Perspectives

Presidential Address 2001—You Can Change The World

Cathy Ficker Terrill, AAMR President 2000–2001

In the words of Margaret Mead, “Never doubt that a small group of thoughtful committed citizens can change the world: indeed it’s the only thing that ever has.” You can and will make a difference. But the important question is, Shall we expend our energies to help people or to empower them? The empowerment of people with disabilities has forged a new civil rights movement.

Americans have a long history of organizing for social, economic, and political justice. The civil rights workers in the 1950s as well as activists of the civil rights movements of the 1960s are now part of the disability movement. Many of those who first joined the disability movement for social justice during the 60s have gone on to become leaders of the movement for the next 3 decades (Bobo, Kendall, & Max, 1996). Advocates have been mobilizing people with disabilities and their families for freedom, authority, support, and responsibility.

The disability movement is unique and has much to offer other social and civil rights movements. The disability movement is a montage of diversity. No one leader or organization can claim to speak for all people with disabilities. The disability movement accepts differences as paramount and includes a powerful coalition of millions of people with disabilities, their families, and advocates (Shapiro, 1993).

“You Can Change the World” is a motto of many individuals who have made a difference in this world. This presentation is about making a difference in the lives of others. It is about the empowerment of people with disabilities and their families to have a better life. A better life as defined by the individual. In this paper I describe several recent and wonderful innovations in this field, including self-advocacy, family support, self-determination, Partners in Policymaking, outcome-based services, supported employment, home ownership, the Olmstead integration mandate, and direct-support staff.

Self-Advocacy

Self-advocacy is an outgrowth of many changes that have occurred in this country after World War II. Self-advocacy is speaking and acting on behalf of your own rights. According to Keith George and Harold Monroe of the Warren–Washington Self-Advocacy Group in New York, “It is the best kind of advocacy because no one knows better than you what your needs are. To be a good self-advocate you need to know about your rights and responsibilities.”

According to Goode and Bittinger (1991), many changes in society paved the way for self-advocacy. The establishment of the Association for Retarded Citizens, normalization, the movement to help people leave large state institutions, the civil rights movement, and an emphasis on consumer empowerment helped pave the way for self-advocacy.

America’s first self-advocacy group, People First, was formed in 1974 in Salem, Oregon (Goode & Bittinger, 1991). People First today is a large association with many groups across the states. A national self-advocacy group was formed in 1992 called SABE, Self-Advocates Becoming Empowered. Because of the efforts of two courageous self-advocates, Nancy Ward and Tia Nelis, self-advocacy is a recognized national advocacy movement.

Thirty-seven states have state self-advocacy organizations. Three states have 2 statewide organizations, for a total of 40 self-advocacy organizations. Most states have some groups even if they do not have a statewide group yet.

According to Bonnie Shoultz from the Center on Human Policy at Syracuse University in New York, there is little research on self-advocacy. However, she suggested that one could make a really long list of positive outcomes enjoyed by at least some self-advocates. These outcomes would include:

• Enhanced self-confidence
Greater self-assertion
Improved public speaking abilities
Skill development of all kinds (e.g., understanding of political issues and better citizenship arising from understanding of rights and responsibilities)

People First of Illinois crafted and promoted state legislation to require a majority of people with disabilities and families to be on state and local agency boards. Individual members of People First of Washington helped their friends with disabilities gain power within the individual program planning process. Speaking for Ourselves in Pennsylvania trained self-advocates to serve on important government committees and policy boards. Self-advocates from Tennessee joined to file litigation to close institutions. These are but a few examples of how a small number of people working together are changing the world.

I asked Tia Nelis what she did to change the world. She stated that she helped to start a self-advocacy organization and got people to start working together and learning about how to start an organization. People First of Illinois is now a nonprofit organization that is 10 years old. They have 26 chapters and over 1,000 members. Many people now are learning how to advocate for themselves. They are part of boards and committees that make a difference. People First of Illinois has won many awards. People have a voice and can advocate for what they want in their lives. They can work together with others to advocate for things that are going to help people with disabilities. It is a support group for people, a place where you can talk. People can learn how to be on boards and committees that make choices and affect people's lives. People First is a place where friendships are made strong. It is where you can talk with others about having a disability. It is a place where you are accepted for who you are.

I asked Nancy Ward how she changed the world. She stated that she was one of the founding members of Self Advocates Becoming Empowered (SABE). The idea was to have the dream a group of people were having in 1990 become a reality. She saw this happen at a national self-advocacy conference hosted by People First of Tennessee in 1991. The vision was to have a national self-advocacy organization that would be developed by and for people with disabilities. She knew that what was needed was a way to share all the wisdom that the self-advocacy organizations have so the wheel would not have to be reinvented. Another goal she had was to develop a way to communicate with self-advocates and other interested parties. Nancy wanted to develop a way for self-advocates to know about the national self-advocacy organization. Members of SABE wanted to share their excitement with everybody and have them be part of the experience. According to Nancy, one of the things that was very cool about starting SABE was that some of the advisors did not believe that they could build such an organization. With a lot of believing in themselves and working together as a team, Nancy and Tia and others have made SABE what it is today.

SABE is now a very powerful organization to be reckoned with.
SABE has been awarded several grants.
SABE has received the Pioneer Spirit award from President Bush.
SABE members have been invited to attend presidential and other federal functions.
SABE has been asked to work with cross-disability organizations.

In the words of Susan B. Anthony, "Cautious, careful people, casting about to preserve their reputation and social standing, never can bring about a reform." Be creative. Think outside of the box. Let us rewire this field.

Family Support

Every action by an individual or a small group of thoughtful citizens is a cause that has an effect that can change the world. According to Zukav (1989) in The Seat of the Soul, we see that there are people in this world who value others more than they value themselves. They are willing to use their vision to create a better tomorrow for others. Key individuals in the field of disabilities know that a stick is a tool, and they know the effects depend on how one chooses to use that stick.

The club that kills can drive a stake into the ground to build a shelter. The spear that takes a life can be used as a lever to ease life's burdens. The knife that cuts flesh can be used to cut cloth. The hands that build bombs can be used to build schools. The minds that coordinate the activities of violence can coordinate the activities of cooperation. (Zukav, 1989, pp. 21–22)

Individuals like Val Bradley, Fran Smith, Allan Bergman, John Agosta, Anne Turnbull, and Kerri...
The needs of families are diverse and cannot be single need or the degree of its impact on a family. They should not be confused with the magnitude of any vices, financial assistance, and other forms of help. The number of needs that a family has, however, is important natural resources in the United States, and they must be supported.

According to Wolfensberger (1976), the origins of family support in the United States can be traced back to the 1700s. The state of Kentucky had a law since 1793 that granted a subsidy or “pension” to needy families who had a member with mental retardation in the household. However, this first family support subsidy was viciously attacked by superintendents of state institutions. Superintendent Stewart from Kentucky stated in 1894 that he was ashamed to tell you of our idiot law and said that he had tried for sixteen years to have the law repealed. He likened this law to the scalp law for foxes under which every fox scalp was awarded with a $2.50 bounty until people took to raising foxes. Now there is a premium offered for idiots. (cited in Estabrook, 1928, pp. 59–61)

Estabrook suggested that the family 4cash subsidy law for children with mental retardation be repealed and the money used to enlarge the institutions instead.

It took the United States almost 200 years to recreate a support program for families of children with disabilities. As we all know most people with cognitive disabilities live at home with their families. Prior to the mid-1970s, families received little or no support. The only support that was offered by the government was out-of-home placement. The first family support program to be started again was in Pennsylvania in 1972 (Agosta & Melda, 1995b). Many other states followed the lead in the 1980s. Depending on the definition of disability used, as many as 4.5 million Americans under the age of 18 years may have a disability (Cedarbaum & Mashaw, 1995).

Family support means different things to different families. The idea is simply to provide whatever it takes for families of people with disabilities to live as much like other families as possible. The term family support can mean provision of resources, services, financial assistance, and other forms of help. The number of needs that a family has, however, should not be confused with the magnitude of any single need or the degree of its impact on a family. The needs of families are diverse and cannot be simply categorized into a small number of service options, such as in-home or facility-based respite care. Family supports must be flexible to accommodate any family on its own terms and in ways that enable and empower the family to take control of the help it receives.

Family support programs vary considerably by state in their design. The programmatic trends clearly favor (a) user friendly approaches to assure that the program is easily accessed and used, (b) flexibility to accommodate the existing diversity in family configurations and needs, and (c) a willingness to have individual families play a leading role in deciding what supports are needed (Agosta & Melda, 1995a). In 1992, family support constituted 1.6% of total mental retardation/developmental disabilities (MR/DD) resources; this grew to 2.8% in 1998. The number of families supported is also increasing, from 174,441 in 1992 to 327,681 in 1998 (Braddock, Hemp, Parish, & Westrich, 2000). Complementing these programs, states have also begun to use other sources of support for families, such as Medicaid or informal community supports, and to weave these multiple sources of funding into a cohesive response to family needs. Although family support is not yet the “law of the land,” the idea continues to gain momentum as well as needed political and financial backing. “We have long recognized that people with disabilities are some of our nation’s greatest untapped resources. We believe that all persons with disabilities must be fully integrated into mainstream society, so they can live fulfilling and rewarding lives” (Clinton & Gore, 1992, pp. 81–83).

Fran Smith made a difference for family support in Louisiana. Her vision was that every family with a child with disabilities would receive family-identified needed supports in a respectful, timely, and dignified way. Fran facilitated a vision-building session with family members and self-advocates. She recognized that the passion people demonstrated at that session would help them to support systems change. The Louisiana Family Support legislation and the process of involving families became a model for 10 other states. Many children with disabilities are now living in warm, supporting families.

So, what will you do? How can you take a vision and turn it into systems change? Who can you find to partner with to change the world, or at least your corner of it? You can make a difference in the
lives of people with disabilities. We need your leadership. We need your vision.

**Self-Determination**

The basic principles of self-determination include freedom, authority, support, and responsibility. Self-determination means that a person makes his or her own decisions, plans his or her own future, determines how government money is spent for his or her own supports, and takes responsibility for the decisions he or she makes. Self-determination has and will continue to change the service delivery system. In essence, it means the money states traditionally spent on care in institutions or group homes or for work training is now given directly to the individuals, who, with few restrictions, get to spend it the way they think best meets their needs (Shapiro, 2001).

A few key people came together in 1994 and decided to do something to further the empowerment of individuals with disabilities. The original folks who worked on self-determination were Don Shumway, Tom Nearny, Richard Crowley, and Dooreen Rosimos. They got the Robert Wood Johnson Foundation involved. The first articulation of self-determination was the monograph entitled *An Affirmation of Community* (Nearny & Crowley, 1994). Nearny wrote the principles of self-determination that were published in a second monograph entitled *Beyond Managed Care* (Nearny & Shumway, 1996).

Today, brokers are operational in state systems. Acumen, a fiscal agent for people with disabilities in Utah, distributes bumper stickers that state, “Fund People, Not Programs.” The role of fiscal intermediaries is being further defined and implemented. People with disabilities have taken control of setting personal budgets with state government funds in Wisconsin. An informed constituency has evolved in support of self-determination. A few states have written self-determination into federal Medicaid programs. By this time next year, self-determination will be part of each of Minnesota’s waiver programs. In fact, Minnesota was one of the first states to modify their Medicaid waiver to include self-determination.

Self-determination offers adults with cognitive disabilities and families of children with disabilities, the opportunity to design their own life goals with a personal support plan. It works for people who want to have authority and control over their own supports and services as well as to have responsibility for managing their funding allocation.

Sometimes when I think of self-determination, I think of the Wizard of Oz. I think of Dorothy on her journey to go home. It was a journey to freedom. Along the way she met some friends and they supported each other. There was mutual respect and interdependence. The lion wanted courage to make choices and to make decisions for himself. The scarecrow wanted a brain. He wanted the capacity to understand so he could make informed choices. The tin man wanted a heart. He wanted to be able to love and be loved. He wanted friends and supports in his community. Dorothy wanted her freedom to go home.

As people with disabilities journey to self-determination, they will acquire new skill sets. People are learning to speak for themselves and becoming the leaders of tomorrow. People are learning how to get information and use that information to change the system. People are learning that with rights come responsibility, and there are many different strategies one can use. People are learning to weave dreams and make those dreams come true. People are asking for control. They want to control their lives and their resources.

**Empowerment and Partners in Policymaking**

People who look to the future are seen as idealists. Often idealists have high hopes for the future and really have an expansive vision about what is possible. Often idealists are told to be a bit more realistic. When someone tells me to be more realistic, it sounds like they are saying, “Give up on your wild ideas.” Realists look upon idealists almost as children, who have failed to “grow up.” To you I say, if that is what it takes to be an idealist, then I hope you never grow up. I hope you will continue to define your dream and pursue it. We need more people to look at things and say, why not?

To the idealists in the audience, allow me to remind you that 20 years ago you would have told me that there could never be democratic elections in Czechoslovakia, or Poland, or Hungary; or that the Communist parties throughout Eastern Europe would lose political control; or that the Berlin Wall itself would never crumble and be reduced to a speed bump. Yet, today these changes are quite real.
Fortunately, the people of those countries took the future into their own hands. Think change. What seems like only a ripple today can become the wave of the future.

What should be apparent to us today is that the distinction between what is possible and what is not possible is always changing. As we advocate to open the communities of tomorrow to people with disabilities through an empowerment model, we must always keep our hope and make plans for the days when the walls that have stood so long, the lack of service and supports wall, the segregation wall, the waiting list wall, the no-choice and freedom wall, and all the walls throughout this great country finally crumble.

Colleen Weick is one of those people who changed the world. She had a vision and that vision was Partners in Policymaking, a leadership training project for adults with disabilities and parents of young children with cognitive disabilities. Partners began in Minnesota in 1987, when Colleen brought together a small group of committed individuals. Partners in Policymaking is a leadership training program to prepare adults with disabilities and parents to speak on their own behalf. The focus is on providing the best and most current information, bringing in national experts with a vision and experience in topic areas and giving participants the chance to apply new skills. Today, Partners has been replicated in 46 states and in several locations in the United Kingdom. Over 8,700 individuals have graduated from Partners. I think it is important to look at how the participants ranked their life changes as a result of their involvement. Here are some quotes from Partner graduates:

• My two sons with disabilities have purchased their own home.
• I am now living in my own apartment.
• My child now attends regular day care.
• My daughter was able to be funded with the Waiver.
• I am President of People First.
• I am President of my local ARC Chapter.
• Today I am the director of the state family support network. (Zirpoli, 2000)

Colleen Weick helped over 1,800 people be involved in systems and individual change. She had a vision and that was to facilitate the empowerment of people to make choices and make a difference. What will you do? What are the “wild” ideas that you have that can make a difference? Who is that small group of people who can help you change the world? Will you partner with self-advocates? Will you collaborate with families? You have the capacity, “Just Use It.”

Outcomes

Jim Gardner designed and developed the Personal Outcome Measures as a basis for organization development and change, person-centered thinking, quality enhancement, and accreditation. He started in 1991 with the help of Bill Murphy. Their vision was to redefine quality as responsiveness to the person receiving supports or services rather than just compliance with organizational process and regulation.

Who Helped?

Help was provided by the Board and staff of The Council on Quality and Leadership in Supports for People With Disabilities, early funders who provided start-up support, Bill Murphy, and the Illinois Planning Council on Cognitive Disabilities. The Health Care Financing Administration (HCFA) provided resources for data collection and analysis. The AAMR is a founding member of The Council and continues to be a very active partner.

What Did The Council Do?

• Decided that quality can and should be measured according to what people want and need and get
• Interviewed people with disabilities throughout the United States and Canada to determine what they wanted from supports and services
• Drafted interim measures and field tested the Outcome Based Performance Measures at 10 sites in North America

In addition, The Personal Outcome Measures are nonprescriptive and culturally relevant. There is no prescribed definition of enough friendship or adequate community participation. Instead, they engaged in a dialogue with each person to determine how he or she defines friendships or community participation and then used that person’s definition to measure the quality of life and quality of services provided.

What Was the Outcome?

The Council put personal into the definition of quality. It demonstrated that individuals, organiza-
tions, and public entities can measure quality of life and quality of services with person-centered outcomes in a valid and reliable manner. The Council demonstrated a practical methodology for measuring quality of life and quality of service that has been replicated by states and other organizations. The Council articulated an alternative definition and measurement methodology for quality that is influencing the HCFA.

How Did This Create Better Futures for People Labeled As Having Developmental Disabilities or Their Families?

Individuals, families, organizations, and public sector agencies can now identify how the individual defines quality of life and quality of services and measure whether people are getting what they want. Funders, regulators, and providers can now be held accountable to delivering quality as defined by the people receiving the service.

The Personal Outcome Measures make person-centeredness more than a philosophy or value system. We can now (a) demonstrate that person-centeredness can be defined and measured and (b) realign service planning, service delivery, service quality, and accountability along “person-centeredness” dimensions.

Supported Employment

David Mank believes that there should be a decent job for everybody who wants one and so do I. David found a small group of committed citizens and helped to start the first free-standing supported employment agency in Oregon. Beginning in 1985, he directed a national scale technical assistance project on supported employment for almost 10 years. He personally logged about a million miles since 1985 and has traveled to every state at least once in the interest of supported employment.

According to David Mank, there are currently over 150,000 adults with cognitive disabilities in supported employment, which is now worldwide, with programs operational in Asia, Europe, and South America. Thirty-six countries represented the International Conference on Supported Employment.

Supported employment, which began as an alternative to sheltered workshops (Mank, Rhodes, & Bellamy, 1986), offers dramatic improvement in integration and wage outcomes (Wehman & Kregel, 1989).

Direct-Support Staff

Training of direct-support staff became a visible national commitment 15 years ago when Congress created training initiatives as part of the Cognitive Disabilities Act of 1987. Bobby Silverstein and a small group of concerned citizens helped to make training of direct-support staff part of the national agenda. Sherri Larson, Amy Hewitt, and John Rose have worked tirelessly to promote workforce development issues. They have built coalitions to promote the professional status of direct-support professionals. Their efforts created the National Alliance for Direct Support Professionals as well as Frontline Initiative, a national publication for direct-support staff. There is work underway for a new national Internet-based curriculum. The AAMR recently created a Division for Direct-Support Professionals as a result of their advocacy and dedication. They made a difference. Will you?

Home Ownership

Home ownership by persons with a developmental disability is a relatively new occurrence in the United States. Generally, all federal benefits are retained if you own and reside in a single family residence. Yet, people with cognitive disabilities have not been considered likely candidates for home ownership. However, Jay Klein changed all this when he started the Home of Your Own Alliance in 1993. Jay believes that each person should have an opportunity for a place to call his or her own. He started a small group of concerned citizens and set out to change the world.

Today, hundreds of men and women with cognitive disabilities are home owners. Home ownership provides a sense of control and belonging that is not available in traditional residential programs. As home owners, people take control of their lives while participating in their communities as taxpayers, borrowers, and neighbors.

The separation of housing and support is critical for people with cognitive disabilities. People need and want control over their lives and home. People who have control in their lives (a) receive 24-hour support, not supervision; (b) live in their own home, not placements; and (c) choose their
homes as individuals, rather than being placed in beds or slots. When the decision of where to live and how to receive supports is separated, consent takes into account individual preferences. The real issue is not whether you own the house, but understanding that you have a real home that you control.

Because an individual has a home that they own or rent, it is the services that change, as an individual’s need changes. The emphasis is on developing and supporting a home and neighborhood life for the individual by providing services, as they are needed.

People with disabilities are often not offered basic choices about where to live, with whom and how they spend time. They are one of the largest underserved groups in the mortgage industry. Disability-related entitlements and low-income assistance programs have been used to help people to own homes with personalized supports that conform to their preferences and needs.

New Home Ownership Options

In September of 2000, the federal government’s Housing and Urban Development (HUD) released the final rule that will allow individuals and families to use Section 8 vouchers for home ownership. It has taken many years and a tremendous amount of hard work from many of you to make this happen. There is much to celebrate in this new rule.

Section 8 vouchers for home ownership will allow many people with disabilities who have low incomes the opportunity to purchase their own homes. In addition, the use of Section 8 vouchers for home ownership will provide many new opportunities for people to contribute to their local economy. According to Jay Klein, national expert on housing, home ownership will allow individuals and families to obtain loans from their local banks, hire members of their communities to perform maintenance and repair work on their homes, and pay property taxes that contribute to the purchase of local services enjoyed by community members. Home owners express a feeling of greater safety, security, and belonging in their communities.

In 1998, 15 state coalitions reported accessing over $20 million to assist people with disabilities to become home owners. These funds were used to (a) reduce the mortgage cost; (b) provide soft second loans for down payments, closing costs, and renovation; (c) fund program operating costs; (d) provide home owner counseling; and (e) offer below-market loans or grants to assist people with disabilities to own homes. The 15 states reported using monies accessed through Fannie Mae, HUD, Housing Finance Agencies, Federal Home Loan Banks, Development Disabilities Planning Councils, and private mortgage companies. In addition, Fannie Mae created HomeChoice, the first national secondary market mortgage product specifically designed to address the needs of low-income borrowers with disabilities. Through HomeChoice, Fannie Mae has made over $175 million in mortgage funds available to people with disabilities and low incomes across the country (Klein & Nelson, 2001b).

Over the past 30 years, people with disabilities have had a significant impact on societal barriers to home ownership. Increasingly, people with disabilities are living in their own homes and receiving the assistance they need to live as valued members of their communities. Funding provided for home ownership from a variety of sources; changes in the underwriting standards of mortgage lenders; relations among affordable housing organizations; and the experiences of people with disabilities, families, and service providers now familiar with home ownership will have desired long-term outcomes. During the next decade, people with disabilities will have many more opportunities to join with their communities and neighbors in exciting new ways through home ownership (Klein & Nelson, 2000a).

Litigation: Olmstead—the Integration Mandate

Last year was the 10th anniversary of the Americans With Disabilities Act (ADA). The ADA gives people with disabilities civil rights just like those of all Americans. The Supreme Court made an important decision in June of 1999. This decision is called the Olmstead Decision. Many people are calling this the integration mandate for people with disabilities.

How Did This Get Started?

It all started with Lois and Elaine, two women with disabilities living in a nursing home. Their lawsuit is known as LC and El v. Olmstead (1999) (Cedarbaum & Mashaw, 1995). They wanted to move into the community. The staff that supported them agreed that they should move to the community. However, the state of Georgia refused to
use their Medicaid money to access community services. These two women decided to fight this decision. They found a lawyer who filed suit for them in Georgia.

What Did the Supreme Court Say?
This lawsuit said that the ADA applied to Medicaid funds, and they should not be forced to receive services in a segregated nursing home. The case went to the Supreme Court, who ruled that when a professional team decides that an individual with a disability can live in a community and can be served there successfully, the person must be given the choice of doing so.

What is Olmstead?
In Olmstead, the Supreme Court agreed that individuals with disabilities have the right to receive public benefits and services in the most integrated setting appropriate to their needs. The Supreme Court said that unnecessary segregation and institutionalization constitute discrimination and violate the ADA “integration mandate.” The decision presents new opportunities for increasing community-based services and supports for people with disabilities.

You Can’t Discriminate . . .
The question presented in Olmstead was, Does Title II of the ADA require a state to provide treatment for persons with mental disabilities in a community placement when treatment can also be provided to them in a state facility? When Congress passed the ADA, it said that there could be no discrimination against individuals with disabilities in providing services funded by state and local governments. Title II of the ADA states:

No qualified individual with a disability shall, by reason of his disability, be excluded from participation in, or be denied benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity.

What Did Congress Say?
Congress told the United States attorney general to make rules, known to most people as “the integration mandate.” The rules state that, “a public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.” It also states that “a public entity shall make reasonable modifications in its policies, practices, or procedures when modifications are necessary to avoid discrimination, unless . . . modifications would fundamentally alter the nature of the services, program or activity.”

A Basic Civil Right
The Supreme Court said that the ADA is a basic civil rights law. The Court agreed with Congress that discrimination against people with disabilities includes segregation, isolation, and institutionalization. The Supreme Court has made it clear that unneeded institutionalization is discrimination under the ADA, and that is against the law.

What Did Medicaid Say?
A letter dated January 14, 2000, was sent to state Medicaid directors from Tim Westmoreland, Director for the Center for Medicaid and State Operations at the HCFA. Mr. Westmoreland strongly urged states to, “increase access to community based services for individuals with disabilities by developing comprehensive, effectively working plans for ensuring compliance with the ADA.”

What Did Health and Human Services Say?
Secretary of Health and Human Services Donna Shalala made an interesting statement to the National Conference of State Legislators on July 28, 1999, in Indianapolis. In her speech she stated:

As we move to implement the Olmstead decision, there are three basic principles that all of us can agree on now. We can agree that no American should have to live in a nursing home or state institution if that individual can live in a community with the right mix of affordable supports. We can agree that we all have the right to interact with family and friends in our communities . . . to make a living . . . and to make a life. And we can agree that it will take time, effort, creativity and commitment from all of us to make this a reality.

Lois and Elaine showed us that we are capable of changing the world. Public policy is a participatory sport. You can and will make a difference. Lois and Elaine opened the doors of integration to many people for years to come. Thank you, Lois and Elaine.

So now I have shared with you how a small group of thoughtful, committed citizens have changed the world. Now what will you do? I am old and getting older by the minute. You are the future of this organization. We need you, your talents, and your capacity. We need your vision and your new ideas. Everyone believes that people with disabilities should have freedom, authority, support, and
responsibility. What will the new model be? What innovation can you bring forward? How will you make a difference in the lives of others?

Often, we glean information about the future by looking to the past. One of the oldest tribes existing today is the Masai in Africa. They may help us relook at the past and remember our priorities for the future. No tribe is considered to have warriors more fearsome or more intelligent that the mighty Masai. While visiting in Kenya, I was surprised to learn that the traditional greeting between Masai warriors is, “How are the children?”

This traditional greeting among the Masai is still used today. It shows the high value that the Masai always place on their children’s well-being. The traditional response is, “All the children are well.” According to Reverend Dr. Patrick O’Neil (1997), this means that peace and safety prevail, that priorities of protecting the young and powerless are in place, that Masai society has not forgotten its reason for being, its proper functions and responsibilities. All the children are well means that life is good. It means that the daily struggles of existence, even among a poor people, do not preclude proper caring for its young people.

I wonder how the world might change if Americans started to greet each other with a similar daily greeting, “How are the children with disabilities?” I wonder if we heard that question and passed it along to each other a dozen times a day, if it would begin to make a difference in the reality of how children with disabilities are thought of or cared for in this country?

How could we impact the future if every adult among us, parent and nonparent alike, felt an equal responsibility for the daily care and protection of all children in our town, in our state, in our country. I wonder if we could truly say without any hesitation, “The children are well, yes, all the children are well.” I trust that you will provide for a future that values the contributions of all children.

References


Author:
Cathy Ficker Terrill, MS, 683 South Prospect Ave., Elmhurst, IL 60126–4327.