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THE INTEGRATIVE ANALYSIS OF SOCIAL FACTORS IN THE LIFE COURSE OF FAMILIES WITH DISABILITIES

The Croatian society context and disability

This integrative analysis contributes to the conceptualization of the social context that shapes the life course of families with children with disabilities and addresses the role of the Croatian society within that process. Development of community based support and human rights protection in Croatia are important societal changes that ensure access to desired family quality of life in the field of disability. For that reason, the analysis is based on respecting opinions and experiences of parents of disabled children in order to provide insight into the family life trajectories to discover the relevant factors of the social context. The narrative approach was used to collect life stories of families with children who had intellectual disabilities. The social context that shapes the family life course and their further opportunities includes: the underdevelopment of community based services; the legacy of institutional care; the great influence of religious beliefs and Catholic Church institutions; the parents' initiative for rights implementation and system changes; the active role of mothers in everyday family life and supportive family relationships. The results emphasize important community development changes in Croatian society by focusing on the context that shapes the life course perspective of families with disabilities.

Key words: biography approach, life stories, quality of life, identity, human rights.

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INTEGRATIVNA ANALIZA DRUŽBENIH DEJAVNIKOV V ŽIVLJENJSKEM POTEKU DRUŽIN Z OVIRAMI: KONTEKST HRVAŠKE DRUŽBE IN OVIRANOST

Članek pripomore h konceptualizaciji družbenega konteksta, ki oblikuje življenjski potek družin z otroki z ovirami, pri tem pa upošteva vlogo hrvaške družbe v tem procesu. Razvoj služb podpore v skupnosti in zaščita človekovih pravic sta na Hrvaškem pomembni družbeni spremembi, ki zagotavljata dostop do kakovostnega družinskega življenja na področju ljudi z ovirami. V tem pogledu analiza temelji na mnenjih in izkušnjah staršev otrok z ovirami. Pri zbiranju življenjskih zgodb družin z intelektualno oviranimi otroki je bil uporabljen narativni pristop. Družbeni kontekst, ki oblikuje življenjski potek družin in njihove priložnosti, obsega: nerazvitost služb v skupnosti; zapuščino institucionalne oskrbe; velik vpliv religioznih verovanj in institucij katoliške cerkve, aktivizem staršev za uresničevanje pravic in sistemske spremembe; aktivno vlogo mater v vsakdanjem družinskem življenju in podporne družinske odnose. V rezultatih poudarimo spremembe v razvoju skupnosti v hrvaški družbi, zlasti pa kontekst, ki vpliva na življenjski potek družin, ki imajo otroke z ovirami.

Ključne besede: biografski pristop, življenjske zgodbe, kakovost življenja, identiteta, človekove pravice.

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Introduction

People with disabilities face different life chances and have different life experiences related to specific disabling barriers in their society. Those differences can lead to specific occurrences in the political agenda,

so, for example, while disabled people's organizations in the United Kingdom were campaigning against the principle of charitable support from the National Lottery, people with disabilities in Thailand were protesting to maintain the employment of disabled Lottery tickets sellers. (Priestley 2001: 4.)

The Republic of Croatia signed and ratified the UN Convention on the Rights of Persons with Disabilities in 2007 (Croatian Parliament 2007). The ratification of the Convention affected any subsequent legislation framework in the field of anti-discrimination so the Anti-discrimination Act was adopted the following year (Croatian Parliament 2008). The National Strategy on Equalization

of Opportunities for Persons with Disabilities from 2007 to 2015 (Government of the Republic of Croatia 2007) emphasized the need for the implementation of rights of disabled people by putting them on the political agenda.

In the Republic of Croatia people with disabilities still face various types of barriers in the field of: early intervention support, access to regular preschool and education systems, access to the labour market and income maintenance, the right to independent living and family life instead of institutional care (Lisak 2013). According to the *Human Rights Watch World Report 2013*,

Officials of the Ministry of Social Policy closed down a state-funded social care home for people with mental disabilities following findings of severe abuse, including lack of food, use of solitary confinement and inadequate sleeping facilities. (Human Rights Watch 2013.)

This highlights the state's intentions to create better living conditions in Croatia for people with disabilities. Still, there are a great number of children and people with intellectual disabilities who live in institutions (UNICEF Regional Office for Central and Eastern Europe 2012). These facts show that even though the master plan for deinstitutionalization was adopted by the government in 2011, still there are issues such as 'small increase in the number of places in community-based housing and support services for people with disabilities' (Human Rights Watch 2013). The formal state care mostly relates to institutional care or family-based care, instead of community based support.

Health care and social services are poor and unequally distributed in the community, which affects to the biggest extent mostly the rural population, vulnerable and discriminated groups such as children, women and persons with disabilities (UNICEF Regional Office for Central and Eastern Europe 2012). According to the statistical report (National Institute of Public Health 2013), 78% of children and adults with disabilities live all their lives within their families and are in need of community based support because social services are underdeveloped or non-existent on local levels, which denies disabled persons access to desirable personal and family life quality.

It is emphasized that development or continuation of community-based services in Croatia should be designed and established to address children and family vulnerabilities through individual plans and strengthen family capacities for providing quality care for their children (UNICEF Regional Office for Central and Eastern Europe 2012).

The historical and political context that shaped the current support system, as well as the theory and practice of the social work profession, was developed by the communist state policy, where public interests were given priority over private ones (Zaviršek 2008). The primary responsibility of the state was to raise the children, considering the parents first of all as part of the labour force (UNICEF Regional Office for Central and Eastern Europe 2012). People with disabilities were considered as not in the labour force and put under the state institutional care into segregated living conditions. From the time of the declaration of national independence in the 1990s up until today, the focus has been on developing community based public services for vulnerable populations such as children and people with disabilities and their families (Lisak 2013), but still the process is slow and influenced by the current economic crisis. Attitudes of relevant policy makers, professionals and even parents still support institutional care, in the sense that a community based service is underdeveloped or non-existent on local or regional levels.

Previous research in Croatia that focused on achieving social standards for people with disabilities has shown that the examples of good social practice are investigated through new models of community based support from the non-governmental organizations in the field of education (Igrić *et al.* 2008), independent living in society and self-advocacy (Bratković, Zelić 2011) of people with disabilities. Still, development of public services under state responsibility and by state funding should be considered more seriously on the policy level.

Previous research focused on the quality of life of people with intellectual disabilities placed in institutions, and people with disabilities who live within their families provided recommendations focused on the need for community based support, family centred approach and supported living in the community (Bratković 2002). That study also emphasized the need for an investigation of subjective perceptions of quality of life by using a qualitative inclusive approach with disabled persons and their families. In accordance with that finding, people with disabilities should be considered as active participants in the process of giving meaning to their lives and shaping their quality of life (*ibid.*).

Another integrative study was focused on the assessment of the situation and needs of persons with disabilities and their families in Croatian society (Leutar *et al.* 2011). To ensure desirable quality of life for people with disabilities and their families, the main functions of the services should aim to: ensure the availability of information, ensure familiarization with granted rights, meet the conditions for raising the educational level of people with disabilities, determine the needs of the labour market, educate in family and partner relationships, support the non-governmental organizations on a local level, organize self-help groups, insure direct payments, support lifelong learning for people with disabilities as additional skills for their employment and empower people with disabilities to advocate for their rights (*ibid.*).

To provide integrative analyse of social factors in the life course of families with disabilities, which was the purpose of the qualitative study presented through this paper, it is important to briefly describe guaranteed family rights and services in accordance with Croatian legislation.

Guaranteed family rights and services

In accordance with the Family Law (Croatian Parliament 2003), which recognizes only different sex families, the regulation of family rights and relations are based on the principles of: equality between women and men; mutual respect and support of all family members; protecting the welfare and rights of children and the responsibility of both parents to raise and educate a child; adequate guardianship of children without parental care and adults with mental disabilities. The social rights and services for people with disabilities and their families are regulated by the Social Welfare Act (Croatian Parliament, 2012). Guaranteed rights, in accordance with the Social Welfare Act (ibid), are as follows: financial support for education, disability living allowance or personal independence payment, assistance and care allowance, parent caregiver status and inclusive allowance (financial support for persons with disabilities to provide the equalization of opportunities for their involvement in daily life). Guaranteed social services, by the same law are as follows: situation assessment and advisory service, early intervention, professional services at home, integration in educational programs, access to day-care, institutional care and professional support for organized housing in the community.

Even though the process of deinstitutionalization has started, which has also been obvious from the rights articulated by the law, through emphasizing the rights on organized housing in the community and family capacity building, still one of the most widespread social services in practice is institutional care. This seems contradictory and sends a completely different message to people with disabilities and their parents. That is the reason why it is important to hear the voices of persons with disabilities and their family members.

Aim and methods

This paper seeks to answer the question – what is the real priority of the actual political agenda and how does the Croatian social context shape the life chances of people with disabilities and their families from their own perspective? Afterwards, what should be done in order to improve the quality of life of persons with disabilities and their families from their own perspective?

This research was done within the doctoral dissertation and included families with disabled members as active participants in the qualitative narrative study in order to provide insight into the family life trajectories by focusing on opinions and experiences of parents of intellectually disabled children to discover the relevant factors of the social context. Through this kind of qualitative study,

life experiences, social factors and family subjective factors were investigated by using the life story and narrative approach with 9 parents of children with intellectual disabilities from three different regions in Croatia: Slavonia, Dalmatia and Central Croatia (capital city Zagreb). Each region was represented by three parents of children with intellectual disabilities under the following criteria: parents of a child integrated in regular educational system, parents of a child integrated in a special educational system and parents of a child who is not included into any kind of support system. The family life period that was investigated in the study was from the child's birth up until 21 years of age and the disability types involved were as follows: Down syndrome, autism spectrum disorders and intellectual disabilities, multiple disabilities. All 9 participants were mothers, from different sex families, with secondary and higher education backgrounds.

The narrative approach was chosen in this study of family life quality because it provides an insight into the entire life course of a person, where the focus is on all past and present experiences that a person had/has (Miller 2000). The reason for using the narrative approach when the focus is on families with disabled children lies in the fact that for these families, from the moment they find out that their child has a disability, a process begins that is lifelong and shapes their quality of life (Brown 1997).

Life course research is defined by Mayer and Tuma (1989) as

the study of social processes extending over the individual life span, or significant portions of it, especially the family cycle and individuals' personal impairment and disability history (Kasnitz 2001: 68).

The life course event history model (*ibid.*) was used to identify and chronologically map essential events in individuals' lives creating an 'event history'.

The integrative qualitative analysis was done with the focus on finding the patterns in the sequencing of life history events, at transitions in identity and experience related to impairment and disability, as well as their placement in the context of other dynamic life course processes (*op. cit.*).

Findings of the integrative analysis

The social objective indicators that have contributed to the families' life history events and shaped their life course, based on life stories in all three regions, were as follows: lack of early intervention support; non-supportive and discriminative treatment from health, social care and educational systems; discriminative relationships in the Catholic Church organization, support from non-governmental associations and supportive relationships in the family (Lisak 2013).

In the life stories from the region of Central Croatia (capital city Zagreb) the specific objective indicators are positive examples of community based support (day centre, faculty centre for rehabilitation and education, private professional practice) and non-supportive and discriminative treatment from staff of the Catholic Church (*ibid.*).

These findings were based on the citations from the narratives:

I know my rights and I was ready to fight for them ... together with other mothers ... we arranged that our kids had the teaching assitant support in schools. I can say that the woman from city department for education was friendly and supportive, she got together with us in a school ... we arranged everything. (Narrative 1.)

I am very grateful for the support that we got from the faculty centre ... those workshops and parents meetings were so important for me ... we shared information ... you could easily find out what to do and where to go. (Narrative 2.)

That day centre for children with several disabilities ... it is something that every parent needs ... they organize early intervention, provide daily support for children ... parents were also integrated into the support group...we got counselling ... I remember that was the first thing I did for myself. (Narrative 3.)

We had to go to a private doctor ... that was very important for us ... after visiting him we were calmed down ... the child functioned better ... much better. (Narrative 1.)

They said he just could not go to kindergarten (catholic kindergarten) ... I don't blame them, they didn't know how to give support ... but I was somehow in shock ... because my sister is a nun and she arranged everything. (Narrative 1.)

In the region of Slavonia the specific objective indicators that shape the life course in the life stories are as follows: increased financial expenses for trips to Zagreb to get assessment and support, non-supportive and discriminative treatment from members of the Catholic Church and financing services by the parents (Lisak 2013).

These findings were based on the citations from the narratives:

The first year we travelled a lot ... we needed to go for assessment ... and support ... in Zagreb ... every week we travelled to Zagreb ... we spent so much money on travelling ... Zagreb is too far. (Narrative 1).

I talked to a priest ... tried to explain to him that my child can't speak ... he asked me if he can learn how to pray ... again I said you didn't understand me, he just can't ... on the first communion ceremony he was just running across the church ... we could not stop him ... they gave him first communion after the ceremony ... The priest said that he was not satisfied with that ... I was so mad and sad ... again I tried to talk to him ... my child didn't get the ceremony confirmation. (Narrative 2).

We paid for an educational rehabilitator ... to come to our home ... when she started to work with him I was so happy ... he was more successful ... she knew some new approaches ... floor time and so. (Narrative 2)

I paid for a teaching assistant ... my child can go to regular kindergarten with other children ... I asked how teaching assistant support was organized in Zagreb ... to find out what to do. (Narrative 1).

In the region of Dalmatia the specific objective indicators that shape the life course in the life stories are as follows: supporting the institutionalization of children with multiple disabilities; understanding disability as a tragedy in the case of families with children with multiple disabilities; lack of awareness of the local community and increased financial expenses for trips to Zagreb to get assessment and support (Lisak 2013).

These findings were based on the citations from the narratives:

They told me to give her away ... to go to an institution ... I didn't want to do that ... she is my angel ... she lives with us ... it's like they want to say 'What can you do?', this is too hard to stand ... to take care of her. (Narrative 3.)

One friend told me I am so sorry ... it is like we are constantly labelled ... people look at that as though your life is a tragedy ... they don't know what to say ... but I could feel what they mean. (Narrative 3.)

We tried to develop some support for our children ... parents came together and invited professionals to come to our organization ... we tried to explain but they just were not aware of that. (Narrative 2.)

When he was young we travelled a lot ... I tried to educate myself to give him support, to work with him ... we travelled a lot to Zagreb ... we used to stay for a few days ... we tried to help him, to get support and to learn how to work with him ... I wanted to know what to do when I back home. (Narrative 2.)

These findings from all the narratives highlighted the specific social context that shaped the life course of families with children with intellectual disabilities and their quality of life.

Social context and the life course of families

Social context represents the contribution of social, political and cultural environment on a life course of an individual at a particular time and in a particular place (Priestley 2001). In this study of life quality of families with children with intellectual disabilities in the regions of Central Croatia, Slavonia and Dalmatia, the social context that shapes the life course

represents: the contribution of the capitalist social order, the rights guaranteed by the democratic political system, the legacy of the socialist tradition within the political system, the values of family life and family support, as well as the importance of Christian values and the Catholic church (Lisak 2013).

The social context that shapes the families' life course and their further opportunities includes: exclusive and discriminative attitudes of employees in the health, education and welfare systems; the great influence of religious beliefs and the institutions of the Catholic Church; the underdevelopment of community based services; the legacy of institutional care; the parents' initiative for rights implementation and system changes; the active role of mothers in everyday family life and supportive family relationships.

Discriminative and exclusive attitudes and treatment by professionals

Discriminative and exclusive attitudes and treatment by professionals in the health, education and welfare systems also contribute to the quality of life of families with intellectually disabled children addressed in this study. Health system professionals do not provide parents with relevant and appropriate information, which leads to lack of assessment and suitable support for their children, and furthermore, tends to develop distrust and fear of the future (Lisak 2013). Serious undermining of the guaranteed rights and personal dignity by health care professionals were present in the case of families with children with multiple disabilities (*ibid.*). Attitudes of the health care professionals towards children with intellectual disabilities and their parents are still shaped by the dominant medical model of disability, which leads to the challenge 'to be sick' as explained by Hunt (1966). The perception of suffering, inability, limitations and pain leads to a tragic life for these children, their worthlessness and helplessness.

Discriminative attitudes of the professionals from the education system represent prejudice as well as lack of knowledge and previous experience, which deprives children of their right to be included in the regular educational system (Lisak 2013). The attitudes of the professionals in the educational system attest to the long-standing history of special educational systems for children with disabilities.

The attitude and behaviour of professionals in the social welfare system is impersonal, exclusive for guaranteed rights and supportive for institutional care (*ibid.*). Multiple and restrictive assessment without appropriate individual plans for support and lack of personal and professional familiarization with a child resulted in excluding a child from the local community (*ibid.*). The above mentioned experience confirms the thesis that the social welfare system in Croatia is formed as a so-called paternalistic model or a model in which 'professionals provide services as a gift to a customer' and such a paradigmatic assumption means that the user is a passive recipient of welfare services and that the services are a 'gift' from the professional group that is 'given' on the basis of needs assessments (Mihanović 2012). In this context, it is impossible not to mention the role of long-term institutionalization of persons with disabilities under the influence of the system of government and politics of socialism (Zaviršek 2008), as a form of absolute social welfare for people with disabilities in segregated conditions, without planning their involvement in the community. This specific context shapes the life course of families and the attitudes of social welfare professionals.

Influence of religion

Even today, in secular societies, religion has significant influence, which is based on diakonia and charitable activities aiming to provide spiritual care and support for their members in the community (Rommelspacher 2010). According to the life stories, the Christian religion contributes to the quality of life of families with intellectually disabled children, in that it empowers parents to deal and cope with disability in everyday life. The Catholic Church

as an organization provides families with experiences of discrimination by excluding their children from religious ceremonies and Catholic Church kindergarten. This leads to recommendations for increasing awareness of accepting differences in the Catholic Church organization. The Catholic Church represents an institution of cultural universalism, which is based on the doctrines of the Christian faith (Staub-Bernasconi 2010). However, if such cultural universalism in social functioning is associated with political structures or economic power structures, it becomes selective in terms of exclusion from the Christian community based on diversity. Based on the fundamental principles of the Catholic religion, every human being should be fully respected in its diversity, which is why the discriminative and exclusive attitudes described in these life stories are contradictory and unacceptable.

The underdevelopment of the community based services and the legacy of institutional care Experiences of discrimination indicate the lack of community based services and the presence of institutional care for children with intellectual disabilities. The reform of the social welfare system started the process of deinstitutionalization and the transformation of state residential care homes (Ministry of Health and Welfare 2011). This transformation process should redefine the role of service providers through the development of a new system of social services which should provide the community with the ultimate goal of increasing social inclusion. It is important to emphasize that the institutional form of care leads to social exclusion of children with intellectual disabilities because they are separated from their families and their natural social environment.

The parents' initiative for rights implementation and system changes

The parents from the life stories are familiar with their guaranteed rights, included in non-governmental organizations and active in improving the quality of service support (Lisak 2013). Due to the experience of discrimination and exclusion from the community, parents become aware of the distinction of their own children and family. Raising public awareness on diversity (Kasnitz 2001) becomes a driving force of activism and struggle in the lives of parents, and it encourages parents to associate with other parents of disabled children.

The system does not provide relevant information about the guaranteed rights, which is the reason for getting information from other involved parents.

The activism of the non-governmental sector is an important determinant of the social context that shapes the quality of life for families with children with intellectual disabilities (Lisak 2013). Professionals and parents work together in creating new models of support for children from the earliest age — an inclusive environment in the educational system and independent living in the community. On the positive side, the non-governmental sector does promote better quality of life for people with disabilities, taking into account the needs of children and their families through their social action. But the question remains, where is the state responsibility for the social change and development of service support? A process called 'NGO-ization' (Zaviršek 2007) indicates the emergence of a large number of non-governmental organizations in the ex-socialistic countries and it seems that they have become the only 'responsible' holders and agents of social change.

The active role of mothers in everyday family life and supportive family relationships Supportive family relations were present in all life stories and family values were fellowship, love and happiness (Lisak 2013). Supportive family relations represent collaboration between partners and getting support from grandparents (*ibid.*). These kinds of supportive family relations empower the parents to cope with everyday life challenges. Even though family

relations were a great support in everyday life, it is important to consider the need for organizing professional support for family members to stay empowered.

The role of mothers in providing everyday support for their children, especially in the first years of a child's life, is an important context that shaped the families' life course (*ibid.*). The role of the mother is connected with a social role of a woman on gender level that is present and expected in the Croatian society. Mothers are overstrained in the process of taking care of a child and do not have free time to consider their own needs. It is necessary to empower mothers of children with intellectual disabilities through professional support and counselling to cope with expectations, advocacy for their needs and to make choices.

Conclusion

Some recommendations are given for improving the quality of life for families with children with intellectual disabilities in accordance with the explained social context; organization of a multidisciplinary team for assessment and support in all systems and in one location; the transparency and availability of information about guaranteed rights and support from the health, education and social welfare systems; awareness of acceptance of every person and respect for diversity in order to prevent rejection and exclusion of children with disabilities from organized systems in the Catholic Church; empowerment of medical doctors for appropriate correspondence with parents of children with intellectual disability and respect for the parents' perspective; empowerment of teachers for supporting inclusion in the regular preschool and school system; organizing systematic support for educational inclusion; supervising professional work in health, education and social welfare systems; supporting the constancy of NGO program funding, which improves the quality of social services on local and regional levels; improving the quality of support systems; organizing systematic support for independent living in the community through organized housing and multidisciplinary teamwork and raising community awareness of children with disabilities and their families through social action and giving positive examples.

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