

BACKGROUND

An estimated 7.37 million people in the United States live with some form of intellectual or developmental disability (I/DD). Since deinstitutionalization began over 50 years ago, people with I/DD are now living with family members, group homes, or on their own. With advances in the medical field, these individuals are living longer and more fulfilling lives. The ability for these individuals to choose how they want to spend their everyday life is essential for living an independent and rewarding life.

However, adults with I/DD may experience a decrease in quality of life due to the amount of ongoing support they require in at least one major life activity. Relying on others can lead to experiences of disconnectedness, limited self-expression, or a sense of irrelevance in the type of occupations the individuals participate in.

In the late 1980's, quality of life began to be referenced to persons with intellectual and developmental disabilities. Because of the deinstitutionalization movement, a paradigm shift brought attention that all people share similar desires and needs in life regardless of the presence of a disability. Throughout the next decade, research was expanded and began to clarify the concept of quality of life.

The focus of this doctoral capstone experience (DCE) is to examine how occupational therapy practice can assess quality of life in adults with intellectual and developmental disabilities.

RESEARCH QUESTION

- How can occupational therapy practice address quality of life in adults with intellectual or developmental disabilities?
- The focus of this Doctoral Capstone Experience (DCE) was to identify assessments and occupational therapy intervention to improve quality of life in adults with intellectual or developmental disabilities.
- Key themes developed throughout this DCE include quality of life, occupational injustice, performance vs. participation, and co-occupation.

OCCUPATIONAL THERAPY INTERVENTION

- The Environment-Health-Occupation-Well-Being (E-HOW) Model: a practice model that provides a framework for occupational therapy practitioners that focuses on well-being and quality of life as the outcome.
- The promotion of health, well-being, and quality of life should be addressed in all client's intervention plans.
- Addressing the physical, social, mental and emotional, and cultural aspects of our client's lives facilitates quality of life and well-being.
- Participation in daily activities that are meaningful to the client promote a positive health trajectory for daily living.

QOL ASSESSMENTS

Assessment	Description	Domain Comparison
1. Multifaceted Life Satisfaction Scale (MLSS)	• An interview structure used primarily with adults with intellectual disabilities.	• Living arrangements and communities • Personal relationships • Recreation and leisure • Employment • Degree of self-direction
2. Comprehensive Quality of Life Scale (Com-QOL-ID)	• A measure of subjective and objective quality of life across 7 domains which is weighted by importance on each domain by the individual.	• Material Well-being • Health • Productivity • Intimacy • Safety • Place in community • Emotional well-being
3. Quality of Life Questionnaire (QOL-Q)	• Designed for people with intellectual disabilities consisting of 40 items score with a 1 to 3 points rating scale.	• Overall satisfaction • Competence and productivity • Empowerment and independence • Social belonging and community integration
4. Personal Wellbeing Index (PWI-ID)	• Designed for use with people who have an intellectual disability or other form of cognitive impairment.	• Standard of living • Health • Life achievement • Personal relationships • Personal safety • Feeling part of the community • Future security
5. Quality of Life Interview Schedule (QUOLIS)	• Measures the QOL of people who are handicapped and are unable to complete a written questionnaire or verbal interview.	• Health services • Family and guardianship • Income maintenance • Education, training and employment • Housing and safety • Transportation • Social and recreational; • Religious and cultural • Case management • Advocacy; Counseling; • Aesthetics
6. Evaluation of Quality of Life Instrument (EQLI)	• An instrument that can contribute to the identification of areas of user dissatisfaction with services.	• Quality of service received • Satisfaction with opportunities for social interaction • Satisfaction with living environment

DISCUSSION

- Any construct or theory of quality of life must be applicable to all populations regardless of disability to ensure equality.
- People with an intellectual and/or developmental disability must have the opportunity to live a meaningful and fulfilling life.
- Best practice in occupational therapy for the promotion of quality of life provides individuals with substantial opportunities for valuable engagement in occupations that are meaningful to them.
- When working with this population, emphasis should be directed towards participation in occupations rather than performance in order to increase quality of life.
- Research suggests that co-occupation enhances the ability of adults with developmental disabilities to participate in meaningful occupations and is more satisfying than engagement in a solitary occupation.
- Providing the opportunity for adults with developmental disabilities to participate in an adult day program where staff members engage in co-occupation can reduce the risk for occupational injustice, therefore promoting their quality of life.
- Direct Support Specialists (DSPs) are the primary facilitators in adults day programs. Therefore, staff training in how to offer choices and facilitate participation is important to improve quality of life in adults with I/DD.

TERMONOLOGY

- **Quality of Life:** an individual's perception of their position in life in the context of culture and value system in which they live and in relation to their goals, expectations, standards and concerns.
- **Developmental Disability:** a life-long disability that starts prior to age 18 and results in significant barriers to participation.
- **Occupational injustice:** occurs when people are required to participate in activities they find meaningless, are deprived of occupations, or are not permitted to choose their occupations.
- **Co-occupation:** involves two people engaging in an activity such that each person influences the other's response.

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