
PERSPECTIVES

Presidential Address 2000—Changing Visions Into Reality

Bernard R. Wagner, AAMR President: 1999-2000

I have had a unique opportunity over the last year to dream, to dream about the future of our field. It began at the New Orleans Conference where we talked about visions for the new millennium. It continued on through representing the organization in a dozen or so conferences and special events across the country and writing a series of presidential columns. Throughout this year of dreaming, my dreams have changed. I think that they have been refined somewhat. I began the year saying that there are basically eight major visions or dreams for our field. At one point in my thinking, I got it down to four by combining, and now I have it back up to six. So, today, you are going to hear about six visions or dreams for the future of our field. I want to put particular emphasis in my discussion on what we need to do to make these dreams become reality. Now, it is one thing to dream; it is another thing to act on those dreams. There is a Japanese proverb that goes "Vision without action is a daydream, action without vision is a nightmare." What it basically means is that we need to both dream and act on those dreams.

The six visions or dreams are

- Self-determination
- Development of a constant, competent, caring workforce
- Home ownership or control and, correspondingly, the declining role for institutions
- Empowered and effective self-advocates
- The enjoyment of maximum quality of life
- Participation in highly valued roles in society

Self-Determination

The first vision is self-determination. Bradley (1994) spoke about the era of community membership. Briefly, what she described is citi-

zens living in their own homes, supported by services and programs developed through person-centered planning. The American Association on Mental Retardation's (AAMR's) policy statement (*AAMR's Policy Statement, 1994*) also captures this idea very succinctly:

AAAMR joins with people with developmental disabilities in supporting the full expression of citizens with disabilities to speak for themselves in making choices about their lives. This includes decisions about living arrangements, work, personal relations, and funding of service needs and supports. (p. 7)

That is a very dynamic statement. I think it describes a revolution in the field. I cannot tell you how excited I am about this as a driving dream for our field. I also am somewhat humbled when I think about my 35-year career because I really only began to realize, maybe 5 or 6 years ago, how very important self-determination is. I reluctantly admit to having spent the good portion of my career making decisions for people or running programs that made decisions for people while only allowing lip service to the idea of participation. Hopefully, I have seen the light.

I think it makes sense to approach every dream with certain cautions. I believe one caution is that we cannot let choice become an excuse for neglect. Let me tell you two real stories of Evergreen clients. One is a gentleman by the name of Robert, who moved out of one of our Intermediate Care Facilities for the Mentally Retarded (ICFs/MR) community homes into his own apartment. It became obvious after a couple of months that Robert was not eating properly. He was beginning to lose weight and was spending his limited funds on junk food and some questionable recreational activity. Our staff debated at length about Robert's right to eat poorly versus our responsibility for Robert's well-being. The decision we eventually came to was that to simply allow the situa-

tion to continue would be allowing choice to become an excuse for neglect. So we did intervene. We arranged a budget, and scheduled staff was there at dinnertime to make sure that Robert ate more appropriately.

A second example, a fellow by the name of Jimmy, posed a similar kind of situation. Jimmy moved out of one of our ICF/MR community homes into his own apartment. Very quickly after moving out, he got a job as a dishwasher in a local restaurant. Jimmy took great delight in walking to and from work. In fact, he took great pride and delight in walking all over. I think he probably loved to walk because of the independence that he gained by walking, not having to rely on arranged transportation. He had spent many years in institutional settings waiting for the institution bus or community home van to go wherever the bus or van was going. The staff was very concerned about Jimmy walking home late at night, 10:30 or 11:00 o'clock, when he was through with his dishwasher job. Jimmy insisted, however, that he wanted to walk home. The end to this tragic story is that one night, while he was walking home from work, a drunk driver left the road, went up 10 yards onto the side of the road, hit and killed Jimmy. Needless to say, we went through a tremendous amount of soul searching as to whether or not we had made a tragic mistake of letting choice become an excuse for neglect. In this particular case, we finally decided that we had not.

I do not necessarily expect you to agree with my conclusions about Robert or Jimmy. What I do encourage, however, is that you take these examples as indications of the very fine line that we walk at times between choice and safety concerns. Very difficult decisions frequently need to be made.

Some of the reality actions I would strongly suggest are, first, to be aware of and honor the individual's values. Jimmy obviously valued independence, again, probably because he had a lifetime of having his independence curtailed. Second, be aware of competing values. The values of the person we serve and support may be markedly different than our own. Obviously, Jimmy valued independence, and my staff was valuing Jimmy's safety. Third, we need to increase the limited number of alternatives that we have available for the folks we serve and support. Maybe where we really blew it with Jimmy was in only offering him the alternative

of walking home or riding in a cab. Possibly a better alternative would have been to help him secure a driver's license and a secondhand car so he would not have had to be dependent upon staff to arrange transportation.

Constant, Caring, Competent Workforce

The second dream I have for the field is the development of a constant, caring, and competent workforce. We are facing extremely problematic demographics. We have a smaller available workforce, more in demand. Right now, we have the lowest unemployment rate in 30 years. We have 5% less people in the 18- to 45-year age bracket from which we typically draw our hands-on staff (Larson, Lakin, & Bruininks, 1998). Braddock and Mitchell (1992) found that our community programs have turnover rates of 50% to 70%. I am afraid that turnover is currently even higher because Braddock's study was done when the unemployment rate was not nearly as low as it is today. The AAMR is beginning to address the need for a competent workforce. One of the major goals in our strategic plan is to "assure a quality and available workforce."

Relevant to this discussion is what I call a "human resource development cycle." That is basically what we do as managers or administrators. We recruit, select, train, supervise, and, hopefully, retain staff. This subject could constitute a major presentation. In fact, AAMR in Louisiana has invited me to do a half-day workshop on this very topic. I am not going to provide a lengthy discussion here, but I do want to quickly go through some ideas in each of these areas.

First, with regard to recruitment, if you are lucky enough to have a university nearby, recruit students, even if you have to hire them part-time. Another means of attracting new employees is word of mouth. Probably 80% of the thousand employees that work at Evergreen came to us as a result of word of mouth from other employees. For a number of years we have had recruitment bonuses. If an employee recruits someone who stays with us for 90 days, they get a \$50 bonus. We are finding that we need to use creative advertising, for example, headlining an ad with "Wouldn't you like to do something your mommy would be proud of?" or "This is a job that beats flipping hamburgers." In other words, something catchy that appeals to a motivation other than the opportunity for huge wages, which we obviously do not offer.

Another important consideration is selection. I am a believer in criterion-based tests, particularly for people whom we expect to keep records and data. I am also very committed to the idea of client and coworker involvement in the selection procedure. Another useful selection technique involves realistic job previews, where you present, as much as possible, the demands of the job available to the perspective employee. For about the last 6 years at Evergreen, whenever someone is being considered for employment in a community home, they have to spend 4 hours in the home, and part of that 4 hours has to include mealtime. This gives the perspective employee an opportunity to get a feel for the work. It also gives the supervising staff and the clients an opportunity to take a look at the "fit" of the perspective employee. One final selection consideration is the compatibility of values. It is very easy to teach things such as signs and symptoms of illness and various teaching techniques; however, it is not nearly as easy to teach values and attitudes. I think part of the selection procedure needs to involve structured interviewing focusing on how the person responds to values, such as the dignity and worth of the individual, and the ideas of empowerment and self-determination.

Specialized training for those working in the field needs to be addressed. The Human Services Research Institute (HSRI) has developed 12 areas of competency that make sense to me. They include abilities in areas such as empowerment, networking, community skills, and so forth. What we lack, however, is standardized curriculum. The materials coming out of HSRI are pretty broad-based. We need to get down to a more specific curriculum. In Louisiana, at least, we re-create the wheel in every program and service when it comes to training curriculum.

To develop capable supervision, we need to creatively use reinforcers and career ladders. Let me share the story of a lady I really respect, who works for us in Texarkana. About 10 years ago, Linda was a college student and came to us as a part-time worker. While she was still going to school, she went through a three-tier ladder that we have for hands-on employees within our Evergreen system. She eventually became a home manager before she even completed her degree. Upon completion of her degree, she became a Qualified Mental Retardation Professional, and today she is a division director in

charge of 13 homes. To me, Linda represents a person who has gone through the process of a career ladder and proves that good things can happen when you recruit college students.

At Evergreen, we have used performance-based bonuses for a number of years. The idea is that every year, if we have money available, we give a bonus that is based not only on the employee's performance evaluation, but also on progress that the folks they serve and support have made. It is a neat system that I would love to share with anyone who is interested.

One other important point about supervision is that we need to train our front line supervisors well. Unfortunately, we frequently take good hands-on employees and make them supervisors without adequately training them. The research constantly shows that one of the top two or three reasons that people leave our employment is inadequate supervision.

Given the high turnover rate in our field, we need to focus on the retention of good employees. I would argue that our retention problems would be lessened if we had adequate wages, career ladders, and reference groups. AAMR can be an excellent reference group, not only for those at the professional level, but also for the folks at the paraprofessional level. One disappointment I have had is that we have not been able to recruit more direct support professionals as AAMR associate members.

All things considered, this vision of developing a caring and competent workforce is probably the biggest challenge facing us as we move into the new millennium.

Home Ownership or Control

The next vision I have for our field is home ownership or control and, correspondingly, a declining role for institutions. AAMR's policy is, I think, a very good one in this respect: "AAMR joins with people with disabilities and their families in calling for an expansion of the American dream of owning one's own home or at least controlling one's home" (p. 7). Historically, AAMR has had a love-hate relationship with institutions. Thirty-eight of our first 40 presidents were, in fact, medical superintendents of state institutions. Many of these early leaders in AAMR went across the country encouraging states to develop institutions. In more recent history, we have had a number of presidents who were very strongly against the con-

tinuation of institutions. Burt Blatt, of course, is the one who comes immediately to mind.

In recent years, we have certainly seen a reduction in institutional placements. When I first came into the field in the mid-1960s, there were 195,000 individuals in state institutions. Today, there are probably less than 48,000. That is a tremendous reduction. Eight states plus the District of Columbia have no institutions. I think we can take pride in this reduction.

One of the reality actions that I would suggest here in this respect is to first encourage everyone who is in an administrative, supervisory, or decision-making position to look strongly at "home of your own" programs. Just in the last couple of years, my agency has gotten involved in helping our folks buy their own homes. We now have 20 people living in their own homes. I would like to share with you just a couple of their stories. The first is Dennis and Betty. They lived in ICF/MR community homes, fell in love, got married, rented an apartment, and then about a year and a half ago, purchased their own home. Then there is Walter. Walter still needs 24-hour-a-day supervision, but he has his own home, which has a small motor repair shop in back. He takes great pride in his home. Walter was the hardest guy in the world to get to work. Once he owned his own home, all of a sudden, he was a hard worker, trying to get money to get furniture, drapes, paint and so forth. The last individual is Grace. Grace is in her early 60s and just recently purchased a modest two bedroom home. She is taking in a renter and is going to become a landlord.

One of the advantages we have seen of the home ownership program includes the pride of ownership, such as in Walter's case. A second advantage is that for many of our folks we have been able to arrange mortgage notes that are less expensive than what they were paying for rent. A third advantage, which I strongly recommend for your consideration, is community acceptance. Evergreen Presbyterian Ministries, over the last 15 years, has opened 71 six-person ICF/MR community homes. I would say that we had serious community opposition in at least 50 of those 71 examples and wound up in court four times. We have 20 people now living in their own homes and have not had a single incident of community opposition. People do not object to a person who has a handicap moving into a neighborhood as a homeowner. One final advantage is that when you have equity in

a home, the equity does not count against the \$2,000 resource limit to remain eligible for Medicaid benefits. This is one way for our folks to accumulate savings.

A second suggestion for reality action is that we need to avoid hostile rhetoric in expressing our viewpoints. Twelve years ago, before Doreen Croser was hired, I had the experience of being acting executive director for 7 months. I had people tell me they were dropping out of AAMR because the association had become so anti-institutional that it was uncomfortable to come to conventions. I had still some other people working in community telling me that they were dropping their AAMR membership for exactly the opposite reason—AAMR was too institutionally bound. I guess that indicates that you cannot please everyone. I believe it indicates as well that we sometimes have a tendency to get a little hostile in our rhetoric. We need to guard against that.

A third reality action that I would strongly recommend is to capitalize on the manpower in institutions. When he stood here before you a few years ago giving his 1994 presidential address, David Braddock stated that "Many of the most courageous staff members in the field today work in large congregate settings" (p. 439). I, myself, spent the first 21 years of my career working in large congregate care settings. I was "deinstitutionalized" 13 years ago. I think it would be a serious mistake not to capitalize on the talent that works in congregate settings.

Evergreen had a very interesting experience (Wagner, Long, Reynolds, & Taylor, 1995). We closed a fairly large 240-person ICF/MR institution. We were able to move a lot of staff members out with clients into community homes. As expected, we found that client behavior improved. What we really found significant was that the staff members' behavior improved as well. They became more excited and responsible about their work. It confirmed to me that the advantage of the community setting has a lot to do with size, accountability, and ownership. No matter how well you run an institution, and I have run a number of them, it is very difficult to avoid the "it's somebody else's fault" mentality. That includes finger-pointing at another shift, department, and so forth. It is much more difficult to finger point when you are talking about a 6-person community home. It is even more difficult to finger-point when you are talking about a single individual or a

married couple or two or three people living in an apartment or home.

Finally, I would like to re-emphasize is that our association should provide a vehicle for genuine professional disagreement and debate. A number of years ago, Wolfensberger (1991), probably one of our strongest advocates in the field, made this point better than I can. In a letter to the editor of our newsletter, he said that he belongs to other associations for advocacy. What he needs from AAMR is a place where issues can be debated and seriously discussed. That does not mean that we avoid taking policy positions. Go back to the policy position we just discussed on home ownership. Full implementation of that policy position would eliminate institutions. It would eliminate, for that matter, ICF/MR community homes. I think we can adopt that kind of policy position and still be a place where our sisters and brothers who currently work in large congregate settings can feel welcome.

Empowered, Effective Self-Advocates

The fourth vision or dream is empowered and effective self-advocates. Historically, the self-advocacy movement began in the 1960s. We now have over 40 states with either People First or Self-Advocates Becoming Empowered (SABE) chapters. AAMR has been struggling to discover how we could best support self-advocates. Our statement on self-determination is basically a statement of self-advocacy. You add to that the policy that AAMR supports increased participation of people with disabilities at conferences and on policy-making boards at all levels and you have a statement about self-advocacy. Bringing that statement to reality will not be easy.

A first reality action to empowerment is that we need to learn to listen. I met a young lady 12 years ago whose story points out my inability to listen, for which I will take full responsibility. I first met Sally when I had just taken the position as president of Evergreen Presbyterian Ministries. I was on our 240-bed ICF/MR campus on a field day handing out awards for academic performance, work, and good behavior. I was reading the list of people receiving certificates for good behavior, and Sally sat there getting more and more agitated. I could see her wiggling in her chair, and as I gave out my last award for good behavior, she jumped up, knocked over the podium, and took

a swing at me. Obviously, she was angry that she did not get an award for good behavior!

Well, it turned out that Sally was the record setter in incident reports for the institution. She really demonstrated big time behavior problems in every sense of the word. When we closed the institution 5 years ago, Sally went into her own apartment with lots of supervision. To make a long story short, I recently had the opportunity to visit Sally in a home that she now owns. She came up to me and gave me a hug and said "Thank you for everything Evergreen's done for me." It took me 10 years to realize that what this gal was telling me with her behavior was that she did not want to live in a congregate setting. What a poor listener I must be!

The second reality action is to develop nonintrusive advisors. I am sure the self-advocates in the audience can confirm that nothing is more troublesome than having us professionals trying to set agendas and lead discussions. Some of the early problems in the self-advocacy movement were directly traceable to our overzealous professional intervention with self-advocates.

The third reality action needed is organizational support. The Arc has had a better history of supporting self-advocates than has AAMR. We have struggled in AAMR trying to figure out how to meaningfully involve self-advocates in our organization. With Cathy Ficker-Terrill coming in as president and her strong background in this area, we, hopefully, can make some headway. Let me share with you one thing we have tried in the South Central Region that is working pretty well. Our region of AAMR is offering to pay AAMR dues for any self-advocate who is a member of a state chapter board. This is really encouraging some of our state chapters to include self-advocates on their boards.

The last point is that we need to offer opportunities to self-advocates to lobby decision-makers and present concerns directly to the public. In Louisiana, we have been struggling with threatened rate reductions. We have begun to let our self-advocates speak for themselves rather than having Dr. Wagner going to the legislature with charts and graphs. We are finding out that self-advocates can have a heck of a lot more influence and impact than I can.

Maximum Quality of Life

The fifth dream is that our folks will enjoy a maximum quality of life. Quality of life is a

subjective concept. After reading two really excellent books (Schalock, 1996, 1997) published by the AAMR on quality of life, I still am not quite sure I understand everything that is involved. It is the kind of concept that I feel "I know it when I see it." Bob Schalock has said that there are eight core dimensions involved in quality of life: emotional well-being, which I take to be some indication of happiness; interpersonal relations (friends); material well-being (does a person have enough money); personal development; physical well-being; self-determination; inclusion; and exercise of rights.

Granted, although I cannot define it more precisely than this, I still believe that we have made tremendous progress over the last 35 years in quality of life for individuals with mental retardation. Let me share a war story with you. In 1975, I was being recruited to be superintendent of a 600-person institution in central Indiana, which has since closed. This institution was probably not very different from a lot of institutions of that time, except in one dramatic way. It had one campus on one side of a valley and a second campus about a mile away on the other side. On the first campus were individuals who had only mild or moderate impairments. They had pretty nice buildings and many scheduled activities. Then you went on the other side of the valley. This was where they served folks who were designated with severe and profound mental retardation. My God, it was unbelievable! Bedrooms had rows of beds with no dressers and 40 to 50 people milled around in large day rooms. Two attendants were locked away behind a nursing station, separated by Plexiglas. I literally got sick to my stomach and almost left the field at that time. I ended up taking the job, and we eventually closed that campus. I could not believe that those kinds of conditions existed and that was only 25 years ago. Hopefully, those conditions do not exist anywhere today.

What do we need to do to ensure quality of life or to continue to improve quality of life? I have already talked about some of this. We need a commitment to self-determination. We need to develop creative alternatives. Again, this is a point I made when we talked about Jimmy, the fellow in the tragic car accident. Let me tell you another story, this time about Dewey. When we were closing our institution about 5 years ago, Dewey came to me and said "Hey, doc, I want to get married. When are you gonna start

a community home for married folks?" My response was "Dewey, why would you want to live in a community home if you were married?" Well, it was all we were offering, either an institution or a 6-person community home.

Another thing that needs to happen to improve quality of life is to eliminate huge waiting lists. We currently have 80,000 people a year waiting for residential services. If the Arc is to be believed, and I think they are, we have over 200,000 waiting for all kinds of services. I do not think it is a far flung assumption to say that most of those people's quality of life would be dramatically improved if they were able to get the services they are waiting for.

A final thing I would suggest is that we need to resist imposing our own perceptions of quality of life on others. Back to the point about how subjective the concept is. Evergreen presently serves almost 700 people. About 450 of those 700 are still in ICF/MR community homes. About 250 are in supported living arrangements (i.e., they live in their own apartments or homes). Most have moved out of some Cadillac community homes. Quite frankly, their apartments and the furnishings are not nearly as nice as the community homes they left. As I visit people who live in their own homes, whenever I can I ask the question, "Do you prefer living in your own apartment or home? To the person the answer is "yes." The independence that they gain contributes much more to their quality of life than a little better neighborhood or nicer furnishings.

Highly Valued Roles in Society

My final vision is that people with disabilities will assume highly valued roles in our society. The power of mental retardation is an interesting concept. In the February 2000 issue of *Mental Retardation*, Smith talked about the power of mental retardation. The point he was making is that people with mental retardation have a tremendous power to enrich our lives. Wolfensberger (1988) talked about the beauty of people with mental retardation. He said that these individuals have the capacity to call forth gentleness, patience, and tolerance from others. As I think about the struggle we are going through right now with name change and coming up with an alternative for the term *mental retardation*, I am really struck that maybe we need to learn something from the civil rights movement. More specifically, from the concepts

of "Black power" and "Black is beautiful." Perhaps the emphasis that we should be adopting in the field is the power and beauty of people with mental retardation.

How do we really start to implement this dream of highly valued roles in society? One thing we need to do is begin to celebrate the people who, in fact, currently have highly valued roles. Let me tell you about some of my heroes. Jimmy, the fellow who was hit by the car, is a hero of mine. He is a hero because he demonstrated to me how important independence is.

The next hero is Benny. Benny demonstrates courage to me. He was discovered about 12 years ago in a locked shack attached to his parents' house, basically caged like an animal. He fed himself with his hands, was incontinent, and suffered from extreme mental and physical abuse. Today, Benny is doing great! He is a resident in a community home. To me, Benny represents courage as much as a congressional medal of honor winner who has fought in the war for us. This is a courageous individual whom we should celebrate.

Next are two of my favorite people, heroes who demonstrate teamwork. Morgan is totally blind. Pat sees well. Morgan is sharper intellectually than Pat is. It is almost as if Pat has the sight, and Morgan has the insight. Together, they are an unbeatable combination. They have lived together as roommates for about 5 years now and are in the process of buying their own home.

My next heroine is Janet. Janet is about 61 years of age and has mild mental retardation. She spent the first 40 years of her life in a large state institution, which says something about whom they were institutionalizing 60 years ago. Janet came out of the state institution to Evergreen. She moved into a community home and was one of our first clients, about 12 years ago, to move into her own apartment. Since then, Janet has worked in the fast food industry and has done a great job. She was twice Employee of the Year for Burger King. On her own, Janet decided she could get a better deal from Luby's cafeteria. She changed employers and is now a respected employee with Luby's. Talk about self-advocacy! To me, Janet is a heroine who really demonstrates the role of hard work.

Finally, there is Christina. She has big dreams. What makes Christina unique is that her dreams are really good! About 6 years ago,

she was mainstreamed into a large high school in central Louisiana. She no sooner got there than she decided that she was going to become a cheerleader. Much to our amazement, she went out for the cheerleading squad and became a cheerleader. Then, a few years later when she was a senior, Christina decided that she wanted to be Homecoming Queen. She saw no problem at all with the fact that she has Down syndrome. She was going to be the Homecoming Queen. Well, lo and behold, she ran for Homecoming Queen and won. Christina is my heroine of big dreams. She did not let her handicaps stand in the way of realizing her dreams. I think it is also a testament to that high school that they did not let her handicaps stand in the way either.

How do we begin to change public attitude? One way is to arrange contacts that call for attention to capabilities rather than disabilities. Look at the roles we have been talking about: homeowners, employees, decision-makers, independent persons, team players, homecoming queen, and landlord. These are highly valued roles in our society, and we need to make sure the public has contact with people who have mental retardation and are occupying those kinds of roles.

This is indeed an exciting time for our field. The challenges are great, but the dreams are spectacular: self-determination; self-advocacy; a supportive, caring workforce; home ownership; maximizing quality of life; adopting or engaging in highly valued roles. The next 35 years are going to be very exciting as we struggle to realize these dreams. I only wish I had another 35 years in the field. Let me leave you with a quote from Mark Twain, which I hope captures the feelings that I am trying to share:

Twenty years from now you will be more disappointed by the things you didn't do than by the ones you did do. So, throw off the bowlines, sail away from the safe harbor, catch the trade winds in your sails, explore, dream, discover.

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