

# Perspectives

## *Parents' Perspectives on Institutions*

### The Editor's Perspective

In 1979, the Center on Human Policy, which I currently direct, issued *The Community Imperative*, a declaration supporting the right of all people with disabilities to community living:

In the domain of Human Rights:

- All people have fundamental moral and constitutional rights.
- These rights must not be abrogated merely because a person has a mental or physical disability.
- Among these fundamental rights is the right to community living.

In the domain of Educational Programming and Human Services:

- All people, as human beings, are inherently valuable.
- All people can grow and develop.
- All people are entitled to conditions which foster their development.
- Such conditions are optimally provided in community settings.

Therefore:

In fulfillment of fundamental human rights and in securing optimum developmental opportunities, all people, regardless of the severity of their disabilities, are entitled to community living.

The Center reissued *The Community Imperative* in 2000 and invited endorsements by individuals and organizations in the field. To date, over 180 professional, self-advocacy, disability, family, and advocacy organizations, including AAMR, The Arc of the United States, and TASH, have endorsed the declaration.

This issue of the *Journal* contains an exchange of parent perspectives on institutions versus community living. Mary McTernan and Nancy Ward, leaders of Voice of the Retarded (VOR), defend the continued existence of institutions. In separate, invited responses to this commentary, Sue Swenson and Terry Kozloff advocate for the full inclusion of people with disabilities in society.

The Center on Human Policy, which was founded by the late Burton Blatt in 1971, probably represents better than any other organization those who desire “to completely do away with institutions to provide services only in community settings,” as written by McTernan and Ward. Readers might wonder why I, as director of an organization that has advocated for community living for almost 35 years, would accept an article submitted by leaders of the organization that has become the strongest proponent of institutionalization. I suspect that some readers of the *Journal* will be critical of me for providing a forum for the publication of out-dated, and potentially harmful, views.

When *The Community Imperative* was first issued, our opinion represented a minority position. Most professionals in the field believed in the need for a full “continuum” of options, ranging from institutions to community settings. Leaders of several national organizations who endorsed the declaration in 1979 were careful to add that they were representing their personal views, not those of their membership. Some leading journals rejected articles consistent with *The Community Imperative* as too “idealistic” or “ideological.” Now that my views seem to be shared by the majority, or at least the leaders of major organizations, I am not going to use my position as an editor to reject minority opinions.

McTernan and Ward write as parents of people with intellectual disabilities. Parents did not create the institutions. Most parents who placed their sons and daughters in institutions in earlier times did so on the advice of professionals. I am not a parent of a child with intellectual disabilities and do not judge those who made what was surely a difficult decision in years past.

I heard an advocate for new approaches in the field refer to this as the “postinstitutional” era a while back. This is not true. The institutions may be dying, but they are not dead yet. Far too many people with disabilities live in public or private institutions, segregated “community” facilities, and nursing homes. Although I personally believe that the time to debate the place of people with dis-

abilities in society has long since passed, the debate must continue as long as many policymakers and members of the public do not question the appropriateness of institutionalization. This is why I invited Kozloff and Swenson to write responses to the McTernan and Ward article.

Institutions represented a bad idea and were based on a faulty vision. The best way to counter bad ideas and faulty visions is to present better ideas and visions. I believe that Kozloff and Swenson have done just that.—S. J. T.

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## Outcomes That Matter: Parents' Perspectives

Mary McTernan and Nancy Ward

As parents and guardians of adults with developmental disabilities who have lived, or are living, in institutions, we understand that many people with cognitive challenges function well enough to live in community homes. We also know that institutions have a role in providing services to people with severe and profound cognitive disabilities, including those who in addition have complex medical and behavioral conditions. We are becoming increasingly concerned about the desire of many professionals and organizations to completely do away with institutions and provide services only in community settings.

This concern is not ours alone. Nearly 30 states have investigative media series, state audits, and/or peer-reviewed studies showing systemic problems with community-based settings. In response to these reports, the Centers for Medicare and Medicaid Services (CMS) has been working hard for several years on objective measures for ensuring quality in Home and Community-Based Waiver Services. The United States Department of Health and Human Services (HHS) is also reviewing these concerns, prompted in part by demands from Senator Charles Grassley, Chairman, and Senator John Breaux, Ranking Member of the Senate Finance Committee, for HHS to improve oversight of quality in waiver services. These initiatives are welcomed and applauded by advocates everywhere because they are beginning to address an existing need to improve outcomes in community settings.

In our roles as president and immediate past president of Voice of the Retarded (VOR), we are acutely aware of this “community versus institution” debate. Organizations that believe public and private Intermediate Care Facilities for Persons with

Mental Retardation (ICFs/MR) are never appropriate have been working for nearly a half a century to close and downsize these settings, and from a national perspective, they have been very successful in most states. Relatively few people currently live in ICFs/MR, although those who do, by substantial majority, are multiply disabled with complex health care requirements, profound mental retardation, limited functional ability, or severe behavioral challenges. These are individuals who are the most challenging, fragile, and expensive to care for in community settings and, in some situations, are inappropriately living in nursing homes, state hospitals, or other settings that do not meet their needs in the same way an ICF/MR would. Organizations that continue to expend energy and resources toward the goal of emptying existing ICFs/MR overlook the fact that quality of facility care has greatly improved since the first closure decades ago. Wouldn't it be better if such energy and resources were directed toward assuring quality services across *all* settings for people with developmental disabilities? Does government policy or human decency justify moving these people?

Even the Supreme Court recognized the need for an array of services in its landmark *Olmstead v L.C.* (1999) decision, relying, in part, on VOR's *amicus* brief. The Court ruled that community placement is appropriate, and institutionalization unjustified, when

(a) the State's treatment professionals have determined that community placement is appropriate; (b) the transfer from institutional care to a less restrictive setting is not opposed by the affected individual; and (c) the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities.

The Supreme Court clarified its ruling by adding,

Unjustified isolation, we hold, is properly regarded as discrimination based on disability. But we recognize, as well, the States' need to maintain a range of facilities for the care and treatment of persons with diverse mental disabilities, and the States' obligation to administer services with an even hand. . . . We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings. . . . Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it.

The Supreme Court recognized what we as parents and advocates have always known: Neither institutions nor community settings alone can meet *all* the needs of *all* people with developmental disabilities *all* of the time. For those who will challenge the assertion that the community cannot serve all needs all the time, we point to the frustration that countless families like ours feel when we realize the disparity between what is promised in community settings and what is actually delivered.

It is this disparity that prompted our organization to secure an important review of the cost comparisons in the literature (Walsh, Kastner, & Green, 2003). Kupfer (1997) explained why an accurate review of cost comparisons was needed:

I said it 15 years ago, but it needs saying again: the view that the 'home' is the best place for every child has dangerous ramifications. Government funds are cut for human services under the guise of anti-institutionalization. Well-meaning reformers who tell us how terrible institutions are should be wary lest they become unwilling accomplices to politicians who only want to walk a tight fiscal line. It takes a lot of money to run residential facilities. No politician is going to say he is against caring for the handicapped, but he can talk in sanctimonious terms about efforts to preserve the family unit, about families remaining independent and self-sufficient. Translated, this means, "You got your troubles, I got mine." (p. 20)

In short, politicians will often say they are closing large facilities for the betterment of the clientele when the real motivation (or at least additional motivation) is cost savings. Advocates, for sometimes more pure motives, will readily climb aboard, happy to have a law-making champion in their corner. The result, sadly, has been the transfer of individuals to underfunded community situations with predictably negative results.

Although addressing the cost argument seemed necessary in light of what we were seeing as the primary justification for deinstitutionalization, as Walsh et al. (2003) stated:

Which is less expensive, institution or community? is the wrong

[question] to ask. Rather, the questions that need to be asked revolve around the individual (i.e., "What does this person need? . . . Where is the best place to provide these needs?" and at what cost? (p. 117)

This brings us to the main point of our paper, namely, outcomes.

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## Measuring Good and Bad Outcomes

It defies common sense to assert that one setting (i.e., institutions) would be wholly bad whereas another (i.e., community settings) would be wholly good. Nonetheless, we hear claims about the alleged superior outcomes in community living as compared to facility settings. All these claims and counterclaims are confusing to parents and other family members, who typically cannot discern the reality among them. If nothing else, parents are unable to reconcile "scientific" studies touting community outcomes with media accounts of problems in community settings.

As leaders actively involved in a national organization, we have the opportunity to stay abreast of trends relating to outcome measures and have come to believe that accurately identifying appropriate and comprehensive measures of quality is a daunting task, even to professionals in the field. For example, we read with interest a recent study in which Perry and Felce (2002) critically examined the effectiveness of widely used quality of life interviews to assess the satisfaction of people who have mental retardation with various aspects of their lives. Although we understand that there has been much written in this area of research (the Perry and Felce article is neither the first nor the last word on the topic), their conclusions seem to confirm what we as parents and advocates have always understood: People with severe and profound mental retardation usually cannot answer survey questions, and there is risk of bias in using a proxy to serve as a substitute respondent. Perry and Felce confirmed our concern that low-language ability and the need to use proxy respondents, among other factors, interfered with obtaining valid responses from two thirds of the sample tested (pp. 450–452). The effectiveness of quality of life interviews related directly, the researchers noted, to level of mental retardation. According to Lakin, Larson, Prouty, and Coucouvanis (2002), nearly 80% of individuals residing in state-operated facilities for more than 16 people have severe or profound mental retardation (p. 31).

Studies such as Perry and Felce's (2002) lead us to approach with skepticism the current emphasis on personal outcome measures to identify quality. These measures rely on subjective, abstract concepts, such as satisfaction and happiness. Obviously, whether our family members are happy is of primary concern to us, but determination of happiness takes more investigation than simply asking individuals with mental retardation (or their staff members) if they are happy.

To truly determine our family members' happiness, as all parents, we must also look to objective outcome measures ("empirical indicators" to researchers). We want to know whether our family member is seeing a dentist regularly to ensure he or she is not suffering from mouth pain or risking the physical ramifications of poor oral health. We want to know that teeth are being brushed daily. We want to know that our family member is consistently getting medication at the right time and in the right dosage. Does our adult child benefit regularly from a day program that is fulfilling and contributes to his or her development? Is our child meeting goals set by a team that includes the individual, professionals, and family? Does he or she exercise daily and eat a healthy balanced diet? Does he or she participate actively or passively in food preparation? Does he or she socialize with peers? Is the staff trained, tenured, kind and attentive to individual needs? These kinds of questions signal the outcomes that really matter to individuals with severe and profound mental retardation who also have medical or behavioral complexities, because attention to these basic areas will translate into good care, security, and happiness.

It is with this background of empirical, objective outcomes that we would like to share our personal experiences. When reading about our observations, consider whether the objective outcomes that are evident carry more credibility than asking a nonverbal individual with profound mental retardation, "Are you happy?" Asking the question just is not enough. We need to seek the answer via objective observations and measures.

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### Nancy Speaks

My daughter, Dianne, age 43, resides in a state-operated ICF/MR in Denton, Texas (called "State Schools" in Texas). At Denton State School and all of the state-operated facilities in Texas, the stereotype of *isolation* (a perceived negative outcome

of large ICF/MR placement) is defied. All of the state facilities in Texas have volunteer services programs that include volunteers and state employees who work with residents and take them out into the community. Activities include community concerts, sporting events, shows, outings to restaurants, special events, Six Flags, the Texas State Fair, and other activities. These opportunities provide entertainment and true integration with the community surrounding our state facilities. Within the facilities' communities, the staff, families, friends, and volunteers join together to provide parties, holiday celebrations, dances, worship services, and other social activities. Volunteer Services provides birthday and holiday gifts for these and other events. Neighbors (with or without disabilities) are invited and participate in these facility-based events. The actual level of activity in these facilities does not match the vision of some people that living in an institution means being locked in dormitories and attended to by cold heartless staff.

My daughter, Dianne, has lived in Texas state-operated facilities since she was 10 years old. This environment for her is the least restrictive, most appropriate, cost effective, safest, and efficient setting according to her unique needs. Everyday she receives training and habilitation to improve her self-help and other skills. She benefits from access to all necessary health care, including physicians, dentists, nurses, and therapists. The dedicated, caring, and compassionate staff members ensure that Dianne remains happy, well-adjusted, and continues to grow in attaining skills so that she may reach her full potential.

Were there ever bad outcomes in Texas facilities and places like them around the country? Of course. Families of individuals who live in facilities know that in the past these places were overcrowded, understaffed, and often had less than desirable living conditions. Today, however, the typical ICF/MR is nothing like those that were the subjects of news stories about institutions in the 1960s and 1970s. Thanks to the advocacy of families of persons with mental retardation in response to the terrible conditions of most facilities between the 1940s and the 1970s, facilities are now subject to federal standards and funding. The results are more staff, more oversight, and plenty of documentation. In my view, this required documentation is the key to achieving and assuring good, objective, outcomes. When staff members have to document something, and be accountable, it is more likely that the activ-

ity actually gets done, and that staff members do more. An added benefit is that I can also go read the documentation on the care received by my daughter and see for myself what has been going on. In speaking with many family members whose sons and daughters live in community group homes, there is often not such complete documentation. As a result, these folks cannot tell what is going on and can only rely on what the staff members tell them.

Of course, good documentation requires good staff. The people who work in institutions in Texas are really no different than those who get jobs with community providers. In fact, many people employed in one system have worked, or will work, in the other during their careers. Wages, training, and benefits, however, are typically far better at state facilities, resulting in less frequent turnover, thereby providing treasured consistency for residents and sustained friendships among staff and residents.

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### Mary Speaks

My daughter, Mary Elizabeth, age 40, lives in a community group home in Massachusetts and returns each day for her day program to a state-operated ICF/MR, where she has lived for 18 years. It has been my observation that, for Mary Elizabeth, the day program staff consistently provide many more integrated community-based activities than does the group home. For example, when Mary Elizabeth lived at the ICF/MR, she was one of four or five individuals in a dining group who regularly went to local restaurants with staff from the facility. These staff members scouted out local restaurants in which the typical food is easily consumed by those who have problems with chewing and swallowing (e.g., local spaghetti or fish houses), and even brought a food grinder along for those who required that their food be blended. I am not aware of any group homes where this kind of effort toward integration and community involvement is typical. When other parents have inquired about similar practices, one staff member responded that the community provider agency only allowed \$5 per week per person for such activities, which did not sufficiently provide for the costs of such outings. Now, at least once a week a group of three to five of the ladies in the day program (most of whom live at the ICF/MR) go to Dunkin' Donuts for mid-morning coffee. They go out another day each week on an excursion that may be a picnic at a local

beach, lake, or park. In the winter they go to the local malls and shop for small personal items. They are seldom deterred by New England weather. There are more often than not at least two people in wheelchairs on each trip. Annually, they go to the New England Flower Show in spring, the Nutcracker ballet at Christmas, and Topsfield Fair in the fall. Tickets for individuals and staff members to these gala events are provided by Volunteer Services at the facility or by family members as birthday or holiday gifts.

In contrast, community activities at the group home are "spontaneous" and left to "staff discretion" (What happened to client choice?). The result is that everything (quality of diet, exercise programs, clothing, holiday celebrations, health care, and community participation) depends on the spirit, initiative, and endurance of the house manager. In too many instances, house managers receive little support and constant obstacles from their superiors. As a parent observer, it often seems that they have an impossible job. When there are no planned community activities on a weekend, evening, or holiday, residents sit, often isolated, alone in their rooms, sometimes for 2 to 3 days in a row. How is this more desirable than sitting in a group with staff at the facility? It is examples such as these that worry parents and family members and suggest a lack of correspondence between the promise of community living and the reality.

I have also been concerned about the problem that, in some cases, staff members in group homes can actually become *more* institutionalized than those working in institutions. These staff members often work with only a small number of other staff members, and many times a person will work alone. In my view, there is not a critical mass of staff members who share ideas, cheer each other along, or develop staff bonds that serve to produce a better quality of life among the residents. Some advocates of institutional closure have argued that the alleged abuses of institutions occurred because the individuals and staff were segregated, making detection of abuse more difficult. These advocates have argued that in the community it is more likely that abuse and/or neglect will be detected because it is "out in the open." In my view, the reality is precisely the opposite. There is simply more oversight in a licensed facility setting, including more staff members, rules, and points of documentation, all of which help prevent inappropriate staff behavior and allow for proper investigation if it does occur. By

contrast, in a community setting, staff members do not enjoy the same level of support from their peers or supervisors. I am very familiar with two group homes here in Massachusetts where the neighbors—long-term acquaintances of mine—repeatedly comment that they never see their group home neighbors. They have said, “They are never outside” and “The van never moves on a weekend.” What is the point of a community residence if they never leave the house? Less oversight, less staff on duty, fewer outings, and only minimal documentation make it all the more difficult for families and guardians to know what is going on inside a group home.

It is my experience that when behavioral problems in the community get beyond the primary staff member's competence, the next step is to call the local authorities (e.g., EMS or police), who often remove people to emergency rooms and mental health facilities to respond to the crisis. This reliance on outside emergency professionals results in waiting for care, which can be detrimental to both the individual in crisis and others in the home. Staff attention is necessarily directed at the one most in need while others are neglected. The reliance on local authorities also comes at an economical cost, yet human and financial costs are rarely considered when reviewing empirical outcomes. In contrast, at facilities there are typically medical and other crisis intervention services on-site, and many layers of “back up” available, including *on duty* supervisory level staff. This allows the individual to be immediately served in a setting familiar to them while their other needs are not neglected. None of this is possible in community settings, no matter how dedicated the staff.

In addition to my daughter, I am also guardian to a man who lived for 36 years in an institutional setting. When it was time for him to move to the community, he found himself in a new home clear across the state with virtually no contact with any of the friends, acquaintances, and familiar surroundings that he had known for a lifetime. Psychologists tell us that a major stressor of modern life for the general population is relocation to a new area or job. How could it be any different for a middle-aged man with developmental disabilities? Unfortunately, in my observation of this transition, it seemed to me that the goal of actually moving someone from an institutional setting to a community setting was *far* more important than addressing the stresses that this man ultimately faced. After several at-

tempts to return to his home (the facility), he was labeled a “runner” (which was never an issue at the facility) and literally locked into his home. People who move to community settings need to do so by their own free choice, not to satisfy the current ideology or the plans of states to downsize their facilities. Although many thoughtful, well-planned transfers have been accomplished, there are situations where, like my friend, good transition planning comes in second to “filling a community bed quota.” Even when transfer is advisable, planners need to consider outcomes beyond location of residence.

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### Common Concerns

As described above, in both of our experiences, reviewers of outcomes must, at least, consider an honest review of integration versus isolation, without regard to setting; competency of supervisory and direct care staff and related issues (e.g., turnover, ability to address behavioral concerns); required documentation and adherence to that documentation; systems to identify and remedy abuse and neglect; the ability to address health care concerns (medical, dental, and therapies); and, when appropriate, sensitive transfer plans that consider the emotional trauma that may be experienced. Consideration of these and other empirical outcomes will give a far more complete picture of an individual resident's true happiness.

Of course, any comprehensive review of system-level outcomes must necessarily consider who is managing that system. The achievement of quality (with all empirical outcomes in mind) will be largely dependent on the program manager who is charged with motivating, directing, and leading the direct care staff. Most people who live in institutions or who have moved to community group homes from institutions in the last few years generally function at cognitive levels that prevent them from arranging, on their own, involvement with various activities in the community. They are dependent on staff for the planning and transportation required for specific activities. Consider the following statement from the National Council on Disability:

It does little good, for example, to give an individual the option to use Medicaid Waiver funds to provide home-based services rather than going to a nursing home (to allow for the money to follow the person) if no accessible housing is available in the community that can meet the individual's needs, or if no acces-

sible or affordable transportation is available between the accessible housing and other locations in the community where the individual needs or wishes to go. Without transportation, the isolation of one's own home can all too easily become as crushing as that of an institution. (Strategies, 2004)

When managers and staff care and when the organizations value involvement in activities, transportation is secured and activities happen—in *both* the institution and the community. When no one cares, no integration happens and people sit at home in front of the television—in *both* the institution and the community.

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### Conclusion: For Outcomes, Does Setting Matter?

Where someone resides should not matter. Quality can and should be achieved in all settings. Our daughters reside in very different settings, but in both cases, their greatest life benefits have come from the involvement and dedication of a well-trained, well-managed, tenured, and compassionate staff, and in both our cases the staff members have been from institutional settings. Of course, families of individuals, such as Mary Elizabeth's, whose loved ones receive community-based care will also be in the position to tout an exceptional team of professionals providing quality support to their loved ones. In these examples, we can predict that there is an effective manager or supervisor behind the scenes making sure that good things happen. Good outcomes seem most likely to occur when the house or unit manager talks often with families and/or guardians who know the residents best. Without direct input from the family or resident who can communicate, good outcomes are less apt to occur. Likewise, we are certain that there are families of facility-based residents who, in reading our observations regarding facility staff involvement, will nod in affirmation. There is good and bad in every setting, but the consideration of outcomes—based simply on the reality of what is happening in the day-to-day life of the individuals using objective measures—is the necessary focus and not simply someone's address.

We have read and heard such ludicrous statements as “All studies show better outcomes in community settings” or “no one wants ICF/MR care anymore.” These absolute statements not only ignore peer-reviewed studies in which investigators have shown more favorable outcomes in some categories in facilities, but they also ignore the fact

that all ICFs/MR are regularly reviewed and certified by federal auditors, ensuring good outcomes at some level and giving family members some piece of mind. These absolute statements also ignore the mounting evidence of real concerns in today's community-based system of care for persons with mental retardation and developmental disabilities.

And what about choice? The thousands of members who make up VOR agree that the vast majority of the 44,000 or so individuals receiving services in ICFs/MR with more than 16 beds desire to be there and need to be there. Consider the example of the gentleman whose story was described above, who, after being taken from his facility home after 36 years, tried in vain to get back. What about his choice? We hear from families every day whose choice of a facility-based setting for their family member is threatened or eliminated due to downsizing and closure.

The notion that community-based care is the only appropriate care for people with mental retardation and developmental disabilities flies in the face of common sense. Our health care system is made up of many elements, from outpatient clinics to hospitals to rehabilitation centers. Each meets a different type of patient need. For example, suggesting that all care for all people with disabilities should be provided in a community setting makes no more sense than suggesting that all surgery should be provided at home.

We come into this debate as president and immediate past president of Voice of the Retarded (VOR). Our observations also come from the heart. We speak here for Dianne and Mary Elizabeth. Assuring good outcomes for our daughters is our primary motivation. In our leadership capacities, we not only speak for our daughters, but for the thousands of families just like us around the country. In our work with VOR, we have communicated directly with hundreds of families, including many of our peers in our own states, working side-by-side on a common vision, namely, achieving good outcomes due to the delivery of appropriate services based on need and choice, regardless of setting. We anxiously await the day that all advocates are working together to achieve this vision, for only together will we succeed.

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