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Daniela Bratković[1], Vesna Mihanović[2], Natalija Lisak[1]
[1] *University of Zagreb, Faculty of Education and Rehabilitation Sciences, Croatia; daniela.bratkovic@erf.hr*
[2] *Polyclinic for the Rehabilitation of Listening and Speech SUVAG, Zagreb, Croatia*

Abstract
The goal of this paper is to establish how persons with intellectual disability experience and evaluate the current situation, and what they consider relevant for further fulfillment of article 19 of the UN Convention on the rights of persons with disabilities. Nine adults with intellectual disability, from various forms of community housing, were involved in the research. Individual topics were identified by using thematic analysis and sorted into the five levels of the Maslow hierarchy of needs. The research has shown that there is several limitations and obstacles left to overcome in the application of Article 19.
Keywords: independent living, social inclusion, UN Convention on the rights of persons with disabilities, persons with intellectual disabilities, qualitative research

INTRODUCTION

The UN Convention on the Rights of persons with disabilities (2006) represents a paradigm shift from viewing a person with disabilities as "object" of charity, medical treatment and social protection to viewing the person as "subject" with rights, capable of making decisions based on a free and informed consent (Brown 2016; Gradwohl, 2017). By accepting the Convention, the international community acknowledged the false dichotomy between civil, political and economic rights on one side, and social and cultural rights on the other. Accepting the inseparable and inter-dependent nature of human rights is a key step to achieving social justice based on human rights (Weller, 2009). The Convention was signed by 187 and ratified by 177 countries around the world. On December 23, 2010 the European Union formally joined the Convention, which represents the first international instrument for protecting human rights that the EU has joined (European Union Agency for Fundamental Rights, 2018).

Article 19, "*Living independently and being included in the community*" focuses on the commitment on behalf of the community and the support system to make it easier for persons with disabilities to do the following: a) choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement; b) have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation and segregation from the community; c) have access to community services and facilities on an equal basis to the general population (UN, 2006).

The right to independent living and community inclusion is deeply rooted in the normative international frame of human rights that persons with disabilities simply didn't enjoy before. Human rights and fundamental liberties can only be fully enjoyed when a person has a chance to live in a community, making this Article a prerequisite for all other rights in the Convention (Gradwohl, 2017). The same Article also speaks of offering various degrees of assistance to both living and community inclusion and prevention of segregation or isolation from that same community (Mansell and Beadle-Brown, 2010, according to Doody, 2012). Independent living is directly connected to individual choice and control over one's own life. The life of a community, however, is firmly connected to social life and inclusion. Therefore, independent living and living in a community as concepts of autonomy and inclusion are strengthened, thus excluding segregation (Gradwohl, 2017).

Image 1: Living in a community (Towell, 2012:9)

Article 19 of the Convention offers persons with disabilities, including persons with intellectual disability, a wide definition of what it means to live in a community, and it consists of three major elements depicted in Image 1 (Towell, 2012). The first element is **choice**. A person has the right to choose and control on where and whom to live with. The second element is **support**, meaning available support in living and social inclusion. And finally, the third element is **community inclusion** which means the community should be organized in such a way to include its members in all social segments through education, employment, social, cultural and political processes. Investing into services alone will not make it possible to achieve the full right of living and community inclusion (Lauren-Bowie, 2013).

Only a small number of research activities linked to the implementation of Article 19 has been carried out so far. According to available sources, there have only been two major researches done in Europe. One study asked persons with disabilities from 31 countries from around the world what they think about the Convention and if it is a useful tool for achieving independent living (Jolly, 2010). Most participants thought that the Convention offered a good "tool" to the movement of independent living, but most also believed that their own governments had too little knowledge about the Convention at the time of its signing and ratification. Half of the participants saw no change for persons with disabilities. The other study, conducted by the European Commission, was aimed at how the Convention was implemented, with the goal of defining further guidelines for the Convention's implementation by the member-states of the European Union (EFC, 2010). The study, among other things, concluded that there is a number of challenges and possibilities in the implementation of the Convention, specifically Article 19. It was also concluded, however, that institutionalized practices, prevalent in many member-states, is slowing down community inclusion of persons with disabilities (EFC, 2010).

Considering that only sporadic research was conducted in countries that ratified the Convention, specifically aimed at changing the legislature, and that currently no similar research was conducted in Croatia, the need for qualitative studies with the emphasis on the experience and perspective of persons with disabilities became apparent. Other authors concluded as well that there is a lack of expert and scientific analysis of the implementation of the Convention, with the focus being on the persons with disabilities, including persons with intellectual disability, as the main subjects and beneficiaries of the implementation (French, 2007; Jolly, 2010). The study conducted by Mihanović, Bratković and Masnjak (2012) speaks volumes on the need for such research, especially in Croatia.

The Republic of Croatia, by ratifying the Convention, took on all the commitments embedded in the Convention's 50 articles. The Initial report on the implementation of the Convention (The government of the Republic of Croatia and MOBMS, 2011) was completed in 2011, according to Article 35 of the Convention, that "obliges State Parties to submit a comprehensive report on measures taken" in the implementation. Although the Report mentions some strategic and legislative indicators that benefit persons with disabilities, it does not analyze the actual situation, but rather leans more on the normative aspect of supporting persons with disabilities, in the form of financial aid, certain services when living in a community and tax benefits to the families of persons with disabilities.

RESEARCH AIM

Most of literature on the implementation of Article 19 is theoretical in nature. Literature that focuses on how independent living and community inclusion is perceived by persons with disabilities is few and far in-between and mostly of a more contemporary date.

Considering that the Republic of Croatia ratified the Convention in 2007, there was a need to conduct a thorough qualitative research to determine in what degree are independent living and community inclusion achieved.

In accordance with that goal, the following questions were set:

1. How do persons with intellectual disabilities experience and value the current possibilities of independent living and community inclusion, in relation to Article 19 of the Convention?
2. What are the expectations and recommendations of persons with intellectual disabilities in regard to the implementation of Article 19, with the goal of improving the quality of independent living and community inclusion of persons with intellectual disabilities in Croatia?

RESEARCH METHODOLOGY

Research participants

The research was carried out in cooperation with the relevant organizations whose members or beneficiaries are persons with intellectual disabilities in the city of Zagreb. Primarily this is the "Self advocates association", the first self advocates organization of persons with intellectual disabilities in Croatia, member of the "European platform of self advocates" (EPSA), "European coalition for community living" (ECCL) and other international organizations that deal with self advocacy activism in the broader movement of persons with disabilities. Furthermore, the state social welfare, in accordance with the transformation and de-institutionalization, provides the service of organized living for persons with intellectual disabilities. Also chosen was a non-government organization that handles the service of organized living for persons with intellectual disabilities.

A group of 9 persons with intellectual disabilities with varying living conditions, skills and experience in self advocacy, was selected in cooperation with the before-noted organizations.
- 3 "new" beneficiaries of assisted living or organized living from a government-funded institution (de-institutionalized)
- 3 long-term beneficiaries of assisted living or organized living from a non-government organization (post de-institutionalized)
- 3 persons living at home with their families, but included in the daily program of a social welfare institution

Out of nine participants, four are male and five are female, between 25 and 65 years of age. Six participants did not possess work capacity. The number of persons who were willing to participate and the number of actual participants is identical, meaning the 100% "sample" was achieved (Lebedina-Manzoni, Jeđud and Novak, 2006).

Methodology

The chosen approach to the study was qualitative and research-oriented, with the goal of understanding the culture, processes, events and experiences of the participants in a given social context. More specifically, it was a hypothetical inductive research model based on social constructivism, symbolic interactionism and phenomenology (Hallberg, 2006) with the focus on gaining practical knowledge (Mešl, 2010), useful for the beneficiaries of community inclusion. The method of semi-structured interview was used to gather the data, which provided the internal/subjective view of the persons on their own situation (Mollenhauer and Uhlendorff, 1992). The interview was arranged in a simple, easy to understand language, using illustrations that represent concrete information to maximize the capacity of each participant and ensure active participation, all the while respecting one of the fundamental principles of inclusive research. The interview covered topics related to independent living and community inclusion linked to Article 19. Each participant was interviewed individually in their living space, according to a protocol devised in advance, but within a flexible time-frame suited to each individual. An introductory conversation preceded each interview. A "Support guide" (brochure) was created for this purpose alone, in an easily understandable language and accompanied by graphic materials. This ensured that each participant could give a valid and informed consent to the research. Each interview was

recorded (audio only) and subsequently transcribed. This method of gathering data provided an individualized and holistic approach, with the use of images, drawings and photographs as alternative or augmentative ways of communicating when the situation required further explanation. Secondary sources which include non-written data (photographs from various stages of the participant's life, earlier audio and video recordings) as well as written data (expert opinions, notes, reports, records etc.) were used for a more detailed insight. Constructive validity, the principle of using multiple sources was used to ensure credibility of each obtained answer.

Data processing method

Thematic analysis that systematically identifies, organizes, analyzes and reports on data patterns (Braun and Clarke, 2006, 2012) was used during the qualitative analysis of the gathered data. Researching the experience of the participants (Caulfield and Hill, 2014) gives the researcher invaluable insight into the dominant and relevant topics that arise from the data (Ibrahim, 2012). This also makes it possible to spot the similarities and differences among the different perspectives of the participants thus creating "the big picture" (Braun and Clarke, 2012; Ibrahim, 2012), as well as making it easier to identify what is important in regard to a specific topic or research question (Braun and Clarke, 2012). Using thematic analysis, it is possible to connect different concepts and compare them to data obtained in different situations and at varying times (Ibrahim, 2012).

THE RESULTS AND THE DISCUSSION

Based on the fields that are at the same time the indicators of the fulfillment of human rights described in Article 19, the questions for the semi-structured interview were arranged in advance with the goal of gaining a better insight into the thought processes and the perspective of persons with intellectual disabilities on their own experiences (Lisak, 2013). This provided us with a thematic map, a web that provides the answer to each research question. Inductive thematic analysis identified the topics, sub-topics and categories grouped according to the form of housing (for each group of participants separately). That was followed by defining final topics, sub-topics and categories that emerged from all the semi-structured interviews with persons with intellectual disabilities from various forms of housing.

According to that, the research findings provided 20 different topics with 45 related sub-topics. After examining the interviews with persons with intellectual disabilities, and field and anecdotal notes, five (5) main topics were defined, all compliant with the Maslow hierarchy of needs (Maslow, 1982). The Maslow hierarchy is based on the theory that human needs can only be satisfied gradually and mostly in a specific order. The hierarchy itself can differ from person to person. In essence, it tells what people need to achieve their own personal goals in life or indicates the life goals of a certain individual. Using this framework to analyze data provided a clear picture on the needs and desires of persons with intellectual disabilities in the context of independent living and community inclusion and how those needs and desires reflect on the quality of their lives.

Level 1. - the main topic PHYSICOLOGICAL NEEDS is based on four topics with the accompanying categories gained from the perspective of persons with intellectual disabilities. These are topics like "the availability of medical services", "the availability of public transportation", "the experience of being institutionalized" and "violence". Most participants have the ability of using the needed medical services, but they're not well informed of the need to take care of their health. Negative experiences of being institutionalized is mentioned by all participants of assisted living housing. Their experiences are on the track of what Goffman called "total institution" in 1968. The participants mention a negative and discriminatory behavior of the staff to some users: "... *I watched the TV until ten. Then some of us had to go lie down, while others were left sleeping...*" (4/9). Some participants mention discrimination, fear of physical abuse, losing one's own personal space, dignity, autonomy, identity, the right to choose and control one's own life: "*I was in a home ... I hated it... it was awful, just awful, thank God I left... it's an institution... I never felt comfortable,*

I had no freedom, I had to eat when they tell me every day, I didn't cook... I didn't like that..." (1/9). The different negative experiences depended on the length of stay in an assisted living program. A very similar situation is mentioned by Schwartz (2010). By analyzing the data in this research, it can be concluded that a large part of a perspective on an institution is based on stories and experiences of other, primarily staff, then the users of the program and finally the advocates of de-institutionalization. Considering that some were activists in the fight for human rights or participated in self-advocacy programs, it is not surprising that they were more informed about the abuse of their human rights than others. Interacting with animals, the feeling of community and belonging to a group were mentioned by all participants as the positive experiences of being institutionalized.

Level 2. - SAFETY as a main topic is based on three topics with the accompanying categories gained from the perspective of persons with intellectual disabilities living in all forms of housing. Some of these topics are: "the advantages of a day-center", "the advantages of having work activities" and "the disadvantages of a day-center". As is noted by Oliver, Huksley, Bridges and Mohamed (1996), work and employment of persons with intellectual disabilities reduce their need for institutionalized support, develops work skills, eagerness to work and social interaction and creates a routine that helps a more structured way of life. Most of the participants of this research were involved in the activities of a day-center. Some participants were involved in working as a part of group or individual supported employment. They gained financial compensation and were mostly satisfied with it: "...*I'll get my money... next week...*" (2/9); "... *I get paid for the work I do ... I'm satisfied, I can go for a coffee...*" (3/9). Some participants think the day-center doesn't have suitable conditions or equipment: "... *a lot of them are there, there's nowhere to sit when you want to...*" (6/9); "...*There's a lot of us...*" (8/9). What is interesting is that only a small number of participants was satisfied with their social role when working in the open job market. Most participants who lived with their parents believe that their specific work roles in the day-center cannot provide them with the wanted status or value in society. Comparable results were obtained by Engeset, Söderström and Vik (2015). Not many studies researched the impact of various life situations on the material prosperity and employment of persons with intellectual disabilities. The studies that are mostly focused on post de-institutionalization and the evidence suggested that there is no major connection between the form of housing in the local community and employment (Noonan Walsh et al., 2007).

Level 3. - BELONGING as a main topic emerged after understanding the messages of the majority of topics and categories. The topics include, among other things: "social network", "provided support", "stigma as an obstacle to equal possibilities", "coexistence in organized housing", "coexistence in biological families", "independent living in the local community", "changing the residential community", "involvement in associations". All participants have faced the problem of lacking an adequate social network, especially the older individuals. Social networks are objective indicators of social relations that show who the individual is connected to (Antonucci, 2001). According to Leutar and Oršulić (2014) and Mandič and Hlebec (2005), social networks are the entire field of formal and informal relations of an individual. Social networks are a part of social relations that include social support, which also includes supportive social interactions (Antonucci, 1985). According to Karačić (2012), a weak social support and social network can lead the person into social isolation. Inadequate social support, often in the form of social isolation or dysfunctional social relations can cause the development of psychological problems (Thompson, Flood and Goodvin, 2006). A study conducted by the National Disability Authority (NDA) in 2011 notes similar findings. This research has shown that post de-institutionalized participants socialize with persons outside of assisted living through joint activities: "...*I have company here, it's where I play with my band...*" (3/9) or they recollect previous contacts with persons that were users of the same institution: "*They were in the institution too... they finished school before me... they played soccer...*" (1/9). De-institutionalized participants make contacts mostly with official staff of the

residential community and other tenants. Both participant groups note that it is more likely that their family members come to visit them in their assisted living facilities than it is for the participants to visit them: "...*Well, once a year. I've been there for Christmas...*" (6/9). Participants who live with their parents also have an inadequate social network. "*Mom, dad, and no one else... There is this A., she's nice, she came around recently... but not in the neighborhood...*" (8/9). Affection is shown to family members, colleagues, official staff and neighbors. All participants are satisfied with the provided support, but it is also true that all participants view that support from their own perspective. The most diversity in perspective can be noticed in post de-institutionalized participants. They are mostly satisfied with the support they have in organized housing and from their friends, while the support they receive from their family members and other tenants they mostly see as unsatisfactory: "*Mom comes around to grandma's and then we see each other...*" (1/9); "*My uncle and aunt live in Zagreb, but they're not OK because they didn't take me in... they should've taken me in to live with them...*", "*...they constantly nag me... something that's good, suddenly isn't good...*" (3/9). De-institutionalized participants are satisfied with the given support, while those who live with their parents express only partial satisfaction, because those who provide the support often change. Each participant who lives with their parents noted advantages in living with their biological family, which does not prevent them thinking about living independently without the parental influence, especially the mothers. Although living in a family home enables the participants to practice the skills of everyday living in a greater degree, there are limitations. The impression is that they passively accept the current situation and do not express any misgivings. The results from this research are similar to the studies conducted by Forrester-Jones et al. (2006) and also Beadle-Brown, Mansell, Whelton, Hutchinson and Skidmore (2006).

Level 4. - SELF-RESPECT as a main topic was created by linking the analyses of two topics and the accompanying categories gained through interviews of persons with intellectual disabilities from all forms of housing. The topics in question are: "independence and the right to change the form of housing" and "organized housing". The former is identified based on statements of the participants included in the assisted living programs, or in other words organized housing. Most of these state that they were not consulted about changing the form of housing: "... *my brother signed the papers and I had to go into the apartment...*" (5/9); "... *D. told me I had to...*" (4/9). It is expected that the very process of de-institutionalization can influence a greater possibility of choice and decision making. Numerous researchers dealt with this issue, for example Emerson et al. (2000), Robertson et al. (2001), Felce, Lowe, Beecham & Hallam (2001), Conroy (1996), Stancliffe and Lakin (2006), Stancliffe (2005), Stancliffe and Keane (2000), Perry and Felce (2005), Tossebro (1995). This research deals with the same issues, but within the topic of "organized housing". It is worth noting that when sub-topics like "daily rhythm", "conducting activities in everyday life over the week and the weekend", that the participants mostly stated that their options are limited. The sub-topics of "choosing and making decisions during shopping" and "choosing and doing activities in your free time" show some interesting differences. Post de-institutionalized participants have a more positive attitude than de-institutionalized. Some topics that arose from interviewing post de-institutionalized participants were included to improve the understanding of the "organized housing" topic. These sub-topics are: "living with pets", "choosing and making decisions on housing", "deciding on the degree of needed support", "realizing your desires", "basic financial support", "inability to leave the organized housing" and "gaining independence". Considering that the participants were included in residential communities (post de-institutionalization) for longer periods of time and since they gained some knowledge of human and civil rights, it can be concluded that they used this knowledge and communication skills to formulate additional advantages and disadvantages that they experienced as beneficiaries of organized housing.

Level 5. - SELF-REALIZATION as a main topic was formed on the basis of the "the knowledge of self" topic (the image of self). The notion of self is the fundamental structure that selects information, rejects them, motivates behavior and influences all decisions made by an

individual (Burušić, 2012). It is therefore necessary to start from the fact that in the case of every individual it is possible to establish the "notion of self" that actively controls the experience and the behavior of human beings. The participants who were a part of the assisted living residential communities are fully aware of their own personal qualities, or in other works of their moral traits: "... *I'm tidy...*" (4/9; 5/9); "... *it's all good on me. I'm fine...*" (6/9); "...*I hang out with people...*" (3/9); "...*I don't like cursing and things like that...*" (1/9). They emphasize those traits that they find dominant when thinking about themselves in a social environment. It can be assumed that these traits were a product of social learning in the institution where it was especially important to "be tidy", "look good", "socialize", "not curse" etc. But all those traits persist although the housing situation has changed which can be a deciding factor when deciding in choosing the type of support. A somewhat lower number of participants has an awareness of their knowledge and skills. These are mostly post de-institutionalized individuals: "... *I have some problems with concentration, but I get along...*" (3/9). The participants who live with their parents are focused mostly on the self-perception of physical manifestation of emotions and the negative evaluation of the emotional regulation of their surroundings. According to Petrović, Stojisavljević and Tadić (2012), there are significant limitations in the research of the notion of self in persons with intellectual disabilities. Studies conducted so far were mostly on children and young persons with intellectual disabilities and rarely on adults. The "image of self" of this population is important for adequate inclusion in the life of the local community and is greatly dependent on the way they are treated by others. "An adequate notion of self can be the indicator of success of community inclusion, a prerequisite of which is a certain degree of self-realization of persons with intellectual disabilities. At the foundation of self-realization is again, the notion of self..." (Petrović et al., 2012, p.526).

CONCLUSION

The perspective of persons with intellectual disabilities encompassed by this qualitative research identified the fields important in their everyday life. The life experiences of these individuals differ based on the form of housing, the length of time spent in organized housing and on the organization and function in the community. The noted perspective is shown through the five levels (main topics) of Maslow's hierarchy of needs. A clear image of the needs and desires of persons with intellectual disabilities in the context of independent living and community inclusion and how that reflects on their quality of life, was formed using Maslow's framework. The results of this research indicate facts that should be considered by actual sector policies and practices because they can improve the fundamental understanding of the concept of independent living and community inclusion based on the model of human rights and the implementation of the Convention of persons with disabilities. Considering that the research was designed in a way to "give voice" to persons with intellectual disabilities, it most certainly contributes to the empowerment of the user's perspective of these individuals as experiential experts and active participants in the mobilization and development of an inclusive community. Their experiences and perspectives should be the foundation for planning service on an individual, organizational and population level (Randt, 2011) and are a key element in reducing social isolation and other marginalized social groups (Abbott and McConkey, 2006). This research has confirmed a number of obstacles, that are only declaratively guaranteed to independent living and community inclusion. A number of recommendations emerged from this (noted further in the text), more specifically recommendations made by the participants themselves in regard to independent living and community inclusion. Recommendations that would improve the quality of their lives. Some of the suggestions are aimed at the social and structural level, while other are more individual and personal. The same was indicated by a study conducted by Weafer (2010).

Key recommendations by the research participants

A better network of social relations is a recommendation given by all research participants. Considering that a part of the participants live with their parents, their expectations to *improve the quality of life in the biological family* is related to free time activities based on their own choices outside of the living space and to participating in the self-advocacy group. All participants expect *improved support* in the day-center and their families as well as greater support from their friends and neighbors. Most participants expect the improvement of the service in the day-center, in the sense of conditions, equipment, being included in deciding on the menus and group leaders as well as being compensated for conducted work assignments. Most participants expect an improvement of service in organized housing to ensure the creation of a daily rhythm during the week and the weekend, doing everyday-life activities, socializing and doing free time activities during the weekend. Also, the desired improvement is also related to better communication between tenants, practicing cooking during the weekend, having pets in the living space, more choice and the ability to make decisions in regard to clothing, food, other house necessities and cosmetics, in free time activities and everyday nutrition. The participants have great expectations regarding tearing down stereotypes and prejudice against persons with intellectual disabilities. In conclusion, the challenges of independent living and community inclusion can only be solved by horizontal and vertical coordination. Vertical coordination from the national to the regional level, and horizontal one is among all interested parties (Magiri Mburu, 2016). In accordance with that, to improve the quality of life of persons with intellectual disabilities, it is necessary to improve the objective prerequisites to achieving their rights, services and support quality, but at the same time take into account their individual perspectives and expectations, personal potential, interests and needs.

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