due process. Later in 1972, the federal court in *Wyatt v. Stickney* broke new legal ground in upholding the constitutional right

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to habilitation, ordering 49 minimum standards implemented, and maintaining a continuing jurisdiction to ensure that Alabama's mental retardation program was operated in a constitutional manner. In quick succession, other major class action suits were launched at New York's Willowbrook (*N.Y.S.A.R.C. v. Rockefeller*, 1973), and Pennsylvania's Pennhurst (*Halderman v. Pennhurst State School and Hospital*, 1974), and in Minnesota, Massachusetts, Maine, Michigan, and many other states (Herr, 1983). Sometimes after decades of litigation, the cases resulted in the closing of institutions and the opening of new community-based services. Almost everywhere there was progress, gains that would have never occurred without our collective leadership, sweat, and toil.

But this humanitarian and legal revolution did more than expose dehumanizing conditions in institutions across the country. It created coalitions for change. Cadres of full-time workers for justice—a national network of legal services for persons with developmental disabilities consisting of Protection and Advocacy offices in every state, Legal Services Corporation field programs, public interest law firms, some intrepid private practitioners, and law-school-based clinics—along with teams of habilitation professionals from every discipline rolled back the era of exclusion. To serve our common clients, we created new program models, service philosophies, legal theories, and ethical sensitivities (Herr, 1979).

But mere words can never capture the sights, sounds, and smells of the wrongs inflicted under exclusionary regimes. Let us try to imagine that we are visiting one of the large state institutions of the not so distant past. Can you see the naked, cowering, brutalized, and dehumanized victims of the state's beneficence in your mind's eye? Well, this is what I saw and sensed as a young lawyer after filing the Willowbrook suit:

- 90 to 100 half-dressed men or women crowded on cold day-room floors;
- solitary confinement cells with poor unfortunates locked away for months and even years;
- the overpowering odor and din of the rooms;
- the gloomy, barren living quarters;
- the oppressive idleness;
- the sight of wounds self-inflicted and otherwise; and

- a catalogue of wretchedness that stretched on and on and on.

A few weeks ago I took my children to see another type of institution on another New York isle. It was Ellis Island, where another form of exclusion was practiced. About 5% of all the would-be immigrants to America passing through this golden gate found only rejection by reason of their suspected disabilities. My Aunt Rochelle was one. In post-World War I America, to be chalk-marked with an "x" for mental defective (or other letter for the alphabet of despised disabilities) could have heart-breaking, even lethal consequences. Aunt Rochelle accompanied by brave Aunt Krendell as her companion were separated from a family of 10 children and deported back to Lithuania, where the Holocaust would eventually crush their lives. Justice failed; fear again prevailed.

### Where Do We Stand Now?

We are now in the midst of an age of advocacy and acceptance. Over the last 3 decades, hundreds, if not thousands, of cases pertaining to people with intellectual disabilities have been decided. They cover almost every area of human endeavor. This collective effort to do justice for people with disabilities is one of the 20th century's most positive legacies. There is now case law and statutory law that reaches from birth to death, crime to punishment, idleness to education, guardianship to liberty, zoning exclusion to inclusion, child neglect to child well-being, and discrimination to self-determination as well as law in countless other domains. Without your involvement and expertise, there would be no such body of progressive policy and human rights vindication.

The measure of our revolution is not in the sheer volume of cases, statutes, and regulations. Their true mark is the changed patterns of our thinking and the newly emerging assertiveness and confidence of self-advocates. The end of the era of exclusion and the justice work of our field and generation—the triumph of inclusion over exclusion, habilitation over stagnation, self-determination over coercion—transcends the activities of courts and counsel. It is now internalized by all who advocate for and support the people so variously named in the 20th century, but so consistently vulnerable to indifference and invidious discrimination. In a long line of *amici curiae* (friend of the court) briefs and public policy positions, AAMR and

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allied organizations—people like you and me—have now placed ourselves firmly on the side of relieving historic wrongs. For reasons I will soon trace, these rights concerns show no signs of abating.

Ours is an age of acceptance at many levels—professional, societal, and personal. Our field is no longer the Cinderella of human services. To some we are now the favored and dynamic sister. Compared to the mental health field, we have forged an incredible consensus and strong coalitions. We have broken completely with the medical model and forged an interdisciplinary habilitation approach. We have funds and friends in places of power that are the envy of many. Funding formulas for serving people in the community are not even tied to doing it for less than in institutions, if excess costs can be justified. When N. R. (Sonny) Kleinfeld (1997a, 1997b, 1997c) of the *New York Times*, winner of last year's AAMR Media Award, sensitively portrayed the basic human desires of James Velez for a home, a job, and an ordinary life, he told of a very expensive, very competent effort by community-support providers to permit James an independent life after 16 years in institutions. The American public now better understands and is willing to support such journeys toward not just independence but interdependence.

Waiting list campaigns in the states are also picking up momentum, giving fresh evidence of acceptance for our field's mission. For example, New York State's comprehensive 5-year plan promises \$129 million to virtually end the waiting list for residential services. To appreciate the magnitude of this shift in service delivery, recall that in 1971 when Willowbrook alone had over 5,300 residents, only 1,500 beds in community programs existed in the entire state. Now over 31,000 people are served in such settings. And that pattern is repeated in state after state. Along with New Jersey, Maryland was one of the first of those states, and it has plans to serve over 5,000 more people with a budget of \$118 million. Already Maryland has provided 2,522 new services and is doing so with insistence on self-determination principles and supporting people in intimate-sized surroundings. The essence of the Maryland approach is choice and planning supports that help people live their dreams

We are also fortunate to live in an age of acceptance and advocacy when strategic alli-

ances between professional and consumer groups are blooming. The AAMR has long been part of the Consortium for Citizens with Disabilities (CCD), a coalition with a policy focus. But now we are launching specific initiatives with our sister organizations:

- to review a possible name change for our field, perhaps to intellectual disabilities or some other option;
- to plan a national criminal justice conference and related activities to correct major defects in the system's treatment of victims and offenders with intellectual disabilities; and
- to develop joint conferences with the Arc on public policy and on general matters.

Unlike the mental health field, we have not been wracked by divisive questions over the very reality of our diagnostic categories or the need for the expertise that you supply. People accept the benefits of habilitation, and we simply do not face a debate parallel to the one that our professional colleagues have sometimes encountered as to "whether mental illness is a legitimate entity" (Appelbaum, 1994, p. 9).

In our field there is consensus that we are moving to the promised land of greater autonomy. We now acknowledge limits on the ways in which we as professionals can deprive people of their rights in the name of treatment. Our AAMR book *Guide to Consent* (Dinerstein, Herr, & O'Sullivan, 1999) contains carefully balanced advice on weighing risks and benefits. As we stated there, our field "recognizes that it is progress indeed that persons with mental retardation are seen as people with the right to have their values and choices honored" (p. 125). In seeking the person's consent and training our colleagues in its nuances, we must respond to "the strengths that each person possesses" and not become overwhelmed by his or her limits. With more and more people with disabilities entering life's mainstreams—whether in the natural supports they receive, the homes they live in, the jobs they gain, the schools they attend, the recreations they enjoy—there will be greater freedom and choice. With these higher vistas, more and more often the consent of the person will be sought and assessed.

We may not have reached an end to ideological battles, but we have at least muted our differences and achieved workable compromises. Interventions that are extreme and come

into conflict with individuals' rights must be subject to the highest level of scrutiny, if not barred outright. We must constantly seek better data for intelligently designed reform. The AAMR and its journals must continue to provide forums for that discussion and debate. We must find ways to achieve better parity in bargaining power between the parties in our field so that just and habilitative outcomes result. Furthermore, if we do not find ways to make the role of direct support professionals more attractive and more justly compensated, we will continue to see some of the best leave our field and see staff turnover undercut our mission to consumers and their families.

In all this, the judiciary must remain the great equalizer between those with and without power. In this term, the Supreme Court upheld the Individuals with Disabilities Education Act (IDEA) as a source of expensive "related services" to permit school inclusion (*Cedar Rapids Community School District v. Garret F.*, 1999), and it ensured the availability of Americans with Disabilities Act (ADA) remedies for people who sought social security disability benefits (*Cleveland v. Policy Management Systems*, 1999). We now await what could prove a watershed decision in the case of *Tommy Olmstead, Commissioner, Georgia Department of Human Resources v. L.C.*, by Jonathan Zimring, *Guardian Ad Litem and Next Friend* (No. 98-8536). On a legal level, the ruling will determine whether the ADA bans segregation based on disability as a form of discrimination. On a political level, these questions have an importance that transcends what the Court might or might not do. They have become a rallying cry for activists in the streets and in the corridors of legislative and executive power. As recently as May 12th, they led to civil disobedience and peaceful protest in the shadow of the U.S. Capitol. Even before the Court heard arguments, this movement for justice caused a score of states to withdraw from an amici curiae brief that asked for a watered-down ADA. If the minority of Georgia and 7 other states should prevail, that will not end the furor. There would still be calls for Congress to pass overriding legislation, for state capitols to act in an era of devolution, and for judges to make incremental progress with the legal tools at hand. [Author's Postscript: Less than a month after this speech was delivered, people with disabilities and their supporting amici such as AAMR won in *Olmstead v. L.C.* On June 22,

1999, the Court ruled by a 6 to 3 margin that unjustified isolation in an institution constitutes discrimination under the ADA. The Court further held that such segregation is impermissible when professionals find that community placement is appropriate, the affected individual does not object to such placement, and the placement can be reasonably accommodated without undue financial burden to the state. In essence, the Court reaffirmed that even individuals with chronic and severe disabilities have the legal right to live in the community.]

Though the Supreme Court may have the final judicial say in a particular controversy, it rarely has the actual last say when popular movements and social trends point in a different direction. For example, when the Court in *Board of Education of Hendrick Hudson Central School District v. Rowley* (1982) denied a bright deaf child a sign-language interpreter and ruled for all children with disabilities that Individualized Education Programs (IEPs) need only confer "some benefit," commentators feared a loss of momentum. But 17 years of subsequent judicial interpretation have found the lower courts quite willing to apply the IDEA vigorously in favor of children denied the individualized program promised by the law. So it could be in 1999 if the Supreme Court tries to rein in the ADA when the issue is shall people live and thrive in greater freedom. The lower courts might still climb a truer path. [Author's Postscript: Although the Court has now upheld the use of the ADA to protect people with mental retardation and other disabilities from over-restrictive institutionalization, much will still depend on lower court interpretation of broad concepts and factual particulars. Thus, the time is right for further negotiation where progress is achievable and vigilance where individual liberty hangs in the balance.]

Having attended the oral argument for *Olmstead v. L.C.*, I note the outcome's unpredictability. At the argument, there was the oddity of the conservative Justice Scalia questioning the doctrine of professional deference to the opinions of state professionals. "You mean the opinion of the state's expert should have more weight than the patient's expert?" he asked skeptically, seemingly unaware of the Court's longstanding doctrine in *Youngberg v. Romeo* (1982) in that exact direction. Then, from the Court's liberal wing came Justice Breyer with his repeated quest for reassurance that a favorable decision for L.C. not lead to a state overreaction in which fragile residents would be

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pushed out into precarious conditions. But I am confident of one result at the end of the day: The clock is not going back because institutions will continue to downsize, close, and be replaced by a continuum of personalized supports.

But again to return to the personal level, consider the victories Lois Curtis and Elaine Wilson have already won. Yes, they have stepped from behind the veil of initials (i.e., *Olmstead v. L. C. & E. W.*, 1999) to tell us that they are already out in the community. Lois moved a few months after the suit was filed, and Elaine followed shortly after. Both women are succeeding in their community-based programs and asking that others like them have the same chance. Elaine, for example, had been in a mental retardation institution during her teenage years, then had been dumped 37 times from psychiatric hospitals to inappropriate board-and-care homes, and even once been threatened with placement in a homeless shelter. Since July 1997, she has thrived in first a group home and then with a companion in her own home. She goes to a prevocational program, and her world is brighter. With good advocates at their side and conscientious habilitation professionals in their corner, women such as Lois and Elaine no longer face the specter of dumping. Justice must prevail, unsubstantiated fears must fail.

Win, lose, or draw, I am so proud of this Association and the principled stand it has taken in the case of Lois and Elaine. Of the 37 national and other organizations with which we are aligned, AAMR has the primary place in the document captioned "Brief for Amici Curiae American Association on Mental Retardation et al., in Support of Respondents." Writing for this broad alliance, my legal colleagues and I made a few basic points:

- Most states have already committed themselves to a policy of community habilitation, thus upholding the victory of Lois and Elaine in the appeals court will not disrupt state programs or budgets.
- States should not choose the more expensive alternative of institutionalization when the individually appropriate and generally cheaper option of community supports "will be as or more effective."
- The historical context—as I reviewed it today—shows that Congress, through passage of the ADA, intended to reverse the legacy of needless segregation and dehumanizing regimes.

- The ADA's express declaration that unnecessary segregation is a prohibited form of discrimination is consistent with 3 decades of increasingly firm federal legislation that points away from isolation and toward the full integration of people with disabilities in the ordinary life of communities.

One way or another, we will work for justice to realize that aim and safeguard people in various stages of transition. And we need to thank our colleagues who still work in institutions for their devotion in a time of transition. Our heroes have laid this transition's groundwork and revolutionized our field. These giants of the 20th century have done much to reverse the ugly images of society's neglect and to foster today's triumphs of individual growth and community acceptance.

But our heroes are also often unsung: the people we support who battle for acceptance and dignity every day. People with disabilities literally want to be "in the swim." Consider the case of David Denain and his climb through the federal courts. Identified by the court as "a mentally retarded student with Down Syndrome," he was a full member of his high school swim team in the 9th, 10th, and 11th grades. Although he was his team's slowest swimmer, his relay team occasionally won points in meets, and David reaped the benefits of better social skills and feeling a part of his high school. When he was a senior he turned age 19, and under the rules of his state's interscholastic athletic conference was deemed ineligible to be on the team. And here's the good part: Everyone worked for justice for David. His school petitioned for a waiver of the maximum-age eligibility rule, his parents urged that he be allowed to swim as a full member of the team because his slow times gave his team no competitive advantage, his allies supported him, his age posed no safety concerns for younger athletes, and he deserved to swim. But the athletic conference took a hard line, denying the waiver.

So David's parents, joined by the Trumbull Board of Education, turned to the courts under the ADA and the Rehabilitation Act. They argued that it was his disability that had caused him to take a longer time than others to complete his education and that he should not be denied the therapeutic effect of participation on the swim team. The federal district court agreed. It not only held that David had been discriminated against solely on the basis of his

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disability, but it ruled that he had also been denied his rights under IDEA since his participation on the team had been a strongly recommended part of his IEP (*Denain v. Connecticut Interscholastic Athletic Conference*, 1996). By the time the athletic conference appealed this order, the swim season was over, and David had prevailed. Because no one would penalize David or his team by attempting a retroactive modification of his eligibility for the season past, the Court of Appeals found there was no longer a controversy (Endnote 1). David's victory was the victory of many people. When he went to court, he was not alone. In addition to his teachers and the school board, even the attorney general of Connecticut was on his side, filing a friend-of-the court brief for his right to "stay in the swim." Both figuratively and literally they had won David's right to be in the mainstream—to be a part of the life of his school.

### **What Are Our Responsibilities and Prospects for the Next Millennium?**

I wish we could stop with such a pretty picture. But our tasks of justice are still many. Let me list 10 of our pressing responsibilities for the future.

First, we must reform the criminal justice system, which is still a lottery when it comes to the protection of the rights of victims and of alleged offenders with disabilities. Consider the infamous sexual assault in Glen Ridge, New Jersey. The assault and the case were recently dramatized for television and documented in a book called *Our Guys* (Lefkowitz, 1997). After years of trial and delay, the judge said, "Enough is enough. This has gone on long enough." And with that he sent four ex-high-school jocks to jail. It was a day of reckoning that had finally arrived because for 8 years these athletes had gotten away with it. Surely, the Essex county prosecutor Robert D. Laurino was right when he said, "Justice was finally done today." No one, let alone a teenage woman with disabilities, should have gone through such ordeals. We must stand with such a victim of manipulation, hideous crime, and its concealment.

We must also be ready to stand with victimized defendants like Anthony Porter, who came within days of execution in Illinois. Thanks to the wonderful investigative work of a Northwestern University journalism professor, the real murderer was found; and thanks to the legal work of Jim Ellis and Lawrence Marshal (Northwestern

law professor), Mr. Porter's life was saved. We have much more work for justice when a person with mental retardation can spend 16 years on death row for a crime he did not commit.

Second, to expand and improve services, we must be better organized for the state-by-state competitions for budgets and political attention in a newly devolving human services landscape. To succeed in the future we will need a realization by leaders and citizenry that further change is still required. We must tap a body of theory—legal, clinical, and philosophical—that can energize us. Most important, we will require a group of actors committed to change and willing to see it through. If we put those ingredients together, we will thrive in the next millennium (Appelbaum, 1994)

Third, we must shape positive public opinion of our endeavors or we will face waning support. We start with some strong assets. According to a 1999 Louis Harris poll, 87% of the public is aware of the ADA. Three quarters of the people think that the benefits of disability programs are "worth the additional costs to government and business." A whopping 83% favors increasing job opportunities for people with disabilities, especially if it means people coming off public benefits. But we know that only a bare one half of one percent are leaving SSI rolls for jobs, and we need to support legislative measures to increase the incentives for doing so (see, e.g., Work Incentives Improvement Act of 1999 bill).

Fourth, we have a massive task to bring more of our constituents into the competitive workforce. While the Presidential Task Force on Employment of Adults with Disabilities gives notice of its first Town Hall Meeting, we in this field already know the dismal state of employment for our friends. They truly need, as the Task Force stressed, "a coordinated and aggressive national policy to bring adults with disabilities into gainful employment at a rate that is as close as possible to that of the general adult population" (Ogle, 1999, p. 26440). Our friends need that aggressive help now to stem their economic stagnation, especially the young people with severe disabilities from diverse linguistic and cultural backgrounds who are at an even greater risk of dropping out of school and facing unemployment. Working for justice in the employment sectors means raising from its current 30% the proportion of adults with mental retardation working in real jobs. It means ad-



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addressing issues of access to employment services and support, creating new forms of post-high-school education and vocational training, changing employer attitudes, and combating discrimination. As Commissioner Paul Miller (1999) of the Equal Employment Opportunity Commission wrote, the first cases for people with intellectual disabilities have been filed or settled. Justice has begun to prevail.

Fifth, we need to speak out for justice whether our position is humble or highly visible. Ours is not a radical cause. It is a decent and just cause. This is evidenced by former U.S. Attorney General Richard Thornburgh, who, while in the service of President Bush, issued a regulation that provides that services or programs shall be offered "in the most integrated setting appropriate to the needs" of people with disabilities. Dick and his partner Ginny, parents of a man with intellectual disabilities, still speak up to open our churches and synagogues, our workplaces, and places of public accommodation. When we witness indignity and gratuitous insult, will we also speak up? Will we say to the insulting or discriminating bully, like Joseph N. Welch said to Joe McCarthy during his worst red-baiting days, "Have you no sense of decency, sir, at long last? Have you left no sense of decency?" Our field presents parallel moments for confrontation. For instance, the legislative history of the ADA reveals that a private zoo barred people with Down syndrome on the absurdly demeaning claim that their presence would upset the chimpanzees. To the zookeeper we must say, "Have you no sense of decency? Regain it, or now face legal consequences!"

Sixth, we need to apply our visions in practice. As Bob Schalock put it, for our friends to have enhanced life possibilities, they must be enriched by self-determination; social inclusion; a stress on strengths and capabilities; a recognition of the importance of natural environments; and a focus on rights, equity, and individualized support services. In short, these are the core quality-of-life dimensions, now conceptualized for older consumers in the book called *Aging, Rights, and Quality of Life: Prospects for Older People with Developmental Disabilities* (Herr & Weber, 1999). Whatever any court will decide, remember that it will be your responsibility to decide in the first instance what constitutes an appropriate setting. It will be your wisdom and program planning that fulfills the

will of Congress speaking for the American people that barriers must be removed from people with disabilities to reverse the historical tendency to "isolate and segregate individuals with disabilities" from the social mainstream of American life.

Seventh, we need to help ourselves to enjoy greater life satisfaction if we are to teach those lessons to our supported friends. It is our responsibility to create work places and careers that foster cooperation, high motivation, job satisfaction, and fairness.

Eighth, we have responsibilities to become politically active ourselves as well as to empower our clients who can and want to vote. The election year 2000 is around the corner, so all of us who can must exercise our civic responsibilities. It also time to update the Voting Accessibility for the Elderly and Handicapped Act of 1984 to improve accessibility to registration facilities and polling places. On March 2, 1999, Senator John McCain (R-AZ) introduced a bill (S.511) to do just that. And to give equal time to the other party, note that Tony Coehlo, a long-time disability activist, now heads the Gore campaign. Disability rights and a national disability policy must be on the American political agenda.

Ninth, we have global responsibilities that we have agreed to undertake. Our mission is international: to spread good practice, policy, research, and universal human rights for people with intellectual disabilities. There are still places in the world where people with intellectual disabilities lead a nightmarish existence. We can help. We must help.

Tenth, we have responsibilities to deal with the demographic juggernaut that will double the population of older people with intellectual disabilities by the year 2030. We have some hard planning and hard work to do if we are to be ready for the baby-boom and younger generations as they experience old age and seek the same pluralistic options for a good old age that we ourselves prize as older adults in the 21st century.

Our rights revolution needs better ways to defend those in the last phases of their life. We must ensure that as people age they are included in communities, not dumped in abusive nursing homes or worse. In too many communities, our support systems and generic aging services are not prepared to accommodate their needs or support their retirements. My clients Mary

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and Grace languished for 50 years in an institution and a bleak nursing home. They now live with fine community supports and services. Mary's painting hangs on my wall; Grace's photographs grace my book's cover. They have flourished. We must free others like them.

### What Visions Will Sustain Us on the Way?

- We have a vision that one day children with and without apparent disabilities will sit at the same tables of learning.
- We have a vision that one day separate large facilities will seem as odd to us as the separate railcars for Blacks and Whites permitted a century ago under so-called separate but equal treatment (*Plessy v. Ferguson*, 1896).
- We have a vision that one day women and men with disabilities will no longer suffer unspeakable crimes or sexual exploitation but will be treated with the dignity due any human being.
- We have a vision that one day choices will be abundant and self-control will triumph over coercion.
- We have a vision, derived from our heroes, that new vision bearers will pick up their banners. One of them is Elaine Wilson. As Elaine, the woman whose Supreme Court case we supported, put it:

I thought I would die in a hospital and there was no way out. Now I have a chance to live like other people. There's no way I'm ever going to give that up. Now I can make decisions that other people made for me.

Elaine's lawyer, Sue Jamieson, gives thanks to our profession and points to other heroes in our ranks. She told me that her clients "most respect the professionals who can provide them with the chance to live like other Americans." She reports that they are "grateful to the professionals who blazed the way and stuck their necks out," that the single most courageous professional that she ever encountered was a mental retardation professional on the hospital staff who saw Elaine and Lois "as people who could live in the community."

Another source of inspiration is Charles Turner. He was my feisty client, unbowed after 63 years of institutionalization, that ended only with his death at the age of 79. Charlie labored for decades, 6 days a week, morning until night, without any pay (Herr, 1998). Eventually, we won Charlie a modest pension for his labors so that he could know that his life's labor had value, so that he could enjoy a few pursuits of

happiness, such as a vacation, gifts for his girlfriend, and a suit to wear when he received an award for his self-advocacy. These are some of the rewards of freedom.

Let us draw vision and strength from the life and teachings of Gunnar Dybwad. On July 12, we will journey to his Brandeis University to celebrate the 90th birthday of this remarkable worker for justice. This occasion will feature a conference entitled "Then and Now: The Dybwad Years and Their Lasting Impact" and the presentation of two volumes: a collection of his speeches (Dybwad, 1999) and a set of essays in his honor (Bersani, 1999). Here's a glimpse at what I will tell him:

Gunnar, you are a godfather to people involved with the disabilities field. Like the other godfather, you make offers we wouldn't want to refuse.

As both a doer and a thinker, you provide hope that we can undo the horror of human abuse. You dared us to believe the formerly unthinkable: the twilight of custodial institutions and the rise of self-advocacy.

In 1971, when I first contacted you to provide an affidavit in *Mills v. Board of Education* [the landmark case ensuring the right to free, appropriate education], you wrote a statement that was memorable, crisp, and bold. You compared giving children two hours of instruction per week to giving a starving child two meals a week. Just as two meals a week do not make a diet, you explained, so two hours of instruction do not make an educational program for a child with a disability.

In *Wyatt v. Stickney* (1972), you used your own initiative in bringing to Judge Frank Johnson's attention the United Nations Declaration on the Rights of Mentally Retarded Persons (1971). Thankfully, you did not first ask for my legal advice. I would not have predicted that the judge would use the U.N. Declaration to support a right to habilitation.

Gunnar Dybwad, you have always been there when an oppressed person was in need. You and Rosemary were never too busy to offer a word of encouragement, or some bold advice. By your integrity and personal vision, truly you became a force for good in my life and in the lives of so many others! (see Herr, 1999)

Our AAMR Mission Statement, and the entire strategic plan, can be another force for good, supplying the vision to sustain us on our climb:

AAMR promotes global development and dissemination of progressive policies, sound research, effective practices and universal human rights for people with intellectual disabilities.

By engaging in this planning and endorsing this mission, we have become a stronger, braver, and more self-reflective organization. We are positioned to truly advance good policies, research, practices, and human rights on a global level.

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But for all our gains, there are still summits to reach. Here are a few concluding thoughts to spur us upward:

- Support the SIGN [Structure, Internationalism, Governance, and Name] Committee as it works to bring our governance, structure, name, and international capabilities in line with our great mission, goals and principles.
- Keep the Strategic Plan constantly before us, making it a living document, not a book-shelf item.
- Enforce discipline on what we undertake, daring to discard what no longer advances the Association we have envisioned for the 21st century.
- Strengthen in the most intensive ways our strategic alliances with the Arc, the President's Committee on Mental Retardation, and other aligned sister organizations so that we can gain strength in numbers and skills while bringing our own distinctive capabilities, gifts, and perspectives to bear. If we truly are committed to working for justice, we can no longer go it alone.
- Act globally and avoid parochialism, whether in terms of the disabilities to which we attend or the nations in which we aspire to aid professional leadership.
- Warmly welcome self-advocates so that their voices can be heard in the deliberations of the Association, and so we can learn from their hard-won truths (Dybwad & Bersani, 1996).
- Be inclusive. We must not only say that we offer "a big tent." We must pull up the flaps and draw in additional direct support professionals, educators, and other professionals from the ranks of bystanders or former members so that they become our customers, members, and future leaders.
- Be brave. Let us remain a courageous source of timely and highly informed advocacy to our highest tribunals and policymakers so that our positions and values are put into play when we need to stand up and be counted. On the mountain of justice and freedom, we must be there when our core concerns are contested.
- Let fellowship and spirituality flourish in our work so that AAMR service and professional activity remain a continuing source of joy and satisfaction to all who undertake it.

Remember Burt Blatt's wisdom that nothing about people with mental retardation

"should lead us to believe that they think less of their freedom than do other people" (Blatt, 1987, p. 332).

Friends, our cause is a universal one. The shameful sights we witnessed still exist in some countries. To remedy that, each of us must become, in our own distinctive way, a freedom fighter. Each of us can bring dignity to the destitute, care and concern for our brothers and sisters who are reaching out to us for love and acceptance. Be a hero by believing, as Burt once said, that you are "more than your brother's keeper. Believe that, while on this earth, you are his savior and he is yours" (Blatt, 1970, p. 259). So, through your imagination, see the face of someone you have saved and who has saved you. And go to the screening of *Best Man* and see the light in Philly Wohl's face when he sees you, his supporters, and proclaims his manhood before God and his friends.

I close with profound and simple thanks to all of you—friends and colleagues for justice—who have made the past year and the past quarter-century so productive and decisive. We began our year together "In Pursuit of Life, Liberty, and Happiness" and continue that ascent toward enchanting visions for the next period of general happiness, which is another definition of the millennium. You are good companions on this climb of majestic beauty.

In our times, the visionary Martin Luther King, Jr. pointed us to that mountain, announcing on the night before his assassination:

And He's allowed me to go up to the mountain. And I've looked over, and I've seen the promised land. I may not get there with you, but I want you to know tonight that we as a people will get to the promised land (King, 1968).

As a field, I know that we—with our good hearts and heads—will get there one day as well. And we will do so sooner, when we all pull together working for justice and freedom. Dr. King's call should be an anthem for our field, for freedom means a great deal for people with intellectual disabilities, for those who stand despised and pushed to the very margins of society. So let us repledge to do justice and resonate once again with this mighty appeal:

When we let freedom ring, when we let it ring from every village and every hamlet, from every state and every city, we will be able to speed up that day when all of God's children, black men and white men, Jews and Gentiles, Protestants and Catholics, will be able to join hands and sing in the words of the old Negro spiritual, "Free at last! Free at last! Thank God Almighty, we are free at last!" (King, 1963)

And let us sing:  
 Oh, oh freedom, oh freedom, oh freedom over me,  
 And if ever I be a slave, I'll be buried in my grave,  
 And go home to my Lord and be free.  
 No more trials, no more trials, no more trials over me,  
 And if ever I be a slave,  
 I will climb for all I crave, and go home to the  
 mountain and be free.

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*Endnote 1:* For cases reaching the opposite conclusion on age-eligibility, see Sandison v. Michigan High School Athletic Assoc., 64 F.3d 1026 (6th Cir 1995); Pottgen v. Missouri State High School Activities Association, 40 F.3d 926 (8th Cir. 1994).

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*Editor's Note:* Dr. Herr believes that professions, like movements, should have song. In that spirit, he shares in this format the song written by Patricia Williams that she performed at the 1999 Awards Luncheon. Ms. Williams has generously donated the ownership of the following song to AAMR. --S.J.T.

#### WE ARE ONE

A new purity of spirit leads me on.  
I am my father's child, our dreams are one.  
In the morning I rise, bidden by a muse I scarcely know,  
Forgotten fears behind me, hardly knowing where I'll go;  
But the vision of a task as yet undone  
Has me setting out before the rising sun.  
We are one. We are one. We are one.  
Uncertainty must find another time.  
Those against us cannot break these ties that bind.  
We are toiling in the vineyard, we are pruning back the vines.  
As the moon rises to greet us  
We form one unbroken line.  
And the bond that made us brothers makes us strong.  
The passions that unite us keep us young.  
And we are one. We are one. We are one.