

Presidential Address 2012

Creating Inclusive Communities: Pathways to the Vision

Sharon Gomez, President, 2011–2012

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In the words of Shafik Asante (2002), a former leader of New African Voices in Philadelphia, Pennsylvania, “Inclusion entails recognition of our universal ‘oneness’ and interdependence. Inclusion is recognizing that we are “one” even though we are not the “same” (p. 1). Fighting for inclusion involves assuring that support systems are in place to ease the person’s entry into social and civic life. Providing and maintaining support systems are civic responsibilities, not a favor to the less fortunate. We were all born “in.” Society will immediately improve at the point we honor this truth! Inclusion, therefore, really means accepting, embracing, and celebrating the gifts, talents, and differences in all of us as a means of shaping communities that are welcoming places for all people (Asante, 2002).

The notion of inclusion has, in one form or another, been a motivating force for reform in the field of intellectual and developmental disabilities throughout the past 30 years. Conceptually, inclusion has evolved from an aspiration linked to place to one tied to participation, choice, and relationships. Probably the earliest expression of the idea of normalization was advanced by Bengt Nirje (1969/1994). The notion was further elaborated on in 1972 by Wolf Wolfensberger in his piece on normalization. He used the concept of normalization or social role valorization to criticize, among other things, infantilizing decorations and language and inadequate day activities.

As the concept of normalization was refined and honed, it spawned more encompassing aspirations, such as community integration and community membership (Bradley, Ashbaugh, & Blaney, 1994). The notion of community integration was directly related to the movement of people out of institutions and implied a re-entry by those who had been excluded. Likewise, community membership implied joining a fellowship from which one had been alienated.

Conceptions that stressed integration and community-based services also influenced public policy, which in turn influenced practice. Phrases such as “least restrictive environment” and “mainstreaming” emerged as part of the landmark right to education legislation. Class action lawsuits brought during the 1970s also echoed these notions, including the *Halderman v. Pennhurst* (1977) litigation, which found a right to habilitation in the community. These powerful legal ideals had a transformative impact on the delivery of educational as well as residential and day services for people with intellectual and developmental disabilities.

As fewer and fewer children and adults left their communities to receive services and as institutional populations began a precipitous decline, the ideals that emerged to goad the system had less to do with opposition to a dominant norm (e.g., exclusion, extrusion, institutionalization, alienation) and more to do with affirmative notions of equality and the accommodation of differences. No longer was the system exhorted to provide better surroundings and opportunities than those available in the institutions, but to facilitate supports that would allow people with intellectual and developmental disabilities to lead lives available to all other citizens; in other words, to invite in those who had been traditionally locked out of our communities. The basis for judgment is now whether people with disabilities are able to enjoy such shared “goods” as relationships, friendships, home ownership, real jobs, spiritual fulfillment, and exercise of personal choice. These assumptions about what constitutes satisfying life have come to be known as inclusion (Bradley, 2000).

The concept is relevant to the whole of society in that all people are unique with unique capacities. Everyone can learn and grow. Everyone has gifts to share and desire opportunities to make contributions. These assumptions do apply to everyone, no matter who they are. With this as a backdrop, the

measure of inclusion for people with intellectual and developmental disabilities and their families is no different than the one we would use for ourselves and our families.

Inclusion is about more than just placing people in neighborhoods, schools, family homes, places of worship, regular recreation activities, etc. It is about supporting people to become connected and a part of the place or activity. The principle of social role valorization has helped us to understand that physical integration is a precondition for social inclusion, not simply an end in itself.

Webster's dictionary defines a *vision* as something seen in a dream; a thought, concept, or object formed by the imagination. During its 2010 Conference (*Building an Inclusive Tucson*), The Tucson Commission on Disability Issues offered a vision of an inclusive community:

An inclusive community for people with disabilities is one that is open and accessible for all. In this community, each member is able to take an active part and is safe and empowered. In an inclusive community, citizens' voices are heard and their contributions acknowledged and valued by the community. In an inclusive community, each person is respected as a citizen who can fully exercise his or her rights and responsibilities. In an inclusive community, each member brings unique strengths, resources, abilities and capabilities.

Knoll and Peterson (1992) offered a slightly different vision of an inclusive community:

In inclusive communities, we move from focusing on services provided exclusively by agencies, to support for involvement in typical community activities, based on the needs and choices of the individual. Disability service agencies work in partnership with community services, support networks (friends, family, peers), and the person with a disability. The primary role is to help connect and support the individual in school, home, community, and work. (p. 5)

A vision of inclusive community points in a different direction than would a vision of human services that meet all needs within their buildings and boundaries. The search for the excellent self-contained service program leaves people wandering in a blind alley, while the search for ways to build more inclusive community directs attention to the network of streets and roads that can lead to opportunities for better lives for everyone (McKnight, 1987).

Many of my colleagues have referred to me as a "dreamer," and I guess I am. With this in mind, I offer my own vision of an inclusive community. In inclusive communities, everyone has equal

opportunity to live, work, play, and grow on their own terms and in ways that are meaningful to them. In inclusive communities, all people are recognized and celebrated for their strength, beauty, courage, and inherent gifts. In inclusive communities, people belong. For children it means being a part of a family and enjoying relationships with adults who nurture them; attending regular schools and being a part of classrooms with children who do not have disabilities; and participating in typical school activities, community recreation activities, and spiritual activities that include children without disabilities. For adults inclusion means the opportunity to choose where one lives, works, and goes for leisure and worship. Those opportunities should include the same range of options available to everyone.

A pathway is a route to or way of access to, a way of reaching or achieving something. To that end, I offer some pathways to realizing inclusive communities:

1. We need a shift in focus in planning supports with people with disabilities from deficiencies and needs to a focus on capacities. All too often what I have seen is that people with disabilities are defined and described in terms of deficits rather than capabilities. People need opportunities in community life to explore and share their gifts, capacities, and strengths; pursue lifestyle choices; and be provided with adequate supports to do so.
2. People who know and love the person best should be involved in helping them discover their desirable future and the paths to take to get there. We call that a Circle of Friends. Mount, O'Brien, and O'Brien. (2002) help us understand that the Circle of Friends is a group of people who care about change happening for the focus person and choose to give their time and resources to working for change. They see themselves as an action-oriented group that exists with and for the person, commit themselves to working alongside the focus person, and meeting from time to time for as long as it takes to assure that the person has a secure and interesting community life. The more diverse the group's skills and connections, the more they can get done. The better they are able to listen and see things from the focus person's point of view, the more the focus person will be strengthened by their support.
3. The role of direct support professionals needs to be re-defined from one of skills developers to

one of community connectors. Community connectors introduce people to community life, support people to become involved in community and civic associations—both formal and informal—of their choosing, and support people to develop relationships with a growing number of others in their community. According to a recent report by Disability Services within the Victorian Department of Human Services in Australia (2002),

One important marker of community inclusion is the range and number of friends and social contacts a person has. There is a growing body of evidence that suggests people with robust social networks lead healthier and happier lives. This is the case for all members of the community. Focusing on friendship networks for people with disabilities represents a paradigm shift from skills development to social inclusion. (p. 5)

This shift will not happen naturally. Staff must receive adequate training in the art of community connecting, and they need also to be well connected in their communities.

4. Organizations providing supports to people with intellectual and developmental disabilities need to engage in a rigorous examination of their mission and purpose and recognize that they serve a role in connecting people and their communities. All too often, organizations become a substitute or artificial community, containing supports within their buildings and boundaries, and people live entirely in a world of paid service. Instead, organizations need to advocate for an array of supports throughout the community and figure out ways for the people they support to have a growing number and variety of relationships with others in the community who do not have disabilities and are not paid to be in their lives. Likewise, organizations should form partnerships with other community organizations to strengthen and enrich the fabric of community life for all of its members. Organizations also need to collect and analyze data on the quality of community life in their local communities and partner with others in the community to take action on issues affecting community life.
5. Research should be conducted to discover effective ways to support people to become active and contributing members of their communities. I am speaking of research in communities to discover places where people can use their gifts and talents to make community life better for all.
6. More affordable and accessible housing options need to be developed in the community. Did you know that 127,588 people still live in some type of institution or nursing facility in the United States (Braddock et al., 2011)? This model of institutional care is outdated, ineffective, and expensive. It is time that institutions are finally removed from the menu of choice. A number of states have done so, with good evidence to support the improvement in quality of life for people with disabilities. With what we know today about how to support people in community settings, where all of us belong, it is simply wrong to offer segregated options, which contradicts the intent of the Supreme Court in the *Olmstead v. L. C.* (1999) decision. People must be afforded opportunities to move from segregation and limitation toward contribution and opportunity in the community.
7. Employment should be available for people in the community based on their interests and skills. Individuals should have opportunities to earn a living wage, acquire benefits, advance their careers, or plan for retirement. Did you know that 435,443 people still attend nonwork day programs or sheltered workshops (Braddock et al., 2011)? With appropriate education, career development, job training, technological assistance, and support, people with intellectual disability can enjoy the benefits of employment. People need meaningful work and meaningful days in the community—not contracts or busy work for which they are paid subminimum wages or no wages at all.
8. The Individuals with Disabilities Education Act (IDEA), which requires that students with disabilities be educated to the maximum extent possible with students who do not have disabilities, should be fully implemented. Despite this law, according to the 2009 statistics on the Office of Special Education Services' IDEA website, 353,459 students remain segregated in self-contained classrooms in separate schools, with limited or no opportunities to participate academically and socially in general education classrooms and school activities. Segregation of students in schools perpetuates the alienation of these

students. Many do not have access to the same academic and extracurricular activities and services provided to other students. With individualized supports all students can participate in regular schools, with access to a general education curriculum, and in inclusive settings with peers of the same age.

9. There must be a systematic reallocation of resources at the federal level away from more segregated forms of habilitation toward more integrated, individualized supports in the community. We need strong public policies that promote the values of inclusion and community. We must diligently seek to end segregation in all its various forms, whether it be in housing, employment, education, recreation, or in our communities of faith.
10. Both in our professional and personal lives, and within our Association, we must promote and practice the values of acceptance and hospitality for all people. If we do not, how can we expect it of others? Hospitality is not a heroic virtue, but a commonplace part of everyday life. We must all be active participants in making our communities welcoming places for all.
11. As an organization, one of the core values of the American Association on Intellectual and Developmental Disabilities (AAIDD) is achieving full societal inclusion and participation of people with intellectual and developmental disabilities. The AAIDD should be at the forefront in the dissemination of promising and emerging practices in the crafting of inclusive communities. We must also “practice what we preach” and become an inclusive community for all professionals in our field.

A focus on creating inclusive communities will yield the following outcomes:

- Acceptance of all people and their gifts
- Full citizenship for all
- Richer and deeper relationships
- Greater cooperation and collaboration among all people
- Greater and more diverse community options for people
- A better world for all people

The whole is greater than the sum of its parts. This well-known adage applies to communities that embrace the diverse gifts and talents of all their

citizens, including those with disabilities. With proper nurturing and care, an inclusive community flourishes and becomes more vibrant, making it a more desirable place for all to live, work, and play. Margaret Mead defined an *ideal human culture* as one in which there is a place for every human gift. In an ideal culture people know each other enough to acknowledge and support one other in the development of their individual gifts. That is community.

Waddie Welcome lived at home with his parents in Savannah, Georgia, for the first 70 years of his life and then with a brother when his parents passed away. Waddie was removed from his brother's home when “well-intentioned” neighbors did not approve of his living conditions. Mr. Welcome spent the next 10 years in nursing homes. Waddie had a dream of moving out of the nursing home and living in a home where he could smell food cooking on a stove and could hear children playing. In their book, Kohler and Earl (2004) offered a beautiful account of how Waddie Welcome and his very committed Circle of Friends, which included a disability rights activist, a state representative, local business people, the president of the Savannah Bar Association, a revered civil rights leader and historian, and newspaper columnists who, along with Waddie's oldest and dearest friend, Addie Reeves, worked collaboratively to turn Waddie's dream into reality. For the last 15 years of his life, Waddie Welcome lived in four or five Savannah homes, where it is said he influenced public policy to be more personal and less institutional. He was named one of Chatham County's 10 most influential people of the decade in December of 1999. He was a founding member of the St. James Storytellers Group and a member of the Circle of Friends. Waddie and his Circle of Friends were featured in a 1997 documentary film, “Waddie Welcome: A Man Who Can Not Be Denied,” produced by the University of Georgia. The film has won top honors at three video and film festivals nationwide. The International Association of People with Severe Handicaps honored Mr. Welcome and his circle with its 1998 Collaboration Award in Seattle, Washington (Kohler & Earl, 2004). Margaret Mead said, “Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has” (cited in Terrill, 2001). Waddie, with a little help from his friends, certainly changed the world for the better for all of us.

Finally, Reverend Jim Lawson (cited in Kohler & Earl, 2004) said,

The beloved community is not a utopia, but a place where the barriers between people gradually come down and where the citizens make a constant effort to address even the most difficult problems of ordinary people. It is above all else an idealistic community. (p. 3)

It is a vision of inclusive community.

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Author:

Sharon Gomez, BS (e-mail: sgomez@epmi.org), Vice President of Operations—Central Region, Evergreen Presbyterian Ministries, Inc., 1015 11th St., Lake Charles, LA 70601.