

BUILDING STRONGER COMMUNITIES FOR ALL: THOUGHTS ABOUT COMMUNITY PARTICIPATION FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

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Prepared for the President's Committee on Mental Retardation's Forgotten Generations Conference,
February 21-22, 1999.

People in the field of developmental disabilities seldom are trendsetters outside of their field, but we were ahead of the general public in talking about community. We advocated that people with developmental disabilities should not be segregated from society in institutions. We argued that they should be in the community. Our initial picture of what we meant by community was vague. Lurking in the back of our minds was as a place where people lived with one another in harmony, where they had meaningful and satisfying face to face relationships, and where they cared about and looked out for each other.

Eventually, other people started to become concerned with community. Their concern did not relate to people with developmental disabilities. It related to their own lives and their fears that they were losing a sense of community. While we have been fighting to get people with developmental disabilities into the community, social critics declared that community was declining in the United States (McKnight, 1980). Rather than people experiencing where they live as a place where people have close face to face relations, where people know each other and are neighborly, too much of our society has become a place where people are isolated and estranged from each other. Malls and super stores have replaced more neighborhood-centered institutions such as the local merchant, the corner store, the butcher, and the baker. Mass media and the Internet have become substitutes for church, civic organizations, and community associations. And so on and so forth.

How can we think about having people with disabilities being a part of the community when community has become such a problem for everyone else, when community is under siege? We must approach the challenge of helping people with disabilities to become part of the community with full appreciation of what is at stake. Thinking about community for people with developmental disabilities might help us think about it for ourselves. What we want for them--being part of the community--is what we search for for ourselves. To try to solve their problem is to address our own. It is what we share in

common that ties us together. That is our humanity. This is what makes "them" "us."

In this essay we present some thoughts and observations on what it means for people with developmental disabilities to be part of the community. Some of these are ones we have made before (Bogdan & Taylor, 1987a), but we reformulate and elaborate on them here.

BEING PART OF THE COMMUNITY

Being in the community is not the same as being part of the community. Early formulations of community living for people with developmental disabilities were generated out of our concern with deinstitutionalization. We wanted people out of institutions and were not clear enough in distinguishing between "being in the community" and "being part of the community." Being in the community points only to physical presence; being part of the community means having the opportunity to interact and form relationships with other community members. Today this is referred to as inclusion.

People can live in the community and experience segregation, isolation, and loneliness. Community placement is merely a first step.

What does it mean to be part of the community?

BEING PART OF THE COMMUNITY MEANS HAVING MEANINGFUL RELATIONS WITH COMMUNITY MEMBERS. To be part of the community is to be a family member, neighbor, schoolmate, friend, casual acquaintance, church member, shopper, co-worker, and significant other. It means being a fellow member of clubs, organizations and associations, and sometimes being a consumer of services as well. Being part of the community means much more than being treated nicely by staff or even having a citizen advocate or volunteer. It means being known as an individual, a unique person, and not as a label, a ward of the state, a client of an agency, a consumer of services, or the recipient of another's charity.

Early sociological and anthropological studies concentrated on how people with disabilities were stigmatized and excluded from the community (Bogdan & Taylor, 1976; Edgerton, 1967; Goffman, 1963). We now understand the dynamics of labeling, stereotyping, and the self-fulfilling prophecy. Unfortunately, we know far less about how people make friends and how those who are different come to be accepted. We still need a sociology of acceptance (Bogdan & Taylor, 1987b).

BEING PART OF THE COMMUNITY MEANS CONTRIBUTING TO THE COMMUNITY. It means being a good citizen. While this usually means holding a job, it does not just mean that. It means contributing in other ways, by volunteering, by celebrating when the community celebrates and grieving when it experiences tragedy, and by engaging in neighborly acts. Ties to the community are fragile when they are not based on reciprocity. Having people with developmental disabilities in a neighborhood should mean a better community.

BEING PART OF THE COMMUNITY REQUIRES BEING SUPPORTED BY SERVICES AND AGENCIES IN SUCH A WAY AS TO BECOME LESS DEPENDENT ON THOSE SERVICES AND AGENCIES. When people with developmental disabilities have to rely exclusively on the services of agencies, they are destined not to become part of the community. The more agencies provide, the less others will be involved in a person's life. Only when support is spread throughout the community can people become part of their communities.

Institutionalization has been defined largely in terms of physical placement in remote facilities, but it can be more insidious. It can also be represented by total consumption of a person's life by an agency or

a program. When this happens, the person becomes the label; the client role takes over and the person becomes lost. When, however, a person has a range of contacts in the community, she or he can escape the client role and relate to people on other terms. We must define community living not simply in terms of people not living in large segregated buildings, but in terms of breaking down the control that services, programs, and agencies have over the lives of people.

Professionals and staff must view themselves not as people who are all things to their so-called clients, but as community organizers and mobilizers, people who help them become part of their communities.

BEING PART OF THE COMMUNITY SHOULD NEVER BE CONFUSED WITH NEGLECT, INDIFFERENCE, OR DENIAL OF SUPPORT. While the goal is for people with developmental disabilities to become part of their communities, this cannot be used to excuse the denial of supports and services to people. To be part of the community does not mean that people with developmental disabilities or their families must do without support from publicly funded agencies.

This is a particularly salient issue with people with mild developmental disabilities today. With the current anti-welfare mentality they are most vulnerable to being abandoned by governmental agencies that search for less inclusive definitions of what constitutes need.

BEING PART OF THE COMMUNITY WILL ULTIMATELY MEAN DOING AWAY WITH CONCEPTS LIKE NORMALIZATION, INTEGRATION, QUALITY OF LIFE, AND INCLUSION. Concepts like integration, normalization, quality of life ("QOL"), inclusion, and others are only vehicles for change and not the end. When we reach a state of full acceptance and inclusion of people with developmental disabilities, we will no longer need these ideas. That we have these concepts does not mean that we have arrived; it only means that we recognize that people with developmental disabilities have been denied. For example, we only examine people's quality of life when we suspect that it is lacking (Taylor, 1994).

Normalization, integration, and inclusion can carry with them a level of self-consciousness that can interfere with people becoming part of the community. Normalization is not normal. Inclusion is not inclusive. When people focus on such concepts, they can find it difficult to have spontaneous and unself-conscious relationships with people with developmental disabilities. Spontaneity is characteristic of mutual relationships.

We can envision a society that would perplex the most adamant believer in normalization or inclusion. This society would be marked by a natural acceptance of people with disabilities. Members of this society would not have the faintest understanding of normalization principles. If one asked them about inclusion, they would not know how to respond. The society would not operate or normalization, just spontaneous, unself-conscious acceptance. Here the use of concepts such as normalization, QOL, and inclusion would represent a step backward.

BEING PART OF THE COMMUNITY IS AN END IN ITSELF. People with developmental disabilities who are part of their communities act in more normal and socially appropriate ways. They may indeed become more independent and productive economically. But the strongest argument in favor of enabling people to become part of their communities is that they lead better, more fulfilling lives.

It is important for agencies to operate under the assumption that people can change, that they can learn new skills, and that the most difficult behavior problems can be overcome. Even if people do not change dramatically and become more independent and productive, however, they should be able to be part of the community. The right to lead a decent life as part of the community should not be made

contingent on becoming "nondisabled" or "normal" (Ferguson & Ferguson, 1986).

BEING PART OF THE COMMUNITY CANNOT BE PACKAGED. Just because an idea, model, or approach seems to work in one place at one time does not mean that it can work anywhere or at any time (Lyle O'Brien, O'Brien, & Mount, 1997). To be sure, we can all learn good ideas from other people and some models are inherently superior to others. We cannot assume, however, that every good idea can be replicated with equal success. We all know that there is a difference between having a home cooked meal and eating in a franchise restaurant. What makes the difference is not the recipe, but the care, attention, and personal touch that go into the cooking.

When people become attached to models or approaches, this can interfere with helping people become part of the community. They develop a vested interest in the model or approach; change means losing face. As we have learned not to invest in the bricks and mortar of institutions, we must not bet on a particular way.

The steadfast adherence to a particular approach can prevent new people in the field from having the opportunity to contribute to the creativity and insight required to develop better ways of doing things. As more and more community programs develop, recruitment of staff is becoming more routine, not like joining a spirited movement as it has been in the past. We will need to find ways of helping new people develop a sense of the history of the struggles that brought us to where we are today, while at the same time being open to fresh ideas. For people with developmental disabilities to become part of the community, what will be needed is a strong commitment, a sense of mission, and clear values (Provencal, 1987; Taylor, Bogdan, & Racino, 1991). None of these things can be packaged.

BEING PART OF THE COMMUNITY IS NOT AN UNREALISTIC GOAL. Although the history of the treatment of people with disabilities in America is rife with instances of discrimination and exclusion, this is not inevitable. To the contrary, an increasing number of examples of full participation of people with developmental disabilities in the community can be found (Andrews, 1995; Bogdan, 1995; Bogdan & Taylor, 1989; Taylor, Bogdan, & Lutfiyya, 1995). Ironically, some of the richest examples of inclusion have resulted not from professional engineering, but as a consequence of ordinary social processes (Andrews, 1995).

Too often we have expected rejection and exclusion of people with developmental disabilities. When such people are not accepted in neighborhoods or included in community groups, it is viewed as a normal and natural outcome of backward attitudes and prejudice. We need to pay more attention to how our own practices, such as grouping people with developmental disabilities, tend to discourage inclusion; we also need to devote greater attention to identifying the kinds of communities or associations in which people with developmental disabilities will be accepted.

BEING PART OF THE COMMUNITY WILL REQUIRE A RETURN TO COMMUNAL VALUES. As an understandable reaction to the anonymity and block treatment of people with developmental disabilities in institutions and segregated settings, the field has turned to a set of new concepts that endorse individual autonomy: self-advocacy, self-determination, person-centered planning, home of your own, individualized services, and others. Although these concepts can help us move to a service system that is more respectful of the uniqueness of all people with developmental disabilities, an exclusive focus on individualism will prevent people with developmental disabilities from being part of the community. Community has to do with "we," not "I." An emphasis on the individual must be balanced with communal values (O'Brien & Lyle O'Brien, 1996).

BEING PART OF THE COMMUNITY MEANS RECOGNIZING THAT PEOPLE ARE MORE THAN MERE VICTIMS. Despite the fact that people with developmental disabilities and their families

have been subjected to prejudice, discrimination, and even abuse, they should not be regarded as passive objects that happily conform to what is expected of them. Although the phenomena known as the "self-fulfilling prophecy" (Wolfensberger, 1972) and the "client role" are real and undoubtedly exercise a strong influence on how individuals and families feel and act, to define people solely as victims is just as dehumanizing as defining them solely as clients of human services. As human beings rather than robots, people with developmental disabilities and their families sometimes conform to the dictates of the human services system and societal expectations and sometimes they do not. Families may reject negative stereotypes of their children and construct positive definitions of them (Bogdan & Taylor, 1989; O'Connor, 1995). People with developmental disabilities do not always view themselves in terms of their deficits and can take an active role in trying to control their lives (Shoultz, 1995; Taylor, 1994, 2000). One of the most striking aspects of deinstitutionalization is that some people emerged from the experience as survivors with their dignity and self-respect intact.

When people with developmental disabilities have become part of the community, it has often been at their own initiative. Inclusion was not something done for them by others, but something that resulted from their own contributions and characteristics.

BEING PART OF THE COMMUNITY WILL TAKE TIME. In helping people with mental retardation and developmental disabilities to become part of the community, there will be frustrations and setbacks. Communities may not always welcome people with developmental disabilities with open arms. Relationships may not always form spontaneously. Acceptance and inclusion will not be accomplished overnight.

When people with developmental disabilities are visible and involved in their communities—in schools, workplaces, and neighborhoods—good things happen. If community members do not step forward to take over for agency staff, this should not be a cause for despair. Progress toward the goal will be measured in terms of kinds of works and subtle gestures, a greeting on the street, an offer of a ride home, an invitation to dinner or a party.

BEING PART OF THE COMMUNITY WILL REQUIRE CHANGES IN THE SOCIETY. For people with developmental disabilities to become part of the community, the society will have to change. Personal relationships are the cornerstone of being part of the community; however, social policies and practices can systematically thwart opportunities for people to come together. Until vested interests, funding mechanisms, economic policies, counter-ideologies, agency policies, architectural barriers, and other forces supporting segregation are confronted and changed, large numbers of people with developmental disabilities will not become part of the community.

One of the major barriers to full community participation for people with developmental disabilities is the economic structure in the United States. Most adults with developmental disabilities, even those who work, are poor. Poverty severely limits where and how people can live.

The concept of normalization, which was popularized in the United States by Wolfensberger (1972) in the 1970s, had its origins in the Nordic countries. We can also learn from how the Nordic countries approach equality.

A central premise in the Nordic countries is that all people have a right to a decent standard of living. Reforms in developmental disabilities have been tied to this idea. It is not that people with developmental disabilities have a right to a decent life because they are disabled; they have the right because they are citizens.

The link between normalization and equality is clear in the Nordic countries. In the United States,

people with disabilities receive government benefits such Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) not because they are citizens entitled to a decent standard of living, but because they have disabilities and presumably are unable to work and contribute to the society. Government support is based on presumed differences from other people. Disability becomes central to a person's status as a citizen. Public policy on welfare and equality runs counter to the ideal of inclusion and being defined as a human being rather than as someone who is different.

CONCLUSION

For people with developmental disabilities to be part of the community, we must have stronger communities, with stronger ties among members. Where do we start?

"Before you seek to change the world," wrote the late Burton Blatt (Taylor & Blatt, 1999), "change yourself" (p. 165). Small, modest acts of neighborliness can make a difference, or at least, that is the hope. Join neighborhood organizations.¹ Lift your head when you walk. Say "Hello" to people. Sit outside. Plant flowers. Buy from your local merchants, even if you have to pay a bit more. Share some of what you have. Take children to the park. Fix it even if you did not break it. Have potlucks. Take an older person grocery shopping. Pick up litter. Talk to the mail carrier. Help someone carry something heavy. Start a tradition. Ask a question. Hire people who do not seem to have anything to do for odd jobs. Organize a block party. Bake extra and share. Ask for help when you need it. Open your shades. Share your skills. Turn up the music. Turn down the music. Listen before you react with anger. Mediate a conflict, rather than taking sides. Learn from new and uncomfortable angles. Work at listening.

Building stronger community ties is also something that we can try to do in our professional lives. Avoid gratuitous put-downs of people who are not as sophisticated as you are. Treat ideological opponents with respect, simply because all human beings are valuable. Take the time to answer questions from a student or colleague. Acknowledge the contributions of others to your own accomplishments. Go out of your way to introduce your staff or students to important visitors.

Understand that by making communities stronger for people with developmental disabilities you just might make life better for yourself. As Blatt (Taylor & Blatt, 1999) concluded, "The individual's life is irrevocably bound to the welfare of the masses, and only good people can save us and, thus, themselves" (p. 167).

NOTE

1. The following points are inspired by the poster, "How To Build Community," designed by Karen Kerney and published by The Syracuse Cultural Workers.

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The preparation of this paper was supported by the Center on Human Policy, School of Education, Syracuse University, through a subcontract with the Research and Training Center on Community Living, University of Minnesota, supported by the U.S. Department of Education, Office of Special Education and Rehabilitative Services, National Institute on Disability and Rehabilitation Research (NIDRR), through Contract No. H133B980047. Members of the Center are encouraged to express their opinions; however, these do not necessarily represent the official position and NIDRR and no endorsement should be inferred.

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