

What is Quality? A Revolution in Thinking and Practice

In the late 20th century, there was a revolution in the way people with intellectual and developmental disabilities were seen and supported by society at large. A key part of this transformation was the invention and evolution of something we now call “person-centered” approaches. It is hard to believe, but that was once a truly innovative concept.

In the 1950s, there were no community service systems. Children with significant disabilities were not allowed in public schools. Adults were expected to live in large isolated institutions. Parents who did not want to send their children “away” began to organize to create services for day activities in their home communities, and that is how the Associations for Retarded Children (ARC) began. The name changed to Citizens, and now it is just Arc.

In the 1960s, people were treated as “groups” in institutional settings – everyone goes to sleep at one time, gets up at one time, showers eats in groups. Then in 1968 the first television expose of inhumane conditions in an institution was shown on five consecutive nights in Philadelphia. It showed conditions at one institution named Pennhurst, and changes began.

In 1970, the first version of the Developmental Disabilities Act was passed. The Act encouraged interdisciplinary planning for individuals, a change from a long history of medical dominance of facilities and services. This began a rapid change away from treating people in groups, toward treating each person and his/her unique talents and needs. The “developmental model” gained sway at the same time, positing that all people are capable of learning and growth. The theory of Normalization spread in the 1970s gained powerful influence. It did not mean that people had to be "normal" – but that people should have access to the normal rhythms and routines of everyday life in regular communities.

Federal Medicaid funds became available in the 1970s, but only in institutions. In the 1980s, Medicaid funds were allowed to be used in community programs. But programs had to meet uniform standards modeled after hospital and institution standards. They went by many acronyms: ICF/MR standards, AC/MRDD (later the Council on Quality and Leadership), and

CARF (originally the Council on Accreditation of Rehabilitation Facilities). They added accountability for program characteristics, but were not directly related to individual quality of life.

During the 1980s, a new way of thinking called “person-centered planning” arose. People left institutions with individual plans and goals, and those goals and plans were made according to what the person and family wanted – according to what they, not professionals, meant by “quality.” Studies uniformly found that people who moved to community living enjoyed better qualities of life.

In the 1990s, person-centered planning was expanded to include awareness of, and shared control of, the money set aside for each person. This was called self-determination at first, and later, self-direction. Years of study showed that people were better off in self-direction situations, and they spent the same or less money.

In the new century, accountability for individual aspirations, via person-centered planning, became the accepted state of the art. The facility standards and certification systems continued, mandated in many states, and added small samples of individuals (not claimed to be statistically valid) to their review processes. Large scale systems for tracking achievement of individual person-centered goals are still at primitive stages.

Future systems may hold increased accountability for individually measured qualities of life – things that really matter, like rewarding relationships, productive and meaningful activities including employment, integration, and exerting control over one’s own life choices.