

I know there is quality in when ...

By Quincy Abbot
October 2004

I know there is quality in Becky s life when:

- She refuses Saturday lunch with me because she is having lunch with her boyfriend.
- We go for a walk in the local park on a Sunday afternoon and fellow walkers say Hi, Becky. It is someone she knows from attending local church services.
- One of the women on her inclusive bowling team invites her to a meal at her house.
- At the voting place four years ago, she was not listed at her current address (she d'moved a few months before), and a former neighbor at the desk said Didn t you use to live at 25 Main Street? Becky responded yès and was allowed to vote.
- She has work or volunteer jobs in the community where she is valued for her contribution.
- She has a boyfriend who makes her laugh and who she makes laugh.
- She has Wilbur, a guinea pig, to care for and love.
- She makes needlepoint and pottery for gifts to family and friends.
- She has the funds to buy a second TV for her bedroom, to take a vacation trip to Cape Cod or to Disneyland, and to belong to CURVES. I must admit that the supplier of last resort for such funds is often Quincy.
- Her three sisters agree that Becky lives life far closer to her potential than any one of them.

But quality also exists in more mundane areas.

I know there is quality in Becky s life when:

- Her apartment and workplace are safe.
- She has good, nutritious food to eat.
- She has regular medical checkups and monitoring.
- She has a stable staff who have known her as an individual for a long time, who trust her and whom she trusts, and who allow her to experience the risks of ordinary life like the rest of us.

Relationships These are just a few snapshots of Becky s life that give me the clues to know that she leads a quality life. What is the single, most important source of this quality in Becky s life? It is long term, enduring relationships with individuals without a disability. In the words of Tom Nerney: the single greatest predictor for health and safety risks is the absence of such relationships. I would go much further and say positively that the presence of long term, enduring relationships with family, staff, co-workers and others in the community, not only minimizes risks, but also contributes to higher levels of quality - self esteem and even self actualization.

Maslov s Hierarchy of Needs. While pondering the subject of quality of life and how we measure it for individuals with or without disabilities, my mind naturally went to Maslov s' Hierarchy of Needs. To refresh your memory these range from the bottom level physiological needs (hunger, thirst, bodily comforts) through Safety/Security needs, Belongingness and Love needs, Esteem needs, Cognitive needs, and Aesthetic needs to the top level needs of Self-actualization and Transcendence. It is interesting that the personal quality indicators that occurred to me first were higher up the scale, even reaching to self-actualization.

Maslov and People with Disabilities. Fifty years ago, when custodial care in institutions was the norm, people with disabilities were stuck at the bottom. Their physiological needs and their safety needs were met and little more; sometimes not even that. As individuals moved into the community, the tendency was still to focus quality assurance at these two levels. However, being in the community opened up the opportunity for satisfying the needs of b'elonging and love and self-esteem. 'Satisfaction based quality assurance tools made a start at this. Tom s' recommendations will improve upon this.

The Challenge. I commented above that Becky s' sisters believe that she comes the closest of the four of them to realizing her full potential, i. e. self-actualization. The challenge that I bring to all of us is to find a way to assure that individuals with disabilities will be supported in realizing these higher levels of human needs.

Perhaps this starts at the bottom. We must first include the higher levels of needs in our person-centered planning. We must incorporate the resources to realize these needs in our funding and then we must find a way to assure that individuals with disabilities have fulfilled those needs. The quality measures must relate back to this individually determined plan. In Connecticut, I am part of the Steering Committee for a federal grant to determine a new Level of Need, i.e. a funds allocation, tool as well as a new Quality Assurance System. Preparing these comments made me realize that so far we mostly contemplate funding Maslov s' first two levels of need and assure quality in meeting the first two levels of need. We, in Connecticut, have some more work to do .and so I assume do the rest of you.