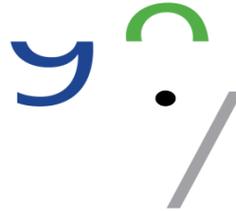


**9th International Conference of the
Faculty of Education and Rehabilitation Sciences
University of Zagreb
17 - 19 May 2017, Zagreb**



**Family Quality of Life-Narrative approach through collecting
the life stories with parents of children with disabilities**

Dr.sc.Natalija Lisak, PhD.

University of Zagreb

Faculty of Education and Rehabilitation Sciences

natalija.lisak@erf.hr

Zagreb, May 2017

Family Quality of Life

- **Definition of FQOL** refers to the extent to which **families' needs are met, family members enjoy their life** together and **have a chance to do the things** that are important to them (Brown & Turnbull, 2000)
- **The International Family Quality of Life Project** examines the quality of life of families who have one or more members with an intellectual or developmental disability (Surrey Place Centre, Toronto, Canada)
- **FQOL Survey (Brown et al., 2006) – 9 domains** (health, financial well-being, family relationships, support from others, support from services, influence of values, careers, leisure and recreation, and community integration) on **6 key concepts** (importance, opportunities, initiative, attainment, stability and satisfaction)

Narrative Approach

- **The Narrative Approach** gives an insight into the whole life course of individuals, where **the focus is on all of past and present experiences** that a person has experienced (Miller, 2000)
- **Life Course Approach** is embedded in narrative approach and uses method of life stories to collect life experiences and explain the social context (Priestley, 2001.)
- **Life story (life history)** is shaped by the knowledge, experience, values and feelings of the person, who tells the story to the researcher (Moen, 2006)
- Results: **significant events** and **factors** that have contributed to these significant events in the life course

The Aim of the Study

The aim is **to gain insight** into **significant events in the life course** of a parents of children with intellectual disability and **the factors which have contributed to significant events** within a certain life stage in their family

Significant event: represents concrete experiences at some stage in our lives that becomes turning point

Example of significant events:

experience of birth of a child, entering into marriage, divorce, illness, retirement, relocation, employment, death of a close person, family illness, the experience of family support, experience of service support system, acceptance/ exclusion

The Research Questions

1. **What significant events shape** the life experiences of person in the certain life stage or life period?
2. **Which factors have contributed** to these significant events in certain life stage or life period?

Factors contributing to significant events :

are indicators that shape our experience of significant event

Indicators on a personal level: personal value system, way of thinking, initiatives, person's ability to cope with certain situations , knowledge and awareness

Indicators on relations level: family relationships, relationships with the wider family, relationships with friends, relationships with employees community relations

Indicators on social level: the existence / non-existence of support services, the human rights situation in the social environment, social values, standards

How to create questions for collecting life stories?

➤ **The research questions** should be followed with the opened questions in life stories

➤ **Research questions:**

1. What are the significant events that have shaped the life experiences of _____ (the subject of the study)?
2. Which factors have contributed to these significant events in the life course _____ (the subject of the study)?



Dokument
na Microsoft Office

Methodology

How to analyse life stories?

- Using the **Life Course Event History Model** – model is drawn from life course and event history analysis (Kasnitz, 2001, in Priestley, 2003)



POSITIVE AND NEGATIVE FACTORS IN THE LIFE COURSE THAT SHAPE THE FAMILY QUALITY OF LIFE

COMMON POSITIVE AND NEGATIVE FACTORS THAT ARE PRESENT IN ALL FAMILIES (OBJECTIVE):

1. lack of early intervention support
2. non supporting relationships from service providers (in health, education and social care system)
3. parental involvement in associations and support from associations
4. supporting relationships of family members, friends and colleagues



SPECIFIC FACTORS IN FAMILY FROM CENTRAL CROATIA

1. positive example of provided services support
2. non supporting relationships from the Catholic Church staff

SPECIFIC FACTORS IN FAMILY FROM SLAVONIA

1. non activism of the other parents of children with disabilities
2. increased family financial expenses
3. Discriminative attitudes in Catholic Church

SPECIFIC FACTORS IN FAMILY FROM DALMATIA

1. supporting the institutionalization of children with multiple disabilities
2. looking at disability as a tragedy
3. lack of awareness of the local community
4. financial expenses for travels to Zagreb

POSITIVE AND NEGATIVE FACTORS THAT SHAPE THE FAMILY QUALITY OF LIFE

COMMON POSITIVE AND NEGATIVE FACTORS THAT ARE PRESENT IN ALL FAMILIES (FACTORS ON PERSONAL LEVEL):

1. parents initiatives in looking for information and support
2. parents advocacy for the rights and awareness of the rights
3. active role of mothers in everyday care for child
4. fear for the future and quality of life
5. empowerment and rely on the faith



DIFFERENCES BETWEEN FAMILIES IN SUBJECTIVE FACTORS:

FAMILY FROM CENTRAL CROATIA

1. initiatives to improve the quality of services support

Recommendations for improving the support system based on life stories

1. The organization of a multidisciplinary team for support at one place

2. Availability of the information about their guaranteed rights

3. The increasing awareness about the need to respect diversities in the systems of the Catholic Church

4. To say “unwanted news” on a professional and ethical way with respecting parents’ perspective

5. Empowerment of preschool teacher in working with a children with intellectual disability and supervision



6. To raise awareness on the right to mainstream education for children with intellectual disabilities

7. Organize systematic and multidisciplinary support for adult persons with intellectual disabilities through community based support

8. The need for additional professional training

9. The need for empowerment and education of parents how to provide support for child with ID and their siblings

10. The need for sensitization of members of the local community (rising awareness)

Conclusion Remarks

➤ **The further researches:**

Should consider perspectives of children with intellectual disabilities, siblings, grandparents, relatives

- **The cultural and social context** contributes to the specific indicators of family quality of life and **on a certain different way shapes the life course** and experiences of people with disabilities and their families (Priestley, 2001)



Natalija Lisak

Faculty of Education and Rehabilitation Sciences

University of Zagreb

natalija.lisak@erf.hr