



Module Five
Quality of Life

Training Outcomes

1. Participants will understand the quality of life characteristics of positive environments.
2. Participants will understand the relationship of quality of life issues and changing problem behavior.

Module Five Quality of Life

THEORY OVERVIEW

Changes in a person's lifestyle are seen as critical to any behavior support plan. Over the last several decades there has been a movement to focus on the quality of life for people with challenging behaviors. In the past, choice and rights for this population has been very limited or non-existent. However, current theory and practice recognizes the uniqueness and strengths of all individuals and focuses on how to maximize support in their lives so they might live in a positive, high quality manner. Additionally, there is a link between having a high quality life where control and choice are present and the prevention of challenging behaviors. Often when people are satisfied with their lives, there is a reduced need to act out or communicate through behavior.

Aspects of Quality of Life

- personal choice and empowerment
- overall life satisfaction
- living environment
- relationships
- recreation and leisure
- education or work
- health care

Measuring and evaluating quality of life can be difficult and subjective. Over the years, many organizations have developed tools to do this. Nearly all tools have some form of data collection strategy, combined with interpretation of subjective information. A person's culture, ethnicity, age, and community are often taken into account when evaluating quality of life issues. Systems set in place to support people in achieving a high quality of life are also subject to evaluation.

There are several movements that have helped create this environment and high quality living for people with challenging behavior.



☞ Examine your own life for a moment. What are the areas which contribute to your overall quality of life and satisfaction?

How do you know when you don't have a high quality of life?

PERSON CENTERED PLANNING

Person centered planning is a way to individualize services with the purpose of increasing the person's quality of life.

Central ideas of person centered planning (Mount 2003):

- direction is given by the person who is the focal point of the planning process
- high involvement from friends, family members, co-workers, neighbors, etc.
- focus on the person's strengths, preferences, talents, and dreams for the future
- personal control of choices in life (where to live or work, recreation, relationships, etc.)
- ongoing support of group and commitment to the person's plan
- flexibility and willingness to make changes to the plan as needed

Some common person centered planning approaches include:

- personal futures planning
- essential lifestyle planning
- whole life planning
- outcome-based planning
- some Person Centered Planning (PCP), Individual Service Plan (ISP) and Individual Educational Program (IEP) planning processes

Key to any good person centered planning process is finding ways the person indicate

their personal preferences and choices. In some cases, people can use primarily verbal communication. In others, it may be a combination of other assistive communication (gestures, sign language, icons or pictures, etc.)

Research demonstrates that there are many positive outcomes to person centered planning including empowerment of the individual, improved social relationships, and improved relationships with the community.

SELF-DETERMINATION

Much like person centered planning, self-determination is a process and movement aimed to help people take control of their own life and choices to improve overall life satisfaction and quality. True practice of self-determination involves teaching people the skills needed to act as a “causal agent” including making informed choices, acting on those choices, and then evaluating the outcome of those choices.

Principles of Self-Determination (Center for Self-Determination 2004)

- Freedom: A person may freely choose their own lifestyle and receive the supports necessary to achieve it.
- Authority: A person will have the power to control the funds needed for the support to lead the lifestyle of their preference.
- Support: A person needs to develop and nurture the natural and informal supports most people have in their lives and in their communities.
- Responsibility: A person has the responsibility to contribute to their community and be accountable for the use of public dollars.

Characteristics of Self-Determination

- Self-evaluation
- Personal Responsibility
- Choice
- Preference
- Autonomy
- Self-regulation
- Empowerment
- Self-realization



Self-Determination is often used as a part of the person centered planning process. Often the ability to make, follow-thru, and evaluate choices can be key in the ongoing follow-thru necessary in true person centered planning.

☞ Who makes most of the choices in your life?

☞ Who makes most of the choices in the lives of those you support?

☞ What are some things you can do to empower people to live more self-determined lives?

PERSONAL OUTCOME MEASURES

One tool to measure the quality of life for people who have challenging behaviors or whom receive supports or services is the Personal Outcomes Measures. These 25 measures were developed by people receiving services, their families, and their staff under the guidance of The Council on Quality and Leadership in Supports for People with Disabilities who uses them to measure quality. The measures address nearly all aspects of life and those paramount to the self-determination and person centered planning movements.



As outlined below, these measures are evaluated individually based on information gathered from the person and those who know them best.

Identity

- People choose personal goals
- People choose where and with whom they live
- People choose where they work
- People have intimate relationships
- People are satisfied with services
- People are satisfied with their personal life situations

Autonomy

- People choose their daily routine
- People have time, space, and opportunity for privacy
- People decide when to share personal information
- People use their environments

Affiliation

- People live in integrated environments
- People participate in the life of the community
- People interact with other members of the community
- People perform different social roles
- People have friends
- People are respected

Attainment

- People choose services
- People realize personal goals

Safeguards

- People are connected to natural support networks
- People are safe

Rights

- People exercise rights
- People are treated fairly

Health and Wellness

- People have the best possible health
- People are free from abuse and neglect
- People experience continuity and security

(The Council on Quality and Leadership in Supports for People with Disabilities 2000)



In addition to the personal outcomes, support organizations are also evaluated on systems and outcomes in place to help promote individual quality of life.

☞ List some of the similarities between person centered planning, self-determination, and personal outcomes measures.

List some of the differences between person centered planning, self-determination, and personal outcomes measures.

☞ Think of a person you support. What specific actions could you take to improve their quality of life and reduce some of their challenging behaviors.

Actions: _____

Behaviors Reduced: _____

Quality of Life Glossary

Causal Agent: Person acting to make things happen in his or her own life.

Person Centered Planning: A process of gathering information about a person from them directly and the people who know them best to assist with future planning and goal development. The person is always present and often directs the planning process.

Quality of Life: Factors present in a person's life which are typically found when they have high levels of satisfaction. Some aspects measured include choice, satisfaction with living and working situations, health care, relationships, community inclusion, recreation and leisure, and rights.

Self-Determination: A movement and principles (freedom, authority, support, responsibility) characterizing situation when people have control over their own lives and have an active part in decision and choices.

Personal Outcome Measures: A tool for measuring satisfaction and quality of life based on 25 outcomes. Utilized by The Council on Quality and Leadership in Supports for People with Disabilities.



Quality of Life Resources and Suggested Readings

Holburn, S., & Vietze, P. (1999). Acknowledging barriers to adopting person-centered planning. Mental Retardation, 37(2), 117-124.

Butterworth, J., Steere, D., & Whitney-Thomas, J. (1997). Using person-centered planning to address personal quality of life. In R. Schalock (Ed.), *Quality of life: Vol. II. Application to persons with disabilities* (pp. 5-23). Washington, DC: American Association on Mental Retardation.

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