



Specialized Housing, Inc.

ON COMMUNITY

A community can be a group of people who have something in common, such as geography, ideology, interests, values. The word “group” often has a negative connotation today among policy-makers and many practitioners working with adults with intellectual challenges. In fact, a group is a very powerful vehicle for these adults. In a group, they can have their interests represented and take action. While the nature of their disability makes it difficult for many of these adults to advocate for themselves, in a group they can advocate for each other. The group offers an opportunity for a voice the individual otherwise would not have. Shared voices have a greater impact than a single voice.

(It is the same for the families, as well, who come together in mutual support of the residents in independent group living. They advocate for each other and share an experience and a sense of kinship that makes for extended family in a very real sense, but that’s a subject for another article.)

Research has shown that all people who have affiliations and connections lead longer, healthier lives, live longer with chronic illnesses. For people with disabilities this may be even more important. When someone with intellectual disabilities develops an illness requiring a complex regimen of care, group support, encouragement, and assistance with details that are hard to understand and manage can make all the difference.

We have spent twenty-six plus years observing the ways adults with developmental challenges create communities, in their households and in the wider community. I am struck by the assumptions we make about the necessity for these adults to “integrate”, to be “included” in our community. We somehow assume that “our” community is more valuable than the community these adults create for themselves.

In “our” community many of these folks feel uncomfortable. They are, by their own reports, often teased for their limitations, excluded when people at work, for example, make plans to go to lunch or to a social gathering after work. Their supervisors frequently are not educated about the most effective ways to supervise them and most important, not educated about the fundamental nature of the disability. In other words, if a worker makes mistakes or is slow to complete a task, this is not willful. He or she may not have understood the instructions or may simply not be able to perform the task any faster.

In “our” community, people with developmental disabilities are confronted with a culture that in many ways has left them behind, a workplace where speed is of the essence, a social culture tied to technologies: voice messaging, text-messaging, e-mailing, face-booking, twittering. Many cognitively challenged adults will never develop the fine-motor and verbal skills necessary in these social networks, and will be confronted continually with their limitations.

I counseled a young woman who was mainstreamed in her high school. She was unable to read or write and she was placed in a history class with an aide. She spent most of the time in history class weeping because she couldn’t understand a word of the lessons. She told me how stupid she felt. Some of the students were kind to her and she asked them for their phone numbers. When she called them after school or on weekends, they were almost always unavailable. Now and then a fellow student took her to the mall on a Saturday. I know, because I worked with her for years, that once these students graduated, they disappeared from her life. She was very lonely and spent most of her time after school playing her own

game of school, filling notebook after notebook with imitation handwriting. It's hard to see what purpose was served by mainstreaming her. In this case, as in many cases, mainstreaming deprived her of the potential to be a part of a community of her true peers.

Programs which provide a college student as temporary friend during the college years are fun, as long as they hold out no promises of lifetime friendships. Most of these temporary friendships are just that; few last for the entire four years of college. If they do, most terminate after graduation. College students move on. This is not to say that the relationships aren't worthwhile. It's a wonderful learning experience, particularly for the students whose consciousness is no doubt changed forever.

Consider a community within the larger community, a community that is tied to the larger community, in a variety of ways, in many reciprocal relationships. The adults we serve create communities for themselves at home, over time, that meet their most basic needs, needs we all have, needs we usually meet within our family or within a culture of our peers. They create a community at home where they can relax, be themselves, where they are not teased or made to feel stupid, where they can do most things at their own pace, spend their time the way they choose, a community in which they are supported, cherished, validated, where they can be of help to another person, ask for help without being shamed. I have even observed housemates acting as translators for housemates with speech that is hard to understand.

One house manager describes the residents he is responsible for and talks about their lives. Their neighborhood candidate for Town Meeting came to their house at their invitation to solicit their votes--a vote is a vote and that house represents 12 votes, which could decide a low-turnout Town election! The residents asked questions about the candidate's positions on issues that concern them, such as safe crossing of streets, dogs in the park, etc.

When the various households receive notices about issues that will come before the Planning Board, they attend. I've been with the residents of one house when they were concerned about a building going up next door. They had questions, good ones, about the type of fence the new owner was planning to construct.

Years ago, about 7 or 8 of the residents in the pioneer house organized by Specialized Housing in 1983 lobbied the MBTA Advisory Board to remove the time restrictions on the use of Special Needs T Passes. They were successful, after a year and a half of letter writing and meetings, and a reception was held at the State House in their honor. This decision had ramifications for every working person with disabilities who uses the T.

Our residents are well known to the tellers and officers of their neighborhood banks, who come out from behind the glass to assist them with deposit and withdrawal slips. They are also well known to neighborhood restaurateurs, convenience store clerks, the hardware store. They are treated as valued customers, which they are. There is something to be said for bringing business to a neighborhood--paying customers are integrated fast.

They are as integrated in their communities as I am in mine. They get to know the people it makes sense for them to know.

We have a great deal to learn from people who are intellectually challenged. I believe that their emotional intelligence is intact. I've often felt that their intellectual challenges enable them to cut to the chase emotionally, to understand instinctually what is important. I have observed very diverse groups of people evolve ways to live together cooperatively and peacefully. We do not "teach" them how to do this. There is no way to teach respect, acceptance, tolerance, emotional supportiveness, helpfulness. These folks learn by doing, by watching their peers in action, and certainly, watching staff in action. They always know which staff person doesn't really like or respect them and they feel free to report this to clinical supervisors who remove staff who are not respectful.

In a way, intellectual deficits have an upside. Emotions are accessible. Communication is direct. People with learning deficits can't use intellectualization as a filter or a barrier to real communication, can't hide behind the fog of words.

The people in these communities are not deluded about who they are. They struggle to understand and compensate for their challenges. They have a forum in their community at home to get support for the troubles they face. They can discuss strategies for coping with the issues they face. They receive enormous support when they experience loss and grief.

They share their lives with people who appreciate their sense of humor. They have a chance to be friends with people who like the same things they do. They are exposed to new activities that may be difficult to pursue independently or alone.

These folks are included in the larger community in natural ways. They have close relationships with people in the larger community, with coaches and personal trainers, with co-workers, with people at their places of worship, with medical and/or psychological support people, with neighbors and friends. They always, as we do, have a peer group to come home to, relax with. When they are home, it is home in the truest sense of the word.

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