

International Foster Care Network

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## Quality of Life of Children and Youth with Intellectual Disabilities in Foster Families

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# DREAM –LIFE -TASK

- ONCE I HAD A DREAM THAT LIFE IS JOY
- AFTER I WOKE UP, I REALIZED IT IS A TASK
- I PUT MY SELF INTO A REALIZATION OF IT
- AND THEN I FOUND JOY IN THIS TASK
  
- RABINDARATH TAGORE

# The term "quality of life"

- The term "quality of life" has evolved over time;
- however, there is still no consensus on how
- QoL is conceptualized or measured,
- and there are many definitions.
- EARLY LITERATURE – OBJECTIVE INDICATORS OF CHILDREN'S HEALTH STATUS ..EMPHASIS ON PHYSICAL FUNCTIONING

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- AFTER THE WIDESPREAD AND ACCEPTED
  - DEFINITION OF HEALTH- WHO:
  - ..MORE THAN ABSENCE OF DISEASE
  - BUT IT CONSISTS OF
  - PHYSICAL
  - SOCIAL
  - PSYCHOLOGICAL DIMENSION

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- SO THESE THREE DIMENSIONS BECAME PART
  - OF THE MANY MEASURES
  - RATHER HEALTH RELATED QUALITY OF LIFE:
  
  - OFTEN ASSESS THE IMPACT OF THE DISORDER OR DISEASE
  - AND INCLUDE LIMITATIONS OR RESTRICTIONS IN FUNCTION



QOL IS FUNDAMENTALLY A HOLISTIC CONCEPT THAT GOES BEYOND THE HEALTH DIMENSION

- WALLANDER AND COLLEAGUES (2001)
- SHOWS THIS MORE COMPREHENSIVE VIEW
  
- "QUALITY OF LIFE IS THE COMBINATION
- OF OBJECTIVELY AND SUBJECTIVELY
- INDICATED WELL-BEING IN MULTIPLE DOMAINS OF LIFE CONSIDERED

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- Another more concise definition is offered by Renwick and Brown (1996, as cited in Zekovic & Renwick, 2003):
  - "[QoL is] the degree to which a person enjoys the important possibilities of his or her life" (p. 24).

## Concept “Quality of life” (Schalock i Begab, 1990)

- Basicly equal for persons with ID and other
- All persons have basic needs (optimal accomodation, relationships, welfare etc.), want to be resposible and achieve right to self-determination as possible (including persons with profound ID)
- Socially is determined by nature and broadness of integration with other people (parents, familly, professionals, friends..)
- Bilogically and psychologically is determined by sattisfaction of basic needs in everyday life
- Self evaluation of quality of life of persons with ID is extremely important, if not possible, parents, relatives or other positive people can represent them)

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- Until recently, in Croatia, there has been only a few research conducted about the quality of life of children with intellectual disabilities in foster homes.
  - The carried ones applied quantitative methods.

- The research by Herenčić and Mihanović (2006) has shown that the quality of life of children with intellectual disabilities in foster homes, throughout Croatia is not of acceptable standard.
- Data show that social workers in most cases visit foster children 1 to 2 times per year. Foster parents say it suits them because they experience visits as "control of their work."
- On the other hand, they want support, usually special teachers or psychologist.

- According to statements by foster parents 90% of children with disabilities settled to foster care thorough Centre for Social Welfare (not through a project of the Society for Inclusion) does not receive any professional support. About 23% of the children once a week goes to a speech therapist, and about 24% once in several months visiting psychologists.
- In 68% of cases foster children attend doctor once in several months.
- Most foster families do not receive additional funds for children with soecuial needs

- Čirkinagić has in 2008 investigated the quality of life of children with intellectual disabilities in a sample of nine foster families (females) from common (standard) foster care and nine female specialized foster cares (Project implemented by Association for Promoting Inclusion in cooperation with Centers for Social Welfare, which care for twelve mild and moderately ID children).

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- Data obtained have shown that there are statistically significant differences in objective characteristics of quality of life among those two groups with better results in specialized foster care homes.

- The study used four questionnaires (Bratković Mihanovic , 2002): Survey about general information on the foster family and the child, the questionnaire for examining objective indicators of quality of life of the child, Structured interview for foster parents to assess their satisfaction with the status of foster parents with respect the technical and financial support that foster parents receive the questionnaire to test awareness and educational attitudes of foster parents.

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- Increasing number of children placed in specialized foster family had in very large extent satisfied the need for security and love, respect for privacy and personal dignity, the possibility of choice, social interaction and participation and adoption of abilities, skills and habits of appropriate age.

- Foreign research applied qualitative approach ( Poston & al, 2003, Schormans & al), using interviews in focus groups and individually, usually with family members; standard and specialized foster family members (grandmothers, grandfathers, uncles, aunts,).
- In just a few cases the subjects were *persons with intellectual disabilities*.
- The problem in those researches were subjects' age (children's and adolescents') as well as the level of intellectual functioning, since the research is based on their self reports.

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- The difficulty in interviewing persons with intellectual disabilities is : *their limited capacity in understanding questions and greater suggestibility (sensitivity for being misled)*.
  - All of that is demanding in sense of the need for educated interviewers and research methodology which would cut down the mistakes of interpretation to the lowest level possible.

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- Qualitative research methods include data on individuals with mental retardation and their personal life situation, where they live, how they spend their time, how others relate to them, what opportunities they have, because all of these things affect their quality of life (Taylor and Bogdan, 1996).

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- These methods are considered to be particularly appropriate for testing the quality of life of persons with severe disabilities, with which it is difficult to apply the direct method of interviewing.
  - Edgerton (1967, according to Taylor et al, 1995) was the first researcher in the field of intellectual disabilities and other developmental difficulties who stressed the importance of qualitative approaches.

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- Other authors are from the early eighties, they implemented a method of "life stories" as a way of evaluating experience in the community of persons with intellectual disabilities (Amado, 1933, O ` Brien and Mount, 1991, Schwartz, 1992, according to Taylor et al, 1995) .

# Planned research

- We expect that results will point towards the key elements of quality of life in the way persons with intellectual disabilities perceive it, which certainly can not be answered adequately through research with average subjects.

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- Persons with intellectual disabilities of various age and severity of intellectual disability in foster care in whole Croatia



Thank you for your attention!