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10<sup>th</sup> International Conference:  
Research in Education  
and Rehabilitation Sciences

**ERFCON**23

May 5-7, 2023  
Zagreb, Croatia

# CONFERENCE PROCEEDINGS

Vol. I



10<sup>th</sup> International Conference:  
Research in Education and Rehabilitation Sciences

**ERFCON 2023**

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# **Conference Proceedings**

Vol. 1

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10<sup>th</sup> International Conference:  
Research in Education and Rehabilitation Sciences

## ERFCON 2023

May 5 -7, 2023  
Zagreb, Croatia

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## Introduction

Welcome to the Conference Proceedings for the 10<sup>th</sup> International Conference: Research in Education and Rehabilitation Sciences - ERFCON2023, Volume 1. This milestone event brings together scholars, researchers, educators, and practitioners globally, facilitating profound discussions, the exchange of innovative ideas, and the presentation of groundbreaking research in the fields of education and rehabilitation sciences.

The themes of ERFCON2023 signify our dedication to exploring uncharted territories and pushing the boundaries of knowledge in special and inclusive education, rehabilitation, speech-language pathology, social pedagogy, and criminology. As we collectively explore new horizons, this conference provides a platform for intellectual exchange, fostering collaboration and inspiring transformative developments.

The Conference Proceedings underscore the importance of diverse perspectives and interdisciplinary collaboration in addressing the multifaceted challenges within education and rehabilitation sciences. By assembling experts with varying backgrounds, our aim is to weave a rich tapestry of insights contributing to the holistic advancement of these critical fields.

Daniela Cvitković, UNIZG, Faculty of Education and Rehabilitation Sciences  
daniela.cvitkovic@erf.unizg.hr

Ajana Löw, UNIZG, Faculty of Education and Rehabilitation Sciences  
ajana.low@erf.unizg.hr

## Academic achievement of elementary school students with LD and ADHD during the pandemic COVID-19: qualitative study

### SUMMARY

To date, several studies have been published on the learning outcomes of students with learning disabilities and/or ADHD during a period of emergency remote teaching during the COVID 19 pandemic, most of which focused on greater grade deterioration as an indicator of learning success than for normal students. What is lacking is research on other learning outcomes as well as the factors that contribute to learning outcomes.

The purpose of this phenomenological study is to explore the learning outcomes as well as the factors that contribute to the learning outcomes during remote teaching for elementary students with ADHD i LD through a qualitative study using a thematic analysis approach.

Both teacher, student, and parent perspectives regarding the experiences and outcomes of distance education were explored through semi-structured interviews. Elementary schools from all parts of Croatia were selected to meet the criterion of maximum variation. The final sample consisted of a total of 11 elementary schools, a total of 11 students, their teachers, and one of their parents. Students from each school were selected with the assistance of school professionals; students were selected if they were being taught under an individualized education plan (IEP) and had a LD and an ADHD diagnosis.

All interviews were conducted in person at the selected schools during the 2021/2022 school year. The duration of the interviews ranged from 20 to 40 minutes. Ethical approval for this study was obtained. All interviews were recorded and transcribed verbatim. In conducting a thematic analysis, we followed the guidelines suggested by Braun and Clarke (2006). Qualitative analysis is ongoing, and findings are presented in the form of themes and subthemes.

**Key words:** *pandemic COVID 19, distance learning, elementary students, learning disability, ADHD*

### Introduction

The COVID-19 pandemic triggered a crisis that resulted in a sudden shift in teaching practices worldwide. Initially, most schools in nearly every country transitioned to remote teaching without adequate preparation. In recent school years, there has been a gradual return to schools

with a so called hybrid teaching approach, combining online and face-to-face teaching. The transition in teaching under these crisis conditions inevitably affected all students, but the challenges of remote teaching are more pronounced for at-risk and struggling students, such as those with learning disabilities (LD) and ADHD (Averett, 2021).

Adolescents with ADHD experienced greater negative affect and more concentration problems due to COVID-19 than their typically developing peers (Becker et al., 2020). Children with LD reported poorer physical health, learning processes, and school-related emotional health compared to controls (Benassi et al., 2021; Marchese et al., 2022). One study indicated that male adolescents with ADHD had lower grades than before, whereas this was not the case for female adolescents and those without ADHD (Breux et al., 2022).

### **Education of Students with Disabilities in Croatia**

According to the Act on Primary and Secondary Education (Official Gazette No. 87/08, 86/09, 92/10, 105/10, 90/11, 05/12, 16/12, 86/12, 126/12, 94/13, 152/14, 07/17, 68/18, 98/19, 64/20, 151/22) and the Ordinance on Primary and Secondary Education for Students with Disabilities (NN, No. 24/2015), students with LD and/or ADHD are taught based on the regular program with an individualized education plan. Depending on the student's needs, individualized procedures allow for various forms of support and academic accommodations related to student independence, methods and work time, review of student knowledge, skills and abilities, monitoring and evaluation of student performance, student activity, appropriate spatial conditions, and technological, didactic, and/or rehabilitative work tools.

### **Remote Teaching in Croatia**

With the onset of the COVID-19 pandemic, all schools transitioned to distance education. In Croatia, various synchronous and asynchronous forms of remote teaching were implemented, ranging from the use of various ICT tools, online chat groups, and virtual classrooms to more traditional forms of remote teaching and learning, such as televised classes for lower elementary grades. Thanks to a previous education reform, schools were equipped with technology that proved helpful during this time, and students were provided with tablets when they shifted to distance learning, helping to narrow the digital divide among students.

Although elementary students (from 1st to 4th grade) returned to classrooms in May 2020, students in upper elementary school grades (from 5th to 8th grade) continued with remote teaching. In the 2020/2021 and 2021/2022 school years, combined teaching—a hybrid model—took place, with teaching occurring partly at a distance and partly at school, presenting new challenges.

### **Factors Affecting Academic Achievement During the Period of Remote Teaching**

Best practices for effective online teaching (Ferdig et al., 2009), which Eutsler et al. (2021) extend to current remote teaching, can be divided into several factors: personal factors (e.g., reflec-

tiveness and commitment to the profession); communication (e.g., sharing student progress, providing multiple opportunities for communication, and delivering quick and meaningful responses); programmatic factors (e.g., the ability to modify content and instruction, maintaining records of students, and understanding students' background knowledge); pedagogy (e.g., encouraging critical thinking, accommodating students' differences, and teaching engaging content); and classroom management (e.g., outlining materials, reminding students of deadlines, and providing technical assistance).

Students with LD face challenges in learning, particularly in areas such as reading, writing, and math. Additionally, those with LD and/or ADHD encounter difficulties related to attention, working memory, metacognitive skills, self-regulation, and processing speed, which can impede learning even under normal conditions (Alloway & Alloway, 2014; Johnson et al., 2010; Reid, Lienemann & Hagaman, 2013). Due to these challenges, they often require additional educational support and academic accommodations. Considering that successful online learning necessitates self-regulation, time management, and organization (Kauffman, 2015), it can be inferred that the need for additional educational support and academic accommodations is even more critical in a distance learning environment than in traditional school conditions.

Petretto et al. (2021), following a systematic analysis of studies addressing online learning for students with LD, concluded that risks associated with e-learning and ICT use for LD students include insufficient attention to making specific 'reasonable accommodations' tailored to each student's needs and inadequate focus on accessibility in the design and implementation of tools, devices, and learning environments. Furthermore, most students who had received school-based counselling/therapy or tutoring did not continue to avail of these services during distance learning (Petretto et al., 2021).

## Research Aim

Previous research has only partially addressed the impact of remote teaching on the academic outcomes of students with ADHD and/or LD. Some studies examined student variables such as concentration autonomy in learning and teacher support (Tessarollo et al., 2022), while others also included parental support (Becker et al., 2020). Still, others solely considered grades (Breux et al., 2022). There is no study that systematically considers teacher, student, and parent perspectives on outcomes. Thus, the aim of this qualitative study was to explore the outcomes of distance education and the factors contributing to these outcomes for elementary school students with ADHD and/or LD in Croatia during the early COVID-19 pandemic from the perspectives of teachers, students, and their parents.

## Methods

### Participants

This study is part of the HRZZ project 'Changes in the Organization of Educational Processes Induced by the COVID-19 Pandemic: Effects on Croatian Pupils' Educational Experiences, Well-being, and Aspirations over Time,' led by Head Boris Jokić.

The elementary schools included in the study were selected based on the results of the quantitative phase of the project, considering the distribution of schools by region. Within each region, elementary schools were chosen to meet the criterion of maximum variation, ensuring diversity among schools based on the size of the settlement and socioeconomic characteristics of the students. The final sample comprised a total of 11 elementary schools that participated in the study.

The selection of students in each school was facilitated by school professionals. Those chosen for participation were students being taught according to an individualized education plan (IEP), i.e., students following the regular curriculum without modified learning objectives but requiring individualization in some aspects of the teaching process. The sample included students with LD and ADHD.

A total of 19 students with LD and/or ADHD, their parents (N=19), and teachers (N=19) participated in the study.

Table 1 *Description of the students involved in the study in terms of country of origin, gender, and level of education*

		Students
<b>Gender</b>	Female	4
	Male	15
<b>Education Level (ES)</b>	Lower (aged 8-10)	5
	Upper (aged 11-15)	14
	Total	19

### Procedure

Qualitative research was conducted using semi-structured interviews with elementary school students with LD and/or ADHD, their parents, and teachers. The interviews covered topics related to experiences with education during remote teaching. Once collaboration with the select-

ed elementary schools was agreed upon, the school professionals employed in those schools contacted the students with disabilities and their parents.

All students provided verbal consent to participate in the study, and their parents gave written informed consent before the interview. In consultation with the students, parents, and researchers, school professionals then scheduled appointments to conduct the interviews.

All interviews were conducted in person at the selected schools, as classes were being held in school contexts at that time. The interviews took place at the end of the 2021/2022 school year, with durations ranging between 20 and 40 minutes. Ethical approval for this study was obtained from the ethics committees of the Institute for Social Research in Zagreb (No. 03/2021).

### Data Analysis

All interviews were recorded and transcribed verbatim. The anonymous transcripts were used for further analysis of the research findings. The chosen method of analysis for this study was a hybrid approach using qualitative methods of thematic analysis, which included both the data-driven inductive approach and the deductive, theoretical a priori coding scheme approach (Fereday, Muir Cochrane, 2006).

We followed the steps described by Swain (2018) for coding the data. The codebook or table of codes was developed a priori based on the research question and theoretical framework. Drawing on existing knowledge about the factors influencing academic achievement in children with disabilities in regular education, as well as literature on best practices for effective online teaching (Eutsler et al., 2021), nine broad code categories formed the code manual: teaching strategies, student-teacher communication, feedback to students, assessment methods, individualization of approach, additional educational support, family learning support, motivation to learn, learning outcomes, and grades.

After developing the coding manual, two researchers tested prior codes on two documents from each participant group (students, parents, and teachers) through a coding process using a priori codes. During the coding of the transcripts, inductive codes were assigned to those data segments that described a new theme observed in the text.

## Results

The emergent themes and subthemes are presented according to the a priori given categories and supported by participant quotes.

### Inadequate Teaching Strategies

In particular, inadequate instructional strategies could be inferred from the statements of parents, but also from students who reported that online school was much worse because it was difficult for them to understand the material during remote teaching.

Some teachers only sent materials and assignments. "Some only send assignments and ask to be returned," said one parent.

When they have synchronous teaching, it's not the same as in the school. For example, one parent said, "It's not the same when a teacher explains something like this to you live and online. This is just for K's sake, so she could understand a little better."

Inadequate explanation by the teacher can also be seen through the students' statements.

A lower elementary-grade student mentioned: "Because it is easier for us when the teacher explains to us than when we are online."

An upper elementary-grade student. "I don't know how the others coped, but I know that there were a lot of ambiguities, that the group was burning with questions all day. There were problems, but I managed."

## **Communication between school and students, parents**

### **Availability of Teachers Throughout the Day**

Teachers and parents, but also some students, indicated that teachers were available almost 24 hours a day during remote teaching.

For example, one parent explained: "Because even when we were online, he always said you can call me anytime, he's really there for them."

An example of a teacher's statement: "Well, I mean, let's say it's another aggravating circumstance because we're available to the students almost 24 hours a day now, but in some ways, I think it's good that he has the confidence to ask me. When I write to him, I reply, 'Sorry, M, I forgot. Yes, if it works like this, feel free to ask if something isn't clear to you.' He likes this communication very much."

### **Communication Satisfaction**

The availability of teachers was mostly described by parents in terms of satisfaction with communication: "About everything, I can say that the school played everything so professionally, they kept us informed about everything."

### **Reminding Students of Their Duties**

According to the statements of parents, teachers, and students, teachers' communication was often aimed at reminding students of their duties.

A parent said: "I mean, several of these professors who are on top of things and so forth kept saying 'E, you did not send the homework, send it, this and that.'"

Some teachers communicated directly with students, while others reminded them of their duties through parents.

A teacher mentioned: "Often it was messages to the mother, not directly to him, but a reminder to the mother that there was an English project, so please have L do a project for such and such day."

For some students, this meant a lot because it motivated them to work.

A student said: "The teacher asks me if everything is okay; now I wonder why he asks me that. I felt very stupid at that moment, so I still told myself that I am going according to a new plan."

### **Asking Questions to Explain**

The teachers-initiated communication primarily to remind them of their duties, while students initiated communication primarily to clarify the material.

A student mentioned: "You can always message the teacher on Teams after class and ask 'Teacher, I don't understand the third assignment, can you show me during the next lesson?' and the teacher will show you.'

A teacher noted: "I'd dedicate myself to inviting the parent, inviting the child, because there were kids calling on their cell phones to explain an assignment."

### **Teachers' Feedback**

In most cases, teachers provided feedback to students on completed assignments. This was indicated by teachers as well as parents and students. Most teachers felt it was important to monitor students' work but were aware that they could not do so in the same way as in live classes: "I could not control how they were writing like in school, could I? B, for example, was given a math assignment and then told to send it." The researcher asked: "And then he would get feedback on it..." and the participant responded: "Yes, yes. Yes, yes."

However, there were also those who did not send feedback after completing the assignments.

Researcher: "Did the teacher send any information, like did you do well, or did you do poorly, did he send you anything like that?"

Student: "I mean, for some subjects yes, for others not."

### **Academic Accommodation**

This theme has turned out to be one of the most important.

#### **Application of Academic Accommodation**

A smaller number of children and parents stated that accommodations continue to be implemented in distance learning.

Student: "She did some assignments for me, so they were easier for me to understand them. It was hard for me to read, so they adjusted it so that ... I do not write as many, but I answer more."



Parent: "For example, specifically in English, when he was online, they had some kind of a listening test, and the teacher sent him a message that he was going to listen to the same text as everyone else, but that she was going to send him a link with different questions. When I heard from her myself, she said that she was going to ask him shorter questions, simpler. I mean simpler sentences, so he could read them, and it would make his work easier..."

### **Insufficient Academic Accommodation**

Some teachers applied some accommodations even during remote teaching, but usually not at all or not sufficiently, which can be inferred mainly from the parents' statements: "Because he... the... online lessons are fine as far as I am concerned. It's just that a child with his difficulties cannot write and follow what is being said at the same time."

Researcher: "Do they adjust the font size, spacing, or something else?"

Parent: "No. Maybe they should adjust the font size, spacing, or something else?"

Some applied some accommodations only when students responded.

Parent: "Let us say he did not have time to finish reading, and then he messaged the teacher that he did not have time and asked for a little more time, and she immediately responded that she did not have a problem with not rushing when he came in and calling out when he was reading. So, in that respect, they are really accommodating him..."

Teacher: "When he asked for support in making the poster and other things, I supported him."

From some teachers' statements, it appears that they are not aware of the situations in which adaptations are required, so they are not likely to apply them fully in school: "It's the word tasks that make his grades a little lower, that is, that for some, the instructional requirements should be reduced after dictation. But if I would ask 'Did you make it, M, did you manage to write that, write that for me...' and then when I ask if you made it, he always actively answers 'I made it, you can go on,' etc."

### **Additional Educational Support**

Even during remote teaching, some schools had online supplemental instruction, and some schools called students and offered in-school support once the strict lockdown ended.

Teacher: "The psychologist who was there even knew how to work with them in some subjects, in a way that invited them to school. I can't remember, but I know she helped some students with difficulties."

Student: "Yes. And even though it was online, there was also additional support."

Interestingly, some parents weren't sure if there was additional support.

Parent: "Well, I don't think so. I'm not sure, I don't think so."

## Lack of Additional Educational Support

Some had no additional support during online classes.

Parent: "Um, um no, they weren't like that, they weren't online, but until last year we actually didn't... everything was suspended."

The student also regrets that it wasn't because she might have learned more: "I mean... honestly it wouldn't have been bad if they had done something with us because I'd have learned more."

## Family Learning Support

Students most often talked about family support. Family support was frequent and necessary when they didn't understand something.

Parent: "So when he does his homework, my husband and I split up, depending on who is better at what subject, we help him... First, we look at the homework, we estimate what he can solve by himself. If we don't help him with everything, we estimate what he can do by himself... if it was a new lesson, for example, fractions in math, my husband explained everything to him in detail from the beginning, with examples and pictures."

Some children who have difficulty with reading, writing, attention, and self-regulation would do nothing if not guided by their parents.

Parent: "Um, I mean, he wouldn't have learned if I hadn't been there."

Parent: "She ended up taking a year so that she could be with him..."

Parent: "Okay, we followed the lessons, you understand that I've to be present so that he can follow."

Some parents didn't support their children, but older brothers, sisters, cousins did.

Student: "I had the advantage that my brother and sister were still at home, so I could take advantage of that. My brother would say to me when he heard that I was working, for example, and since he's good at English, he'd immediately come and help me."

Some parents didn't support the children because they had to work, and one parent said he just didn't feel like it: "You don't judge that we didn't want to work with him, we just... I'm too stupid for that, I don't even know."

## Motivation to Learn

### Decreasing Motivation to Learn

Motivation to learn has decreased in most cases, as shown by the statements of parents, students, and teachers.

Parent: "And then it turned out that, exactly, a certain moment came when something happened in her head, some, I don't know how to say it, I don't want to say blockage, but I think she had enough of all that. And she just stopped doing those tasks, and from that moment on, there wasn't a single task, not a single task, nothing, nothing, nothing."

Student: "Well, maybe a little bit, now I don't feel like it anymore and... no, this now... if it's a pandemic, I don't know why. I liked it better before. I think I learn right away; I say I learn right away and then I go play, and now... I don't really learn."

Teacher: "It often happens that these kids with disabilities or with a certain other way of working give up."

### **Equal Motivation to Learn**

For some children, the motivation to learn has remained the same.

Teacher: "I don't think he has changed too much, that he works online and when we are in person the same amount, at least I think so."

Parent: "Oh no, with M it's always the same, always."

### **Lower Acquisition of Learning Outcomes**

Almost everyone reported poorer learning outcomes; teachers explained that it was not only children with disabilities who had poorer outcomes, but others as well.

Parent: "So, I think not just for them, but for all the kids that were online, they learned very little and yeah, yeah, who knows if they remember anything from online learning, whatever, I do not think it did much. They just, here they just gave up, all together."

Student: "That's because when we were online in fourth grade, I did not get a single subject all day."

When they returned to what they call the hybrid model, partly in person, partly online, there was a lot of catching up to do:

Parent: "There's always some backlog, there's always some catching up to do, some supplementing to do, so I think they are pretty damaged as far as education goes."

Teacher: "I absolutely limit myself to the most important, the most important, um... They came from the lower grades with very, very weak prior knowledge."

### **Evaluation 'Turning a Blind Eye'**

Most teachers spoke about the method of evaluation, and some spoke honestly about reducing the requirements: "There were a lot of leniencies because of the situation and all that. There was a lot of turning a blind eye. Okay, this year it was kind of a generous grading."

## Grades

Most students' grades are worse than before the pandemic.

Parent: "They got worse as soon as she was in fifth grade, and it started toward the end of fourth grade when the pandemic started."

Student: "During the pandemic, honestly... and they're worse and... they were graded worse."

Interestingly, for some, grades stayed the same or even increased, which is consistent with the mentioned method of evaluation.

Researcher: "Okay, and how did the pandemic affect their grades?"

Parent: "No, I'm telling you, M is always the same in school, always."

Researcher: "Oh, and tell me, did the pandemic affect the grades in any way?"

Student: "No, I had the same, sometimes better, sometimes worse. 3, 4, like that."

Student: "No, my grades are fine, the pandemic didn't affect them."

Student: "I don't know if it's because of the pandemic, but they have changed for the better."

## Discussion

Participants in this study provided rich data on their views of academic achievement and the factors that influence the academic achievement of students with LD and/or ADHD during remote teaching.

The themes that emerged from the data suggest that the time between the initial lockdown and the return to school was not easy for all three participant groups. In terms of academic outcomes, there was a decline in the acquisition of educational outcomes, although grades did not decline as much, which we can explain in part by a lowering of the evaluation criteria that teachers talk about.

This result is consistent with the findings of other studies that speak of a decline in learning achievement and academic behavior related to remote learning, not only for students with disabilities (Javornik et al., 2022; Breaux et al., 2022) but also for typical students (Klosky et al., 2022).

We can relate this decline in educational outcomes to factors influencing successful remote teaching, such as inadequate teaching strategies and lack of additional education support and adequate accommodation to students' needs. Teachers did not have time to learn about the new way of teaching, so they did it the way they knew it. Many students mentioned that many things were not clear to them, and they needed more explanations. Teachers tried to make up for this shortcoming by being accessible to students. At that time, they were available to students virtually throughout the day to answer questions, explain the material, en-

courage them to work, and provide feedback on completed assignments. Parents were very satisfied with the teachers' accessibility and level of communication, and their satisfaction was chosen as a theme.

These students need additional educational support and an individualized approach to teaching and assessment to be successful. This theme emerged as one of the most important from the perspective of parents and students. Additional educational support has decreased during this period, preventing students from achieving their educational goals. Other research also shows a decrease in supplemental educational support and accommodations for students with disabilities (Averett, 2021; Hatton & Powell, 2022). In terms of individualization, it can be noted that it was inadequate before the pandemic, and many teachers used some procedures while some did not even know they should use them, such as not insisting that the child take notes after the teacher dictates, as one teacher noted. On the other hand, as Averett (2021) points out, further adjustments are needed considering the changes in teaching and learning conditions.

From the participants' statements, it appears that some students were motivated to learn. It is possible that these were students who needed less learning support due to lower difficulties, as suggested by the findings of He et al. (2021). They compared a group of students with ADHD with greater learning difficulties and those with lesser learning difficulties and found that the students with greater learning difficulties showed less motivation to learn during remote teaching than the students with lesser learning difficulties. However, for most of the children, learning motivation has decreased, which, together with difficulties in self-regulation, had a negative impact on learning. Considering all of this, family support for learning was critical during this time. Averett (2021) also points out that parents felt they had to take a very active role in their children's distance learning by acting as co-educators. Both Croatian studies and studies from other countries show that parental learning support was also important for students without disabilities (Garbe et al., 2020; Kolak, Markić & Horvat, 2020).

In summary, the findings suggest that teachers need more education about teaching methods for distance and hybrid teaching, as well as more about students with LD and ADHD and how to adapt to the needs of students both in school and remote teaching.

This study has both strengths and weaknesses. The strengths include a wide range of subjects from all parts of Croatia to obtain the widest possible variety of samples. Another advantage of the study is that it considers the perspective of students as well as their teachers and parents.

The shortcoming is that we have only touched on the themes of instructional strategies and individualization of approach, as well as assessment methods, but have not delved further. A deepening of these themes would possibly provide even more concrete suggestions for future practice.

## Conclusion

The aim of this qualitative study was to explore the outcomes of distance education and the factors contributing to the outcomes for elementary school students with ADHD and/or LD in Croatia during the COVID-19 pandemic, from the perspective of teachers, students, and their parents. There was a deterioration in educational outcomes and motivation to learn, which we can attribute to factors such as inadequate teaching strategies, lack of additional education support, and adequate accommodation to students' needs.

Teachers were available to students and communicated with them and their parents throughout distance education to compensate for these deficits, but family support was necessary. The results suggest that teachers need more training on teaching methods under such distance learning circumstances, as well as more training on students with LD and ADHD and on accommodating students' needs both in school and in distance learning.

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Olivera Rashikj-Canevska, University „Ss. Cyril and Methodius“, Faculty of Philosophy in Skopje,  
Institute of special education and rehabilitation  
oliverarasic@fzf.ukim.edu.mk

Natasha Chichevska Jovanova, University „Ss. Cyril and Methodius“, Faculty of Philosophy in Skopje,  
Institute of special education and rehabilitation  
natasac@fzf.ukim.edu.mk

Jasmina Troshanska, State University of Tetovo, Faculty of pedagogy  
jasmina.troshanska@unite.edu.mk

Teuta Ramadani Rasimi, State University of Tetovo, Faculty of pedagogy  
teuta.rasimi@unite.edu.mk

Kristina Dimitrovska, University „Ss. Cyril and Methodius“, Faculty of Philosophy in Skopje,  
Institute of special education and rehabilitation  
kristinaad48@gmail.com

## First reactions and future expectations of parents of children with developmental disabilities

### SUMMARY

The birth of a child in the family is usually a period filled with joy and the formation of new feelings such as immense happiness, pride, self-realisation, success, and confirmation of identity. However, the birth of a child with developmental disabilities represents a strong challenge and a threat to the disruption of family life. The main aim of this study was to examine the reactions and feelings of parents as part of a family unit with a child with special needs. Several stress factors, positive and negative emotions, impact of disability on family members, and expectations for the future were investigated. Data were collected by surveying a group of 77 respondents who were parents of children with developmental disabilities.

The results of this research indicate that, although all parents faced similar challenges, emotions, and struggle with similar problems, to a large extent the emotions that dominated, the time needed to accept reality, and the challenges they faced were directly associated with the type of disability of the child. A total of 52% of respondents experienced some changes in marital relations after the arrival of a child with a disability in the family, 45.5% of respondents answered that someone from the family was forced to leave the workplace, 49.35% of parents answered that they neglected their own social life, and 51.94% of parents pointed out that the biggest challenge they were currently facing was psychological stress. In fact, parenting a child with a disability can present a unique and complex set of challenges.

**Key words:** *disabilities, families, first reactions and expectations*

## Introduction

Before giving birth, it feels like you're getting ready for a wonderful trip to the place you've been dreaming about all your life. You buy a bunch of travel guides and make wonderful plans, what to see and visit, where to go, everything is so exciting. After months of excited anticipation, the big day finally arrives, and the birth of a child with a disability suddenly takes you in a completely new direction, to a completely unknown place.

Regardless of the type and degree of disability, it always represents a complex triad of interactions, on the one hand including the child with a disability, and on the other hand the affected family, as well as the environment in which the disability manifests itself (Heiman, 2002).

When a child with special needs is born into a family, all aspects of the family are affected, including parents, brothers, sisters, friends, and close relatives. Many researches indicate that birth of a child with developmental disabilities undeniably causes a stressful change in the family and often changes its daily functioning, thereby determining the direction of its further development. There are great and difficult demands placed on the family, that is, on all its members, placing them in front of serious challenges and temptations, which can endanger not only each of them individually but also the family as a whole (Chichevska-Jovanova N., 2015).

How parents or other family members react to their child's disability, cope with the new situation and expectations for the future will largely depend on how they find out they are a parent, grandparent, sibling, or other member of the family to a child with a disability. Parents faced with the immediate crisis of preterm birth, or the initial diagnosis of a developmental disability mobilize their resources to cope with the crisis, albeit sometimes in ways that can affect them emotionally for years (David, 2013). Greater difficulties and consequences, in general, have parents and families of children whose disabilities begin to manifest in later development, and not immediately after birth or in the first months of life (Chichevska-Jovanova, 2023). In many cases, the initial reactions of the parents will be negative, similar to those related to sadness, anger, and rage. Some families flexibly adapt and mobilize for effective action, while others freeze in varying degrees of rigid, ineffective reactions, or tend to resist or even deny the diagnosis itself (Falik, 1995). Parental acceptance of children affects children's development, social behaviour skills, and adaptability (Carrasco, 2019).

Many studies have investigated the difficulties they encounter parents in raising children with developmental disabilities (Lučić, 2019). Research points to several important risk factors that parents of children with disabilities face. They are more likely to experience major life changes, including divorce, surgeries, and frequent moves. They also experience stress during the day much more often than other parents. Such anxieties often become a source of cumulative stress, which in combination with various life events leads to problems for themselves. According to VanLeit and Crowe (2002), mothers of children with developmental disabilities neglect

their own needs. In most cases, they do not find time for other activities, including family walks, socializing with other family members, and household chores. Mothers of children with multiple disabilities spend 39.7 hours per week nurturing their child, mothers with children with Down syndrome need 32.8 hours, while mothers of typically developing children spend about 33 hours per week (Crowe, 1993). In a study conducted at a pediatric clinic in Taiwan, it was determined that 44% of parents of children with physical disabilities have poor mental health, and 41.8% of mothers of children with cerebral palsy have an increased risk of developing psychiatric disorders diseases (Jen-Wen Hung, et al., 2010, Chichevska-Jovanova, Rashikj-Canevska, 2015).

Parents' perceptions of children with disabilities determine how parents educate and care for the child. Perceptions and expectations of parents of children with disabilities depend to a great extent on the socio-cultural arrangement, moral values and traditions, organization and accessibility to services and support, as well as the economic status of the parents. Very often we can see negative perceptions, including feeling pessimistic, embarrassed, withdrawn, and even rejecting the existence of children with disabilities (Junaidi, Dewantoro, 2020).

## **Objective**

The main goal of our research was to determine the first reactions of parents upon learning about their children's disability, as well as their plans and expectations for the future. To determine if there is a difference in the reactions between parents of children with different types of disabilities, what changes happened within families after having a child with disabilities, what challenges parents faced and what are their biggest fears for the future.

## **Research Problems and Hypotheses**

Our previous experiences and the analysis of literature made us start from the assumption that the birth of a child with a disability causes major changes in the life of the parents, more precisely in the social life, the time set aside for themselves, commitment to other brothers and sisters, psychological stress, work status, marital relations, etc. In correlation with the main hypothesis and its precise explanation, we also set auxiliary assumptions, that is, in the largest number of cases, negative emotions will dominate among parents, and in the largest percentage, expectations and fears for the future will be related to the independence of children, i.e. adults with disabilities.

## **Methods**

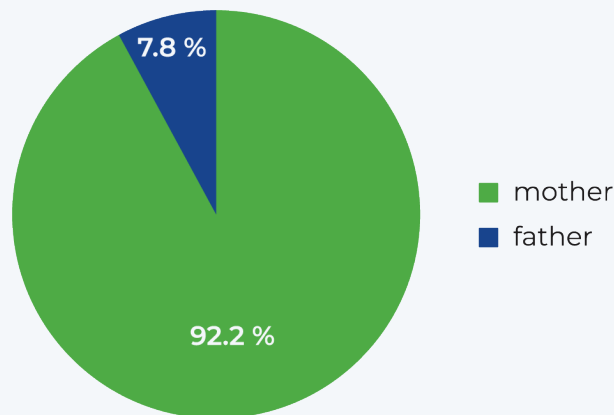
For the purposes of this research, the methods of descriptive analysis and comparison were used, as were the techniques of documentation analysis and surveying, and as an instrument, a survey questionnaire was used, which was answered by parents of children with de-

developmental disabilities. The survey consists of 4 parts and a total of 41 questions. The first part consists of general questions related to the gender of the parent, gender, age and type of disability of the child. In the second part of the questionnaire, there are 17 questions related to the past, that is, how the parents found out about the disability in their child, their first reactions and the impact of the disability on part of their life. The third part of the questionnaire consists of 13 questions, 12 of which are in the form of statements, and parents have to rate their agreement or disagreement with the statements according to a 5-point Likert scale: 1 – do not agree at all, 2 – do not agree, 3 – neither agree nor disagree, 4 – agree, 5 – completely agree.

A total of 77 parents of children with developmental disabilities were included, of which 92.2% (71) are female, and 7.8% (6) are male (Figure 1).

The main limitation of the study is that it is a convenient sample with a small number of respondents, that is, respondents who were available in the field and agreed to participate in the research.

Figure 1 *Distribution of parents by gender*



## Results and Discussion

Considering that the group of respondents consisted of parents of children of different ages and with different disabilities, we will first give an overview of the demographic data. From Figure 2 we can see that 28.60% of the respondents' children are female, while the majority or 71.40% are boys. In terms of age, the largest percentage or 31.2% are in the category from 6 to 10 years old, 28.6% from 10 to 18 years old, 22.1% are aged from 3 to 6 years old, 13% are over 18 years old and 5.2% are aged from 0 to 3 years (Figure 3).

Regarding the type of disability of the children, the representation of children with an autistic spectrum disorder and children with multiple disabilities is equal, or 18.2% of the respondents' children, 15.6% are children with speech and language disorders, 13% are children with

Figure 2 *Distribution of children by gender*

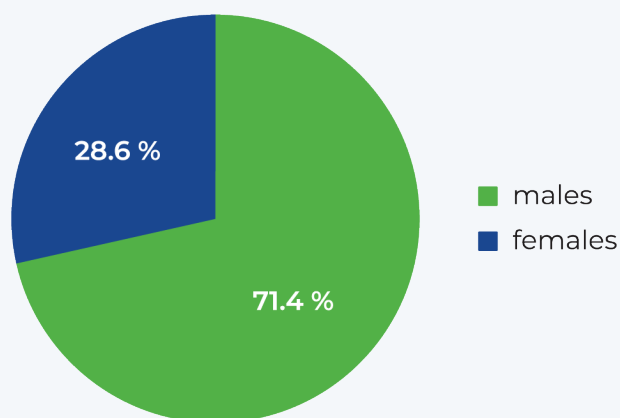
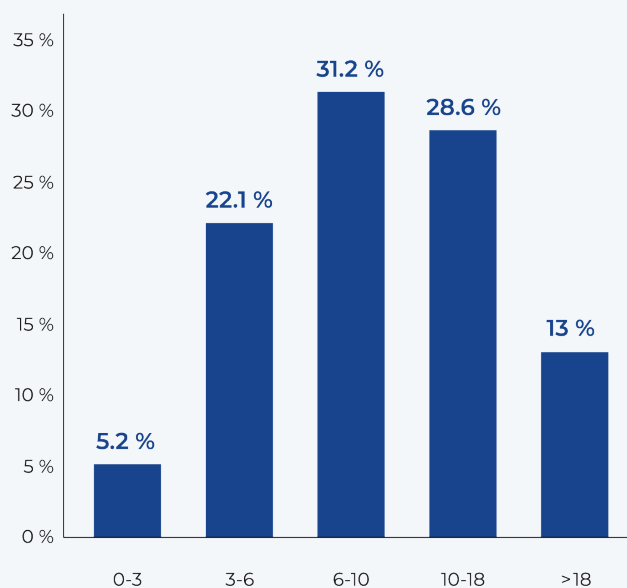


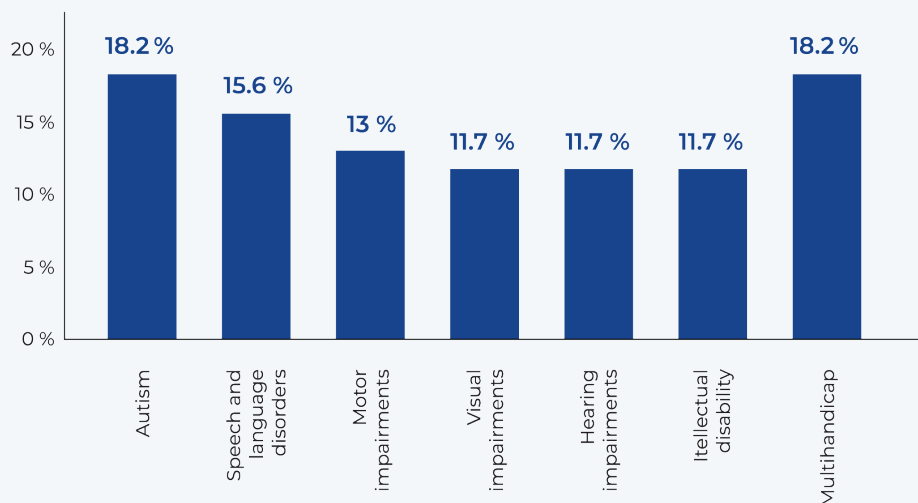
Figure 3 *Distribution of children by age*



motor impairments and there was also an equal distribution of children with visual impairments, hearing impairments and children with intellectual disability, i.e. 11.7% each (Figure 4).

Given that the first reactions, acceptance and expectations for the future depend on the way and time of discovering the disability in one's child, as well as on the availability of services and support, we will briefly focus on the analysis of respondents' answers related to

Figure 4 Distribution by type of child's disabilities



the discovery of disability in their children. Unfortunately, and contrary to all efforts for early childhood intervention, the largest number of respondents, 17 (22.1%) indicated that their child's disability was determined around the second year of life. In 16 respondents (20.8%), the diagnosis was made around 18 months of age, and the smallest number of respondents indicated that the disability was determined during pregnancy, 3.9% (Table 1). In correlation with the time of determining the disability with the age of noticing the first symptoms, 15 respondents answered that they noticed the first symptom of deviations in development around the first, that is, around the second year of life. As many as 14 respondents or 18.2% noticed the first symptoms immediately after birth. The most suspected signs, 44.2% of the parents (34 respondents) noticed in the area of Communication (social smile, eye contact, turning on sounds, reaction to own name), 31.1% or 24 examinees noticed a delay in motor development (lying on stomach, crawling, first steps...), seven parents (9.1%) pointed about the lack in their children's play (lack of imagination, imitation, disinterest...). Some other signs that were listed by a few examinees were lack of eye tracking, missing laughing for up to 8 months, hearing problems and reaction to voice etc. In addition to the ever-increasing awareness of the importance of early diagnosis leading to appropriate support and intervention for children showing developmental delays, in many countries the determination of the first signs of delayed development still takes place after the age of 18 months or two years. Similar to our findings are the results from Sidney obtained by Boulton and coworkers (2023). They found out that the average age at which caregivers identified developmental concerns was 3.0 years of age, but the average age of receiving a developmental assessment was 6.6 years. Only 46.4% of children received a diagnostic assessment by 5 years of age, even though 88.0% of caregivers were concerned about their child's development by that age. A popula-

tion-based cohort study provided in the USA (2022) by Straub and associates reported that the incidence and timing of neurodevelopmental condition diagnoses varied by insurance type, with diagnoses made earlier for privately insured children, relative to publicly insured children (Boulton, 2023).

Table 1 *Discovering the disability and noticing first signs*

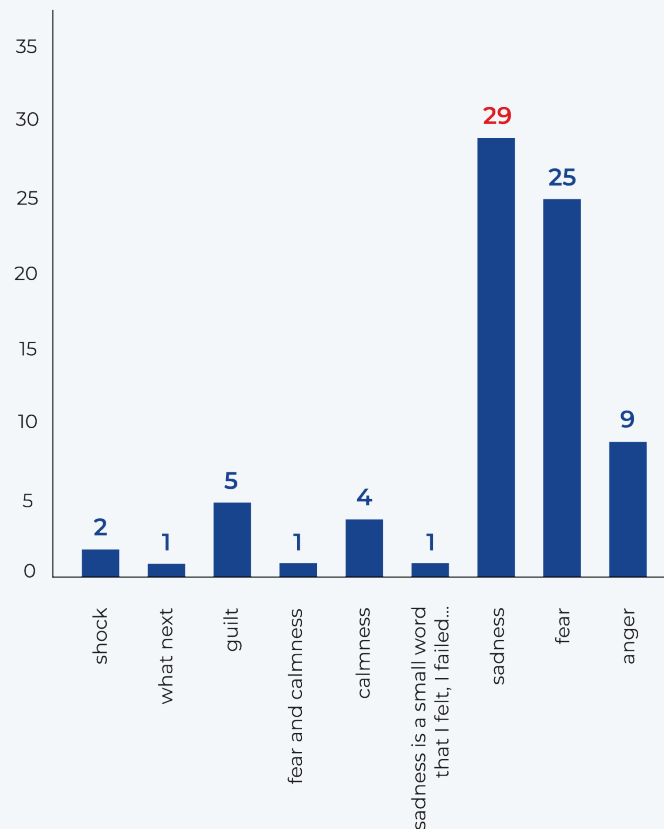
When you officially found out about your child's disability?			When did you notice the first sign?	
	N	%	N	%
During pregnancy	3	3.9	/	/
Immediately after birth	7	9.1	14	18.2
Up to 3 months	8	10.3	8	10.4
From 3-6 months	11	14.3	12	15.6
Up to 1 year	9	11.7	<b>15</b>	<b>19.5</b>
Up to 18 months	16	20.8	8	10.4
Up to 2 years	<b>17</b>	<b>22.1</b>	<b>15</b>	<b>19.5</b>
After 2 <sup>nd</sup> year	6	7.8	5	6.5

In the largest number of cases, delays in development were noticed first by the mother, i.e. 55 respondents or 71.4%, in 11.7% (9 respondents) the family pediatrician first noticed developmental disabilities, and in 3.9% of cases it was the father and the same number of grandparents. Based on the data from many studies we can state that the diagnostic process is rarely a positive experience for families and might therefore contribute to the stress felt by families of children with disabilities. Smith et al. (2010) also pointed out that in their study, in the largest number of cases, deviations in children's development were noticed and reported by mothers, especially in families where the child with a disability is the second child. Mothers in Smith's study reported that very few eligible children (2% at 12 months and 9% at 24 months) were identified by medical professionals as having any problems that could interfere with development.

The second part of the questionnaire referred to the emotional state of the parents and facing the disability, so to the question "What was the first thing you felt when you found out about your child's disability?" with the possibility of multiple answers, twenty-nine parents or 37.7% of the respondents answered that felt sadness, 25 parents (32.5%) had a huge fear. Anger

as the first feeling appeared in 9 respondents (11.7%), 5 (6.5%) respondents felt guilty, and 4 (5.2%) respondents felt calm (Figure 5). Starting from the fact that a large number of families break up after the birth of a child with developmental disabilities, and, it even leads to the separation of the spouses. The respondents were asked to answer what was the reaction of their partners when facing the disability. Forty-two parents (54.5%) pointed out that they talked openly with their partner and approached the best possible solution for their child, 13 parents (16.9%) faced distancing from their partner and going to work more often, 11 (14.3%) indicated that it took longer for the partners to accept the situation, and eight of the respondents, i.e. 10.4%, wrote that the partner still could not face the problem. Regarding support from relatives and friends, 70.1% (54) of the respondents had constant support from those close to them in every field, on the contrary, 15.6% (12) of them faced distancing by the close people around them, and 10.4% (8) of the parents answered that the people around them were scared and only came at their request.

Figure 5 Emotional state of parents when encountering a child's disabilities





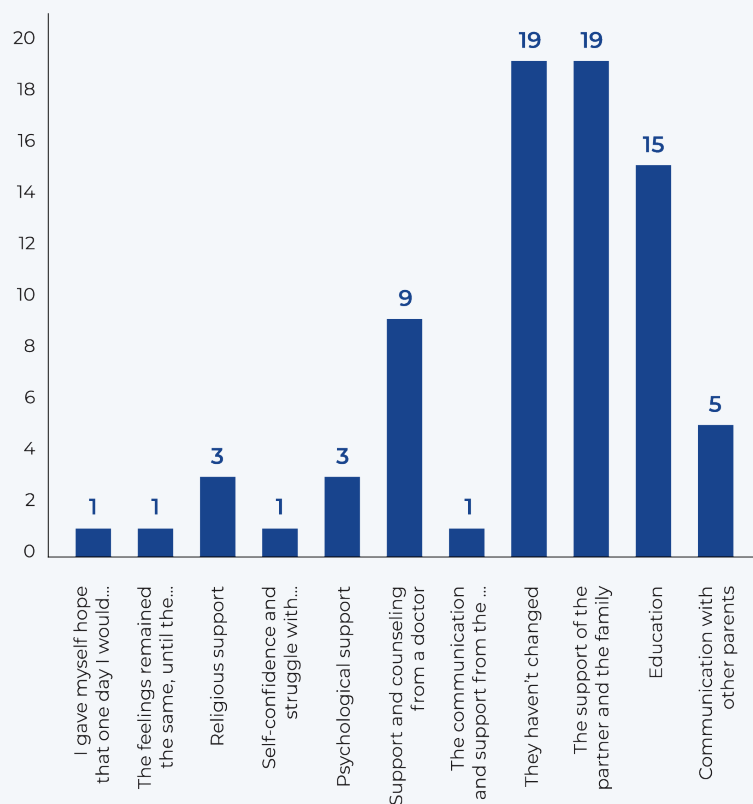
Regardless of gender, race, ethnicity, or nationality, parents when faced with information about their children's disability go through a range of emotions, starting from the most negative to complete acceptance of the new situation. In correlation to our results, Haiman (2002) found that most parents had to make changes in their social life and expressed high levels of frustration and dissatisfaction, although many try to maintain their routine life. In 1993, Tunali determined in his research that parents of children with disabilities face a series of problems, primarily financial, but also emotional, namely a sense of guilt, blaming each other, shame and a feeling of rejection by other family members. He also identified changes in family goals and expectations, related to the need for intensive care of children with disabilities, which often interferes with the work, and careers of parents, and some even leave work to care for children with disabilities. All these data were also confirmed by the respondents included in our study, although exactly 3 decades have passed since 1993 and things should be getting better with the progress of science and technology, but also of social order. Interestingly, religion and society have a great impact on parent's view of their child's disability, so in Indonesia, parents of children with disabilities consider that having a disability is God's will (Junaidi, Dewantoro, 2020)

The following open-ended question made the parents think and indicate what was the biggest concern that affected them at the moment when they found out about their child's disability. Most of them declared that the question "What to do next?" was a huge burden for them, they were worried about what would happen to the child after they were gone whether he would be able to manage, and who would take care of him if he cannot do it himself. A large number of parents also emphasized that they were most worried about the future of their child, whether he would be able to become independent, whether he would walk, whether he would start to speak, etc. Among other things, the parents indicated the fact that there are not enough professional staff, resources and centers in our country and that there is no one to provide them with help and professional support. Some of them pointed out that their biggest concern was that there was no cure for their condition, while others wondered if there would be an improvement in the condition with the current treatments or if the condition would last a lifetime. The parents were asked to answer whether there were changes in the initial emotions and feelings over time, but also to indicate the reason for the changes. Nineteen parents (24.7%) answered that there was no change in emotions at all and that they still faced the same difficulties. The same number of respondents answered that they face positive changes thanks to the support of their partner, 19.5% (15) pointed out that their feelings changed as a result of personal education, and 11.7% (9) said that they changed their negative feelings as a result of support and counseling from a doctor (Figure 6).

Naturally, the future brings great uncertainty and fear of the unknown, but for parents of children with special needs, the worry and anxiety are stronger. The analysis we made of

the literature led us to the conclusion that the same questions and worries about the future are everywhere, among our respondents, that is, parents are worried about the moment when they will not be able to take care of their children with disabilities. Parents expressed their concern about their child's ability to function in a less restrictive environment or less sheltered settings. Comparing ours with the social order in developed countries around the world, we can point out that parents of children with disabilities in countries in transition like ours have a greater burden on organizing the future of their children, as a result of the lack of sufficient service and support for independent living of persons with disabilities, as well as the realization of personal income (Kochovska et al, 2018, Rashikj-Canevska, 2023). Green, Darling and Wilbers (2013) made a meta-analysis of qualitative studies of parents of children with disabilities from 1960 to 2012 and like our findings pointed out that some aspects of the parenting experience have changed very little. Parents continue to experience negative reactions such as stress and anomie, especially early in their children's lives, and socially imposed barriers such as unhelpful professionals, and a lack of needed services continue to create problems and inspire an entrepreneurial response.

Figure 6 *Reasons for the change in initial feelings*



When it comes to changes, the respondents were asked if after the birth of a child with a disability, they were forced to make changes in their work status, i.e. if one of the parents was forced to leave their workplace, with as many as 39% (30 parents) answering that they were forced to leave the workplace, and 6.5% (5) answered that their partner left the workplace.

The third part of the questionnaire consisted of 12 questions conceptualized as statements graded according to the Likert scale, to which the parents had to express their agreement or disagreement with a score from 1 to 5. In this part, most of the questions are related to the difficulties that respondents face as parents of children with developmental disabilities.

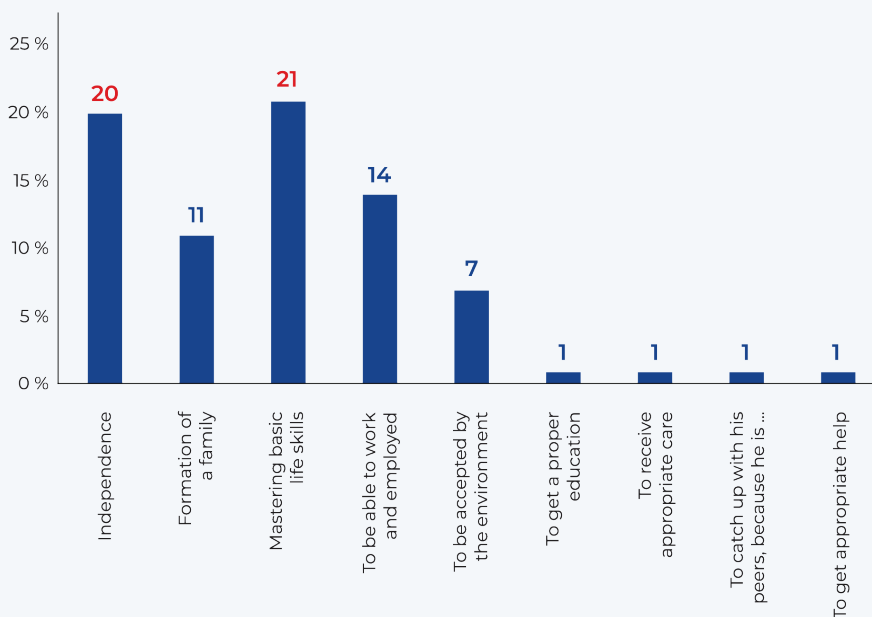
From the answers shown in Table 2, it can be concluded that the largest number of parents, 53 agree that the biggest challenge they are currently facing is finding the necessary institutions and services that will be appropriate for their child's needs. Forty-eight pointed out that the biggest challenge they are currently facing is the shortcomings in the educational process, 47 parents agreed that they experienced a great personal transformation as a result of caring for a child with a disability. A large number of parents (43) agree with the statement that they do not devote enough time to themselves and that they give up their social life. They least agree with the statement that they feel like they don't pay enough attention to the siblings of a child with disabilities (33 parents) and that they feel constant judgment from the surroundings (32 parents).

Table 2 *Parental statements*

N	Statements	1 – Do not agree at all	2 – Do not agree	3 – I neither agree nor disagree	4 – I agree	5 – I agree at all
1	My child needs constant supervision and support, and therefore I need to devote all my time to him.	12	3	20	13	29
2	I am having difficulty in providing full day supervision for my child.	20	6	17	10	24
3	I feel like I don't pay enough attention to his/her siblings.	<b>33</b>	3	17	6	18
4	I feel that I don't pay enough attention to myself.	13	4	6	11	43
5	I feel like I'm neglecting my own social life.	13	4	9	13	38
6	I feel constant judgment from the surrounding.	<b>32</b>	9	20	5	11
7	The biggest challenge we are currently facing is the financial part (lack of funds for therapies, medicines, etc.)	16	9	12	11	29
8	The biggest challenge we are currently facing is psychological stress.	12	4	15	6	40
9	The biggest challenge we are currently facing is my employment status.	27	11	18	3	18
10	The biggest challenge we are currently facing is finding the necessary institutions and services that will be appropriate for my child's needs.	5	6	8	5	<b>53</b>
11	The biggest challenge we are currently facing is the shortcomings in the educational process.	6	2	13	7	48
12	I believe that I experienced a great personal transformation as a result of caring for a child with a disability.	9	2	12	7	47

The last part of the questionnaire consisted of 7 questions, several of which were related to the plans and wishes for the children's future. Regarding the biggest wishes for their child about the future, most of the respondents, 27.3% (21) pointed out mastering of basic life skills as their biggest wish, 20 respondents (27%) highlighted the desire for independence of their children, 14 respondents (18.2%) have a desire for their child to be trained and employed according to their characteristics and abilities, and 14.3% (11 respondents) marked forming their own family and good quality of life for the child as their greatest desire (Figure 7).

Figure 7 The most important wishes for the child's future



## Conclusion

Understanding the first reactions and expectations for the future among parents of children with developmental disabilities is vital for providing appropriate support and intervention. By recognizing the range of emotional reactions, addressing the unique needs of each family, and promoting resilience, professionals can better support parents as they navigate the challenges and joys of raising a child with a developmental disability. Strengthening family relationships, providing accurate information and resources, and advocating for disability rights are essential components of this support.

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Jovana Uzelac, University of Novi Sad, Faculty of Medicine  
jovana.uzelac@mf.uns.ac.rs

Špela Golubović, University of Novi Sad, Faculty of Medicine  
spela.golubovic@mf.uns.ac.rs

Sandra Glamocak, University of Novi Sad, Faculty of Medicine  
sandra.glamocak@mf.uns.ac.rs

## Which areas of the child's development do parents perceive as priorities?

### SUMMARY

**Introduction:** In accordance with the “family in the center” approach, the parental perception related to the areas of the child’s development to which the support of experts should be directed is largely respected. This contributes to an easier selection of support, more active participation of parents in the process of its implementation, which aims at the child’s better functionality within that domain, as well as others that are connected to it. Aim: To determine which areas of the child’s development the parents perceive as important and what affects their perception.

**Materials and methods:** The sample consisted of 82 respondents, 42 parents of children with disabilities and 42 parents of children without disabilities, aged three to six years. The majority of children with developmental disabilities (59%) exhibit problems in speech and language development, and 32% exhibit combined disabilities. The two examined groups were equal in all variables, except for the variable related to work status. For the purposes of the research, an instrument was used to examine parental priorities (Treatment Priorities), which were completed by both groups.

**Result:** Parents of children with disabilities perceive the domains of Communication, Social Development/Interpersonal Skills and Pre-Academic Skills as important, and these are also the domains in which this group of children has the lowest level of functioning. Parents of children without developmental disabilities perceive the Self-Care domain as important, and at the same time, within that domain, this group of children has the lowest level of functioning.

**Conclusion:** Based on the results of the research, it was determined that the low level of functioning of children with developmental disabilities and children without developmental disabilities within certain domains of development affects the parental perception of that domain as more important than others.

38 **Key words:** *developmental domains, parental perception, children with developmental disabilities, children without developmental disabilities*



## Introduction

A paradigm shift in special education and rehabilitation represents a significant step in the process of changing a perspective, both in assessing child's abilities and providing an adequate support. This refers to redirecting approach from a child to a parent-centered, as well as to all those who are in direct contact with the child (Grant et al, 2016). Hence, with a "family-centered" approach, parents are given the opportunity to define their priorities and goals regarding professional support directed towards their child and an active and equal partnership with professionals in its implementation, contributing thus to higher levels of their satisfaction, acceptability, and engagement. Furthermore, all that can have a positive impact on a child's development, on the achieved outcomes, in addition to overcoming stress and improving quality of life perception (Ghanadzade et al, 2018; McWilliam, 2001). Parents' perceptions when seeking professional support arise from their perception of the priority of specific child development domains, which are changing according to the child's age, as well as through inclusion in different types of support over time. In this regard, the areas that parents consider as a priority at school age were related to participation in academic skills, recreation and leisure, while at adolescent age they were based on the area of daily living skills, and through emerging into adulthood, the perception of priorities has changed the focus on work related skills (Lai & Weiss, 2017; Baltus Hebert, 2014). In addition, the perception of priority domains for development will depend upon the type of disability the child has, the degree of disability severity, and the presence of comorbidities (Wilson et al, 2018).

Accordingly, priorities of parents of children with autism are mostly derived from the area of communication and social interaction skills, whereas mobility and self-care were identified as priorities of parents of children with cerebral palsy and parents of children with Prader Willi syndrome, who among other skills, identified the reduction in problem behaviour as a priority given that the core characteristics of this syndrome may resemble those of eating disorders, such as overeating (Ghanadzade et al, 2018; Pituch et al, 2010a; Chiarello et al, 2010). In other words, the results of the present study have shown the tendency of parents' perception of the extent to which areas the manifestation of their child's problems in functioning is most pronounced, that is, in those in which the child exhibits a low ability. In this regard, parents' priority perceptions for the child's developmental domains are based on deficits and needs for improvement in these areas, and not on the use of the child's strengths (Ghanadzade et al, 2018). Paying attention to this aspect gives us an insight into how parents perceive domains of a child's development, what is their priority, but also to what extent they need support in shifting the focus from the child's weaknesses into his/her strengths. This can be achieved by encouraging the domain of development within daily living routines, where the support will be in the areas in which the child has a certain level of ability, and thus help encourage the areas in which the child manifests various problems in functioning.

The objectives of the present research are:

To examine which areas of development parents perceive as a priority and determine whether there is a relationship between priority perceptions for the child's domain of development and problems in child's functioning.

Research objective is derived from the following hypothesis:

Hypothesis I: The areas of child's development, such as communication skills, social interaction skills and self-care are perceived as priorities by parents of children with disabilities.

Hypothesis II: There is a statistically significant relationship between parents' perceptions of priorities for the child's domains of development and the domains in which the child manifests the most problems in functioning.

## **Research Methodology**

### **Research procedure**

The consent to conduct research was obtained from the Ethics Committee of the Faculty of Medicine in Novi Sad. After obtaining the consent, a meeting was held with the directors of the institutions, where they were informed in detail about the research subject, goal and purpose of the research and the instrument that will be used. Afterwards, the directors gave their written consent to conduct research at the level of pre-school institutions in the northern part of Vojvodina. The detailed instructions with the objective to clarify each item in the questionnaire, were also presented to the employees of the above-mentioned institutions - educators, special education teachers and speech therapists, in spoken and then in written form. They delivered the questionnaire in an electronic format, with a written explanation for filling it out, so that they would be able to provide adequate help to parents when filling out the questionnaire. After obtaining consent to conduct research in those institutions, individual interviews were conducted with parents whose children reside in those institutions. Furthermore, the purpose of research objectives was explained to them, first in spoken, and then in written form. Each parent, if he/she agreed to be included in the research, gave written consent to participate in the research. Participation is voluntary and anonymous, and there is also the possibility of withdrawal at any stage of filling it out. Educators/special educators/speech therapists handed questionnaires to parents upon admission and dismissal of children. Parents who needed assistance in filling out the questionnaire, questions were presented orally and their answers were recorded. In the questionnaire, parents were given an e-mail address, as well as the phone number of the main researcher, so that, in case they have doubts, they could easily get in touch.

## Sample

Our sample of 82 respondents, included 41 parents of children with developmental disabilities and 41 parents of children with disabilities, ages 3 to 6, who attend preschool institutions in the northern parts of Vojvodina. In the total sample the presence of a problem in the domain/domains of development was noted in 50% of children. In the sample of children with developmental disabilities the largest percentage (59%) of problems was reported in the domain of speech and language development, followed by multiple disabilities, which occur in about 32% of the examined children. Within this group, the mixed disorders including speech-language and emotional development were the most common, and furthermore within speech-language, motor and social development. The largest percentage of parents (45%) indicated that they had extensive information about their child's problem, while 2.4% of parents were informed below average.

Socio-demographic data of parents of children with developmental disabilities and parents of children with disabilities are shown in the Table 1.

Table 1 *Socio-demographic characteristics of families of children with developmental disabilities and without disabilities*

Sample description	Without developmental disabilities	With developmental disabilities	Chi-square/ t-test	p-level
<b>Questionnaire filled out by</b>				
<i>mother</i>	36 (87.8%)	38 (92.7%)	.554	0.457
<i>father</i>	5 (12.2%)	3 (7.3%)		
<b>Parental age range</b>				
<i>range</i>	25-50 years	23-50 years	-0.220	0.826
<i>(M; SD)</i>	36.41 (6.50)	36.71(5.51)		
<b>Marital status</b>				
<i>Married</i>	34 (82.9%)	34 (82.9%)	1.167	0.558
<i>Divorced</i>	4 (9.8%)	2 (4.9%)		
<i>Extramarital union</i>	3 (7.3%)	5 (12.2%)		
<b>Place of residence</b>				
<i>urban</i>	30 (73.2%)	32 (78.0%)	.265	0.607
<i>rural</i>	11 (26.8%)	9 (22.0%)		

<b>Father's and mother's education level</b>				
<i>Primary school</i>	0 (0.0%)	1 (2.4%)	8.830	0.116
<i>Secondary school</i>	17 (41.5%)	15 (36.6%)		
<i>College</i>	4 (9.8%)	0 (0.0%)		
<i>University degree</i>	16 (39.0%)	14 (34.1%)		
<i>Master's degree</i>	4 (9.8%)	10 (24.4%)		
<i>Doctoral degree</i>	0 (0.0%)	1 (2.4%)		
<b>Employment status</b>				
<i>employed</i>	40 (97.6%)	34 (82.9%)	4.986	0.026
<i>unemployed</i>	1 (2.4%)	7 (17.1%)		
<b>Monthly family income</b>				
<i>10 000-50 000 RSD</i>	10 (24.4%)	8 (19.5%)	.905	0.636
<i>50 000-100 000 RSD</i>	19 (46.3%)	17 (41.5%)		
<i>More tha 100 000 RSD</i>	12 (29.3%)	16 (39.0%)		
<b>The number of household members</b>				
<i>Two members</i>	1 (2.4%)	1 (2.4%)	3.222	0.521
<i>Three members</i>	15 (36.6%)	10 (24.4%)		
<i>Four members</i>	20 (48.8%)	25 (61.0%)		
<i>Five members</i>	2 (4.9%)	4 (9.8%)		
<i>Six members</i>	3 (7.3%)	1 (2.4%)		
<b>Number of children</b>				
<i>One child</i>	1639.0%	1229.3%	2.094	0.553
<i>Two children</i>	2253.7%	2356.1%		
<i>Three children</i>	37.3%	512.2%		
<i>Six children</i>	00.0%	12.4%		
<b>Child's gender</b>				
<i>boy</i>	22 (53.7%)	27 (65.9%)	1.268	0.260
<i>girl</i>	19 (46.3%)	14 (34.1%)		
<b>Child's age</b>				
<i>3 years</i>	11 (26.8%)	6 (14.6%)	2.042	0.564
<i>4 years</i>	13 (31.7%)	15 (36.6%)		
<i>5 years</i>	9 (22.0%)	12 (29.3%)		
<i>6 years</i>	8 (19.5%)	8 (19.5%)		

According to Table 1, there is no statistically significant difference between the basic socio-demographic characteristics of families of children with developmental disabilities and families of children without disabilities. The only exception is the employment status variable in the case where a statistically significant difference between the examined groups has been found. In the group of parents of children with disabilities, there is a higher percent-

age of those who are unemployed compared to parents of children without disabilities (17.1% versus 2.4%).

## Instrument

For research purposes, two instruments were used:

The respondents first filled out a general questionnaire related to demographic data, as well as domains of the child's functional difficulties, divided into two sections.

The first part included general information about the parents, comprising 10 questions, which are related to age, place of residence, level of education, occupation, employment and marital status, monthly income, number of children and family members, while the second part includes general information about the child and consists of six questions, which are related to the presence of a developmental disability, the domain/domains in which it is manifested, gender, child's age and the level of parent's information and knowledge about the child's problem. Most of the questions in this part are closed-ended, where parents indicate the answer that applies to them or their child, but also a few open-ended questions, requiring the completion of the statement.

The second questionnaire, designed to examine parents' priorities (Treatment Priorities), was developed by prof. Jeff Sigafoos, prof. Vanessa Green, and prof. Mathew McCraden. In addition, we applied the Treatment Priorities questionnaire, obtaining written permission for its use from the corresponding author, prof. Jeff Sigafoos. Moreover, for research purposes, it was translated from English to Serbian, with changes that have been made in accordance with the characteristics of the target group. The aim of the present questionnaire is to identify parents' priorities when seeking professional support, in relation to the child's current abilities, as well as to observe the extent to which children receive support required to develop skills that have been identified as a priority by their parents. In its original version, the questionnaire consists of questions related to 54 skills, representing 10 areas of the child development, within which specific skills were listed (self-care skills - 7 items, domestic living skills - 5 items, community living skills - 5 items, work related skills - 4 items, recreation and leisure - 5 items, communication skills - 8 items, motor skills - six items, social skills - 7 items, academic skills - 6 items and problem behaviour - 11 items). In accordance with the age group that includes children between the ages of three and six, the areas of daily living skills within the domestic and community living were excluded from the questionnaire, as well as those related to work, while the area of academic skills was renamed to pre-academic, with changes that have been made in individual skills within it. Namely, the item related to listening to lessons was renamed to listening to educators/professionals, while the skills related to reading, writing and calculation, in accordance with the age-expected performance, were renamed to "reading" picture books, counting/recounting and graphomotor activities. Also, from the area

related to motor skills, the part related to using a wheelchair was excluded, while from the area of social skills, the item related to creating emotional connections was excluded. Each of the mentioned areas is divided into three sections. The first part refers to the child's current abilities, and the responses were rated on a scale ranging from 0 to 4, where 0 implies independent functioning/independence, and 4 implies that the child is completely dependent on others when performing the same. The second part refers to the extent to which the given skills are a priority for parents, and responses are also ranked from 0 to 4, where 0 means no priority, and 4 means that the given skill is perceived as a very high priority. The third part involves the child's involvement in support within the skills that the parents perceived as a priority, and the responses are ranked on the scale ranging from 0 to 2, where 0 means yes, 1 no, and 2 I'm not sure. The area concerning problem behaviour is somewhat different in its first part, since it ranks the extent to which it is problematic to control the child's behavior. In the same context, 0 means that the above mentioned is not a problem at all, while 4 means that controlling it implies a crucial problem. Responses are evaluated by observing the ranking scores for each skill within the domain (from 0 to 4, or from 0 to 2, depending on the part), with a higher number indicating a higher parents' priority for that area. The questionnaire was used in a large number of research studies. It is reported that the validity index is 0.99 (Content Validity Index) (Ghanadzade & Alimi, 2016). It takes 10 minutes to complete the questionnaire, it will be distributed in an online form, via Google questionnaire, and the respondents will be supported while filling it out by examiners and professionals employed by the aforementioned institutions.

### Statistical analysis

The SPSS 22.0 software package was used for data entry and processing. For the purposes of analysis and description of the structure of the sample by relevant variables, frequency and percentage displays were used to show the representation of a certain category or response. Descriptive statistics methods were used to determine measures of central tendency (arithmetic mean), measures of variability (standard deviation) and extreme values (minimum and maximum) of observed numerical features. To check the reliability of the scale as a whole, the measure of internal consistency expressed by Cronbach's alpha coefficient was used. Although specific measures used met the criterion of a continuous (numerical) variable, the broken normality of the distributions allowed the use of non-parametric methods within determined hypotheses. In the framework of comparative statistics, the following techniques were used: Chi-square test, t-test and Spearman's rank correlation coefficient. In the applied tests, the limit values of the risk probability are at the significance level of 95% ( $p < 0.05$ ) (difference in statistical parameters significant) and 99% ( $p < 0.01$ ) (difference in statistical parameters highly significant).

## Research Results

In order to test the reliability of the Parental Priorities Questionnaire (TP), Cronbach's alpha coefficient was calculated.

Table 3 shows Cronbach's alpha coefficient for each area of the Parental Priorities Questionnaire (TP) individually, including both the parent's priorities dimension and the child's current abilities dimension.

Table 3 Scale reliability measure

Questionnaires /Dimensions		Item number	Cronbach's alpha coefficient
<b>Current abilities</b>	Self-care	6	0.919
	Leisure and recreation	4	0.846
	Motor skills/Physical development	5	0.882
	Communication	7	0.950
	Social development/Interpersona skills	5	0.821
	Pre-academic skills	5	0.863
	Problem behaviour	10	0.836
<b>Parents'priorities</b>	Self-care skills	6	0.978
	Recreationand leisure	4	0.947
	Motor skills/Physical development	5	0.969
	Communication skills	7	0.994
	Social development/Interpersonal skills	5	0.975
	Pre-academic skills	5	0.977
	Problem behaviour	10	0.977

Based on the data obtained from the present research, it was determined that the reliability of the dimensions of *the Parental Priorities Questionnaire* (TP), both in the area of the assessment of current abilities and in the area of assessment of priorities is excellent, i.e. that all dimensions have good metric characteristics expressed by Cronbach's alpha coefficient. In order to determine whether there are differences between parents of children with developmental disabilities and parents of typically developed children in defining priorities in seeking professional support, as well as in assessing current abilities, t-tests for independent samples were applied. Alternatively, a series of the Mann-Whitney U tests were applied in the case where the deviation of the domain from the normal distribution was noted. The following tables show the values of t-tests and the level of significance, as well as arithmetic means and standard deviations.

Table 2 Differences in the average achievement between the two examined groups with regard to dimensions of the Parental Priorities Questionnaire (TP) - the area of priority assessment for seeking professional help

		Groups:	Arith. mean	Std. deviation	Mann-Whitney U test	df	p-value
<b>Current abilities</b>	Self-care	Without disabilities	0.75	0.81	-3.027	80	0.003
		With disabilities	1.41	1.14			
	Recreation and leisure	Without disabilities	0.27	0.45	486.0*	80	0.000
		With disabilities	0.96	1.04			
	Motor skills/Physical development	Without disabilities	0.03	0.16	530.5*	80	0.000
		With disabilities	0.43	0.85			
	Communicationskills	Without disabilities	0.22	0.41	-6.071	80	0.000
		With disabilities	1.45	1.24			
	Social development/Inter-personal skills	Without disabilities	0.11	0.22	447.5*	80	0.000
		With disabilities	0.65	0.79			
	Pre-academic skills	Without disabilities	0.91	0.46	-4.990	80	0.000
		With disabilities	1.67	0.86			
	Problem behaviour	Without disabilities	0.26	0.33	-5.029	80	0.000
		With disabilities	0.83	0.65			
<b>Parents' priorities</b>	Self-care skills	Without disabilities	1.91	1.42	-1.517	80	.133
		With disabilities	2.38	1.37			
	Recreation and leisure	Without disabilities	1.48	1.42	-2.527	80	.013
		With disabilities	2.23	1.26			
	Motor skills/Physical development	Without disabilities	1.10	1.31	-2.672	80	.009
		With disabilities	1.91	1.42			
	Communicationskills	Without disabilities	1.48	1.41	-4.850	80	.000
		With disabilities	2.90	1.23			
	Social development/Inter-personal skills	Without disabilities	1.54	1.38	-3.332	80	.001
		With disabilities	2.51	1.26			
	Pre-academic skills	Without disabilities	1.83	1.48	-3.372	80	.001
		With disabilities	2.80	1.11			
	Problem Behaviour	Without disabilities	1.29	1.34	-2.824	80	.006
		With disabilities	2.15	1.40			



According to Table 2, the results of the applied tests show that the mean scores between the examined groups (children with developmental disabilities and children without developmental disabilities), on the domains of the TP questionnaire, both in the dimension concerning parents' priorities and in the dimension concerning assessment of the child's current abilities, statistically significantly differ. In other words, differences in the assessment of current abilities are reported in the domains of self-care skills, recreation and leisure, motor skills/physical development, communication skills, social development/interpersonal skills, pre-academic skills and problem behaviour, as well as differences in defining the priority of seeking professional help in the mentioned domains between the mentioned groups, with the exception of the domain of self-care. Thus, parents of children without developmental disabilities identifies the domains of communication, social development/interpersonal skills and pre-academic skills as a priority, while parents of children with developmental disabilities identified the domain of self-care as a priority. In general, on the given domains, there is a positive correlation between the child's current abilities and parents' perception of their priority.

## Discussion

Based on the results of the present research, parents of children with developmental disabilities perceived all the areas offered as priorities - self-care, recreation and leisure, motor skills/physical development, communication skills, social development/interpersonal skills, pre-academic skills and problem behaviour. However, a more detailed analysis shows that parents of children with developmental disabilities reported the areas of communication, pre-academic skills and social interactions as the highest priority, and that the areas of motor skills/physical development and problem behaviour, compared to others, are reported as lower priority. This can be related to the fact that, in the largest number of children included in our sample, problems predominantly occur in the domain of speech and language development, and that, in relation to multiple disabilities, one of them always involves speech and language, which greatly affects communication itself and all skills within it. Also, in relation to children's age included in the research, it is acceptable that the area of pre-academic skills is on the priority list, because they usually become the focus in this period, and by the age of six they should be fully adopted, due to starting school and mastering the requirements related to reading, writing, arithmetic and other academic challenges. With regard to the aspect of motor skills/physical development, which, according to the results of the present research, is reported as a lower priority, this may be the result of the very small percentage of children who manifested problems within this domain, as well as the fact that in our sample they occur in very small numbers and as an integral part of multiple disorders. Similar results were obtained by Ganadzade et al. (Ghanadzade et al, 2018), where, in addition to

the areas of social interactions, communication and academic skills, the area of self-care is also reported, as well as community living skills. Self-care was reported as parents' priority in several studies. (Rodger et al., 2004; Verketeker et al., 2006; Siebes et al., 2007; Pollock & Stewart, 1998). On the other hand, in the research conducted by Pituch et al. (Pituch et al., 2011), the area of self-care was not perceived as a high priority by parents; however, in addition to those that have been mentioned by Ganadzade et al. (Ghanadzade et al., 2018), the areas that include recreation and leisure and work related skills have been also reported. Additionally, Pituch et al. (Pituch et al., 2010b), in the study involving parents of children with Cri du Chat syndrome, reported the area of communication, community living and academic skills as a priority. These results can be related to the fact that the research included children and adolescents at different ages (2 - 21 years old), with different areas of focus on each of them. Communication and social interaction skills were perceived as a high priority by parents in the study by Rodger et al. (Rodger et al., 2004), which included children between 2 and 4 years. The other authors (Petrina et al., 2015; Lai & Weiss, 2017; Whitaker, 2007) also singled out the area of social interaction, although Petrina et al. singled out social skills, as well as emotional functioning. Friendship making skills have been perceived as very close to social interactions and emotional functioning, and progress in these two domains encourages its improvement. Therefore, this is the main reason why, as indicated by parents' perspective, areas of social interactions and emotional functioning are more important aspects, and for that reason listed as a priority. On the other hand, Rodger et al. (Rodger et al., 2004) prioritized the aspect of problem behaviour, which is contrary to what is stated in our study, in which problems in the area of self-care were not perceived as a priority. Furthermore, parents' perception of problem behaviour as a priority was reported in another study by Pituch et al. (Pituch et al., 2010a), as well as in the study by Wilson et al. (Wilson et al., 2021) and in the study by Trickett et al. (Trickett et al., 2017). The difference is reflected in the aspects of problem manifestation, where parents of children with autism spectrum disorders perceive as a priority the reduction of inappropriate behavior, self-stimulatory behaviors and tantrums in the study by Pituch et al. (Pituch et al., 2011), or sleep problems in the study by Wilson et al. (Wilson et al., 2021) and Trickett et al. (Trickett et al., 2017), whose study included children with Angelman syndrome. Parents of children with Prader-Willi syndrome emphasize the importance of reducing eating disorders, that is, overeating (Pituch et al., 2010a). The lack of consideration of the importance of perceiving behavioral problems can be partially explained by the parents' different perceptions that is, considering this disorder as a separate entity, and not as an integral part of the child's problem. With regard to the aspect of motor skills/physical development, which, according to the results of our research, is perceived as a lower priority, this may be due to the very small percentage of children who manifest problems within this domain, as well as the fact that they occur in very small numbers in this sample and as an integral part of multiple disabilities. On the other hand, the results of the research by

Chiarello et al. (Chiarello et al., 2010) which included children with cerebral palsy, between 2 to 21 years of age, mobility has been reported as an important aspect of motor development. Also, in the same study, the areas of self-care, recreation, social skills, but also productivity, mostly within the home and school environment, were perceived as priorities. Mobility, in addition to the mentioned areas, was also recognized as a priority by parents in the research conducted by Brandao et al. (Brandao et al., 2010), especially in children whose motor functioning is at level 4 and ages 3 - 6 years old, but also in the research conducted by Law et al. (La et al., 1998). According to Knox (Knox, 2008), standing and walking are perceived as priority motor skills by the parents of children whose motor functioning is at level 1 to 4, however, in addition to the above mentioned, at level 3 and 4, mobility on the floor is also a priority, especially at the age of up to 4 years. With respect to motor functioning at level 5, in addition to the above mentioned, sitting and communication are regarded as the highest priority.

Parents' priority perception of the developmental domain largely depends on the level of the child's abilities within the mentioned area. This means that parents perceive as a priority those areas in which the child has the most problems in functioning, that is, the lowest level of ability. In this regard, children with developmental disabilities have the most problems in functioning in the area of communication, social interaction and pre-academic skills, while, on the other hand, children without developmental disabilities have the most problems in functioning in the area of self-care. The aforementioned data are confirmed by the results of the research by Ghanadzade et al. (2018), where the relationship between parents' priorities and the child's current abilities was shown to be linear. The above data support the fact that parents focus on solving problems in functioning and improving the level of skills in the above areas. On the other hand, in the studies conducted by Pituch et al. (Pituch et al., 2010) and Pituch et al. (Pituch et al., 2011), findings showed slightly different results with regard to the areas of communication and academic skills and parents' perception. The results display a quadratic relationship between the area of communication and academic skills and their priorities. As for the domain of communication, the results indicated that parents of children with medium and high levels of impairment, perceive this area as a high priority, compared to parents of children who manifested minimal deficits. With respect to the area of academic skills, it is perceived as a very low priority by parents whose children have minimal or deficits are not manifested, and with the increase of the degree of deficit, the parents' perception of priority of this area also increased. Wherein, in cases of high degree of impairment, the consideration of academic skills as a priority is again reduced to a minimum. Parents, in general, perceive certain areas as a higher priority, when children within them have medium or lower abilities, and as lower when children show a high level of ability. Interestingly, differences in perception occur with regard to the aspect of communication and academic skills because they have been ranked as higher priority if children manifested a certain level of ability within them, and ranked as lower priority, with an increase

in the level of ability, that is, functioning. This can be associated with the concept of the zone of proximal development, which is a Vygotsky's construct, because these skills were emerging, and were ranked as a priority, which means that their consideration moves in the direction of recognizing strengths in child's functioning (Gahandzade et al, 2018; Pituch et al., 2011). The relationship between parents' priorities when seeking professional support and the child's current abilities can also be seen through a study conducted by Knox (Knox, 2008), which supports the fact that aspects of standing and walking are perceived as a priority by parents of children with spastic diplegia and parents of children with hemiplegia perceived a hand function as a priority, while parents of children with spastic quadriplegia and athetosis, identified aspects of communication, mobility on the floor, sitting and skills related to feeding as a priority i.e. areas of motor development and self-care. In other words, they considered as priority those skills that are most difficult for the child to learn, due to his/her condition.

## Conclusion

Based on the obtained results, we can conclude that the first hypothesis which refers to the areas of development that parents perceived as a priority was partially confirmed, precisely by the results that the parents of children without developmental disabilities perceived the areas of communication, social development/interpersonal skills and pre-academic skills as priorities. The second hypothesis, which refers to the presence of a relationship between the child's current abilities and the area of the child's development that parents perceive as a priority, was confirmed. We can conclude that both parents of children with developmental disabilities and parents of children without developmental disabilities, regarding the priority perception of the child's domains of development, in most cases focus on the child's weaknesses, selecting specifically those areas of functioning in which the child has the most problems. Therefore, it is necessary to direct them towards their child's strength - based approach, which can be used for the purpose of improving other areas. Furthermore, it is necessary to encourage them to get involved even more in the provision of support itself, both by defining priorities and goals, and by directly participating in encouraging the child's development, using everyday situations as learning opportunities. On the other hand, given that the area of self-care is perceived as a priority by a large percentage of parents of children without developmental disabilities, we have come to the conclusion that it is necessary to empower parents, in terms of understanding its relevance and importance, to improve skills within its framework, but also in terms of how to achieve it as stated above.

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Jasmina Troshanska from MK, University of Tetovo  
jasmina.troshanska@unite.edu.mk

Teuta Ramadani Rasimi from MK, University of Tetovo  
teuta.rasimi@unite.edu.mk

Natasha Chichevska Jovanova from MK, University Ss. Cyril and Methodius  
natasac@fzf.ukim.edu.mk

Olivera Rashikj Canevska from MK, University Ss. Cyril and Methodius  
oliverarasic@fzf.ukim.edu.mk

## Healthcare access barriers for individuals with autism: The awareness of medical professional

### SUMMARY

**Introduction:** Autism spectrum disorder (ASD, autism) is a complex, life-long disorder characterised by two core symptoms, which range in severity: persistent deficits in social communication and social interaction, and restricted and repetitive patterns of behaviour. These behaviours are mainly unfamiliar to healthcare workers, hence the access to healthcare services for individuals with autism becomes challenging. This presentation aims to discuss results regarding the knowledge of autism among medical workers based on their experience and to highlight its importance as a possible barrier to accessing healthcare services.

**Methodology:** To examine the knowledge of autism, a survey was conducted involving 70 medical personnel. In addition, to gather more detailed information about specific experiences of the medical personnel, an interview was conducted with 6 medical doctors.

**Results:** All respondents said that they faced difficulties when working with children with autism - 43% had a problem communicating during the medical examination, while 41% found it difficult to administer medical therapy. In hospitals, individuals with autism are usually referred to one of the medical personnels in the department who is highly skilled in providing services. According to the information from the interviews, this highly skilled person usually has constant close contact with a person or child with autism in their family or friends circle.

**Conclusion:** Medical personnel agreed that they need additional education, informative material, materials for visual communication, and more time to perform a medical examination of patients with autism. Also, they stated that there was a lack of support for families and provision of resources in order for them to prepare children with autism before a doctor's visit.

**Key words:** *autism, healthcare, medical personnel*



## Introduction

In recent decades, much research has focused on the diagnosis, different treatments, education, or inclusion of children with autism spectrum disorders. On the other hand, a minor part of the research focused on the quality of availability of the institutions and services where these children are treated or educated. Every visit to the medical facilities is stressful for every parent, but experiences show that visiting a doctor with a child with autism greatly stresses the parent and child. A child's communication and interaction problems, sensory needs, and behavioural challenges can significantly complicate a medical examination.

It remains unclear why this is happening when it is well known that according to the international documents for human rights, every person must have accessible health services for general healthcare needs like the rest of the population, including promotive and preventive services and treatment of acute and chronic illness.

The reason for all this probably lies in the inaccessibility of sufficient information about people with autism during studies in medical staff, the inaccessibility of additional education that will follow the new inclusive trends of society or the insufficient awareness of the child's family with autism.

This research aims to discover the barriers faced by children with autism and their families when visiting medical facilities and awareness of autism among medical professionals. Assessing this problem can set the base for establishing more effective medical treatment and improving the quality of life for people with autism and their families. A total of 70 medical personnel participated in the research. Analyses of the survey responses verified the lack of education, informative material, materials for visual communication and more time for medical examination of patients with autism. The information evaluated here can be used for further research, raising awareness, improving the education of medical professionals, and supporting families.

## Objective

Autism spectrum disorder (ASD) is a neurological and developmental disorder affecting how people interact, communicate, learn, and behave. Although scientists can diagnose autism at any age, it is described as a "developmental disorder" because symptoms generally appear in the first two years of life (National Institute of Mental Health, 2023). To meet diagnostic criteria for ASD according to DSM-5, a child must have persistent deficits in social communication and interaction. This means a child has deficits in social-emotional reciprocity, nonverbal communicative behaviours used for social interaction, and deficits in developing, maintaining, and understanding relationships. Also crucial for diagnosis is that the child manifests restricted, repetitive patterns of behaviour, interests, or activities, inflexible adherence to rou-



tines, or ritualized patterns of verbal or nonverbal behaviour, sensory issues, or unusual interest in sensory aspects of the environment. All these symptoms must be present in the early developmental period. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay (Center for Disease Control and Prevention, 2022). According to the CDC, around 1% of the world's population has autism spectrum disorder – over 75,000,000 people. In 2022, 1 in every 100 children are diagnosed with autism spectrum disorder and in 2023, the CDC reported that around 1 in 36 children in the U.S. is diagnosed with autism. Autism prevalence has increased 178% since 2000. The country with the highest rate of diagnosed autism in the world is Qatar, and the country with the lowest rate is France. Also, statistics showed that medical expenditures for children and adolescents with autism were 4.1 to 6.2 times greater than those without autism (Zauderer, 2022).

Due to the diagnostic process of children with autism, but also due to the presence of medical comorbidities such as epilepsy, bowel disorders, cranial abnormalities, diabetes mellitus, sleep disorder or muscular dystrophy, adolescents with ASD often visit medical institutions (Kohane, McMurry, & al., 2012).

According to WHO: "People with autism require accessible health services for general health-care needs like the rest of the population, including promotive and preventive services and treatment of acute and chronic illness. Nevertheless, people with autism have higher rates of unmet healthcare needs than the general population. They are also more vulnerable during humanitarian emergencies. A common barrier is created by healthcare providers' inadequate knowledge and understanding of autism" (World Health Organization, 2023). EU reports that professionals need better knowledge: "Professional understanding of risks for poor health conditions and behaviours in autistic adults is uneven across health areas" (ASDEU, 2020). Studies show that people with autism die 12 years earlier than the general population, and one reason is poor access to health services (Simpson, 2020).

Because of the specific characteristics, children and youth with ASD adjust to new environments more efficiently with a structured routine (National Institute of Mental Health, 2023). Also, a hospital setting is incredibly challenging for them, considering the sensory input, social demands, and disrupted routine. Some of the children can have challenging behaviour while visiting medical institutions. Negative interactions with the healthcare system and concerns about the quality of care provided to this population have been reported by individuals with ASD, their families, and healthcare providers (Feil, 2014). Patients need to be treated as individuals, and healthcare professionals need to take the time to learn more about people with autism and Asperger syndrome, for example, what makes them anxious and their pre-

ferred communication method (Aylott, 2010). In Macedonia and the region where the health system is at a lower level, there is a lack of regulations for adequate health care for people with autism spectrum disorders. Therefore, it is necessary to conduct research in this area and raise awareness about autism in medical institutions. Although the results are part of a small sample, they will provide a base for further research and improvement of health services by implementing project activities in the field.

## Research Problems and Hypotheses

The only official document in the RN Macedonia where we can find data about the health-care system and autism is “Official Gazette of the Republic of Macedonia”, which states that “Measures to be taken to improve the situation”: 1) training of health professionals working in prevention teams for autism recognition; 2) introduction of M-chat as mandatory screening of all children aged from 18 to 24 months old in mandatory systematic examinations of preschool children” (Ministerstvo za zdravstvo, 2018).

Our experience shows that in the diagnostic process, when parents are concerned about the child's development, sometimes, medical professionals are not informed enough to meet the problem of the child and parents. As a result of insufficient knowledge of the problem, the diagnosis of children with autism is late. Also, medical students have neither theoretical nor practical experiences with specific tools for recognizing early signs of autism. In our country, many families receive advice from medical professionals on using alternative treatments and methods which are unproven and uncertain. This practice shows us a lack of information about autism and the use of information from the Internet that, although helpful, can sometimes be confusing, inappropriate and inaccurate.

Despite this information, around Europe and the world, organizations work on improving awareness of medical professionals and improving medical services by creating and producing materials and training for medical institutions and families (SANTE BD, 2023).

This research aims to discover challenges in medical treatment by medical staff and awareness of autism in medical professionals. Assessing this problem can set the base for establishing more effective medical treatment and improving the quality of life for people with autism and their families. Based on the goal, we raised two research questions:

1. Do medical professionals embrace basic knowledge of ASD?
2. What are the challenges of medical treatment of children and adults with autism based on medical professionals' perceptions?

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Based on the research question, we yielded several hypotheses. The first one: 1. Medical pro-

professionals often encounter patients with autism, from whom more children than adults; 2. Medical professionals have basic knowledge of autism and can recognize the characteristics of children with autism, 3. The following hypothesis was that medical professionals had attended training to recognize early signs of autism, and the last one 4. Medical Professionals face difficulties in the medical treatment of patients with autism.

## Methods

The study aimed to survey participants who work in the hospital (secondary healthcare), which covers the Polog region in RS Macedonia, with a population of 251 552 citizens (Wikipedia, 2023). The participants work in the hospital as medical doctors with different profiles. After analyzing the literature and existing information in Macedonia, we created a questionnaire for this research. We were using the Knowledge About Childhood Autism Among Health Workers (KCAHW) questionnaire (Baker et al., 2008) to guide survey creation for this research, and the terms used in the survey adapted to the local language, which did not identically translate the terms. After piloting, a survey was used for the research. Surveys were distributed to the potential participants using the link by Google Forms and were available from June 1<sup>st</sup> to July 2<sup>nd</sup>, 2022. The survey had 18 questions, and the first five questions collected demographic information from the participants about gender, age, nationality, current working area, and years of service as doctors. The remaining questions targeted their awareness of autism spectrum disorders. When the survey ended, raw data was moved to Excel, and the frequencies were counted for the number of responses in each category. Due to the small sample, the data were analyzed through descriptive statistical procedures. Seventy medical doctors participated in the study, of which 39 were women, and 31 were men. The youngest respondent was 32 years old, and the oldest was 63. The arithmetic mean of the age was 49.34. Doctors with different working profiles and experiences (Table 1).

Table 1 Socio-demographic and working experience profile (n=70)

Socio – demographic and working experience profile	Parameters	Frequency	Percentage
Gender	Female	39	56.7 %
	Male	31	43.3 %
Nationality	Macedonian	18	25.7 %
	Albanian	52	74.3 %
Current working area	General practitioner	12	17.1 %
	Pediatric Medical	13	18.6 %
	Internal medicine	7	10 %
	Surgery	10	14.2 %
	Intensive care	4	5.8 %
	Cardiology	6	8.6 %
	Orthopedy	7	10 %
	Psychiatry	2	2.8 %
	Anesthesiology	6	8.6 %
	Immunology	2	2.8 %
	Otorhinolaryngology	1	1.4 %
Years of experience as doctor	Less than 10 years	12	17.1 %
	From 10 to 20 years	29	41.4 %
	From 20 to 30 years	23	32.9 %
	More than 30 years	6	8.57 %

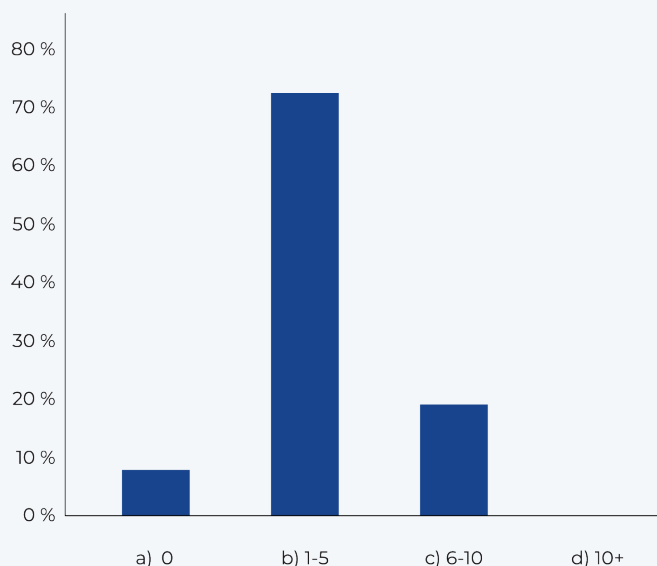
In order to get more in-depth information about doctors' experiences, six interviews were conducted with doctors working in hospitals from other cities in Macedonia. Doctors were between 45 and 52 age old; 5 were women and one man. One of the doctors was also the mother of a child with autism. The questions in the interview were open-ended to allow the doctors to express all the challenges they face when contacting patients with autism, their experiences and readiness to work with these patients, and also what they can do to improve conditions. Interviews were conducted online on Zoom from June 1<sup>st</sup> to July 12<sup>th</sup>, 2022. To analyse the Interviews, we used Atlas software, with transcribed data divided into categories, encoded and data grouped in 4 themes.

## Results and discussion

### Results of the survey processing

Regarding the first hypothesis, “Medical professionals often encounter patients with autism, from whom more children than adults”, starting with the question that doctors responded, “How many patients with autism have they met in the last six months?”. To this question, 7% of the doctors answered that in the last six months, they did not have a patient with autism, 74% of the doctors answered that they had 1-5 patients with autism, 19% of the patients met 6-9 patients with autism, and none of the doctors met more than ten patients with autism (Figure 1). Furthermore, in the next question, “The age of autistic patients that visit the doctor more often”, 78% of them say that the age of autistic patients whom they go to the doctor more often is 2-3 years old, 15% of them declare that it is the age group of 4-5 years and 6% of them declare that it is the age group over six years old (Figure 2). Based on the results, we can conclude that the first hypothesis is confirmed.

Figure 1 *Percentage of the doctors meeting children with autism in the last six months*



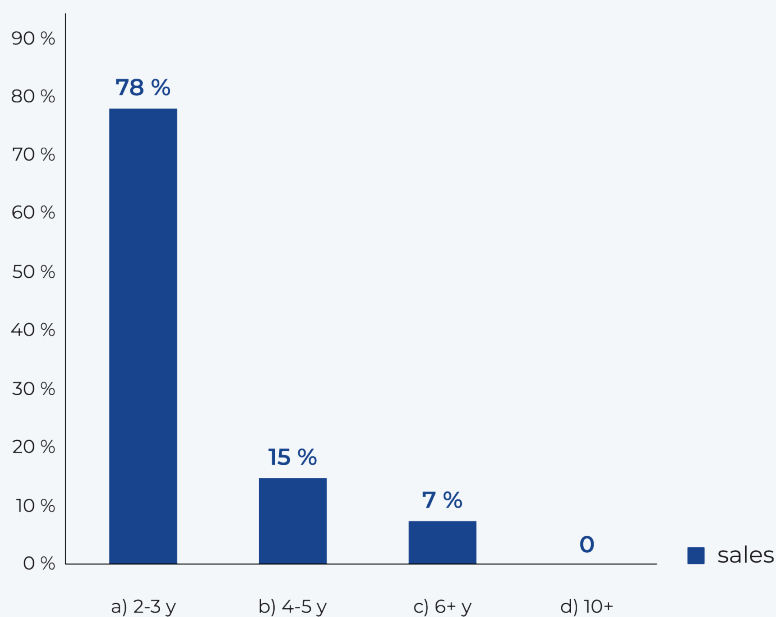
The second hypothesis is “Medical professionals have basic knowledge of autism” they can recognize the characteristics of children with autism. We will refer to several questions of the instrument to answer it, and we will refer to the survey question: “Do you know what autism is? “All respondents, 100% of doctors, said that “yes” they knew about autism. Furthermore, table 1 presents seven questions that are signs of recognizing autism early on and concerning awareness of autism and its recognition by medical professionals. It can be noted that

the highest percentage of doctors (88.6%) notice the child's behaviour as deaf. Furthermore, autism is associated with epilepsy (62.8%), absence of speech (61.4%), eye contact disorder (60%) and stereotypical behaviour (54.2%). It is characteristic that many of them (68.6%) stated that the absence of social smiles is not a sign of autism, and 64.2% said that autism is not associated with abnormal eating habits.

Table 2 Doctors' awareness of autism spectrum disorders

Questions regarding awareness of autism spectrum disorders	Answers		
	Yes	No	I don't know
Disturbance of eye contact, facial expression, and body movement during social interaction	42 (60%)	12 (17.1%)	16 (22.8%)
Child can appear as if deaf	62 (88.6%)	8 (11.4%)	0
Delay or total lack of development of spoken language	43 (61.4%)	20 (28.5%)	7 (10%)
Social smile is usually absent in a child with Autism	20 (28.5%)	48 (68.6%)	2 (2.9%)
Stereotype and repetitive movement	37 (54.2%)	21 (30%)	12 (17.1%)
Autism is related to abnormal eating habit	10 (14.2)	45 (64.2%)	15 (21.4%)
Autism could be associated with Epilepsy	44 (62.8%)	12 (17.14%)	14 (20%)

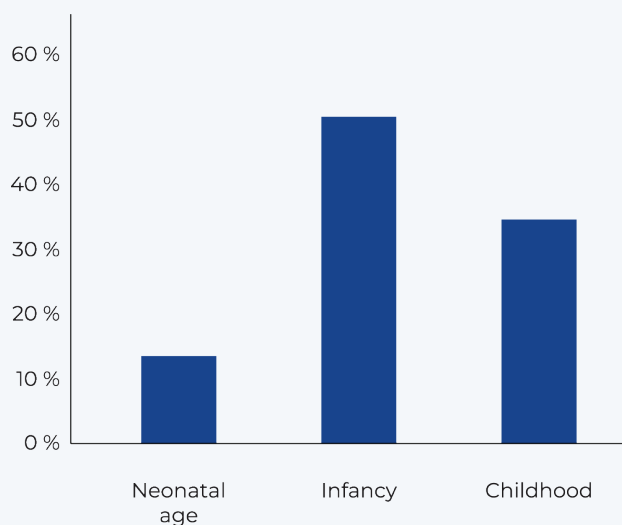
Figure 2 Percentage of the children that visit doctors based on age



In addition, when asked about the onset of autism, 50% answered that it is in infancy, and only 14% answered that autism onset is in neonatal age (Figure 3). Based on the results regarding the second hypothesis, we can conclude that it is confirmed.

The third hypothesis, “Medical professionals had attended training for recognition of early signs of autism”, we can see in Figure 4 that according to the results, 55% of the medical staff of the hospital say that they sometimes participate in the training developed on the diagnosis of autism, 30% of them always participate, and 15% of them have never participated, which leads to refuse the third hypothesis.

Figure 3 Knowledge of medical professionals on the onset of autism



The last hypothesis, “Medical Professionals who face difficulties in the medical treatment of patients with autism”, was assessed with the question, “Do they face difficulties in treating patients with autism? All responded 100% with yes, and the second question, “What is their biggest challenge in working with an autism patient?” most often pointed to communication with the child (43%), then giving therapy (41%), and the child’s behaviour (16%). This issue also had the opportunity to list something else, but no respondent sought another challenge (Figure 5), which concluded that the last hypothesis was confirmed.

## Results of the interview processing

When processing interviews, the answers were grouped into four categories: education, procedures for treating autism in health institutions, autism awareness and availability of training. In each category, data were grouped into two themes presented in Table 3.

Table 3 Results from the interview

Category	Theme	Statements
Education	Education during studies	"During the studies, autism was not covered as a condition or problem in our subjects."
	Education in the framework of professional development in the workplace	<i>"I did not attend training, I did not have experience, I did not have a chance to see another doctor treating autism."</i>
Procedures for the treatment of autism	Doctor's decisions	<i>"I approach them friendly; I let them sit in my chair and relax... I do not send them into a lab where it is crowded; instead, I call a nurse to take their blood in my office where they have already been adapted to the environment."</i>
	Parents' decisions	"To draw blood out from children with autism in their homes, because the child finds it difficult to experience the moment going to hospital".
Autism awareness	Personal experiences	<i>"My child has disabilities, so if a patient with autism appears at the hospital, other doctors and nurses send him/her to me".</i>
	Experiences from the environment	<i>"We have a child with autism in the neighbourhood; therefore, it is easier for me to work with them. I can cope with the situation."</i>
Availability of training materials	Materials for doctors	<i>"I think there is a lack of training for doctors and material to work with the child with autism, something to show. We only have medical materials, toys, strips, etc."</i>
	Materials for parents and children	<i>"Parents need to prepare their children properly for the most basic examinations, at least, that occur more often, such as taking blood, going to the dentist, family doctor, etc."</i>

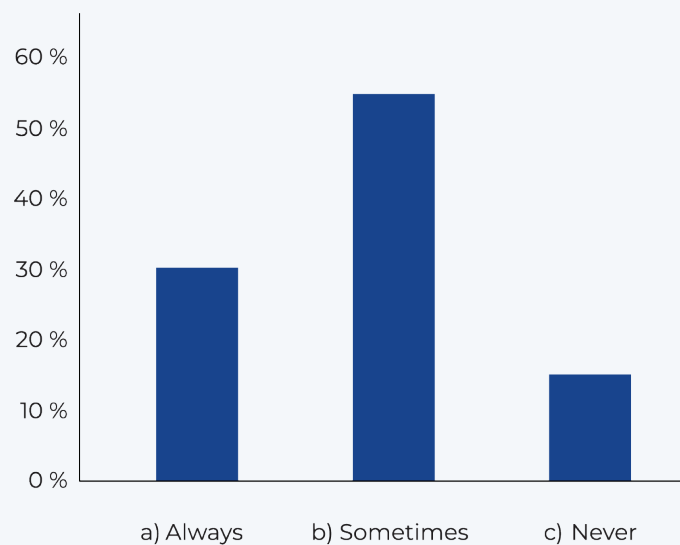
## Discussion

The findings of our study clearly show that medical doctors in the Polog region have a knowledge about autism even though they have no education about autism. It was remarkable that autism is not part of the subjects during medical studies, and some doctors never had the opportunity to see practice on how someone treats a child with autism when entering a medical ordination. In the study of Altay, from Edirne, Turkey, two-thirds of family physicians with a mean professional experience of  $16.9 \pm 8.8$  years were not trained in ASD (MA, 2019). Perhaps shortcomings also exist in secondary medical schools, which we did not anticipate in our research. Esegibe et al. state that the same data was presented publicly in Ghana at



a conference in 2014 (Eseigbe et al., 2015). There is still no official epidemiological data on autism in Macedonia, so autism services are challenging to plan and predict. The first epidemiological study on autism began in 2000 (Trajkovski et al., & M, 2005) as a part of the project. This gap has been in the media in the last 20 years. Parents' awareness is also more splendid and more common than before. Most doctors in the Polog region met children between the ages of 2 to 4 years old (78%). Young children usually visit general practitioners and pediatric medical doctors. In our case, the total number of these specialists is 25, which shows that this result is not because of the sample of the type of doctors but because children visit medical institutions more often than adults with autism. The medical trend of looking at autism during early development still prevails; 74% of the doctors had 1-5 patients with autism in the last six months of the research period. After diagnosis, most parents visit different specialities, seeking a "cure" for their child in the form of alternative treatments and supplements. These "treatments" sometimes can be life-threatening (Tochi, 2015). Due to the lack of treatments and specialists provided by state health, parents often pay for services in private clinics, which affects their family's quality of life (Troshanska et al., 2018).

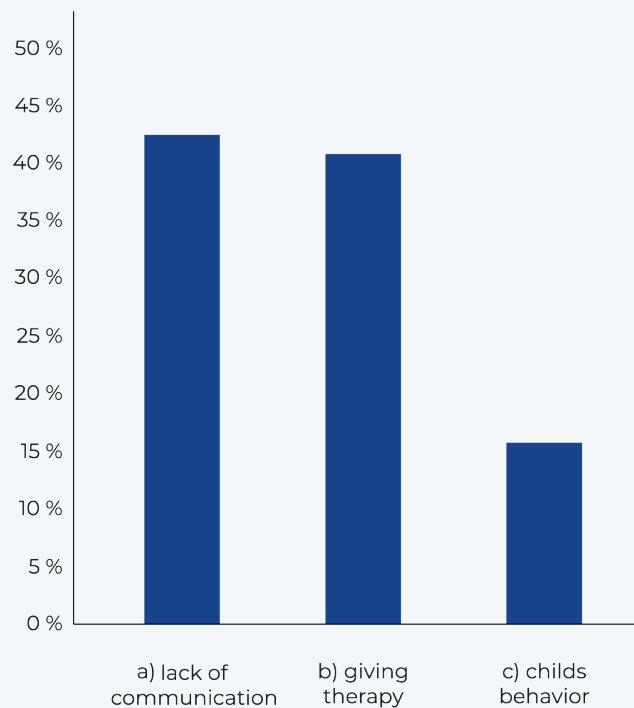
Figure 4 *Trainings on autism by medical professionals*



Regarding the awareness of signs of autism, our respondents showed good knowledge; that is, they usually recognize the children so that they look like deaf children due to lack of speech and stereotypical movements. They do not consider an eating problem as an early sign, as well as a lack of a social smile and 50% of them stated that autism onset in infancy. Furthermore, the lack of additional education and monitoring of new diagnostic procedures, the region's traditional beliefs, and the country's weak health system led to inadequate treat-

ment of children and persons with autism in any clinic. Procedures for treating autism depend on the doctor's personality, and our interviews showed that the child with autism, for any intervention, is often sent to the doctor who has the most empathy due to personal or family reasons. In addition to the lack of training for the medical staff, there is also a lack of materials that will serve both doctors and parents to better communicate with children with autism. Often, children with autism come unprepared for interventions. The doctors stated they have a big problem with communication, behaviour and applying appropriate therapy.

Figure 5 Challenges during treatment of autistic patients by medical professionals



Limitations: This study was limited to medical doctors from one region in the Western part of Macedonia. Also, the sample was small. The impact of selection bias can result from sampling, and the number of questions was limited to not extend the time for answering the questions in the survey or interview. This study is a preliminary study made to prove the need for applying a project to assess the knowledge and needs of the medical staff and conduct more extensive research that will cover the entire territory of the country.

## Conclusion

Our study indicated a lack of systematic education of medical doctors about autism. Nevertheless, even with this fact, medical doctors have good knowledge about autism. Early intervention is medical, mainly in the first years of life, before or after diagnosis, and parents often search for a “medical cure” for autism. A big challenge for doctors is communicating with autistic patients and their behaviour and problems when administering therapy. Because of this, they require education, training, and materials to support communication. Autistic patients should be prepared and familiar with the procedures during the examination through appropriate materials. However, it is also necessary for doctors to prepare for a meeting with an autistic patient. In that way, the health treatment of children and people with autism will be better, and the family’s quality of life will also be improved.

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Goran Basic, Linnaeus University  
goran.basic@lnu.se

Lina Olsson, Växjö municipality

Belinda Färdig, Växjö municipality

## Interactions of power and social pedagogical recognition: an analysis of narratives in an upper-secondary school context in Sweden

### SUMMARY

The aim of this study is to contribute new knowledge about interactions of power and social pedagogical recognition in narratives of students who use alcohol and drugs in an upper-secondary school context. In this context, the student narratives create and re-create a series of images of varied treatment by professional actors (e.g., teachers, student coordinators, counsellors). The reproduced power interactions in narratives describing the practices of professional actors are significant for student learning, teaching, nurturing, inclusion, change, discipline, and identity creation. In these interactions of power, professional actors are portrayed as significant power-wielding others or as rejected power-wielding others. These two verbal portrayals contribute to the verbal production of four analytical categories: 1) social pedagogical identity, which in previous studies has been classified as social identity (e.g., alcohol and drug user, ethnic identity, victim identity), and pedagogical identity (e.g., pupil identity, teacher identity, desired successful pupil identity, desired successful teacher identity, invisible student identity); 2) social pedagogical interactions of power related to verbal representations of situational images, control, monitoring, invisibility, discipline, prejudice, devaluation, victimhood, and the other; 3) varied descriptions, narratives, representations, and reproduction of social and pedagogical aspects of learning, teaching, nurturing, inclusion, change, and discipline; and 4) varied constructions, reconstructions, productions, and reproductions of learning, teaching, nurturing, inclusion, change, and discipline in the social and pedagogical sense. The social pedagogical recognition of the “other party” in the pupil–professional actor relationship is especially important for achieving the aims of including pupils who use alcohol and drugs in a learning context and enacting positive change through the creation and re-creation of social pedagogical identities (e.g., successful pupil identity) in the upper-secondary school context.

**Key words:** *insignificant power-wielding other, meaningfulness, reliability, account, rejection, ethnic identity, self-esteem, self-awareness, social pedagogical order, social pedagogical disorder*

## Introduction

The Swedish National Agency for Education (2015, 2020) and the Swedish Schools Inspectorate (2015) have noted that some pupils in Sweden either leave senior-level comprehensive school without meeting the entry requirements for admission to upper-secondary school or drop out of upper-secondary school early<sup>1</sup>. Social and pedagogical activities in schools are dramatised as playing a crucial role in the development of children and young people. School dropouts or failures in the school context are portrayed as a crucial dimension for the development of alcohol and narcotics use, criminality, mental illness, and difficulties in establishing oneself in the labour market (Björkenstam et al., 2011; Bäckman et al., 2014; Gauffin et al., 2013; Engdahl and Forslund, 2016). Conversely, a good connection to the school context and good school results are portrayed as being associated with a reduced risk for the social and pedagogical problems that can affect a young person (Hjern et al., 2014; Winnerljung and Andreassen, 2015).

DuPont et al. (2013) stress that various types of school problems among students may lead to an increased risk of alcohol and narcotics use in adulthood. The school problems highlighted in that study are described as originating in low self-esteem, which leads to problematic relationships with teachers and schoolmates, low attendance, and poor academic performance. Previous research on this phenomenon has shown that poor school involvement, shortcomings in teacher–pupil–parent relationships, insults from or violations by teachers, incidents of violence, and unsafe places in school contribute to an increased risk of dropping out of school. This effect in turn increases the risk of both alcohol and narcotics use and other health-related problems (Fletcher et al., 2008; DuPont et al., 2013).

As an environment, schools can contribute to stability for students, and education is a central resource for an independent life, establishment in the labour market, and participation in society at large (Foster, 2012; Björk et al., 2019; Basic and Matsuda, 2020; Johnsson et al., 2021; Basic et al., 2021). Fothergill and Ensminger (2006) and Trenz et al. (2015) highlight that it is important for students to have a good connection to school and positive relationships with teachers and peers, as well as good grades in upper-secondary school. These components provide a protective dimension against risky consumption of alcohol and narcotics use in adulthood (Trenz et al., 2015). In previous research, upper-secondary school thus was dramatised as a place that can be safe – where recognition can be bestowed in the social and pedagogical senses – which in turn can strengthen the self-esteem of the student (see further sections

<sup>1</sup> Some parts of this text were previously published in English, in the scientific articles, “Interactions of Power and Social Pedagogical Recognition: An Analysis of Narratives of Pupils Who Use Alcohol and Drugs in an Upper Secondary School Context in Sweden” (Olsson et al., 2023); “Inclusive Educational Spaces and Social Pedagogical Recognition: Interaction- and Social-Pedagogy–Inspired Analysis of Space Dynamics in Compulsory, Upper-Secondary and Post-Secondary Education” (Basic et al., 2021), and in Swedish, in the independent work at the first cycle, “A social pedagogical analysis of stories by professional actors working with young people and young people who use alcohol and/or drugs. Inclusion, learning, change and identity formation” (Olsson and Färdig, 2021).

“Theoretical starting point”, and “Interactions of power and social pedagogical recognition”).

Allan and Persson (2016) emphasise that a teacher’s encouragement, commitment, and ability to motivate (inspire) contribute to the reproduction of the perception of students as included and participatory in the school context. A reciprocal relationship between pupils and teachers, characterised by trust, is also presented as important for the engagement of both populations. Allan and Persson show that encouraging pupils to take responsibility for themselves and to support and help others in the classroom contributes to experiences of inclusion and participation. Other dimensions highlighted as contributing to inclusion and participation among students were their own norms and values in relation to their academic goals, which were reproduced as being in line with the norms of the organisation (school). These dimensions highlight the importance of helping students become more self-aware and to recognise their own position in the respective school context. Student strengths in relation to learning goals have been presented as important factors for higher motivation and achievement (Allan and Persson, 2016).

Sharma and Branscum (2013) detail the importance of prevention efforts in schools for young people with problematic substance use. Prevention efforts in the school context are presented as being able to foster identity formation of the young people based on the rejection of drugs. The authors point to the fact that many students experiment with drugs without becoming addicted, whereas others do become addicted. The kind of drug dependency that they develop is reproduced as a complex problem said to involve a range of different professional actors, whereas the issue of successful cooperation among professionals, pupils, and relatives is crucial for the creation and re-creation of student identities based on the rejection of drugs.

The aim of the present study is to contribute to the development of new knowledge about interactions of power and social pedagogical recognition in narratives of students who use alcohol and drugs in an upper-secondary school context.

Through this analysis, the study contributes to the development of knowledge regarding the narrative management of the combination of interactions of power, social pedagogical recognition, inclusion, learning, change, and identity creation with students who use alcohol and drugs. It also adds information about the importance of stories for the representation of inclusion, learning, change, social pedagogical recognition, and lack of recognition in the upper-secondary school contexts, the identity production and reproduction of students who use alcohol and drugs, and alternative approaches to analysis compared to typical psychiatric and medical perspectives. In addition, this study contributes to the development of knowledge about how interactions of power and social pedagogical recognition in upper-secondary school contexts work in relation to students’ past and present experiences regarding normatively right and normatively deviant behaviour in these situations.

## Theoretical starting point

The general scientific theoretical points of departure for the study are interactionist (Blumer, 1986), constructionist (Berger and Luckmann, 1966; Burr, 2015), and ethnomethodological (Garfinkel, 2002). Social reality is not a stable and immutable social phenomenon; rather, it is changeable and characterised by constant interactive processes, changes in interpersonal encounters, and dynamic activities tied to the various situations in the contexts in which they occur (Blumer, 1986; Goffman, 2002; Collins, 2004, 2008; Miller 2018; Basic et al., 2021; Basic, 2022). The words *Context* (with Collins' conceptual apparatus) or *region* (with Goffman's conceptual apparatus) are used to connote the delimited field where a series of interactive activities (situations – interactive rituals) are played out and can be delimited by the actors' observational and hearing abilities. Empirical examples of these interactive flows in the countless interpersonal exchanges that occur in a context contain the interactive behaviours of persons in a specific situation, the narrative representations of a particular situation by actors, and the productions and reproductions of important social objects such as language, text, documents, laws, news, images, and videos (Silverman, 2006; Hammersley and Atkinson, 2007; Riessman, 2008; Silverman, 2015).

In the interactive sense, the delimited field of “context” can be analysed as consisting of three subregions. The front-stage subregion is where the performance of the actors themselves (as action, reproduction, and/or production of social objects) takes place. The back-stage context (behind the scenes) is a subregion that is inaccessible for those in the surroundings (the audience). In this context, actors who are acting, characterising, and/or producing can affect their future performances and reflect on their previous performances, prepare, or unwind (Blumer, 1986; Goffman, 2002; Collins, 2004; Basic et al., 2021). Some contexts can be both back stage and front stage. Upper-secondary schools, for example, treatment rooms, outpatient treatment units, classrooms, and different offices (e.g., of the counsellor, head teacher, school nurse) can act as either. The designation of front stage or back stage depends on the actor's particular performance and the function of the contexts at the time.

The third context is outside/off-stage (the outsider/exclusion region). This subregion represents everything that does not belong to the front or back stage contexts. Actors in the third subregion are outside actors because they act, reproduce, and/or produce on the outside. In their relationships with actors established in the front or back stage contexts, the actions of outsiders take the risk of creating and re-creating disputes in the interaction. An outside actor who steps onto the front stage or back stage creates momentary confusion by disrupting the social order and driving a redefinition of the situation in the context (Blumer, 1986; Goffman, 2002; Collins, 2004; Basic et al., 2021).

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Theorists' contextual reasoning on this subject made us interested in what could be appear-



ing in different characterised situations in the upper-secondary school contexts. Using this question as a starting point, we found that the study informants (pupils who use alcohol and drugs in the contexts of upper-secondary school in Sweden), when constructing and reconstructing their identities, typify actors from both the front-stage and back-stage subregions, as well as from the outside (off-stage). Just as the classroom and teacher's and counsellor's office can be both a front stage and a back stage, the typified actor can be both a professional actor in these subregions and an actor outside the organisation, such as another pupil and/or a parent.

Typifications accomplish an important purpose in interactive creation and re-creation. Division into categories and typification of individuals, professions, and events into types – their identification through categorisation – is essential for navigating the multitude of daily interactions. Typification is not a static process; rather, it changes from one interactive flow (situation) and context to the next. The productions, representations, and actions of an actor represent a cause for and a response to the productions, representations, and actions of the other. In this procedure, the associations and self-esteem of the involved players, their creation and re-creation of various social and pedagogical identities, and their recognition in these identities take shape and are altered and established (Blumer, 1986; Goffman, 2002; Collins, 2004; Miller 2018; Basic et al., 2021). Considering these perspectives, the stories and practical actions (interaction) of both pupil and professionals in the upper-secondary school contexts, as well as their analysis, can be considered as meaning-making actions. These actions can add to the improvement of knowledge that can support the involvement and success of both pupil and professionals in circumstances that exemplify these contexts.

An essential starting point in analyses embedded in the scientific theory above is that actors in all social contexts are categorised in relation to their interactive positioning in a given situation, in which particular actors get the advantage in relation to the others. Therefore, some actors in the context will have better authority and greater social status than others. Consequently, they have an advantage in defining and re-defining how actors, groups, contexts, and society should act and be represented, produced, and reproduced (Blumer, 1986; Goffman, 2002; Collins, 2004; Miller 2018; Basic et al., 2021). In its most serious form, this advantage might lead to the subjugation of individuals with lesser social status.

### **Power in upper-secondary school contexts**

Weber (1968) analyses power as a direct action by an actor X that forces an actor Y to act in accordance with X's will, even if the action does not support Y's interests or desire. Weber draws attention to two dimensions of power relations/interactions. The initial dimension is kept out of the practical implementation of pressure(s) or related threat. The other dimension arises when exposed individuals give in or surrender to and accept the power of the one exerting

the pressure. The power of the executor of pressure often contains an order with substance that particular individuals or groups are supposed to follow (Weber, 1968; Collins, 1986, 2008; Basic, 2022). Collins' (2004, 2008) analysis of power, conflict, solidarity, resistance, and status is inspired by Weber's perspective. Collins considers that in all social arenas, the practice of power is always met with opposition from other people and thus creates new conflicts. For Collins, "conflict and solidarity are two sides of the same coin" (Collins, 2008: 40; Basic, 2022: 4). Mobilisation against an enemy in interaction and in situation often leads to solidarity among individuals and groups, and vice versa.

Power relations/interactions in interpersonal encounters are influenced, for example, by the personalities of the parties involved, verbal ability, knowledge, domination techniques, posture, and strength, and the individual's class and position in the context, age, sex, ethnicity, and group affiliation. An individual's economic class, educational level, gender, or ethnicity is related to whether an individual and group are at an advantage or disadvantage during interactions in a given context (Weber, 1968; Collins, 1986, 2008).

All power relations/interactions are characterised by a certain degree of resistance. With this resistance comes an opportunity to change power relations/interactions, which injects a certain degree of freedom into all relations by increasing individual awareness of how power functions and can be influenced. Power is dynamic and constantly changing – conscious or unconscious actions can always shift the power balance. However, power relations/interactions are not phenomena that merely inhibit and oppress; they also can be seen as something beneficial that moves people forward. Power relations/interactions are created and re-created in every situation, in every relationship, and in every context. The interactive normalisation contributes to the construction of what the establishment considers normal and abnormal. By constantly correcting and adapting their behaviour, actors who act and are represented as acting in power relations/interactions adapt their actions in accordance with normatively accepted expectations in a given context. This adaptation can be seen as a form of disciplinary power relations/interactions, which contribute to the creation and re-creation of normatively accepted behaviour within the given context (Weber, 1968; Collins, 1986, 2008).

In the upper-secondary school context, professional actors are expected to have knowledge about interventions that may be relevant in the practical social pedagogical work with young people who need help and support. With this knowledge and the formal position of the professional actor, an interactive power advantage is actualised in the relationship with the pupil. At the same time, the professional actor is expected to relate to the normatively accepted behaviour in the upper-secondary school context, to discipline in relation to the pupils and other staff in the school, and to structural frameworks that produce economic constraints, time constraints, and demands for measurable, evidence-based interventions in the school (Weber, 1968; Collins, 1986, 2008).

## Social pedagogical recognition

The social pedagogical perspective is centred on theoretical and methodological logic, which contends that society is not governed solely from the top down. Additionally, this perspective presumes that normality, in the teaching situation, and fellowship are not exemplified by a transparent structure or order in either the social or pedagogical sense. Social pedagogical order – or social pedagogical disorder – does not arise only from normative standards in teaching situations linked to the school's written and unwritten routines, rules, values, norms, and curricula. Rather, both social pedagogical order and social pedagogical disorder are created and re-created through interpersonal interactions, constitutive rules, conflicts, meaning-making, monitoring, and control. Moreover, social pedagogical order and disorder together are influenced by the actors' practical actions in unlike situations in social pedagogical context (Hämäläinen, 2012; Eriksson, 2014; Basic and Matsuda, 2020; Úcar et al., 2020; Basic et al., 2021; Greve et al., 2021). When a teacher meets a pupil, the exchanges between the two include the production, creation, negotiation and adjustment of the social pedagogical order – and disorder – in teaching and other situations in the upper-secondary school context. Indeed, these phenomena appear to be shaped and reshaped uninterruptedly in school situations, where a series of interactions and events plays out that are describable and observable, retold, presented, and reproduced in a range of interpersonal interactions, both during the school situation and after it has played out.

The vital point of the social pedagogical perspective is that it requires an analytical interest about the other, including the other's understanding of both social and pedagogical phenomena; the other's actions, founded on the understanding; and the other's interests, which are represented in connection with those actions (Hämäläinen, 2012; Eriksson, 2014; Basic and Matsuda, 2020; Úcar et al., 2020; Basic et al., 2021; Greve et al., 2021). This vital point is about obtaining an awareness and turning the analytical focus towards several factors. The first set of factors relates to identities: the different social identities of the actors involved (e.g., class, gender identity, ethnicity, victimhood) and the different pedagogical identities (e.g., pupil, teacher, successful pupil/teacher, or devalued pupil/teacher) that are acted out in circumstances and created and re-created (or constructed and reconstructed) and the interpersonal interactions involved (including oral and written descriptions and narratives). The second set of factors involves features associated with social and pedagogical aspects, including social and pedagogical control, social and pedagogical codes, social and pedagogical monitoring, social and pedagogical preconceptions, social and pedagogical devaluation of actors, and the costs that are produced in interactions inside social pedagogical practice. A third set of factors within the analytical focus consists of variations in the descriptions, perceptions, narratives, and representations of the social and pedagogical aspects of teaching, learning, and nurturing. Finally, the analytical focus also captures the constructions, reconstructions,

representations, productions, and reproductions of teaching, learning, and nurturing in the social and pedagogical senses (Hämäläinen, 2012; Eriksson, 2014; Basic and Matsuda, 2020; Úcar et al., 2020; Basic et al., 2021; Greve et al., 2021).

The analytical ideas discussed in social pedagogical publications (e.g., a social pedagogical recognition, inclusive educational context, social pedagogical development, spatial dynamics in schools, and educational collaboration) are relevant to school practices. The primary relevance relates to the systematic quality of work carried out, or anticipated to be carried out, in the school context, and the secondary relevance relates to the scientific analyses (research) conducted inside the framework of research and development projects. The present study takes the analytical position that the inclusive situation in the school context and social pedagogical recognition in the teaching and other situation (i.e., social pedagogical recognition of both the pupil and the teacher) are two of the most significant analytical aspects of the teaching and other situation in the school context that support achieving the learning objectives (or other indicators of success in the practical work on the school context) in succeeding steps. These principles (i.e., inclusion and recognition) must be attained in the teaching and other situation in the school context as a prerequisite for other in-context goals the teacher seeks to accomplish across different educational alliances and in various educational situations. If the analytical basis discussed in the social pedagogical literature and applied in the present analysis is not attained in the teaching and other situation in the school context, then employee competence development, systematic quality work, and different education programmes that are carried out or probably will be carried out in this context may make less of an impression. Moreover, teachers will be less likely to make an impression in teaching the students, which is an essential component of education programmes in the school context.

## Discussion

The aim of the present study is to contribute new knowledge about interactions of power and social pedagogical recognition in the narratives of upper-secondary school pupils who use alcohol and drugs.

The element of certain actors commanding an advantage relative to others is significant in the analysis of the present study in two ways: first, in the representation of relationships between students who use alcohol and drugs and professional actors in the contexts of upper-secondary school, and second, in the representation of the interactions of power, social pedagogical recognition, inclusion, learning, change, and identity creation in this context. For this study, therefore, the narratives of the pupils are analysed less in terms of static typifications and more in terms of situational and context-bound (institutionally positioned) interactions in the here and now (Blumer, 1986; Goffman, 2002; Collins, 2004; Miller 2018; Basic et al., 2021).

In accordance with interactionism, constructivism, and the ethnomethodological approach (Blumer, 1986; Berger and Luckmann, 1966; Burr, 2015; Garfinkel, 2002), the study analyses how the pupils who use alcohol and drugs themselves use identity-related (e.g., narratives, vocabulary, metaphors, status symbols, roles) in the day-to-day of the contexts of upper-secondary school in Sweden, such as when they describe school conditions, talk about advantages in the interaction, formulate criticism, and process their experiences. Stories with this category of pupil can motivate compassion and build a distinct typification associated with the category. This typification may be connected with mental health issues, traumatisations, medication needs, and victimhood (Blumer, 1986; Berger and Luckmann, 1966; Burr, 2015; Garfinkel, 2002). This work, however, also is associated with a particular status: The pupil possesses knowledge and skills that others do not. In the current study, we analyse both the content of informants' identity formation and its dynamic, i.e., how pupil identities are managed, used, challenged, and/or reinforced (Blumer, 1986; Goffman, 2002; Collins, 2004; Miller 2018; Basic et al., 2021).

The narratives of students who use alcohol and drugs in the contexts of upper-secondary school can include teachers, student coordinators, and counsellors. Interactional, social constructionist, and ethnomethodological perspectives capture the content of students' experiences and their social design, as well as the constituent and substantive aspects of personal accounts. The study thus adheres to the scientific theoretical and methodological traditions of the social sciences, in which verbal illustrations are regarded as both experiential and discursive.

In the narratives about teachers, student coordinators, and counsellors in upper-secondary school contexts, pupils produce and reproduce a series of verbal representations about varied treatment by professional actors in relation to the student category of pupils who use alcohol and drugs. These verbal portrayals originate in a professional context in which the professional actors have an interactive advantage in relation to students who use alcohol and drugs, and in this sense, the student narratives about the behaviour of the professional actors in the upper-secondary school context become a verbal construction of the interactions of power that flourish in that context. The interactions of power depicted in the narratives about professional actors are reproduced as important for student learning, change, discipline, inclusion, and identity creation (Weber, 1968; Collins, 1986, 2008; Basic, 2022). These interactions are reproduced by the pupils, and through these reproductions, the interactions contribute to the production and reproduction of professional actors' agency or lack of agency in the different situations made in these narratives. In these constructions of interactions of power, a series of images of the professional actor is produced, which are classified here as "significant power-wielding other" and "rejected power-wielding other".

In the construction of the professional actor as a significant or a rejected power-wielding

other in the upper-secondary school context, four analytical categories are also created. The first is a social pedagogical identity (Hämäläinen, 2012; Eriksson, 2014; Basic and Matsuda, 2020; Úcar et al., 2020; Basic et al., 2021; Greve et al., 2021), which in the analysis above is classified as social identity (e.g., alcohol and drug user, ethnic identity, victim identity) and pedagogical identity (e.g., pupil identity, teacher identity, desired successful pupil identity, desired successful teacher identity, invisible pupil identity). The second created and re-created phenomenon is social pedagogical interactions of power related to verbal representations of situational images, control, monitoring, invisibility, discipline, prejudice, devaluation, victimhood, and the other. Third among these phenomena are the varied descriptions, narratives, representations, and reproductions of social and pedagogical aspects of learning, teaching, nurturing, inclusion, change, and discipline. Finally, the fourth phenomenon consists of varied constructions, reconstructions, productions, and reproductions of learning, teaching, nurturing, inclusion, change, and discipline in the social and pedagogical senses.

In the verbal accounts of the different dimensions that the students highlight in their narratives, the importance of the professional actor's successful actions in the upper-secondary school context is emphasised in both the social and pedagogical senses. The pupils' portrayals of these successful actions relate to meaningfulness and reliability in the relationship between the pupil and the professional actor and to success in the encounter with pupils who use alcohol and drugs. These social pedagogical aspects that are reproduced in the pupils' narratives are a particularly important dimension of success in relation to the goals of ensuring inclusion in a learning context of the students who use alcohol and drugs and of achieving positive change through the production and reproduction of social pedagogical identities in the upper-secondary school context. A form of identity production that is sought after in the present context relates, for example, to a social pedagogical identity as a *successful pupil* who does not use alcohol and drugs – which predicts success and the recognition of the pupil in both the social and pedagogical senses. The pupils highlight the importance of the social pedagogical recognition of the pupil from the professional actor in the upper-secondary school context, so that this recognition appears to be significant for the students' social pedagogical goals in terms of learning, teaching, nurturing, inclusion, and change.

Other dimensions presented in the narratives relate to interactive disciplining of pupils – which does not appear to contribute to recognition of their social or pedagogical identities or of the social or pedagogical identities of the professional actors in the upper-secondary school context. In these narratives, the teacher is formed as disengaged, unsupportive, and unmotivated in the relationship with the pupil; exclusionary in the social pedagogical situation; or invisible to the pupil (and the pupil's social pedagogical identities).

All of the important prerequisites for achieving social pedagogical recognition in the pupil-

professional relationship are absent in the verbal portrayals when important professional actors, such as teachers, student coordinators, counsellors, head teachers, and members of the student health service are re-created as uninvolved, unsupportive, uninspiring, exclusionary, and invisible in relation to pupils who use alcohol and drugs. These professional actors are constructed as limited in their ability to achieve social pedagogical recognition in relation to the pupil because of an *inability* to perform several key actions related to social pedagogical activities in the upper-secondary school context: include and engage the pupil in key activities; motivate the pupil to perform during these activities; create and re-create relevant activities that contribute to the pupil's learning, teaching, nurturing, inclusion, and change; prevent drop-out and academic failure; and promote self-esteem and self-awareness during interactions with the pupil as an important starting point for social pedagogical goals of achieving academic performance and learning success and of forming new social-pedagogical identities – such as the identity of a successful pupil.

Two of the most important analytical elements to take into account in the upper-secondary school context where it is expected that students will learn and be educated, taught, nurtured, included, and changed are: the interactions of power, and social pedagogical recognition (i.e., both of the students who use alcohol and drugs and of professional actors, such as teachers, student coordinators, counsellors, head teachers, and/or members of student health services). This study shows that the fulfilment of social pedagogical recognition in this context in relation to this student population is an analytical interactive basis for fulfilling learning outcomes (or other measures of success in the practical work with pupils who use alcohol and drugs). This social phenomenon also seems to serve as an analytical interactive basis required to achieve in the different social, pedagogical, and learning situations in the secondary school context to gain any other measure of success for these pupils. In practical social pedagogical situations in upper-secondary school contexts, the systematic quality work, competence development of professional actors, and various pedagogical trainings that are carried out or are expected to be carried out do not have the same impact without establishment of the analytical interactive basis we examine in the present analysis.

The present study contributes to the development of new knowledge on interactions of power and social pedagogical recognition through the narratives of upper-secondary school pupils who use alcohol and drugs, thus actualising a wide range of questions that can be explored in future research or development projects. One question is how the conditions for learning, teaching, nurturing, inclusion, and change for this student population can be improved through better resource management, governance, and collaboration among different professional actors in school contexts. This overarching question provides an analytical basis for investigating seven additional themes: 1) successes and obstacles in the work of teachers and other professional actors with pupils who use alcohol and drugs in relation to processes im-



portant for learning, teaching, nurturing, inclusion, and change; 2) successes and obstacles in the school's organisation of this work; 3) successes and obstacles in the organisation of this work in relation to processes important for resource management, governance, and collaboration among different professional actors in the school context; 4) the work conditions and prerequisites of teachers and other professional actors for creating teaching that contributes to the inclusion and learning of pupils who use alcohol and drugs; 5) the identity creation of pupils, teachers, and other professional actors during social pedagogical activities in school in relation to processes important for learning, teaching, nurturing, inclusion, and change; 6) the creation of shared collective identities in the pupil–teacher–other professional relationship, collective identities that the present study indicates can be considered important for learning, teaching, nurturing, inclusion, and change in this student population; and 7) the creation of exclusion and vulnerability or inclusion and participation in the pupil–teacher–other professional relationship.



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## Ethical issues in doctoral supervision: an analysis of inherent conflicts and roles in supervision practice

### SUMMARY

This study aimed to provide new knowledge about ethical issues in doctoral supervision by analysing conflicts and roles that are assumed and acted out in supervision practice. This analysis was based on a literature review of various studies from the field of educational sciences, social pedagogy, doctoral supervision in theory and practice, and theories and practice of teaching and learning. The literature review identified several ethical issues relevant to doctoral supervision. These issues mostly arose from disappointed expectations, for instance, in the supervisor's or doctoral student's knowledge/competence, cultural viewpoint, roles, participation, language proficiency, and criticism/feedback. This analysis found that conflicts and the roles adopted and acted out during a supervision situation were not static – multiple roles could be assumed simultaneously, and the roles changed frequently. These changes provided opportunities to prevent or remedy ethical issues and conflicts in supervision. Changes could also lead to the creation and replication of a stable relationship between the doctoral student and the supervisor. To prevent ethical issues and conflicts, the relationship between a doctoral student and a supervisor should be characterised by mutual respect, responsibility, integrity, and recognition. These components are necessary to: (1) create the conditions for successful knowledge development in supervision, (2) complete a third-cycle education programme, (3) qualify the doctoral student to hold a doctoral degree, and (4) prevent ethical issues and conflicts connected with doctoral student supervision, through the constructive alignment of various elements in the third-cycle programme.

**Key words:** *higher education teaching, social pedagogical practice, supervisor role, doctoral student role, social meaning, pedagogical meaning, social pedagogical order, social pedagogical disorder*

### Introduction

The purpose of this article was to gain new knowledge about *ethical issues in doctoral supervision* by analysing the conflicts and the roles assumed and acted out in supervision practice<sup>1</sup>.

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82 <sup>1</sup>Some parts of this text were previously published in English, in the scientific articles, "Ethical issues in doctoral supervision: An analysis of inherent conflicts and roles in supervision practice" (Basic, 2023).

The approach was to review and analyse relevant research in the following fields within the educational sciences: *Doctoral Supervision in Theory and Practice* (Lindén 2005; Emilsson & Johnsson 2007; Lee 2008, 2012; McCallin & Nayar 2012; Lindén et al. 2013; Brodin et al. 2020), *Theories and Practice of Teaching and Learning* (Fox 1983; Kolb 1984; Kugel 1993; Biggs & Tang 2011; Svinicki & McKeachie 2011; Bradbury 2019), and *Social Pedagogy* (Eriksson & Winman 2010; Hämäläinen 2012; Úcar 2013; Eriksson 2014; Kornbeck & Úcar 2015; Hämäläinen & Eriksson 2016; Basic & Matsuda 2020; Janer & Úcar 2019, 2020; Úcar et al. 2020; Basic et al. 2021; Greve et al. 2021; Kesak & Basic 2023). The present study was focused on the actions of the actors (supervisor and doctoral student) in the supervision situation and their influence on each other in the interactive flow, before, during, and after the supervision situation.

The literature reviewed from the educational sciences (*Doctoral Supervision in Theory and Practice*) highlighted the fact that relationship-building between the doctoral student and supervisor was important in achieving a successful outcome through supervision. The literature also highlighted the importance of creating and maintaining a balance in the doctoral student-supervisor relationship. Furthermore, the literature suggested that deviations from this balance might give rise to conflicts and other issues in the supervisor-doctoral student relationship. Both too much distance and too much familiarity in the interactive flow between the doctoral student and the supervisor can lead to issues and role confusion in the expectations each party imposes on the other, before, during, and after the supervision situation (Lindén 2005; Emilsson & Johnsson 2007; Lee 2008, 2012; McCallin & Nayar 2012; Lindén et al. 2013; Brodin et al. 2020).

Based on the literature reviewed from the educational sciences in the field of *Theories and Practice of Teaching and Learning*, various theoretical models for teaching and learning processes were available. These models provided insight into the different roles that the teacher (supervisor) and student (doctoral student) could assume and act out. The literature showed that teaching and learning are not distinct from other social interactions. The components of teaching and learning include the teacher's role, the supervisor's role, the student's role, the doctoral student's role, the negotiated norms, the morals, the prevailing structure in the teaching situation, and the teachers'/supervisors' and students'/doctoral students' approaches to explaining and assigning meaning to different teaching situations. The common feature in these components is that they are all manifested and played out in a myriad of everyday interactions, both within and outside the context of the teaching situation (Fox 1983; Kolb 1984; Kugel 1993; Biggs & Tang 2011; Svinicki & McKeachie 2011; Bradbury 2019). In the framework of the present study, the supervision of doctoral students was analysed as a teaching situation linked to a number of ethical issues. These issues are acted upon, they unfold in supervision situations, and they constitute interpersonal interactions between doctoral students and their supervisors. These interactions contribute to the construction and reconstruction of different supervisor and doctoral student roles, which are played out in the relationship. In turn, these roles affect the dynamics of the situation and the future actions and perceptions of the actors involved.

Based on the literature, one of the roles a teacher/supervisor can assume and act out is the role of *conveyor*. A knowledge conveyor depicts knowledge as an object that is transferred from one place to another; that is, from the teacher (supervisor) to the student (doctoral student). When the supervisor adopts the role of a conveyor of knowledge, the doctoral student may view the supervisor as unaware that the supervision situation lacks the appropriate context for deploying the knowledge imparted. In those situations, a supervisor might attempt to create a context during supervision that allows the doctoral student to participate actively.

Another role that a teacher (supervisor) can assume and act out is the role of *modeller*. A knowledge modeller treats knowledge as a static phenomenon that cannot be changed or developed; thus, to the modeller, teaching (supervision) is a process where the student (doctoral student) is shaped according to a predetermined pattern. When a supervisor adopts the role of modeller, the doctoral student may perceive the supervisor as acting through *predetermined patterns* or routines that the supervisor is reluctant to change (Fox 1983; Kolb 1984; Kugel 1993; Biggs & Tang 2011; Svinicki & McKeachie 2011; Bradbury 2019). Taking on the roles of conveyor and modeller can lead to role confusion for the doctoral student, who has developed and continues to develop knowledge in critical thinking through the university and through research generated at the university. Consequently, adopting the conveyor and modeller roles can lead to a number of conflicts in the supervision relationship. Some of these conflicts are highlighted and analysed in the present study.

Another role that a teacher (supervisor) can assume and act out is the role of *tour guide*. When a supervisor acts as a tour guide, knowledge production is treated as a process of exchange between the supervisor and the doctoral student; in this role, the supervisor helps the doctoral student navigate through difficulties and stimulates the doctoral student's participation and knowledge development. The doctoral student is expected to participate actively in knowledge production in collaboration with the supervisor. Thus, the supervision is focused on the interactive process between the two parties (the supervisor and the doctoral student), who jointly undertake the process of developing the knowledge needed for goal fulfilment in the student's third-cycle programme (Fox 1983; Kolb 1984; Kugel 1993; Biggs & Tang 2011; Svinicki & McKeachie 2011; Bradbury 2019).

The analytical basis that helps create the conditions for knowledge development in supervision does not differ from the analytical basis applied to other teaching situations, where participating actors are expected to learn, formulate, develop, change (for the better through knowledge development), and socialise. In the teaching situation, the conditions for knowledge development are created through: (1) beneficial social interactions, (2) positive encounters, (3) good relationships, (4) good fellowship, and (5) changes for the better. These activities comprise a form of interactively anchored recognition of the actors in the educational situation, in both the social and pedagogical senses.

## Social pedagogical perspective

The social pedagogical perspective is based on theoretical and methodological reasoning, which argues that society is not governed exclusively from the top down. Furthermore, this perspective assumes that normality, in the teaching situation, and fellowship are not characterised by a clear structure or order, in either the social or the pedagogical sense. Social pedagogical order – or social pedagogical disorder – does not arise solely from normative guidelines in teaching situations that are related to the university's and school's (department) written and unwritten rules, routines, norms, values, and curricula. Instead, both social pedagogical order and social pedagogical disorder are produced and reproduced through interpersonal interactions, constitutive rules, meaning-making, conflicts, control, and monitoring. In addition, both social pedagogical order and disorder are influenced by the actors' practical actions in different teaching situations (Eriksson & Winman 2010; Hämäläinen 2012; Úcar 2013; Eriksson 2014; Kornbeck & Úcar 2015; Hämäläinen & Eriksson 2016; Basic & Matsuda 2020; Janer & Úcar 2019, 2020; Úcar et al. 2020; Basic et al. 2021; Greve et al. 2021; Kesak & Basic 2023). When a supervisor is assigned to a doctoral student, the interactions between the two involve the production and reproduction of the social pedagogical order – and disorder – in teaching situations. Indeed, these phenomena appear to be created and recreated continuously in supervision situations, where a series of interactions and events play out that are observable and describable, reproduced, retold, and presented in a range of interpersonal interactions, both during the supervision situation and after it has played out.

The central point of the social pedagogical perspective is that it requires an analytical curiosity about the other, including the other's interpretation of both social and pedagogical phenomena; the other's actions, based on the interpretation; and the other's interests, which are actualised in connection with those actions. This central point is about acquiring an awareness and turning the analytical focus towards: (1) the different social identities of the actors involved (e.g., ethnicity, gender identity, victimhood, class); the different pedagogical identities (e.g., student, pupil, doctoral student, teacher, supervisor, professor, successful pupil/student/doctoral student/teacher/supervisor/professor, or devalued pupil/student/doctoral student/teacher/supervisor/professor), which are acted out in situations and created and recreated (or constructed and reconstructed); and the interpersonal interactions involved (including written and oral descriptions and narratives); (2) the social and pedagogical codes, social and pedagogical control, social and pedagogical preconceptions, social and pedagogical monitoring, social and pedagogical devaluation of actors, and the sacrifices that are produced and reproduced in interpersonal interactions within social pedagogical practice; (3) variations in the perceptions, descriptions, narratives, and representations of the social and pedagogical aspects of learning, teaching, and nurturing; and 4) the representations, constructions, reconstructions, productions, and reproductions of learning, teaching, and nurturing in the so-



cial and pedagogical senses (Eriksson & Winman 2010; Hämäläinen 2012; Úcar 2013; Eriksson 2014; Kornbeck & Úcar 2015; Hämäläinen & Eriksson 2016; Basic & Matsuda 2020; Janer & Úcar 2019, 2020; Úcar et al. 2020; Basic et al. 2021; Greve et al. 2021; Kesak & Basic 2023).

The analytical concepts discussed in social pedagogical publications (e.g., an inclusive educational space/context, social pedagogical recognition, spatial dynamics in schools and universities, social pedagogical development, and educational collaboration) are relevant to university practices; first, with respect to the systematic quality of work carried out, or expected to be carried out, at the university level; and, second, with respect to the scientific analyses (research) that are conducted within the framework of research and development projects. The present study takes the analytical position that the inclusive teaching situation and social pedagogical recognition in the teaching situation (i.e., social pedagogical recognition of both the doctoral student and the supervisor) are two of the most important analytical aspects of the teaching situation that contribute to achieving the learning objectives (or other markers of success in the practical work on the third-cycle level) in subsequent steps. These precepts (i.e., inclusion and recognition) must be achieved in the supervision situation as a prerequisite for the other goals that the supervisor aims to achieve across different educational collaborations and in different educational situations in the third-cycle programme. If the analytical basis discussed in the social pedagogical literature and applied in the present analysis is not achieved in the teaching situation, then, the systematic quality work, employee competence development, and different higher education programmes that are carried out, or are expected to be carried out, at universities will be less likely to make an impact. Moreover, supervisors will be less likely to make an impact in the supervision of doctoral students, which is an essential component of third-cycle education programmes.

A number of social and pedagogical phenomena related to ethical issues in the supervision of doctoral students remain unknown and should be investigated further. The present article describes a detailed investigation of some of these phenomena through a detailed analysis that centred around the following three questions: What ethical issues are apparent in the literature in connection with the supervision of doctoral students? How are supervision conflicts and the different roles adopted, or expected to be adopted in connection with supervision, related to the emergence of these ethical issues? How can these ethical issues be prevented?

Through the analysis, this study aimed to contribute to the development of knowledge, regarding: (1) the analytical management of ethics, supervision, conflict, and roles in supervision interactions; (2) social pedagogical recognition and lack of recognition of doctoral and supervisor identities at the university level; (3) identity creation and re-creation among doctoral students and supervisors in relation to ethics, supervision, conflict, and roles in supervision interactions; and (4) alternative approaches to analysis, compared to the standard legal perspectives.



## Methodological Starting Points

This narrative (or traditional) literature review is based on a qualitative method (Silverman 2015, 2006; Machi & Brenda 2016; Onwuegbuzie & Frels 2016; Basic et al. 2021: 4). The empirical studies and empirical sequences in these studies that are reanalyzed in the present analysis, are of a secondary nature (Wästerfors et al. 2013; Björk et al. 2019; Johnsson et al. 2021). The choice of the relevant empirical studies and the primary analysis of the empirical data in these studies were performed in relation with prior analyses (Fox 1983; Kolb 1984; Kugel 1993; Lindén 2005; Emilsson & Johnsson 2007; Lee 2008, 2012; Biggs & Tang 2011; Svinicki & McKeachie 2011; McCallin & Nayar 2012; Lindén et al. 2013; Bradbury 2019; Brodin et al. 2020).

Table 1 *The corpus of studies that were reviewed and analysed in this literature review*

<b>Theoretical starting points for re-analyzis</b>	<b>Reviewed: doctoral supervision in theory and practice</b>	<b>Reviewed: theories and practice of teaching and learning</b>
<p>1) Interactionist, constructionist and ethnomethodological scientific theoretical starting points (Larochelle et al. 1998; Taber 2011; Farr et al. 2019; Krompák et al. 2021).</p> <p>2) The concepts of “social pedagogical recognition” and “educational collaboration” and the over-all perspective from social pedagogical work (Eriksson &amp; Winman 2010; Hämäläinen 2012; Úcar 2013; Eriksson 2014; Kornbeck &amp; Úcar 2015; Hämäläinen &amp; Eriksson 2016; Basic &amp; Matsuda 2020; Janer &amp; Úcar 2019, 2020; Úcar et al. 2020; Basic et al. 2021; Greve et al. 2021; Kesak &amp; Basic 2023).</p>	<p>Lindén 2005; Emilsson &amp; Johnsson 2007; Lee 2008, 2012; McCallin &amp; Nayar 2012; Lindén et al. 2013; Brodin et al. 2020.</p>	<p>Fox 1983; Kolb 1984; Kugel 1993; Biggs &amp; Tang 2011; Svinicki &amp; McKeachie 2011; Bradbury 2019.</p>

Based on the purpose of the study, re-analysis is performed in the present literature study and the research question by re-analyzing the selected studies with the help of 1) interactionist, constructionist and ethnomethodological scientific theoretical starting points (Larochelle et al. 1998; Taber 2011; Farr et al. 2019; Krompák et al. 2021), (2) research particularly related to the concepts of “social pedagogical recognition” and “educational collaboration” and the over-all perspective from social pedagogical work (Eriksson & Winman 2010; Hämäläinen 2012; Úcar 2013; Eriksson 2014; Kornbeck & Úcar 2015; Hämäläinen & Eriksson 2016; Basic & Matsuda 2020; Janer & Úcar 2019, 2020; Úcar et al. 2020; Basic et al. 2021; Greve et al. 2021; Kesak & Basic 2023).

In the spirit of interactionism, constructivism, and the ethnomethodological approach, this narrative (or traditional) literature review analyses how doctoral students and supervisors themselves (in the analyzed literature) use identity-related and cultural resources (e.g., narratives, metaphors, vocabulary, roles, educational status symbols, Basic et al. 2021: 4-5) in the day-to-day interaction in the educational collaboration, such as when they talk about advantages in the educational interaction, describe working conditions, formulate criticism, and process their experiences. The fact that certain actors/types command an advantage in relation to others is important in the analysis of the present study in two ways: first, in the representation of relationships between doctoral students and supervisors (here, in the literature regarding social pedagogical recognition and educational collaboration in educational space/context), and second, in the representation of the relationships of these doctoral students and supervisors to the spatial dynamics in the organisational and practical work of universities. For this study, therefore, the representation of working with doctoral students is analysed less in terms of static typifications and more in terms of situational and space-bound (institutionally and materially positioned) interactions described in the analysed literature.

## Discussion

The present study aimed to gain new knowledge about ethical issues that arise in doctoral supervision through analysis of the conflicts and roles that are assumed and acted out in supervision practice.

In a postgraduate context, social pedagogical control and social pedagogical monitoring (related to curriculum, written and unwritten rules, schedules, tests, research and development work, and various practical teaching and research situations) contribute to the production and reproduction of different roles for doctoral students and supervisors. The social pedagogy defines who they are and who they are expected to be, what they know and are expected to know, what they believe and are expected to believe, and what they learn and are expected to learn. All these roles are played out according to the unique social pedagogical normative order in the university, which is an important pillar of the doctoral student and supervisor identities. These identities are created and re-created during social and pedagogical activities.

Furthermore, the social pedagogical control and monitoring that occurs outside of the university is also important for the production and reproduction of different roles for the doctoral student and the supervisor. Interpersonal interactions related to family, ethnicity, religion, class, gender, control, monitoring, etc., contribute to the creation and re-creation of roles related to the expectations imposed on doctoral students and supervisors in a university setting and in society in general.

This analysis showed that the relationship between a doctoral student and a supervisor demanded stability and should be characterised by mutual respect, responsibility, integrity, and social pedagogical recognition. Within the framework of the present study, this type of relationship stability was required to: (1) create the conditions for successful knowledge development in supervision, (2) complete the postgraduate programme, and (3) achieve the learning objectives that lead to a doctoral degree. The remaining question is what can be done in postgraduate education practices within a university to achieve a stable, mutually beneficial relationship, which has the capacity to prevent the emergence of ethical issues and conflicts in connection with the supervision of doctoral students? One potential answer that became evident in the literature relates to the concept of constructive alignment (Biggs & Tang 2011).

The concept of constructive alignment is based on the analytical argument that all teaching activities (including supervising doctoral students) that are carried out through interactions with students (or doctoral students) should be coherent. Thus, the different components of teaching should be connected to form a cohesive whole. In practice, the supervisor should, first, maintain a common thread when planning and formulating learning objectives, goals, and expected learning outcomes for a doctoral student. These goals and outcomes should be related to the scientifically based research or development work that the doctoral student will undertake and to the postgraduate education programme as a whole. Second, this common thread should run through the subject content that the supervisor teaches and through the working methods and supervisory activities that the supervisor chooses to use. Third, this common thread should shape the approach the supervisor takes in supervising the doctoral student. Fourth, this common thread should shape the way the supervisor evaluates his/her supervision, and it should shape the doctoral student's postgraduate education as a whole. It is essential that all four of these elements are included in the scientifically based research or development work that the doctoral student carries out and in the postgraduate education programme to which the doctoral student is admitted.

These four items may sound redundant at first; some doctoral supervisors may argue that their supervision activities are already shaped and implemented in accordance with the principles of constructive coordination. However, the literature has suggested that constructive coordination has declined in some supervision assignments. Indeed, this decline has been observed in the author's own experiences in research, development work in the internship, and courses in higher education pedagogy. Moreover, the doctoral student's subordinate position in the relationship with the supervisor has contributed to creating and recreating a culture of silence at the university in relation to "research supervision".

Ultimately, it is the supervisor's responsibility to make changes and improvements to the supervision process and to prevent ethical issues and conflicts from arising in connection

with the supervision. An interesting question that was raised during our work on this study was whether and how doctoral students and supervisors take note of the importance of leadership in the social pedagogical work with doctoral students at the university. Another important question is how narrative leadership is handled at the university in the supervisors' social pedagogical work and in the doctoral students' reproduction of supervision situations, in relation to the following issues: How can equivalent education for doctoral students be organisationally ensured? How can the quality of education (supervision of doctoral students included) be ensured for doctoral students? What teaching materials are suitable in a supervision situation? How can supervisor competencies be developed? How can universities create the conditions for successful collaborations between supervisors and doctoral students?

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Karmen Korda Orlović, Croatian Institute of Public Health  
karmenkorda@gmail.com

Petra Čukelj, Croatian Institute of Public Health  
petra.cukelj@hzjz.hr

## **Socially unacceptable speech - analysis of Facebook users' comments about the 21st Zagreb LGBTIQ+ community, individuals, and families' Pride parade in Zagreb**

### SUMMARY

The Pride parade of the LGBTIQ+ community, individuals, and families has been held for over two decades in Zagreb. Although there is a noticeable decrease in incidents such as violence and homophobic violations, socially unacceptable behaviour, i.e., speech, continues to be observed in online environments, especially on social networks. This study aimed to analyse users comments on the news about the 21st Zagreb Pride parade and to determine the existence and scope of socially unacceptable speech in social media comments. A qualitative analysis was conducted to analyse the contents of Facebook users comments on three articles about the 21st Pride parade that were shared on the Facebook profiles of the three most-read Croatian news portals. The unit of analysis were public user comments. A total of 1185 comments were analysed. An inductive coding method was used. A total of 10 categories of comments were identified - "call to violence", "pride - shame", "disease", "politics and current topics", "disgust and insult", "relativisation problems/highlighting other social problems", "imposition", "religion", "a number of participants", and "positive comments/support". Most of the comments were categorised as "pride - shame" (20.8 %) (stating that the parade is essentially shame, not pride), followed by "disgust and insult" (14.1 %), "politics and current topics" (12.8 %), and "disease" (12.3 %). The lack of positive or supportive comments (3.5 %) was of particular concern. These results indicate a worrying amount of socially unacceptable/hate speech on social networks directed toward the LGBTIQ+ community. It is imperative to stop and prevent such behaviour in online environments.

**Key words:** *socially unacceptable/hate speech; social media; content analysis; LGBTIQ+phobia*

### **Introduction**

Social media networks have marked the last decade. They have become an indispensable means of communication for almost all generations, and their popularity is not waning. Facebook is still the most used social network, with over 2.9 billion users at the beginning of 2023 globally (Laub, 2019; Statista, 2023). In 2021, more than 1.9 million people used Facebook in



Croatia, and it is particularly interesting that it recorded an increase in the number of users over the age of 45 (arbona.hr, 2021).

Social media networks imply an entirely new understanding of communications as such and have completely moved away from traditional media. Users can create different textual and/or audiovisual posts, comment, react, share content, communicate publicly, privately, in open or closed groups. And that is the primary difference between traditional media and social media networks – on social media networks, users create content for other users (Chakravarthi et al., 2022; McGowan et al., 2012), which is often not subject to any control. Precisely because of the fact that the users themselves create and react to the content, it is clear that the amount of communication that takes place on social media networks is simply immeasurable.

Social media platforms have provided a space for people to express their opinions and beliefs, but unfortunately, some use this space to spread hate and prejudice. In accordance with this, although the Internet and social media networks make the impression that they “give us the world in the palm of our hands”, we are witnessing numerous harmful phenomena that occur in the online world, such as hate/socially unacceptable speech and homo/-bi/-transphobia.

Due to its availability and possible contribution to the understanding of numerous social phenomena, online content, including social media network’s content, is becoming more and more interesting to researchers.

### **Socially unacceptable/hate speech**

Although at first it may seem that socially unacceptable speech (or discourse) is a less negative term than the term hate speech, and that hate speech is the strongest form of socially unacceptable speech (Fišer et al., 2017; Hietanen & Eddebo, 2022), their characteristics are so similar that they are used as synonyms in this paper. Hate speech has been demonstrated to be a multifaceted phenomenon explored by multiple scientific disciplines (Ernst et al., 2017). Socially unacceptable/hate speech is generally defined as expression of ideas, allegations, or opinions that express or call for violence, hatred, humiliation, contempt, or discrimination based on one’s nationality, ethnicity, gender, gender identity, sexual orientation, religion, language, or political orientation (Kučič et al., 2019; Munivrana Vajda & Šurina Marton, 2016). It refers to any form of speech that aims to harm or show disrespect towards an individual or a group based on their identity or to any kind of offensive material intentionally employed to insult and diminish individuals within a specific social group (Chetty & Alathur, 2018; Simpson, 2013). Hietanen and Eddebo (2022) provided a comprehensive definition of hate speech according to which hate speech comprises spoken or written expressions that, whether intentionally or inherently, gravitate towards morally prohibited objectives, which can lead to actual or potential harm within the context in which they are uttered. Such expressions also



convey ideas that, from a formal standpoint, violate particular ethical standards. It is important to emphasize that socially unacceptable/hate speech violates one's fundamental human rights (Chetty & Alathur, 2018). It can be direct or indirect – direct hate speech implies the situation in which the victims are hurt immediately by the contents of hate speech, and indirect hate speech implies the situation when the harm (immediate or delayed) is caused by the agents instead of the original actor (Chetty & Alathur, 2018).

Cyberhate is a term that arose with the emergence and expansion of social networks and cyberspace in general. The definition of cyberhate is quite similar to ones of socially unacceptable/hate speech – it also implies the use of violent, aggressive, or offensive language that is focused on one's identity, whether it is about its gender, sexual orientation, nationality, religion, or race, but it is carried out through the Internet and social media channels (Castaño-Pulgarín et al., 2021). It refers not only to the verbal (or written) presentation of various insults, humiliations and calls to violence, but also includes the use of symbols, memes, photos and other digital forms of communication (Simpson, 2012). Although it takes place in the virtual world, cyberhate, or hate/socially unacceptable speech on the Internet and social networks, is definitely not harmless. In addition to causing extreme discomfort to those to whom the hate speech is directed, it can lead to an actual and severe threat in the “real” or “offline” world. Hate speech on the Internet and social networks was already linked to some actual attacks, hate crimes, and even murders (Laub, 2019; Castaño-Pulgarín et al., 2021). The speed and low cost of hate speech spread on social networks is particularly frightening (Ștefăniță & Buș, 2021). Those comments tend to reach much wider audience since the socially unacceptable/hate speech spreads rapidly due to a coordinated group effort, making it far more successful than individual attempts (Mathew et al., 2019). The rapid spread of hateful content and comments is further enhanced by algorithms that allow users, in this case of social networks, to more easily find content they are interested in and find like-minded people (Laub, 2019).

It is also important to note that repeated exposure to socially unacceptable/hate speech on a regular basis can result in individuals becoming desensitized to this type of verbal aggression. Consequently, they may start to form less favorable opinions about the targets of this hate speech and become more inclined to distance themselves from these individuals, ultimately fostering greater prejudice against outgroups (Mathew et al., 2019).

It is almost impossible to research socially unacceptable/hate speech and not touch on the relationship with freedom of speech, that is, not look back at the border that separates these two concepts.

In essence, freedom of speech is in some way “responsible” for the appearance of hate speech (Chetty & Alathur, 2018), and the line between them is in many cases very thin. That is why discussions about where freedom of speech ends and socially unacceptable/hate speech

begins are very common. Socially unacceptable/hate speech often tests the limits of free speech and violates fundamental human rights (Chetty & Alathur, 2018).

## **LGBTIQ+phobia**

Homo/bi/transphobia or LGBTIQ+phobia refers to the overall psychological and societal animosity targeted at individuals who identify as LGBTIQ+. This form of discrimination entails the endorsement of heterosexuality as the sole valid sexual orientation and the sex assigned at birth as the only accepted gender identity (Sándor, 2020). Homophobia and biphobia entail the irrational fear, hatred, prejudice, or discrimination directed towards individuals who identify as homosexual or bisexual (LGB), including those who are perceived to have this identity, and transphobia involves the rejection and denial of an individual's right to express their personal gender or sexual identity as they see fit (Bandalo et al., 2011). It may include spoken words, gestures, or the making, showing and dissemination of images, written or other material (Sándor, 2020) (which includes comments on social media), and is described as socially unacceptable or hate speech (Chakravarthi et al., 2022).

Pride parades, which have been held around the world for decades, are a central event that, among other things, raises awareness of the importance of the continuous fight against LGBTIQ+phobia.

Pride parades of LGBTIQ+ people and families in Zagreb have been held continuously since 2002. In the beginning, they numbered around 300 participants and were marked by violence and incidents. Since then, Pride has been held every year, with fewer and fewer incidents and incomparably more participants (zagreb-pride.net, 2022).

On June 4, 2022, the 21<sup>st</sup> Pride parade of LGBTIQ persons, communities and families was held in Zagreb under the slogan "Give us our four walls". Although there was no news about the incidents in the media, one could get the impression that the violence shifted into socially unacceptable/hate speech that moved to the vastness of the Internet, primarily to social media networks.

## **Aim and methods**

The main aim of this paper is to analyze and describe users' comments on the news about the 21<sup>st</sup> Zagreb Pride parade, as well as to determine the existence and scope of socially unacceptable speech and homo/-bi/-transphobia in social media comments. The following research problems operationalize this aim:

1. To identify how social media users react to the news about the 21<sup>st</sup> Zagreb Pride parade.
2. To identify types of user's comments.

3. To present the incidence of socially unacceptable/hate speech and LGBTIQ+phobia in comments on selected articles.

This study is based on the grounded theory (Castaño-Pulgarín et al., 2021; Tie et al., 2019). Content analysis was used to evaluate Facebook users' comments, as well as to establish the frequencies of individual categories. The unit of analysis was the publicly available comments of users of the social network Facebook on the shared first articles about the 21st Pride on the Facebook pages of three very popular Croatian portals - Index.hr, 24sata.hr and dnevnik.hr. All three articles were shared on June 4 – Index.hr shared its article at 4:22 p.m., 24sata.hr at 6:55 p.m., and dnevnik.hr at 4:11 p.m. Comments were collected on June 6 in the afternoon. A total of 1185 comments were analyzed. All comments that contained only emojis and those whose content was not clear were excluded from the analysis (comments that were full of nonsense that made it impossible to read the meaning of the comment, etc.).

Only “standalone” comments are included in the analysis, meaning the initial comments, and not responses from other users to individual comments. The reason for this is that discussions often develop below certain comments, which may or may not be related to the topic of the original comment. Additionally, comments directed at journalists are excluded (e.g., derogatory names for journalists, discrediting their work, accusations of promoting a specific political agenda, etc.).

Although not analyzed in this research, data on the number of individual reactions (Like, Love, Care, Haha, Wow, Sad and Angry) to shared articles was also collected.

Conventional qualitative content analysis and an inductive approach to coding were used. The reason for this is the heterogeneity of user comments – it is nearly impossible to predict categories based on existing theories, constructs, concepts, or models (Ernst et al., 2017; Madden et al., 2013). The first step in this process was material editing, followed by the material reading and defining the coding framework. The next step was coding and it was done manually in Microsoft Office Excel by both authors separately. To measure inter-rater reliability, Cohen's Kappa was used (Pykes, 2021), and the agreement was almost perfect ( $\kappa = 0.9$ ). It is important to note that researchers coded some comments with two codes because some comments met the criteria for entry into more than one category. In such cases, researchers discussed the codes and decided on the code they both agreed upon. After the coding process was finalized, patterns search and final editing of topics and categories were conducted. Finally, descriptive statistics were used to show the frequencies of individual codes and categories.

## Results

At the time of data collection, posts with shared articles on Facebook had a total of 932 „likes“, 430 „angry“, 310 „haha“, 110 „love“, 62 „care“, 75 „sad“, and 7 „wow“ reactions.

A total of 10 categories of comments were identified - "Call to violence", "Pride – shame (what is pride/shame)", "Disease", "Politics and current topics", "Disgust and insult", "Relativization/ highlighting other social problems", "Imposition", "Religion", "Number of participants" and "Positive comments/support".

Table 1 *Frequencies of comments in each category*

Category	N	%
Pride – shame (what is pride/shame)	247	20.8%
Disgust and insult	167	14.1%
Call to violence	154	13.0%
Politics and current topics	152	12.8%
Disease	146	12.3%
Imposition	137	11.6%
Relativization/highlighting other social problems	56	4.7%
Religion	56	4.7%
Positive comments/support	41	3.5%
Number of participants	29	2.4%

The frequencies of comments classified into each category are presented in *Table 1*. Most of the comments<sup>1</sup> were categorized as "Pride – shame (what is pride/shame)" (20.8%), and categories "Disgust and insult" (14.1%), "Call to violence" (13.0%), "Politics and current topics" (12.8%), and "Disease" (12.3%) follow. The category "Pride – shame (what is pride/shame)" implies all of those comments stating that the parade is essentially shame, not pride, and that there is nothing to be proud about if you are a member or supporter of LGBTIQ+ community (e.g., "A better title is "thousands in the parade of shame"", "What a pride. Shame on you", "The question is whether it is pride or SHAME", etc.). The category "Disgust and insult" includes all comments expressing disgust in any way (e.g., "Yuck, shame on you", "EW", etc.), while the category "Disease" implies all comments in which the authors state that being a member of the LGBTIQ+ community is a sign of a (mental) illness and that they should be "treated" (e.g. "And you should be given four walls somewhere in some madhouse to treat you", "How many sick people in one place", etc.). "Call to violence" is an especially worrying category (13.0%). It includes all comments whose authors express in any way a desire to harm Pride participants and/

98 <sup>1</sup> All comments listed as an example of a particular category are translated verbatim from Croatian to English, without censoring and without emoji's.

or members and supporters of the LGBTIQ+ community (e.g., “Give you 4 walls, but no way out and turn on the gas.”, “It’s not clear to me, why hasn’t it occurred to anyone to throw a bomb at that “pride” parade??””, etc.). The category “Politics and current topics” (12.8%) was established as there were many comments referring to the visit and support of the mayor of Zagreb and the city government to Pride, as well as the current situation in the world, primarily the war in Ukraine and the monkeypox epidemic. Thus, comments such as “There will be monkeypox next week”, “You slob mayor, you didn’t support the graduates like this the other day...” or “Go to Putin for treatment...” are classified in this category. “Imposition” (11.6%) is the category that includes all comments in which authors express that Pride participants can express their sexual or gender orientation “within their 4 walls”, i.e., that they only provoke and should not impose by organizing Pride (e.g., “Those parades are pure provocation.”, “This is the terror of the minority over the majority.”, “Well, there are your 4 walls, you can do what you want there. You don’t want that either, you want the whole world”, etc.). The “Relativization/highlighting other social problems” (4.7%) category includes those comments whose authors emphasize the pointlessness of holding the Parade and the greater importance of dealing with, according to them, other, more important issues and problems. Examples of such comments are “Can I ask what the parade is about? Is it maybe because of the high prices in stores or maybe because of the increase in utilities? Or maybe against a corrupt government?” or “You are only capable of that, but you are nowhere near making changes for the better”. The “Religion” (4.7%) category includes comments in which the authors mention God, faith, sin, and the sacred music concert that took place in Zagreb on the same day (e.g., “Terrible, this is the work of Satan. God release us from the devil.”, “Forgive them, God, because they don’t know what they are doing”, etc.). The category with the fewest comments (2.4%) is “Number of participants” and it includes comments referring to the number of Pride participants (e.g., “Are there so many”, “And we started with about a hundred people, I’m expecting them a little more as if to welcome the national football team”, etc.).

Finally, the category “Positive comments/support” (3.5%) includes all comments of support, i.e., all comments that have at least an indication of support for holding the Pride Parade, and comments that were concerned with the number of negative comments – “SUPPORT ... for a society of tolerance and equal opportunities” or “The wealth of a person is to accept differences without prejudice and judgment, because we are all so different and why make life miserable for ourselves and others, when we can be in harmony with the immediate and wider environment”.

Two themes – Positive and Negative comments (that can also be named LGBTIQ+phobia), and three sub-themes – Support, Hate speech, and Disapproval, emerged from the codes and categories.

Table 2 Identified themes and sub-themes

Theme	Sub-theme	Category
Positive comments	Support	Positive comments/support
Negative comments (LGBTIQ+phobia)	Hate speech	Call to violence
		Pride – shame (what is pride/shame)
		Disease
		Disgust and insult
		Imposition
		Politics and current topics
	Disapproval	Relativization/highlighting other social problems
		Religion
		Number of participants

Themes and sub-themes with its categories are presented in the *Table 2*. As already mentioned, they were identified through an inductive process, that is, by analyzing the obtained categories and their further classification based on common characteristics.

## Discussion

Presented results indicate a worrying amount of socially unacceptable/hate speech on social media networks directed toward the LGBTIQ+ community. It is imperative to stop and prevent such behavior in an online environment. According to Singh and Motliceck (2022), LGBTIQ+phobic content consists of hurtful comments directed at the LGBTIQ+ community, and results in offensive language that creates serious social issues that can make online platforms a hostile and uncomfortable environment. Accordingly, the entire theme “Negative Comments”, which emerged from the codes, categories, and sub-themes, essentially corresponds to the above definition. Thus, LGBTIQ+phobia includes both hate speech and inappropriate comments that do not meet the criteria to be classified as hate speech (in this paper, category “Disapproval”).

Socially unacceptable/hate speech is typically described as any form of expression, ideas, or opinions that promote or incite violence, hatred, embarrassment, or prejudice based on factors such as nationality, ethnicity, gender, gender identity, sexual orientation, religion, language, or political beliefs. This encompasses any type of communication intended to harm or show disrespect to individuals or a particular social group, often involving offensive content aimed at diminishing their standing within society (Chetty & Alathur, 2018; Kučiš et al., 2019;

Munivrana Vajda & Šurina Marton, 2016; Simpson, 2013). While having in mind such a wide definition of socially unacceptable/hate speech, the classification of codes into categories, and categories into sub-themes should be approached with special caution, because it is easy to get into a situation where every comment from the sub-theme “Negative comments” is classified into the category “Hate speech”, which would then lead to equating the terms LGBTIQ+phobia with socially unacceptable/hate speech.

Although the number of comments in the “Hate speech” sub-theme is truly worrying, it is also interesting to pay attention to the comments in the categories that make up the “Disapproval” sub-theme. As already stated, these are commenting whose authors do not explicitly express hatred, but still for some reason do not agree with the Pride or completely relativize the importance and necessity of organizing it. Thus, these comments can best be described by the definition of Sándor (2020), according to which LGBTIQ+ phobia includes the acceptance and emphasis of heterosexuality and heteronormative principles as the only valid ones, as well as the sex assigned at birth as the only accepted gender identity. Therefore, outrage over the number of Pride participants, mentioning religion and the “incorrectness” of LGBTIQ+ sexuality according to religious or any other principles, but also denying the problems that this community faces on a daily basis also falls under the definition of LGBTIQ+ phobia, regardless of what individuals’ comments begin with the sentence “I have nothing against them, but...”.

## Limitations

Although qualitative research is perceived as inferior to quantitative due to the lack of evidence, qualitative methodology can greatly contribute to gaining insight into a large amount of data and facilitate the understanding of numerous (social) processes and mechanisms (Buljan, 2021). Still, it is important to be conscious of all possible limitations that can occur and to manage them as much as possible.

One of the first potential limitations to this research can be presented with the question „Who are social media users who comment on certain posts and feel the need to express their opinion in the comment section?”. Also, we need to ask ourselves who these users represent. And what about those users who use social media but never leave comments or engage publicly? Although the sample of this research is exclusively publicly available comments in which users express their opinions and/or attitudes, based on these comments we cannot assume, let alone conclude about those who write them (as much as we think we can).

Another important limitation of this research lies in the fact that the authors, no matter how hard they try, cannot remain unbiased in the entire process, as personal political and ideological convictions of the authors could influence the interpretation of the comments. Analyzing

content full of hate is not easy, so the authors had to constantly stop and “separate” from the data in order to ensure the most objective approach to the entire process.

In addition, only comments below the three shared articles were taken into the sample. It is important to note that the news portals that published the articles are in the middle of the ideological-political spectrum (and were chosen specifically because of this), which means that the sample did not include comments on the articles from the portals aligning with the left and right poles of the spectrum.

Finally, it is necessary to mention the great challenge of coding comments that can be classified into more than one category. Such comments were coded into the category whose elements predominate or into the category that represents a “severe” form of LGBTIQ+ phobia.

## **Conclusion**

The rise of digital media, particularly the increasing influence of social media networks in personal and public communication, has created opportunities for various online platforms that motivate passive spectators to become more engaged and communicate actively (Hadži et al., 2022).

This research shows that socially unacceptable/hate speech and LGBTIQ+ phobia is present in the analyzed sample and that social media users react very negatively to the Pride Parade news. Users tend to leave comments in which they explicitly or implicitly wish harm to LGBTIQ+ people, insult them, express disgust, call them “sick”, etc. Also, the amount of positive and supportive comments is discouraging.

Considering that today anyone can comment on social networks and that the control of published content is rather weak, in future research it would be useful to focus on finding answers to who the people behind certain comments are, what their characteristics and patterns are, and why some people tend to „spread hate” online.

The impact of hate speech on social media can be devastating, leading to increased levels of harassment, discrimination, and even violence. As such, a push to combat hate speech on social media should be performed through prevention, better moderation, content regulation, and education.



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Marta Cifrek-Kolarić, Prison in Zadar  
marta.cifrekkolaric@zsd.pravosudje.hr

Maja Laklija, UNIZG, Faculty of Law, Social Work Study Center  
mlaklija@pravo.hr

## Professional stress and burnout among treatment staff in correctional institutions in Republic of Croatia

### SUMMARY

The objectives of this study are to examine the differences in the experience of emotional responses to work, symptoms of stress and intensity of burnout at work with regard to the socio-demographic characteristics of treatment workers in criminal bodies in the Republic of Croatia. The analysis was conducted on the sample of 60 respondents. According to results, treatment staff in correctional institutions experience more positive than negative emotional responses to work. They experience different behavioural and physical symptoms of job stress and symptoms of social isolation. 25% of respondents experience high level of job burnout. Also 25% of respondents experience symptoms of initial burnout. Socio-demographic variables did not have a significant effect on the experience of job stress and job burnout. The only differences were found in burnout intensity compared to the current job position (senior treatment advisors experience higher burnout intensity than treatment staff who work as a head of treatment department) and physical symptoms of job stress compared to gender (women more often than men experience physical symptoms of stress). Of the considered organizational factors (examined in this study) support of management and satisfaction with work organization and work atmosphere are the significant factors that contribute to experiencing job stress and job burnout. These data can be useful to those responsible in the Ministry of Justice and Public Administration (Directorate for the Prison System and Probation) to improve the quality of various aspects of work and job processes in order to reduce the risk of professional stress and burnout.

**Key words:** *emotional responses to work, symptoms of work-related stress, burnout, treatment staff in correctional institutions*

### Introduction

Professionals and researchers are showing an increasing interest in the mental health of workers, work-related stress, and burnout, directed at developing support programs and protecting workers' well-being. Workers in helping professions are particularly prone to work-re-

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lated stress (Cuculić, 2006) in light of daily interactions with service users facing existential and emotional distress (Ajduković and Ajduković, 1996). Interest in the psychological well-being of workers in the prison system is notably increasing among researchers in Croatia and worldwide (Novak, Laušić and Jandrić Nišević, 2008). In 2007, the College of Education and Rehabilitation in Zagreb, Croatia conducted a research project on “Emotional well-being and job burnout among workers in prisons” (Mikšaj-Todorović and Novak, 2008). Additionally, in 2017, the Institute of Social Sciences Ivo Pilar implemented the project “Psychosocial environment in prisons from the perspective of prisoners and officials” (Ministry of Justice, 2017). Finally, in 2019, the Ministry of Justice and Public Administration in Croatia initiated the project “Improving the quality of the judiciary by strengthening capacities in the prison and probation system and the support mechanisms for victims and witnesses”.

Due to daily interactions with disadvantaged populations, workers in the helping professions are more exposed to work-related stress and at greater risk of burnout (Ajduković and Ajduković, 1996). Burnout syndrome is more frequent among workers who idealize the profession and workers with exceptionally high personal expectations. It is also common among workers who hold subordinate positions and struggle to establish appropriate boundaries in their workplace. Various external factors contribute to job burnout, such as excessive demands, inefficient organization of work, lack of support, and professional isolation (Ajduković, 1996). Maslach et al. (2001) integrated internal and external factors of burnout and defined the following main organizational predictors of burnout: job burden, lack of control or rewards, unsupportive communication, unfair treatment, and conflicting values. The risk of job burnout increases with a growing mismatch between expectations and any of these areas.

Our research focused on treatment workers<sup>1</sup> who faced a higher risk of experiencing work-related stress and burnout due to daily interactions with prisoners. Accordingly, the present study examined various aspects of work-related stress and burnout among treatment workers in correctional institutions in Croatia. Research results offered a baseline for creating guidelines to improve the system, working conditions for treatment officers, and the overall quality of services.

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<sup>1</sup> The duties of treatment officers, as outlined in the Execution of Prison Sentence Act (Official Gazette 128/99, 14/21), include: a) general tasks (implementing special treatment programs; organizing and implementing general treatment programs and other activities to assist prisoners with rehabilitation and social reintegration; reading personal correspondence of prisoners; and maintaining required prisoner records), and b) professional treatment activities (assessing the risk factors for recidivism and treatment needs; formulating, implementing, reviewing, and evaluating programs; conducting psychosocial and social-pedagogical interventions and special programs; performing security interventions within the scope of treatment officer's work; and preparing professional opinions on the execution of prison sentences).

## Work-related stress and burnout syndrome among workers in correctional institutions

There have been relatively few studies conducted in Croatia on this topic, with the majority of research coming from the USA, Australia, the Netherlands, Denmark, and Canada (Novak et al., 2008). However, it was difficult to compare research findings as the term “workers in correctional institutions” included different categories of workers across studies, depending on the organization of the prison system in the observed country (Mikšaj-Todorović and Novak, 2008) and due to a broad definition of the sample, professional activities, and working conditions across studies (Novak et al., 2008).

Dowden and Tellier (2004) found that demographic variables such as gender, age, marital status, level of education, and the number of children in the family did not significantly predict work-related stress. Korda (2018) reached similar conclusions, whereas Novak (2009), based on a sample of workers in correctional institutions in Croatia, found that women were more prone to workplace stress caused by organizational challenges. Moreover, the length of employment in the penal system correlated with the number of workplace aspects that caused stress and the corresponding stress levels. Based on a literature review on stress and burnout among workers in correctional institutions, Novak et al. (2008) identified the following risk factors of work-related stress: job burden, lack of autonomy (in professional practice, utilizing expertise and professional competences, and decision-making), monotony of work, challenging roles (inadequate information for performing professional services and conflicting demands), challenging interpersonal relationships, insecurity (job insecurity and promotion opportunities), health and safety risks, inadequate salaries, and low social status. Among the common responses to stress the authors mentioned withdrawal (absence from work/sick leaves and resignation), psychosomatic reactions, negative attitudes, and burnout.

According to Kišak Gverić (2010), treatment staff in the penal system had more positive emotional responses to work than negative ones. Among the prevailing positive work-related emotions, about 50% of treatment officers reported feeling happy, fulfilled, and satisfied, while the negative emotions included fatigue, anger, resentment, anxiety, and depression. The predominant counterproductive behaviors involved various forms of work avoidance and inappropriate interpersonal behavior. Common physiological manifestations of stress included fatigue, sleepiness, and headaches. Research on job satisfaction among workers in the helping professions indicated that workers in hospitals and prisons were most satisfied with the nature of work, but least satisfied with salary, rewards, and promotion opportunities. Notably, workers in prisons were less satisfied with the nature and organization of work compared to healthcare workers, which could be attributed to the objective workplace characteristics of prisons, such as safety risks around prison population and strict rules of conduct

(Kišak Gverić, Doležal, Mikšaj-Todorović, and Habazin, 2015). Moreover, research showed that correctional officers, who experienced less work-related stress, had higher job satisfaction and commitment to the organization/system, greater self-efficacy, better interpersonal relationships and a more altruistic approach to work. They were equally less inclined to change profession and less absent from work (Vickovic and Morrow, 2020). According to Lambert et al (2020), the opportunities to influence decisions and the quality of supervision represented significant negative predictors of work-related stress. On the other hand, workers, who felt burdened by their professional role and feared violence, experienced higher levels of work-related stress. Armstrong and Griffin (2004) found that treatment and judicial police officers considered their work moderately stressful. Notably, older workers, men and those with longer professional experience reported significantly fewer health problems. Notwithstanding, more experienced workers did indicate more work-related stress. Furthermore, older treatment officers reported significantly higher levels of work-related stress, while age did not appear as a significant predictor of work-related stress for judicial police officers.

Korda (2018) conducted research on well-being, job satisfaction, and exposure to stress based on a sample of 699 officers from all correctional institutions in Croatia. The results indicated that correctional officers were satisfied with their work, life, health, achievements, and relationships. They experienced moderate stress at work, and their health, education, and relationships with friends and family suffered to a certain extent because of their work. Furthermore, higher levels of stress strongly correlated with lower satisfaction with work and life, as well as negative aspects of teamwork, dissatisfaction with rules and regulations, poor health, and relationships with friends and family. However, work-related stress did not appear significantly linked to the aspects of work that research generally considered significant predictors of work-related stress, such as workplace safety. Namely, the results indicated that treatment officers were more satisfied with their work, workplace environment, professional impact, and the quality of supervision than security officers.

Furthermore, prison officers appeared to be significantly more prone to job burnout than the general population (Lambert, Barton-Bellessa, & Hogan, 2015). According to Griffin, Hogan, Lambert, Tucker-Gail, and Baker (2010), organizational aspects such as job satisfaction, work-related stress, and work commitment were more significant predictors of burnout than personal variables. Only age appeared to be significantly associated with burnout, with younger workers reporting higher levels of depersonalization compared to their senior colleagues. Furthermore, research indicated that age mostly negatively correlated with the three dimensions of burnout. Men reported higher levels of depersonalization and a lower sense of personal achievement compared to women. However, not all studies established significant correlations with regard to gender (Carrola, Olivarez, & Karcher, 2016; Griffin et al., 2010). Further research studies indicated that junior, young and ambitious workers, as well as young women with considerable

family responsibilities and children, were at greater risk of burnout (Novak et al., 2008). The level of education negatively correlated with the risk of burnout. The findings concerning the length of professional experience seemed inconsistent (Griffin et al., 2010).

Job satisfaction significantly negatively correlated with emotional exhaustion and the perceived sense of achievement (Griffin et al., 2010). Namely, prison officers who faced greater work-related stress equally reported higher levels of emotional exhaustion and depersonalization. Moreover, work commitment strongly correlated with emotional exhaustion (workers who strongly identified with the profession also reported higher levels of emotional exhaustion) (Griffin et al., 2010). Roy, Novak, and Mikšaj-Todorović (2010) reported significant differences in the results for Croatian and American prison officers across all three dimensions of burnout. Namely, the American prison officers experienced more symptoms of depersonalization, while the Croatian prison officers more often reported a low sense of professional achievement and symptoms of emotional exhaustion. According to Novak (2009), higher autonomy decreased the incidence of emotional exhaustion. Moreover, for workers in the penal system, the actions of superiors and their attitude towards the staff represented the greatest source of stress, notably instances of dishonesty, inconsistency, ambiguous rules and uneven distribution of responsibility. Among prison officers, job burnout was associated with frequent absences from work, pronounced intention to change profession, and lower satisfaction with personal life (Catiglione, Rampullo, and Giovinco 2017). The main organizational predictors of burnout among prison officers involved prison overcrowding, shift work, conflicting roles and conflicts with superiors, lack of opportunities for promotion, inadequate support from superiors and colleagues, monotony of work and lack of autonomy (Catiglione et al., 2017). According to Novak (2009), workers in correctional institutions were dissatisfied with remuneration, as well as opportunities for promotion and improvement of their financial situation.

## **Research aim and objectives**

This research study aimed to determine the emotional responses to work, symptoms of stress and the intensity of burnout among treatment workers in correctional institutions in Croatia. Research objectives were to 1) measure the differences in the experience of emotional responses to work, symptoms of stress and the intensity of burnout against the socio-demographic characteristics of treatment workers in correctional institutions; and 2) examine the relationship between emotional responses to work, symptoms of stress and the intensity of burnout and the working conditions of treatment workers in correctional institutions.



## Research methodology

### Research sample

The research sample consisted of 60 treatment workers in correctional institutions in Croatia, of whom 52 (86.67%) were women and 8 (13.33%) were men. The study involved all correctional institutions in Croatia, including 7 penitentiaries, 14 prisons, 2 juvenile detention centers and the Diagnostic center. The sample was convenient. The heads of treatment departments in the correctional institutions provided the lists of treatment workers, which comprised 129 employees (98 women (76%) and 31 men (24%)). Therefore, around 53% of all female and 26% of all male treatment officers participated in the study. Participants' age ranged from 29 to 61 years ( $M=46$ ,  $SD=9.45$ ). In terms of profession, 53% were social pedagogues, 28.33% social workers, 16.67% psychologists, and 12% of participants practiced other professions (teachers, professors, criminologists, pedagogues, political science specialists, and theologians). In terms of job position, 68.33% were senior treatment counselors, 15% were heads of treatment departments, 8.33% were heads of treatment sections, and 8.33% were assistant treatment specialists. 63.33% of participants had over 15 years of overall professional experience, and 3.33% had less than 5 years of professional experience. Most participants had between 5 and 15 years of service in the prison system (66.67%), 30% had over 15 years (10% from 16 to 20 years and 20% over 20 years), while 3.33% of participants had less than a year of service in the prison system. Most participants were married (56.67%), 21.67% were divorced, and 16.67% were single. Finally, 76.66% had children.

### Measuring instrument

The measuring instrument consisted of:

**A questionnaire on the socio-demographic variables and aspects of working conditions of treatment workers**, constructed for the purposes of research. The first part of the questionnaire included the following socio-demographic variables: gender, age, profession, current job position, length of overall professional experience and service in the prison system, marital status and number of children in the family. In the second part of the questionnaire, participants assessed different aspects of their working conditions on a scale of 1-5, namely: organizational environment (assessment of workplace atmosphere, satisfaction with the organization of work and perception of management support at the correctional institution) and job burden (general assessment of job burden, administrative burden, and burden from interaction with prisoners).

**Questionnaire on emotional responses to work/ Job-related affective well-being scale** (Van Katwyk, Fox, Spector, & Kelloway, 2000) consisted of 30 items. Each item represented an emotion, and participants indicated how often they experienced it at work in the previous 30 days (never, rarely, sometimes, often, almost always). The scale originally included emotions



of different intensities, divided into four subscales based on the interaction of two dimensions: (dis)satisfaction and intensity. The subscales were: 1) satisfaction, high intensity, 2) satisfaction, low intensity, 3) dissatisfaction, high intensity, and 4) dissatisfaction, low intensity. In the research, Cronbach's Alpha ranged from 0.90 to 0.95 for the scale. Due to the nature of the profession, notably interaction with prisoners and high unpredictability of events and interventions, Mikšaj-Todorović and Novak (2008) decided to eliminate the 30-day timeframe for prison officers to avoid distorting research findings concerning the general emotional responses to work. For the Croatian sample, the Cronbach's Alpha of the scale without the timeframe was 0.94. The original factor structure was not confirmed, and the following subscales were established: **positive emotions** (items 3, 5, 6, 10, 11, 12, 13, 18, 19, 20, 21, 25, 26, 27 and 29) and **negative emotions** (items 1, 2, 4, 7, 8, 9, 14, 15, 16, 17, 22, 23, 24, 28 and 30) (Kišak Gverić, 2010; Mikšaj-Todorović and Novak, 2008).

**The Self-assessment questionnaire on the symptoms of stress** (Ajduković and Ajduković, 1994) consisted of 26 items assessing physical, behavioral, and psychological indicators of stress. Participants rated the frequency of experiencing each symptom in the previous three months on a scale from 0 (not experiencing it at all) to 6 (experiencing it every day), resulting in a theoretical range of answers of 0-156. Due to missing data on the psychometric characteristics and scoring method of the questionnaire, the authors analyzed the main components to verify the factor structure of the questionnaire. Twelve items (5, 7, 14, 15, 16, 17, 18, 20, 21, 22, 25, 26) were excluded to optimize the structure of the questionnaire because they either projected onto several other components or lacked significant saturation (based on the criterion  $>0.40$ ). The scree test was used to determine the number of significant components, resulting in an optimal structure with three significant components. Varimax rotation was used to rotate the extracted main components. Correlations of variables above 0.50 were considered significant for interpreting the components. In our research sample, the questionnaire's latent structure could be reduced to three factors that accounted for 65.8% of the variance: **1. Behavioral symptoms of stress**, a factor that accounted for 29.68% of the variance and saturated items 8, 9, 10, 11, 19, 23 and 24 (Cronbach's Alpha of 0.88); **2. Physical symptoms of stress**, a factor that accounted for 21.42% of the variance and saturated items 1, 2, 3, 4, and 6 (Cronbach's Alpha of 0.80); and **3. Social avoidance/withdrawal**, a factor that accounted for 14.7% of the variance and saturated items 12 and 13 (Cronbach's Alpha of 0.92) (Cifrek Kolarić, 2022).

**The questionnaire on the intensity of burnout** (Ajduković and Ajduković, 1994) consisted of 18 statements that represented cognitive, behavioral, and emotional burnout symptoms. Participants rated the presence of each symptom on a scale from 1 (rare and less pronounced) to 3 (persistent and more pronounced). The total score was calculated as the sum of all answers, with a theoretical range of 18 to 54. The normative orientations of the questionnaire were as

follows: scores of 18 to 25 indicated no burnout (isolated signs of stress might be present), scores of 26 to 33 indicated initial burnout (significant warning signs in light of ongoing stress exposure), and scores of 34 to 54 indicated high intensity of burnout (professional assistance required). The questionnaire demonstrated satisfactory reliability (*Cronbach's alpha* of 0.86) across different professions.

## Data collection methods and procedures

The Central Office of the Directorate for the Prison and Probation System provided its consent for the research to be conducted. In early 2022, link to the questionnaire was sent to the official email addresses of treatment officers in correctional institutions in Croatia. The instructions accompanying the questionnaire informed the respondents about voluntary and anonymous participation, the research purpose and objectives, the time required to fill out the questionnaire, and the possibility of withdrawing from the research at any point without any repercussions. If participants felt distressed after filling out the questionnaire, they were referred to the Department for Psychosocial Assistance for Workers in the Prison System at the Central Office of the Directorate for the Prison and Probation System. Descriptive analysis, t-test, analysis of variance, and correlation analysis (Pearson correlation coefficient) served to verify research objectives and hypotheses. SPSS software was used for data processing.

## Results and discussion

### Aspects of working conditions of treatment workers in the prison system in the Republic of Croatia

46.67% of the participants assessed the workplace atmosphere as pleasant or exceptionally pleasant, whereas for 13.34%, it was unpleasant or exceptionally unpleasant. One third of the participants (33.33%) were satisfied or completely satisfied with the organization of work, while slightly under one third of the participants (28.33%) were dissatisfied or completely dissatisfied. A significant share of neutral responses (neither satisfied nor dissatisfied) concerning the workplace atmosphere (40%) and the organization of work (38.33%) might indicate unclear or ambivalent attitudes about these aspects of working conditions. Furthermore, more than half of the participants (58%) estimated that they were often or very often under pressure of deadlines at work. Based on a sample of prison officers in Croatia (judicial police, treatment officers, administrative and health care staff, and vocational teachers), Korda (2018) found that the average assessment of satisfaction with the workplace atmosphere and the organization of work varied around the scale average for all departments. However, considering the entire sample, officers appeared more dissatisfied than satisfied with the workplace atmosphere at the correctional institution.

Table 1 Assessment of job burden (work in general, interaction with prisoners and administrative tasks) among treatment workers in the prison system (N=60)

	Work in general		Interaction with prisoners		Administrative tasks	
	f	%	f	%	f	%
I am not burdened at all.	0	0	4	6.67	1	1.67
Not burdened.	7	11.67	14	23.33	4	6.67
Neither burdened, nor unburdened.	21	35	20	33.33	7	11.67
I am burdened.	18	30	17	28.33	17	28.33
I am extremely burdened.	14	23.33	5	8.33	31	51.67
Total	60	100	60	100	60	100

About half of the participants (53.33%) felt burdened or extremely burdened with work in general, while as much as 80% of respondents felt burdened (28.33%) or extremely burdened (51.67%) with administrative tasks (Table 1). Administrative tasks belonged to the general responsibilities of treatment and included, for example: reading and recording prisoners' correspondence, maintaining personal records, entering data into the Zpis digital platform, business correspondence, etc. Among the daily activities of treatment officers, a significant amount of time was dedicated to administration. On the other hand, only 36.66% of treatment officers perceived interaction with prisoners as burdening or extremely burdening. These findings could be attributed to the increasing administrative burden in the daily practice of treatment officers. The administrative tasks reduced the available time and resources for treatment programs and activities related to their area of expertise, aimed at rehabilitating, resocializing, and socially integrating prisoners. Research showed that a sense of fulfillment from helping service users and contributing to their well-being had a significant impact on job satisfaction in the helping professions, despite job burden or emotional exhaustion (Kišak-Gverić et al., 2015). Therefore, devoting more time to administrative tasks than to professional activities and interaction with prisoners likely affected the sense of achievement and overall job satisfaction among treatment officers. According to Tewksbury and Higgins (2006), organizational circumstances accounted for high levels of work-related stress among prison officers (stress was often attributed to a bureaucratic and rigid hierarchical environment, rather than interaction with service users).

In our research study, approximately 84% of treatment workers reported having support from prison management, yet 40% considered the support to be insufficient. About 16.67% of participants felt that they did not have the support of their superiors. The research did not examine the specific aspects of support that were deemed inadequate. However, Korda (2018) found that some prison officers did not feel appreciated for their accomplishments and efforts in their department, lacked feedback to track their progress, and/or did not receive clear instructions and expectations from superiors. Additionally, some officers lacked trust in prison management and perceived the warden to be incompetent and indifferent to their well-being. Kišak-Gverić et al. (2015) reported that treatment officers were more satisfied with the support of colleagues and superiors in terms of interpersonal communication, cooperation, and supervision, rather than with the organization of work, salary, rewards, and promotion opportunities. Nevertheless, there were also highly ambivalent attitudes towards satisfaction with superiors, cooperation, and the organization of work.

### **Perception of work-related stress and the burnout syndrome among treatment workers**

Perceived work-related stress was assessed based on the frequency of positive and negative emotional responses<sup>2</sup> to work and the self-assessment of stress symptoms by treatment workers. Among treatment officers, negative emotional responses to work (M=2.31, SD=0.77) were less prevalent than positive ones (M=2.75, SD=0.81) and occurred more frequently in categories of *sometimes* or *rarely*, compared to positive emotional responses reported more often in categories of *sometimes*, *often*, and *daily*. The t-test for dependent samples confirmed that treatment officers significantly more often experienced positive emotions related to work ( $t=-2.4$ ,  $p=0.02$ ).

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<sup>2</sup> Previous research has linked emotional responses to work with job satisfaction, described as a subjective evaluation of professional benefits in relation to expectations, needs, and aspirations (Kišak Gverić, 2010). However, in this study, emotional responses were considered an indication of work-related stress, as an extrinsic factor that determined both emotional responses to work and overall job satisfaction, in accordance with previous research on work-related stress (Novak et al., 2008).

Table 2 Arithmetic means, standard deviations and relative frequencies of results based on the Questionnaire on emotional responses to work among treatment workers in the prison system (N=60)

ITEMS <sup>3</sup>	M	sd	% of responses				
			never	rarely	sometimes	often	almost every day
1. My job makes me feel angry.	2.62	0.89	11.7	26.7	53.33	5	3.3
2. My job makes me feel anxious.	2.50	0.95	18.3	26.7	41.7	13.3	0
3. I feel at ease at work.	2.80	1.01	8.3	31.7	36.7	18.3	5
4. I feel bored at work.	1.62	1.01	63.3	21.7	8.3	3.3	3.3
5. I feel calm at work.	2.70	1.11	15	30	30	20	5
6. I feel fulfilled at work.	2.93	1.06	6.7	30	35	20	8.3
7. I feel depressed at work.	2.12	1.08	38.3	23.3	28.3	8.3	1.7
8. I feel despondent at work.	2.18	1.13	36.7	25	23.3	13.3	1.7
9. I feel resentful at work.	2.62	1.12	18.3	30	26.7	21.7	3.3
10. I feel elated at work.	2.28	0.99	26.7	28.3	36.7	6.7	1.7
11. I feel energized by my job.	2.65	1.04	13.3	31.7	36.7	13.3	5
12. I feel enthusiastic at work.	2.85	0.97	6.7	30	40	18.3	5
13. I am excited about my job.	2.70	0.10	10	35	33.3	18.3	3.3
14. I find my job tiring.	3.00	0.97	6.7	21.7	41.7	25	5
15. I find my job frightening.	1.97	1.04	45	21.7	26.7	5	1.7
16. My job makes me furious.	2.00	1.11	45	21.7	25	5	3.3
17. My job makes me gloomy.	2.30	1.15	33.3	20	35	6.7	5
18. My job inspires me.	2.82	1.08	11.7	26.7	36.7	18.3	6.7
19. I find my job relaxing.	2.10	0.99	33.3	31.7	28.3	5	1.7
20. My job makes me feel satisfied.	3.10	1.11	6.7	25	31.7	25	11.7
21. My job makes me feel proud.	2.98	1.00	5	26.7	41.7	18.3	8.3
22. I feel miserable at work.	1.98	1.20	50	20	15	11.7	3.3
23. My job frightens me.	1.85	0.94	43.3	35	16.7	3.3	1.7
24. I feel confused at work.	2.32	1.02	25	31.7	31.7	10	1.7
25. I feel cheerful at work.	2.15	0.90	23.3	48.3	18.3	10	0
26. I enjoy my job.	3.55	1.03	3.3	10	35	31.7	20
27. My job makes me feel happy.	3.05	1.03	5	25	40	20	10
28. I find my job frustrating.	2.82	1.02	11.7	23.3	40	21.7	3.3
29. I am delighted by my job.	2.52	0.98	16.7	33.3	31.7	18.3	0
30. I am annoyed by my job.	2.72	1.08	13.3	30	33.3	18.3	5

<sup>3</sup> In the table, items in the category of negative responses to work are marked in gray

In terms of positive emotional responses to work, participants generally felt happy, fulfilled, satisfied and proud; overall, they enjoyed their job. Namely, half of the participants (51.7%) felt that they enjoyed their job *often* or *almost every day*. Notably, about one quarter felt happy (25%), satisfied (25%), fulfilled (28.3%) and proud at work (26.6%) *often* or *almost every day*. Furthermore, 31.7% of the respondents *sometimes* felt satisfied at work, 35% liked it and felt fulfilled, 40% felt happy about their job, and 41.7% of the respondents *sometimes* felt proud of their job. The most common negative emotional responses to work involved fatigue, frustration, resentment, and anger, with one third of the respondents (30%) experiencing fatigue at work *often* or *almost every day* and one quarter (25%) feeling frustration and resentment. The majority of research participants *sometimes* felt angry at work (53.33%), while 8.3% felt this way *often* or *almost every day*. These findings are consistent with those of Kišak Gverić (2010), who suggested that treatment workers experienced more positive than negative emotional responses to work. According to Kišak Gverić (2010), fatigue, anger, resentment, anxiety, and depression were the prevailing negative responses, while happiness, fulfillment, and job satisfaction were the most common positive responses. However, by comparing our results with results of Kišak-Gverić (2010) it is determined that participants in our study reported about lower frequencies of positive emotions related to work. Specifically, Kišak Gverić (2010) found that over 50% of participants felt happy, fulfilled, and satisfied at work *often* or *every day*, while our survey indicated the same for about 25% to 30% of participants. Moreover, our study indicated slightly higher frequencies of negative responses to work among treatment officers compared to Kišak Gverić (2010), with 30% of our research participants experiencing fatigue *often* or *almost every day*, compared to 16.2% in Kišak Gverić (2010). Compared to the research study by Kišak Gverić (2010), which was conducted from 2007 to 2009 and based on a similar sample, it appears that treatment officers nowadays experience less positive and more negative emotional responses to work. However, it is possible that some respondents participated in both studies, but at different ages and stages of their personal and professional lives. Additional research could investigate whether the variation in sample characteristics between the two studies and/or other factors contributed to this pattern, such as changes in the organizational structure, culture, and/or the type and scope of their work.

The results indicate that 63.4% of the participants experienced chronic fatigue several times a month or more, 43.3% had difficulty sleeping, and 40% reported headaches. Irritability (occurring several times a month or more for 36.7% of participants) and helplessness (31.7%) prevailed among the emotional symptoms of stress (Table 3).

Table 3 Arithmetic means, standard deviations and relative frequencies of results based on the Self-assessment questionnaire on the symptoms of stress among treatment workers in correctional institutions (N=60)

ITEMS	M	sd	% responses						
			Never	Once or twice	Once a month	Several times a month	Every week	Several times a week	Every day
1. Chronic fatigue	2.87	1.65	8.3	16.7	11.7	30	16.7	10	6.7
2. Headache	2.02	1.57	21.7	18.3	20	28.3	1.7	8.3	1.7
3. Gastrointestinal and digestive disorders	1.28	1.38	40	23.3	13.3	18.3	1.7	3.3	0
4. Body aches	1.53	1.86	46.7	13.3	11.7	11.7	6.7	5	5
5. Sleeping disorders (waking up, falling asleep)	2.33	1.85	16.7	26.7	13.3	18.3	5	15	5
6. Cardiac and breathing difficulties	1.15	1.56	53.3	13.3	13.3	13.3	0	5	1.7
7. Low energy and activity	2.3	1.56	8.3	30	16.7	28.3	8.3	1.7	6.7
8. Inflexibility with family members	1.63	1.53	28.3	26.7	16.7	18.3	3.3	5	1.7
9. Inflexibility with colleagues	1.63	1.65	25	36.7	13.3	15	1.7	1.7	6.7
10. Conflicts with colleagues at work	0.95	1.32	48.3	28.3	15	3.3	0	3.3	1.7
11. Conflicts with family members	1.2	1.22	31.7	40	13.3	8.3	5	1.7	0
12. Social withdrawal	1.45	1.68	38.3	30	3.3	15	6.7	3.3	3.3
13. Social avoidance	1.43	1.65	40	25	8.3	15	3.3	6.7	1.7
14. General dissatisfaction	1.73	1.85	36.7	16.7	20	6.7	8.3	6.7	5
15. Depression	1.67	1.68	30	26.7	16.7	13.3	5	3.3	5
16. Indecisiveness	1.5	1.49	31.7	25	21.7	13.3	1.7	5	1.7
17. Irritability	2.12	1.71	21.7	16.7	25	18.3	6.7	6.7	5
18. Helplessness	1.83	1.69	23.3	30	15	18.3	5	1.7	6.7
19. Aggression	1.05	1.52	50	25	11.7	6.7	1.7	0	5
20. Learning/attention disorder	1.68	1.54	25	30	18.3	11.7	11.7	0	3.3
21. Memory and recall deficit	2	1.64	18.3	28.3	20	15	8.3	6.7	3.3
22. Time management difficulties	2.02	1.57	21.7	18.3	23.3	18.3	11.7	5	1.7
23. Use of sedatives	0.67	1.43	73.3	13.3	1.7	3.3	3.3	3.3	1.7
24. Increased alcohol consumption	0.38	1.06	81.7	10	3.3	1.7	1.7	0	1.7
25. Increased/reduced food intake	1.62	1.87	43.3	15	8.3	21.7	0	5	6.7
26. Sexual dysfunction	0.68	1.38	73.3	10	3.3	6.7	1.7	5	0

About 1/3 of participants struggled with time management (36.7%) and remembering and recalling (33.3%) several times a month or more, among the cognitive symptoms of stress. Among the behavioral symptoms of stress, low energy and activity prevailed (for 45% of respondents) and increased/reduced food intake (for 33.4%), occurring several times a month or more (Table 4).

Table 4 *Descriptive statistics of subscales of the Self-assessment questionnaire on the symptoms of stress*

	Min	Max	MUR	sd	M	sd
Behavioral symptoms of stress (7 items)	0	40	7.52	7.54	1.07	1.08
Physical symptoms of stress (5 items)	0	24	8.85	6.02	1.77	1.2
Social avoidance/withdrawal (2 items)	0	12	2.88	3.2	1.44	1.6

Table 5 *Results of the analysis of differences on the subscales of the Self-assessment questionnaire on the symptoms of stress*

	t	p
Behavioral vs. physical symptoms of stress	-4.83	0.00**
Behavioral vs. social avoidance/withdrawal	-2.12	0.04*
Physical symptoms of stress vs. social avoidance/withdrawal	1.59	0.12

\* difference is significant at the level of  $p < 0.05$

\*\* difference is significant at the level of  $p < 0.01$

In this study, treatment workers experienced physical symptoms of stress and symptoms of social avoidance and withdrawal significantly more frequently than behavioral symptoms of stress (Table 5). The results indicated that most participants experienced these symptoms less than once a month on average (Table 6).



Table 6 Arithmetic means, standard deviations and relative frequencies of results based on the Questionnaire on the intensity of burnout among treatment workers in the prison system (N=60)

ITEMS	M	sd	% responses		
			rarely	sometimes	always
1. I feel hostility and anger at work.	1.45	0.5	55	45	0
2. I have noticed withdrawing from colleagues.	1.53	0.65	55	36.7	8.3
3. I feel coerced to do tasks at work.	1.33	0.57	71.7	23.3	5
4. I am becoming increasingly insensitive and callous towards service users and colleagues.	1.43	0.53	58.3	40	1.7
5. My job is very tedious, boring and routine.	1.68	0.73	46.7	38.3	15
6. I have noticed negative thoughts about work and focus only on the negative aspects.	1.55	0.65	5.3	38.3	8.3
7. I feel like I have been accomplishing less than ever before.	1.63	0.69	48.3	40	11.7
8. I have difficulties organizing my tasks and time.	1.6	0.59	45	50	5
9. I feel more irritable than ever before.	1.52	0.62	55	38.3	6.7
10. I feel powerless to change anything at work.	1.98	0.77	30	41.7	28.3
11. I bring work frustrations into my personal life.	1.52	0,6	53.3	41.7	5
12. I intentionally avoid socializing at work more than ever.	1.43	0.67	66.7	23.3	10
13. I wonder if my job is suitable for me.	1.67	0.8	53.3	26.7	20
14. I have negative thoughts about my job even in the evenings before sleep.	1.42	0.59	63.3	31.7	5
15. I start every working day with the following thought: "I am not sure I will make it through another day."	1.3	0.56	75	20	5
16. I find that nobody at work cares about what I do.	1.67	0.73	48.3	36.7	15
17. I spend more time avoiding work than actually working.	1.08	0.28	91.7	8.3	0
18. I feel tired and exhausted at work, even if I have slept well.	1.55	0.65	53.3	38.3	8.3
TOTAL SCORE	27.35	7.83	/	/	/

In the *Questionnaire on the intensity of burnout* (Table 6), participants tended to choose responses of rarely or sometimes, with few selecting always. The items most frequently marked with always were: *I feel powerless to change anything at work* (28.3%) and *I wonder if my job is suitable for me* (20%). The items most often marked with sometimes (40% to 50%) referred to: *I have difficulties organizing my tasks and time*, *I bring work frustrations into my personal life*, *I feel powerless to change anything at work*, *I feel like I have been accomplishing less than ever before*, and *I am becoming increasingly insensitive and callous towards service users and colleagues*. As a result, the item *I feel powerless to change anything at work* appeared to reflect the main professional challenge for participants, with 70% of respondents indicating they felt that way sometimes or always. The results indicate that 48.33% of the participants

did not show significant symptoms of burnout. However, 51.67% experienced burnout to some extent, with symptoms of initial burnout (25%) and high-intensity burnout (26.67%).

### **Differences in the experience of emotional responses to work, symptoms of stress and the intensity of burnout with regard to the socio-demographic characteristics of treatment workers**

Variance analysis was used to determine the differences in emotional responses to work, symptoms of stress, and burnout with regard to the socio-demographic characteristics of the participants. A t-test for independent samples was used to determine differences with regard to gender and marital status. Based on the questionnaires, women experienced physical symptoms of stress significantly more often than men (Table 7), in line with other research studies indicating that women reported physical symptoms of stress 50% more often than men (Lukačić, 2015). Physical symptoms of stress also appeared more intense, numerous, and frequent for women than for men (Barsky, Peekna, and Borus, 2001). Various psychosocial factors might have accounted for the gender discrepancies (e.g. different socialization of boys and girls, girls being allowed to complain about physical discomfort, the notion that taking care of the body and health was a sign of femininity, which caused men to withhold the physical symptoms of stress). Biological factors also played a part (e.g. gender differences determining different physiological responses to stress) (Lukačić, 2015). Men exhibited higher levels of the hormone cortisol in response to a stressful stimulus compared to women (entailing a higher risk of cardiovascular diseases and diabetes). Conversely, women generally had lower levels of cortisol and a lower reactivity of the hypothalamic-pituitary-adrenal axis (HPA) and the autonomic nervous system (entailing a higher risk of autoimmune diseases) (Kudielka and Kirschbaum, 2005).

Furthermore, there were considerable differences in the intensity of burnout based on the current job position, but no significant differences in emotional responses to work, symptoms of stress, and burnout among treatment officers for other socio-demographic variables (Table 8). These findings are consistent with research studies that have shown that socio-demographic variables were not significantly related to the experience of work-related stress and burnout among prison officers (Dowden and Teller, 2014; Korda, 2018; Novak et al., 2008). The results showed that senior treatment counselors experienced higher levels of burnout in comparison to the heads of the treatment departments/sections with respect to the burnout intensity concerning their present job position (Tables 7 and 8).

Table 7 *Arithmetic means, standard deviations and the results of the analysis of differences on the subscales of the Questionnaire on emotional responses to work, the Self-assessment questionnaire on the symptoms of stress and the overall results of the Questionnaire on the intensity of burnout for different socio-demographic variables (N=60)*

M	Positive emotions			Negative emotions			Behavioral symptoms of stress			Physical symptoms of stress			Social avoidance/withdrawal			Burnout intensity					
	sd	t/F	p	M	p	M	sd	t/F	p	M	p	M	sd	t/F	p	M	p	M	sd	t/F	p
<b>Sex</b>	Men	2.37	1	-1.44	0.16	0.66	0.63	-1.17	0.25	0.9	0.6	1.56	1.9	0.23	0.82	25.75	7.27	-0.62	0.54		
	Women	2.8	0.77		-1.18	0.27	1.14	1.12		1.9	1.22	1.42	1.57		0.82	27.6	7.95				
<b>Age</b>	Under 40 years old	2.83	0.82			1.26	1.45			1.64	1.11	1.43	1.55			28.05	9.24				
	40 to 49 years old	2.84	0.89	0.53	0.46	1.26	0.9	1.51	0.23	1.93	1.23	1.59	1.79	0.11	0.9	27.81	8.66	0.26	0.77		
	50 years and older	2.61	0.82			0.77	0.74			1.77	1.3	1.35	1.56			26.46	6.04				
<b>Marital status</b>	Single, divorced or widowed	2.46	0.88			1.07	1			1.78	1.07	1.33	1.54			26.44	6.51				
	Marital, extramarital relationship	2.2	0.67	-1.3	0.2	1.08	1.19	-0.21	0.98	1.76	1.41	1.6	1.71	-0.64	0.53	28.71	9.48	0.06	0.95	0.19	0.28
<b>Number of children</b>	No children	2.92	0.7			1	1.05			1.45	1.11	1.38	1.29			27.24	8.65				
	1 child	2.33	0.72			1.17	0.91			2	0.86	2.22	2.15			29.33	8.82				
	2 children	2.8	0.7	1.15	0.34	0.91	0.85	0.65	0.59	1.76	1.21	1.24	1.44	0.86	0.47	25.52	6.95	0.8	0.5	0.86	0.42
	3 or more children	2.68	1.15			1.44	1.61			2.11	1.56	1.32	1.86			29.73	7.51				
<b>Profession</b>	Social worker	2.58	0.6			1.03	0.95			1.56	1.21	1.71	1.95			27.88	9.23				
	Social pedagogue	2.77	0.88			1.43	1.44			1.91	1.21	1.28	1.45			27.9	7.73				
	Psychologist	3.18	0.1	1.39	0.26	0.76	0.66	1.27	0.29	1.76	1.17	1.4	1.76	0.23	0.88	25.90	8.54	0.26	0.86	0.18	0.91
	Other professions	2.59	0.72			0.82	0.72			1.83	1.32	1.38	1.31			26.92	5.99				
<b>Job position</b>	Assistant treatment specialist	2.71	0.97			1.03	0.9			1.72	1.22	1.2	1.64			26.8	8.32				
	Senior treatment counselor	2.61	0.78	2.41	0.09	1.17	1.18	0.64	0.53	1.88	1.24	1.61	1.72	0.73	0.49	28.93	8.07	0.65	0.53	3.32*	0.04*
	Head of treatment department/section	3.4	.74			0.8	0.8			1.46	1.12	1.04	1.18			22.93	5.27				
<b>Total professional experience</b>	Up to 10 years	2.86	0.97			1.79	1.85			1.8	1.26	1.7	1.89			28.6	9.47				
	11 to 20 years	2.78	0.75	0.53	0.59	1.02	0.83	2.92	0.06	1.64	1.11	1.38	1.4	0.15	0.86	27.29	8.06	0.2	0.82	0.16	0.85
	Over 20 years	2.68	0.81			0.87	0.79			1.86	1.28	1.4	1.4			26.97	7.3				
<b>Professional experience in the prison system</b>	Up to 10 years	2.79	0.9			1.1	1.29			1.83	1.2	1.35	1.59			27.1	7.99				
	11 to 20 years	2.65	0.62	0.06	0.94	1.06	0.81	0.03	0.97	1.43	1.03	1.94	1.7	1.62	0.21	28.72	8.89	1.25	0.29	0.48	0.62
	Over 20 years	2.77	0.88			1.01	0.91			2.12	1.42	0.92	1.36			25.92	5.76				

\*difference is significant at the level of  $p < 0.05$

Table 8 Scheffé post hoc test of the significance of differences in burnout levels among workers in treatment departments in the prison system in Croatia, based on their current job position

	Senior treatment counselors	Heads of treatment departments/sections
Assistant treatment specialists	0.84	0.62
Senior treatment counselors		<b>0.044*</b>

Greater professional responsibility and autonomy, as well as the influence on decision-making in the organization, and higher financial income could account for the lower intensity of burnout among heads of the treatment departments/sections, compared to senior treatment counselors and assistant treatment specialists. These circumstances seemed to provide an effective protection against work-related stress and burnout (Catiglione et al., 2017; Lambert et al., 2020; Novak et al., 2008). With slight differences, assistant treatment specialists appeared to be more prone to burnout than the heads of treatment departments/sections, taking into account that only five research participants were assistant treatment specialists.

### **Correlation between the experience of emotional responses to work, symptoms of stress and the intensity of burnout and some aspects of the working conditions of treatment workers**

The results showed that the assessment of workplace atmosphere and satisfaction with the organization of work significantly negatively correlated with negative responses to work, behavioral and physical symptoms of stress, social avoidance and withdrawal, and the intensity of burnout. In contrast, there was a significant positive correlation between the assessment of workplace atmosphere and satisfaction with the organization of work, and positive responses to work (Table 9).

Table 9 Correlation between the emotional responses to work, symptoms of stress and the intensity of burn-out and some aspects of the working conditions of treatment workers (N=60)

	Positive responses	Negative responses	Behavioral symptoms of stress	Physical symptoms of stress	Social avoidance/ withdrawal	Burnout intensity
Assessment of work-place atmosphere	<b>0.406**</b>	<b>-0.433**</b>	<b>-0.423**</b>	<b>-0.264*</b>	<b>-0.258*</b>	<b>-0.460**</b>
Satisfaction with the organization of work	<b>0.438**</b>	<b>-0.471**</b>	<b>-0.509**</b>	<b>-0.354**</b>	<b>-0.276*</b>	<b>-0.546**</b>
Exposure to deadline pressure	-0.047	-0.025	-0.103	0.185	-0.122	-0.065
General assessment of job burden	-0.243	0.225	-0.199	<b>0.396**</b>	0.183	-0.181
Assessment of job burden from interaction with prisoners	-0.218	0.096	-0.058	0.132	0.108	0.082
Assessment of administrative burden	-0.202	0.016	-0.113	0.150	0.128	0.059
Assessment of management support at correctional institution	<b>0.445**</b>	<b>-0.442**</b>	<b>-0.344**</b>	<b>-0.328*</b>	-0.254	<b>-0.465**</b>

\*significant correlation at the level of  $p < 0.05$

\*\*significant correlation at the level of  $p < 0.01$

The research findings suggested that treatment officers who expressed higher levels of satisfaction with the workplace environment and the organization of work also reported fewer negative and more positive emotional responses to work. Additionally, they experienced fewer physical and behavioral symptoms of work-related stress, exhibited a lower tendency to avoid social interactions, and overall had a lower level of burnout. Moreover, management support acted as a major factor. Namely, participants who perceived more support also experienced more positive and fewer negative responses to work, fewer behavioral and physical symptoms of work-related stress and a lower intensity of burnout. Among other aspects of the working conditions, the assessment of job burden had a significant impact on experiencing physical symptoms of stress; that is, the participants who experienced a greater job burden generally reported more physical symptoms of work-related stress.

According to research results, treatment officers regarded management support, the organization of work and the workplace atmosphere as the most significant organizational factors that contributed to work-related stress and burnout. Novak (2009) found that, regardless of professional autonomy, the correctional officers perceived the actions of superiors and their attitude towards workers as the predominant source of stress. These results were also consistent with the research findings on the impact of organizational factors on the experience of work-related stress and burnout among prison officers (e.g. Catiglione et al., 2017).

Convenience sampling represented an important limitation in the present research study. Despite clear indication that the research was anonymous and that the results would be presented for the entire sample, some participants might have provided socially acceptable answers. A significant methodological limitation also involved the verification of the factor structure of the Self-assessment questionnaire on the symptoms of stress, which was performed on a relatively small sample. Given the correlational nature of the research study and the calculation of Pearson correlation coefficients for the relationships between variables, definite conclusions on the cause-and-effect relationships between variables were not possible based on the research results.

## Conclusion

Research results revealed that treatment workers in correctional institutions experienced more positive than negative responses to work, with occasional physical and behavioral symptoms of work-related stress and symptoms of withdrawal and social isolation occurring on average less than once a month. Women reported physical symptoms of stress significantly more often than men. Senior treatment counselors experienced burnout significantly more than heads of treatment departments/sections. Around 52% of the participants exhibited symptoms of burnout, with 25% of participants having the symptoms of initial burnout and approximately 27% experiencing high intensity burnout. Treatment officers in Croatia identified management support, the organization of work, and the workplace atmosphere as the main factors contributing to work-related stress and burnout. A significant positive correlation was determined between satisfaction with workplace atmosphere and the organization of work and the positive responses to work. Accordingly, dissatisfaction with workplace atmosphere and the organization of work also correlated with negative responses to work, behavioral and physical symptoms of stress, social avoidance and withdrawal and the intensity of burnout. Moreover, the general assessment of job burden significantly correlated with experiencing physical symptoms of stress.

124 As treatment workers in correctional institutions performed demanding support work that involved daily interaction with a specific population, research findings contributed to deter-

mining and understanding the intensity of work-related stress and burnout for the target group. Research results also helped to interpret how different socio-demographic variables and aspects of working conditions shaped the experience of work-related stress and burnout. The research also confirmed that organizational factors had a more significant impact on experiencing work-related stress and burnout than socio-demographic variables. The results suggested that professional autonomy and influence on decision-making could effectively safeguard workers against work-related stress and burnout. Additionally, dissatisfaction with the workplace atmosphere and the organization of work, job burden, and inadequate management support in correctional institutions represented major predictors of work-related stress and burnout. The authorities at the Central Office for the Prison and Probation System could use the present research findings to plan and improve various aspects of the system, notably to reduce the incidence of work-related stress and burnout among treatment officers. The research results offered useful insights into relevant aspects for improving the work processes of treatment officers.

The future research might consider including a larger sample of treatment workers in correctional institutions and examining the impact of a wider range of personal and professional variables (e.g. personality traits, self-confidence, strategies for coping with stress, job satisfaction, work commitment, conflicts of family and professional roles, etc.). Other organizational factors that contribute to work-related stress and burnout should also be taken into account (e.g. physical working conditions, safety aspects, relationships with superiors, financial income, type and size of the correctional facility, etc.). Variables concerning interaction with prisoners (e.g. attitudes towards perpetrators of criminal acts, apprehension towards prisoners, challenges in establishing relationships and interacting with prisoners, etc.) should also be considered. Moreover, it is essential to investigate the distinctions between various types of institutions, such as prisons or penitentiaries, as the interactions of treatment officers with diverse populations, notably in terms of different duration of the prison sentence, could reflect on the nature and extent of their work. In light of the research results, further studies might examine the impact of the increasing administrative burden on job satisfaction and work-related stress among treatment officers, notably in conjunction with professional autonomy and the opportunities to participate in decision-making that were found to be significant factors contributing to job burnout.

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Neven Ricijaš, UNIZG, Faculty of Education and Rehabilitation Sciences

neven.ricijas@erf.unizg.hr

Dora Dodig Hundrić, UNIZG, Faculty of Education and Rehabilitation Sciences

dora.dodig@erf.unizg.hr

Sabina Mandić, UNIZG, Faculty of Education and Rehabilitation Sciences

sabina.mandic@erf.unizg.hr

## Gambling characteristics of addicts in therapeutic communities in Croatia

### SUMMARY

Addiction is a multidimensional problem correlated with other mental health issues, one of them being other types of addiction. Research on the comorbidities of different types of substance addictions has been well established. The focus of this study was to explore gambling behaviour and gambling related problems among addicts who seek psychosocial interventions within different therapeutic communities (TC) in Croatia. The study was conducted based on a sample of 265 addicts (m = 84.7%; f = 15.3; Mean age = 35.9; SD age = 9.22) within seven therapeutic communities. Since TC provide different types of psychosocial support for various clients, the inclusion criterion was that the individual had been diagnosed with at least one addiction (alcohol, drugs, and/or gambling addiction). This allowed us to examine the extent to which professionals working at TC face gambling problems as a specific behavioural addiction. In addition to general demographic characteristics (age, gender, and so on), this study explored the prevalence of gambling in the past three months, the level of problem gambling (Problem Gambling Severity Index – PGSI), preferred game, age at the first onset of gambling, and comorbidities associated with different addiction-related problems. The results show that 29.2% of addicts have symptoms of problem gambling (gambling addiction), which is ten times more prevalent than that reported among the general population. As expected, these problems are more prevalent among males (31.7%), even though a considerable percentage of female participants also suffered from gambling addiction symptoms (17.5%). At the same time, 18.8% of gambling addicts had never been diagnosed with the gambling addiction, highlighting the need for adequate assessment and intervention programs within TC.

## Introduction

Addiction is a global health and psychosocial problem that affects millions of lives and causes intense pain and suffering. It may involve the use of legal and illegal psychoactive drugs (e.g., alcohol, nicotine, opioids, stimulants, steroids, prescription painkillers, tranquillisers, or cannabis), or the object of addiction may be a behaviour/activity (e.g., gambling, video games, etc.) (West, 2013, pp. 11). Based on this definition, it is already clear that today's contemporary approach to addictions does not presume only substance abuse, but also behavioural addictions. Until recently, however, the term addiction was almost exclusively limited to substance-using behaviours, whereas now the transformation of addiction from a narrow concept that required ingestion of psychoactive drugs to one that presupposes psychoactive experiences (i.e., shifts in subjective states) is nearly complete (Rosenberg & Curtiss Feder, 2014; Schaffer & Schaffer, 2016). There are several arguments in favour of such an approach, ranging from those from the field of neuroscience, which suggest that reward is reward regardless of whether it comes from a chemical or an experience, to the fact that symptoms and negative psychosocial consequences are quite similar regardless of the object of addiction. This is also confirmed by the addiction criteria. For example, following the work of Brown (1993), Griffiths (1996, 2005) defines six components of addiction within his biopsychosocial framework:

1. Salience - refers to when a particular activity becomes the most important activity in a person's life and dominates their thinking (preoccupations and cognitive distortions), feelings (cravings), and behaviour (deterioration of socialized behaviour).
2. Mood modification - refers to the subjective experience people report as a result of engaging in the activity in question (i.e., experiencing an exhilarating "rush" or "high" or, paradoxically, a calming and/or destressing feeling of "escape" or "numbing").
3. Tolerance - refers to the process of requiring increasingly larger amounts of the particular activity to achieve the previous effects.
4. Withdrawal symptoms - refers to the unpleasant emotional states and/or physical effects that occur when the particular activity is discontinued or suddenly reduced. Such withdrawal symptoms may be psychological (e.g., extreme mood swings and irritability) or more physiological (e.g., nausea, sweating, headaches, insomnia, and other stress-related reactions).
5. Conflict - refers to conflict between the addict and his/her environment (interpersonal conflict) or within the person (intrapsychic conflict) related to the activity in question.
6. Relapse - refers to the tendency to repeatedly relapse into earlier patterns of the particular activity and to the fact that even the most extreme patterns that were typical at the height of addiction can quickly reappear after many years of abstinence or control

Based on all of the above, there is no doubt that behavioural addictions (e.g., gambling) share the same underlying mechanisms and general clinical manifestations as other substance ad-

dictions. Therefore, it is not surprising that behavioural addictions are not only recognised in the new versions of diagnostic manuals (e.g., DSM-5 [APA, 2013]; ICD-11 [WHO, 2022]) but are also part of the current definitions of addictions. Consequently, the American Society of Addiction Medicine defines addiction as “a treatable, chronic medical disease involving complex interactions among brain circuits, genetics, the environment, and an individual’s life experiences. People with addiction use substances or engage in behaviours that become compulsive and often continue despite harmful consequences” (ASAM, 2019). After analysing and exploring different theories and models of addiction, West (2013, pp. 27) defines addiction as “a repeated strong incentive to engage in a purposeful behaviour which is not of vital importance, and which is a result of engaging in that behaviour with significant potential of causing unintended harm”.

Regarding gambling addiction, studies have shown that the past year prevalence of pathological gambling among adults in the general population ranges from 0.12 to 5.8% worldwide and from 0.12 to 3.4% in Europe (Shaffer & Hall, 2001; Calado & Griffiths, 2016). A study conducted on a representative sample of Croatians (aged 15-64) found that 2.2% of the population have a probable gambling addiction problem with loss of control (9+ on the PGSI), 2.9% have a moderate risk and 4.3% have a low risk of gambling-related problems (Glavak Tkalić & Miletić Sučić, 2017). In addition to differences in the gambling market and the general regulation of gambling in different societies, the differences between the various studies can also be attributed to the characteristics of the samples, as well as the instruments used to assess problem gambling (Jackson et al., 2010).

Because of similar vulnerabilities and underlying mechanisms, contemporary studies have also focused on exploring comorbidity between gambling-related problems and other mental health problems. Lorains, Cowlshaw, and Thomas (2011) conducted an extensive literature review to explore the prevalence of common comorbid disorders, including alcohol use disorder, depression, substance use disorders, nicotine dependence, anxiety disorders, and antisocial personality disorder, in population-representative samples of problem and pathological gamblers. In their analysis, they drew on 11 eligible studies and found that problem and pathological gamblers had high rates of other comorbid disorders. Nicotine dependence had the highest average prevalence (60.1%), followed by substance use disorder (57.5%), any type of mood disorder (37.9%), and any type of anxiety disorder (37.4%). A similar systematic review was conducted by Dowling et al. (2015) with the aim of exploring the prevalence of comorbid psychiatric disorders among treatment-seeking problem gamblers. Their findings, which included 36 studies, revealed high rates of comorbid current (74.8%) and lifetime (75.5%) Axis I disorders based on DSM-IV. When it comes to comorbidity with other addictions, the highest mean prevalence was found for nicotine dependence (56.4%), followed by cannabis use disorder (11.5%), alcohol abuse (18.2%), alcohol dependence (15.2%), and substance use disorders (excluding alcohol) in general (7.0%). A more recent analysis of the co-occurrence of sub-

stance use and other potentially addictive behaviours was conducted by Kotyuk et al. (2020) in a rigorous study of 3 003 adolescents and young adults (mean age 21 years). Their results showed a strong association between (A) smoking and problematic Internet use, exercising, eating disorders, and gambling; (B) alcohol use and problematic Internet use, problematic online gambling, gambling, and eating disorders; and (C) cannabis use and problematic online gambling and gambling. The authors conclude in favour of a large overlap between the occurrence of these addictions and behaviours and emphasise the importance of examining the possible common psychological, genetic, and neural pathways of all addictions.

When it comes to the prevalence of gambling-related problems in the population of substance addiction treatment seekers, Bodor (2018) found that in alcohol addiction clubs (AA) in Croatia, 10.0% of alcohol addicts meet the criteria for pathological gambling (measured with SOGS) and 12.9% have some gambling-related problems. In a representative U.S. sample of patients reporting past-year treatment for substance use problems, Cowlishaw & Hakes (2015) identified that approximately 4% of patients were classified as pathological gamblers and around 7% as problem gamblers. These rates are higher than the rates for pathological/problem gambling in the general population of adults, therefore studies confirm that gambling problems are more common in people with substance use problems and vice versa.

In general, addiction treatment in Croatia is organized through inpatient (hospital) and outpatient treatment. Available services related to drug addiction treatment include pharmacotherapy (methadone and buprenorphine for opiate addicts), psychotherapy for addicts, family support and psychotherapeutic treatment, education about the disease, relapse prevention strategies, infection prevention with testing (HIV, viral hepatitis, syphilis), social interventions and support for social reintegration measures, urine testing, comorbidity therapy, somatic health care, use of self-help programs – NGO support programs, clubs for addicts in treatment, etc. (Hrvatski zavod za javno zdravstvo [Croatian Institute of Public Health], 2023). In addition to public/governmental institutions, non-governmental institutions also play an important role in providing various treatment and rehabilitation services (Zoričić, 2020). They are organised in the form of therapeutic communities, rehabilitation centres for drug addicts, and non-governmental organisations that provide services in the areas of social work and counselling, psychosocial help and support, occupational therapy, health care, and psychological support (Vlada Republike Hrvatske, Ured za suzbijanje zlouporabe droga [Government of the Republic of Croatia, Office for Combating Drugs Abuse], 2023).

Currently (last update 11.7.2023, Croatian Institute of Public Health), a total of 9 therapeutic communities in Croatia offer addiction treatment programs (Vlada Republike Hrvatske, Ured za suzbijanje zlouporabe droga [Government of the Republic of Croatia, Office for Combating Drugs Abuse], 2023). The analysis of the coherence of Croatian addiction policy conducted 10

years ago (Jerković et al., 2013) concluded that the policy and the national body responsible for policy coordination should focus on all psychoactive substances as well as on all addictive behaviours and should not distinguish between substance-related and non-substance-related addictions. In line with this recommendation, in February 2023, the Croatian Parliament adopted the National Strategy of Action in the Field of Addiction until 2030 (Official Gazette, 18/23), which integrates a strategic approach to all legal (alcohol, tobacco) and illicit drugs, as well as to various addictive behaviours (gambling, video games, Internet addiction).

Due to the confirmed coincidence of substance use and gambling (Barnes et al., 2015), as well as the fact that little research has been conducted on this topic in Croatia, it seems reasonable to explore gambling characteristics of clients in therapeutic communities, as they are a rather under-studied group of addiction treatment seekers, and this paper aims to fill this research gap. Considering that the gambling market in Croatia is very liberal and poses a significant health and psychosocial risk (Ricijaš et al., 2019), while at the same time generating high social costs (Globan et al., 2021), the results of the present study could be useful for future strategies and addiction-related policies.

## **Objective, Research Problems and Hypotheses**

The main aim of this study was to explore the frequency of gambling and the prevalence of gambling-related problems in the population of clients in Croatian therapeutic communities (TC). The purpose of the study was to gain insight into the extent to which professionals working in TC encounter gambling-related problems, as gambling may not be the primary addiction for administration in TC.

Specific objectives are to explore gender differences in gambling frequency and prevalence of gambling-related problems, as well as differences in gambling frequency and preferred gambling activity with regard to gambling-related problems.

The hypotheses are that gambling is prevalent among TC clients and that the prevalence rate of gambling-related problems is much higher compared to the general population. It is hypothesised that men gamble more frequently and have more gambling-related problems, while those who have developed gambling-related problems prefer games with higher addictive potential (i.e., sports betting, slot machines, and roulette).

## **Methods**

### **Participants, Procedure, and Ethics**

132 This study was conducted in 2021 and 2022 with N=263 participants (n=222 males [84.4%]; n=40 females [15.2%]; Mage=35.90; SDage=9.22) from 7 therapeutic communities [TC] in Croa-

tia (1. Cenacolo; 2. Mondo Nuovo; 3. Susret; 4. Ne-Ovisnost; 5. Pet Plus; 6. Papa Ivan XXIII; 7. Moji Dani), who were undergoing a therapeutic treatment for their addiction.

The questionnaire was administered in an individual or group context by a therapist in the TC. Participation in the study was voluntary, the questionnaire was completely anonymous, and participants were informed about the main aim of this study. The sample is convenient. All participants gave verbal consent to participate, their participation did not cause any additional stress, and the entire data collection procedure was carried out in accordance with the WMA Helsinki Declaration (2013) and Ethical Code of the University of Zagreb (2007).

## Measures

This study aimed at keeping the client's anonymity as much as possible, as well as administering short and coherent instruments. Therefore, only gender and age were measured as socio-demographic variables. Participants were asked to mark which addiction they had been officially diagnosed with prior to TC: alcohol addiction, gambling addiction and/or drug addiction.

*Gambling Activity Questionnaire* (GAQ; Ricijaš et al., 2011) was used to assess the self-reported frequency of gambling in the past three months period. This questionnaire is focused on assessing the frequency of participation in six major types of games of chance within the Croatian context (lottery games, scratch cards, sports betting, slot machines, roulette and card games) and is one of the most commonly used instruments for assessing the frequency of gambling in Croatia and neighbouring countries (Bijedić et al., 2015; Ricijaš et al., 2016; Adilović, 2018; Zibar, 2023). Participants marked on a six-point scale how often they played a particular game of chance in the last three months (never; 1x per month or less; 2x per month; 1x per week; a couple of times per week; [almost] every day). They also had to mark only one game that they find the most attractive.

*Problem Gambling Severity Index* (PGSI) was used to assess gambling-related (psychosocial) problems. PGSI was developed by Ferris and Wynne (2001) and is one of the most commonly used instruments to assess problem gambling in the adult population. It consists of 9 items (e.g., "Have you bet more than you could really afford to lose?") and participants must choose and answer between 4 categories (0=never; 1=sometimes; 2=most of the time; 3=almost always). The total score ranges from 0 to 27, and problem gambling is further categorized based on the total score (0=no problem gambling, 1-2=low level of problems with few or no identified negative consequences [low-risk gamblers]; 3-7=moderate level of problems leading to some negative consequences [moderate-risk gamblers], 8+=problem gambling with negative consequences and a possible loss of control [problem gamblers]). Cronbach's alpha was excellent in the present study ( $\alpha=.947$ ). For the purpose of this study, PGSI scores were also re-catego-



rized into three categories (1=no problem gambling [score 0]; 2=some gambling problems [score 1-7]; 3=problem gambling [score 8+]) in order to compare participants based on their level of gambling-related problems, but also to obtain relatively even distribution of participants within categories by merging low and moderate levels of problem gambling.

## Statistical Analysis

In order to choose an appropriate statistical analysis for exploring differences in the frequency of gambling, we tested the normality of the distribution of all items in the GAQ for the entire sample and separately by gender. We tested for Skewness and Kurtosis measures (Table 1) using the medium sample size criterion ( $50 < N < 300$ ) according to Kim (2013). The Z-value was measured using the formula  $Z = \text{statistic} / \text{standard error}$ , and the criterion of Z-value within  $\pm 3.29$  was used as the threshold for normal distribution (Kim, 2013). Since Z values of all variables were not within the criterion range, we performed a nonparametric analysis. Mann-Whitney U and Kruskal-Wallis tests were used to explore differences in the frequency of gambling in relation to gender and the levels of problem gambling, respectively, while the Mann-Whitney U test was also used as a post-hoc test. To control for sample size, effect sizes of significant differences were calculated using the formula  $r = Z / \sqrt{N}$ . The Chi-square test was used to test differences in dichotomous variables.

Table 1 *Skewness and Kurtosis for the frequency of gambling*

Type of game	Min	Max	Skewness			Kurtosis		
			Stat.	Std. Error	Z	Stat.	Std. Error	Z
Total sample (N=263)								
Lottery games	0	5	2.34	.14	16.55	6.22	.28	22.01
Scratch cards	0	5	3.46	.14	24.41	13.12	.28	46.47
Sports betting	0	5	1.03	.14	7.27	-0.45	.28	-1.60
Slot machines	0	5	1.16	.14	8.20	-0.22	.28	-.77
Roulette	0	5	1.86	.14	13.13	2.12	.28	7.52
Cards for money	0	5	2.71	.14	19.12	6.68	.28	23.65



Males (n=223)								
Lottery games	0	5	2.41	.15	15.66	7.03	.31	22.97
Scratch cards	0	5	3.50	.15	22.75	13.34	.31	43.55
Sports betting	0	5	0.88	.15	5.72	-0.75	.31	-2.45
Slot machines	0	5	1.10	.15	7.15	-0.39	.31	-1.28
Roulette	0	5	1.79	.15	11.66	1.87	.31	6.10
Cards for money	0	5	2.60	.15	16.90	5.89	.31	19.25
Females (n=40)								
Lottery games	0	4	2.08	0.35	5.87	3.67	0.69	5.29
Scratch cards	0	4	3.25	0.35	9.17	12.36	0.69	17.80
Sports betting	0	4	2.44	0.35	6.91	4.83	0.69	6.95
Slot machines	0	5	1.58	0.35	4.47	1.33	0.69	1.92
Roulette	0	4	2.33	0.35	6.59	4.08	0.69	5.88
Cards for money	0	5	3.67	0.35	10.36	16.70	0.69	24.05

## Results and Discussion

Based on the hypothesis that gambling is significantly represented among clients of therapeutic communities, we first examined the prevalence of their gambling in the past three months (Table 2), and the results confirm their quite intense gambling activities in the measured period. The common criterion for regular gambling is considered to be once a week or more in various studies (Felsher et al., 2004; Ricijaš et al., 2016) and our results show that almost a quarter of participants regularly bet on sports results (24.3%) and/or played slot machines (23.2%). As expected, lottery games (5.3%) and scratch cards (3.8%) were not as prevalent when it comes to regular gambling, but it is worth noting that 14.1% of participants played roulette regularly. Unexpectedly, no gender differences were found, except for sports betting, but with a very small effect size ( $r=.20$ ). Regular sports betting was more prevalent among men (27.2%) than among women (10.0%).

Table 2 Frequency of gambling (past 3 months) with gender differences (Mann-Whitney U-test)

Type of game	Gender	Frequency of Gambling (%)						Mann-Whitney U-test			
		Never	1x per month or less	2x per month	1x per week	Couple of times per week	(Almost) Everyday	RANK	MW U	p	r
Lottery games	M	65.9	23.3	6.3	2.7	0.9	0.9	131.91	4440.5	.958	
	F	67.5	17.5	5.0	5.0	5.0	0.0	132.49			
	ALL	66.2	22.4	6.1	3.0	1.5	0.8				
Scratch cards	M	80.7	12.1	3.1	1.3	1.8	0.9	131.41	4329.0	.670	
	F	77.5	15.0	5.0	0.0	2.5	0.0	135.28			
	ALL	80.2	12.5	3.4	1.1	1.9	0.8				
Sports betting	M	49.8	16.1	7.2	<b>7.6</b>	<b>10.3</b>	<b>9.0</b>	<b>138.14</b>	<b>3090.0</b>	<b>.001</b>	<b>.21</b>
	F	80.0	5.0	5.0	2.5	7.5	0.0	97.75			
	ALL	54.4	14.4	6.8	6.8	9.9	7.6				
Slot machines	M	57.8	13.0	4.9	4.9	8.5	10.8	132.90	4259.0	.612	
	F	60.0	12.5	10.0	5.0	7.5	5.0	126.98			
	ALL	58.2	12.9	5.7	4.9	8.4	9.9				
Roulette	M	65.0	16.6	4.0	2.2	7.6	4.5	134.81	3834.0	.089	
	F	80.0	5.0	2.5	5.0	7.5	0.0	116.35			
	ALL	67.3	14.8	3.8	2.7	7.6	3.8				
Cards for money	M	76.7	13.0	2.2	1.8	2.7	3.6	131.88	4432.5	.933	
	F	30	17.5	5.0	0.0	0.0	2.5	132.69			
	ALL	76.4	13.7	2.7	1.5	2.3	3.4				

**Legend:** M=males (n=223); F=females (n=40); ALL=total sample (n=263); MW U=results of the Mann-Whitney test, p=significance; r=effect size; bold letters=significant differences

The PGSI was used to explore adverse gambling-related consequences in the past six months. Based on the original categorization, the results in Table 3 show that only 42.7% of all participants have no gambling-related problems. The fact that 12.2% of participants have a low level of gambling problems, 15.6% have a moderate level, and 29.4% meet the criteria for problem gambling (probable gambling addiction) represents an alarming result in terms of exposure TC therapists have with gambling-related problems among their clients, confirming our hypothesis of more intense gambling involvement and gambling-related problems in this population. Gender differences were not found, and our hypothesis could not be confirmed. Women seeking treatment within TC also manifest a high prevalence of gambling and gambling-related problems.

Table 3 Gambling-related problems and gender differences

GENDER * PGSI CATEGORIES		No GP	Low level GP	Moderate level GP	PG (GA)	$\chi^2$	p
Males (n=223)	N	93	25	34	70	3.703	.295
	%	41.9	11.3	15.3	31.5		
Females (n=40)	N	19	7	7	7		
	%	47.5	17.5	17.5	17.5		
Total (N=263)	N	112	32	41	77		
	%	42.7	12.2	15.6	29.4		

**Legend:** GP=gambling problems; PG=gambling problems; GA=gambling addiction;  $\chi^2$ =chi-square; p=significance

To further explore the differences in gambling frequency with regard to gambling-related problems, we first re-categorised the PGSI results into three levels (no problems, moderate problems, and problem gambling). The results of the Kruskal-Wallis test (Table 4) show significant differences across all types of games, but the effect sizes are particularly large between non-problematic gambling and problem gambling on slot machines ( $r=0.77$ ), sports betting ( $r=0.64$ ) and roulette ( $r=0.60$ ), confirming our hypothesis. These are all highly addictive games whose risk of developing gambling-related problems is also demonstrated in this study. In the results presented in Table 5, we can also notice that slot machines and sports betting are the most attractive games to participants with problem gambling i.e. probable gambling addicts.

Table 4 Differences in gambling frequency with regard to gambling-related problems (PGSI)

	NO PROBL	SOME PROBL	PROBL GAMBL	K-W test	M-W U-test (as post-hoc test)					
					NO vs. SOME	r	NO vs. PG	r	SOME vs. PG	r
Lottery games	112.84	134.24	156.05	$\chi^2$ /sig	3405.0*	0.18	2905.0***	0.33	2327.5*	0.17
Scratch cards	11.98	133.50	146.36		3654.5	/	3455.0**	0.25	2523.0	/
Sports betting	93.48	131.93	186.40		2788.0***	0.33	<b>1353.5***</b>	<b>0.64</b>	1542.0***	0.40
Slot machines	86.50	131.61	196.85		2475.0***	0.44	<b>885.0***</b>	<b>0.77</b>	<b>1205.5***</b>	<b>0.51</b>
Roulette	99.08	132.57	177.64		2962.0***	0.34	<b>1807.0***</b>	<b>0.60</b>	1762.5***	0.35
Cards for money	106.29	135.70	164.19		3135.0***	0.33	<b>2441.0***</b>	<b>0.51</b>	2164.5**	0.23

**Legend:** M rank=mean rank; K-W test=Kruskal-Wallis test;  $\chi^2$ =chi-square; sig=significance; MW U=results of the Mann-Whitney test, r=effect size; \*p<.050, \*\*p<.010, \*\*\*p<.001; bold letters= significant differences with large effect size (higher than r>0.50)

Table 5 *The most attractive game of chance with regard to gambling-related problems*

Type of game	No problem (n=112)	Some problems (n=73)	Problem gambling (n=77)	Total sample (n=263)
Lottery games	17.4%	5.6%	1.3%	6.5%
Scratch cards	4.3%	2.8%	1.3%	2.3%
Sports betting	24.6%	26.8%	23.4%	20.5%
Slot machines	17.4%	31.0%	57.1%	30.0%
Roulette	5.8%	12.7%	11.7%	8.4%
Cards for money	30.4%	21.1%	5.2%	15.2%
Non (missing)	38.4%	2.7%	/	17.1%

Participants were also asked to indicate what addiction they were officially diagnosed with prior to arriving at TC. The results in Table 6 show the comorbidity of the self-reported gambling addiction diagnosis with alcohol and drug addiction. We can see that n=16 participants were diagnosed with both gambling and alcohol addiction, and n=23 participants with gambling and drug addiction. In other words, of all participants who were previously diagnosed with alcohol addiction, 13.6% were also diagnosed with gambling addiction, and of all participants who were diagnosed with drug addiction, 10.8% were also diagnosed with gambling addiction. Although it may not seem so at first glance, these are high percentages, especially given that the prevalence of gambling addiction in the general population is significantly lower (Glavak-Tkalić & Miletić Sučić, 2017).

Table 6 *The comorbidity of self-reported GA diagnosis with other addictions diagnosis*

GA * AA / DA		NO	YES	$\chi^2$	p
		GA	GA		
NO AA (n=145)	N	121	24	.452	.605
	%	83.4	16.6		
YES AA (n=118)	N	102	16		
	%	86.4	13.6		
NO DA (n=51)	N	34	17	16.116	.000
	%	66.7	33.3		
YES DA (n=212)	N	189	23		
	%	89.2	10.8		

**Legend:** GA=gambling addiction; AA=alcohol addiction; DA=drug addiction; GP=gambling problems; PG=problem gambling;  $\chi^2$ =chi-square; p=significance

We were also interested in exploring the prevalence of problem gambling symptoms using the PGSI self-assessment in the groups of participants who had or had no prior diagnosis of gambling addiction (Table 7). The results show that of all previously diagnosed participants (n=40), 87.5% currently have serious problems with gambling, 7.5% have some problems, while 5.0% (n=2) do not meet the criterion for problem gambling at this moment. We could explain this with the fact that PGSI measures gambling-related problems over the past six months and that GA diagnosis was provided earlier and symptoms were resolved/treated in the meantime. But even more interesting is that 18.9% of all TC clients not previously diagnosed with gambling problems meet the criteria for problem gambling based on the PGSI criteria and 31.5% have some gambling problems.

Table 7 *Self-reported GA diagnosis with regards to PGSI (3-level) categorization of gambling-related problems*

GA * PGSI (3 levels)		NO	YES	$\chi^2$	p
		GA	GA		
No problems	N	110	2	77.002	.000
	%	49.5	5.0		
Some problems	N	70	3		
	%	31.5	7.5		
Problem gambling	N	42	35		
	%	18.9	87.5		
Total	N	222	40		
	%	100.0	100.0		

**Legend:** GA=gambling addiction;  $\chi^2$ =chi-square; p=significance

Considering the presented results as a whole, it can be concluded that the findings are consistent with previously presented research results that consistently confirm the significant comorbidity of different addictions and the greater representation of various addictive behaviours within groups of addicts (Lorains et al., 2011; Dowling et al., 2015; Kotyuk et al., 2020). What is surprising is the lack of gender differences, especially considering that gambling is generally considered a male phenomenon. This tendency may be explained by the characteristics of the sample itself, i.e., the fact that these are clients of TC, a population with extremely pronounced problems and a generally pronounced risk for various risk behaviours and mental health problems, which further suggests the importance of adequately dealing with and addressing this problem in the group of clients in need of treatment. Regarding the type of games, frequent gambling on sports betting, slot machines and roulette was to be expected, especially in the sample of problem gamblers, as these are the most attractive games in the Croatian gambling market, but also because they represent the games with the highest addictive potential. It is also important to address the fact that gambling-related problems are represented to a greater extent than is formally recognized or diagnosed. This finding is not surprising given that gambling is often referred to as a hidden addiction due to its specific characteristics (Ladouceur, 2004). Moreover, addictions to psychoactive substances have been the focus of interest of researchers and practitioners for decades, and various detection and screening mechanisms exist in this field, while gambling is often neglected in this context. Therefore, it is necessary for professionals working at TC to have specific competencies for both assessing and treating gambling-related problems, regardless of whether this is the primary reason for admission to the treatment modality they provide. Following treatment procedures, these competencies are particularly important for relapse prevention strategies, as gambling products and activities are intensively advertised and promoted in the Croatian context, but are also highly available and accessible, both land-based and online (Ricijaš et al., 2019). In addition, some specific competencies (not relevant in the context of psychoactive substance addiction) are needed in this area for relapse prevention strategies, such as incorporating technological options to block and/or limit any type of online gambling. Given the close relationship between gambling and other forms of addiction, the absence of a comprehensive approach to gambling-related problems reduces the possibility of quality rehabilitation for clients at TC, which increases the risk of relapse.

## Conclusions and Limitations

Providing treatment for persons who have problems with addiction requires a variety of complementary knowledge and skills to successfully address clients' needs. This study shows that gambling-related problems are commonly in comorbidity with other addictions among TC clients and that professionals working in TC should have specific competencies in all types of

addictions (alcohol, drugs, and gambling). As far as addiction to psychoactive substances is concerned, competencies are systematically acquired both through basic education of helping professionals and through additional training. However, gambling addiction is neglected in this context. Therefore, it is necessary that professionals who provide treatment in different settings, including therapeutic communities, learn to recognize the problem and treat it appropriately. The results are even more meaningful if we take into account that this need is also recognized in the National Strategy of Action in the Field of Addiction until 2030 (Official Gazette, 18/23), which emphasizes that an integrated addiction policy should include behavioural addictions in addition to psychoactive substance addiction and that efforts should be directed toward the development of interventions across the whole intervention spectrum and towards specific educations and training of experts working with addicts.

This study also suffers from certain methodological limitations. The major limitation is the fact that this is a self-report study and, as with all self-reports, the results depend on the honesty of the participants, who are subject to bias due to social desirability, memory bias, response bias, subjective interpretation of questions, and limited insight into their own thoughts, emotions, and behaviours. To minimise all of the aforementioned potential risks, a brief and coherent anonymous questionnaire was administered using previously tested reliable instruments to keep all participants who agreed to participate in this study motivated and honest. Although not without limitations, this study offers important insights into the gambling characteristics of addicts in therapeutic communities and highlights the need to incorporate gambling-oriented strategies and interventions for this complex group of clients.

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## Implementation of social and emotional skills in the primary education

### SUMMARY

Social and emotional learning should be a central feature of primary school, and to large extent in all forms of learning afterwards. In faculties where students acquire specific professional competencies for delayed entry into the labour market, it would be necessary to add knowledge on cooperation, communication, negotiation, conflict resolution, and other social skills to make them truly competitive or to make the best use of their knowledge. Implementing social and emotional skills in the basic curriculum represents, on the one hand, a much-needed skill for pupils in concrete situations, and, on the other hand, an investment in social and emotional skills for the future of the individual, i.e., when entering the labour market and beyond. It is also part of a prevention program for all pupils and is particularly important for pupils with pre-existing problems such as anxiety disorders and behavioural and emotional problems. If in the past we have provided social skills training for specific groups, most often excluded from the school curriculum, today we are faced with the challenge of how to include a wider range of children in such learning. For social pedagogy and reflection on children with emotional and behavioural difficulties, this study makes a particularly important contribution in the field of research regarding the impact of social skills on children with perceived difficulties. The research method used was a review of literature and documents in the field of social and emotional learning with to the purpose of implementation in the primary education curriculum in Slovenia. A review of the literature shows that the concept has been used extensively worldwide.

**Key words:** *social competence, curriculum, education policy, monitoring social and emotional learning, school curriculum*

### Introduction

Social and emotional learning is a term coined by the Fetzer Institute in 1994. In the literature and scholarship on education, different theoretical frameworks can be found to define social and emotional skills. Zins and Elias (2006) define social and emotional learning as the process of acquiring and effectively applying knowledge, attitudes and skills that are important in identifying and managing feelings and concerns toward others; making responsible decisions; establishing positive relationships, and acting appropriately in difficult situations.

CASEL ('The Collaborative for Academic, Social and Emotional Learning') defines social and emotional learning at three levels: relationship-based learning environments and teaching methods, evidence-based social and emotional learning programs and integrating social and emotional learning into the core curriculum. According to recent research reports (Durlak, Weissberg, Dymnicki, Taylor, 2011; Domitrovich, Greenberg, 2000; Durlak and Dupre, 2008), social and emotional learning programs and interventions should include specific criteria: programs should be based on rigorous scientific theories, programs should be delivered by school staff, and social and emotional skills should be integrated into the curriculum alongside reading, mathematics, history and other core subjects. These skills should be embedded in the day-to-day reactions between pupils and teachers, rather than appearing as separate learning. It is further recommended that school staff monitor the quality of programs through guidelines. Teaching should be geared towards creating a safe environment, both in the classroom and throughout the school, as such an environment promotes pupils' social and emotional development.

Social and emotional skills at school are reflected in the promotion of lifelong learning and academic performance, fostering a positive school climate. Students who are able to regulate their emotions and maintain positive relationships with others have been shown to be more motivated in school. These students are able to use their resources, their academic performance has improved, and we can also look for shifts in children's mental health. The World Health Organization describes a healthy school environment as one that includes active forms of learning, encourages participation and fosters warm and equitable relationships. The school is an institution that not only provides education, but also plays an important role in promoting students' health and determining their development (Collaborative for Academic, Social, and Emotional Learning, 2005).

## **Objectives and Research Problems**

In this paper, we wanted to answer the question whether and to what extent social and emotional skills influence the development of children and individuals, seeking answers to the assumption that social and emotional learning is an important element of the educational curriculum for all learners and also for children with behavioral and emotional difficulties or other difficulties, such as anxiety. We also wanted to answer the question what are positive effect and negative or none effect measured in different researches. What are the elements that show positive effects and elements that show none or negative effect? This kind of detection can help the policy makers to understand the importance of implementation of social in emotional learning in the primary education.

## Methods

This paper systematically looked at the field of social and emotional learning in relation to the outcomes of such learning, using a combination of content analysis. We reviewed some research that has emerged in recent years (from 2017 till 2022) in databases such as Web of Science, Proquest, Scopus, etc., which publish results measuring social and emotional skills. Papers are therefore reviewed in a systematic way (Weber, 1990) by identifying the key effects of social emotional learning.

### Data processing

For data processing, we used an analysis of the articles reviewed. Article review analysis means that articles are reviewed and interpreted in a way to extract meaning in order to gain understanding and develop empirical knowledge (Strauss, 2008 in Bowen, 2009). We collect data in table which show assessment of social skills.

## Results and Discussion

### Research Overview - Integrating Social and Emotional Skills Into the Education System

In the following, we will review the scholarly treatment of the topic, i.e., what has been researched in this field in recent years and where are the opportunities and threats for implementing social and emotional learning in the primary curriculum. Awareness of the topic and a review of the literature show that in recent years this field has become an important professional, scientific and educational area, which is unfortunately undernourished in practice.

The Organization for Economic Co-operation and Development (OECD, 2015), in its global drive for educational excellence and equity, has placed a particular emphasis on social and emotional learning in schools. The emphasis on the inclusion of 21st-century competencies (Voogt and Roblin, 2012) has meant that the assessment of social and emotional skills is being embedded in curricula around the world. Studies have found that people's use of social and emotional skills helps prevent problematic behaviors such as substance use, interpersonal violence, bullying and school failure (Durlak, Weissberg, Dymnicki, Taylor and Schellinger, 2011). Similarly, studies (Taylor, Oberle, Durlak and Weissberg, 2017) have also found these skills to be effective in promoting the well-being and academic achievement of students in a variety of socioeconomic and cultural contexts. However, there is debate about how these skills should be measured and understood in schools.

A key competency for 21<sup>st</sup> century schools is to serve culturally diverse students with different abilities and motivations to learn (Durlak, Weissberg, Dymnicki and Taylor, 2011). The authors state that many students lack socio-emotional competence and, as a result, become less connected to school, particularly in the transition from primary to secondary school, and this disconnection manifests itself in academics, behavior and health.

The article *Social and Emotional Skills in a Reform Curriculum* (Restad, Elde Mølstad, 2021) explains the Norwegian context, where the school system has a long tradition of emphasizing social goals and community development. The Norwegian curriculum has been developed in parallel with international processes. In 2013, the Norwegian government ordered an official commission to assess whether the content of the curriculum adequately covers the competences and skills needed in students' future lives as citizens and workers. Two main themes emerged from the analysis of the documents, i.e., the debate on the nature and understanding of social and emotional skills, and the debate on whether and how to assess such skills. After a review of policy documents and relevance, nine elements of the Norwegian curriculum (three reports, three articles, two books and one journal article) were included in the study, four sources were from the USA, three were published by the OECD, and the remaining two were from Sweden and New Zealand (Restad, Elde Mølstad, 2021). Based on two official reports, the following documents examined from the countries mentioned, official reports seem to support a more systematic assessment of social and emotional competences through processes and evaluation at system level, but not as a complete assessment system. The policy documents agree on strengthening the focus on social and emotional learning as part of the mandate of schools. The documents also point that the measurement of social and emotional skills in schools can be assets in the longer term. The OECD research on social and emotional skills can be understood as a social structure that is expanded by the need to develop social and emotional learners, skills for "greater well-being and better school performance" (Durlak et al., 2011) and to improve economic and social outcomes (OECD, 2015).

### **The Effects of Measuring Students' Social and Emotional Skills**

The association between social and emotional competencies acquired in primary school is linked to positive academic, social, and mental health (Jones et al., 2017). Similarly, studies also show that classrooms function more effectively and students learn better when students are able to better focus their attention, manage uncomfortable emotions, navigate relationships with peers and adults, and manage to deal with their problems (Jones et al., 2017). Children with better developed social skills are more likely to form friendships and also persist in relationships, have more positive relationships with teachers, participate in class and engage positively in learning. Therefore, children who have social and emotional learning skills (SEL) better developed, get along better with others, do better in school, and have more successful careers as adults.

Social and emotional skills acquired in childhood continue to manifest themselves 20 or 30 years later, including financial stability as well as psychological and mental health (Jones et al., 2017). Although the research reveals that there are strong reasons for making social and emotional learning skills a central feature of primary school, it also analyses that research on



SEL mastery among students shows none or no significant effects. This is largely attributed to the difficulty in defining the objectives of the program or in defining the objectives of the program in detail. To find sufficiently comparable results, the authors make three recommendations for policymakers, practitioners and researchers (Jones et al, 2017). They focused on 4 fields in their research: setting, i.e., where the intervention took place, program goals, program options (training, tools, etc.) and outcomes. The research shows that the more general metrics are used, the less chance there is to see program outcomes. There is a need for precision in program selection and outcome measurement (Jones et al, 2017).

Research on the effects of social and emotional skills has been described in an in-depth Meta-Analysis and follow-up (Taylor, Oberle, Durlak, & Weissberg, 2017), which reviewed 82 school-based social and emotional learning interventions, 38 of which were outside the US. It included 97.406 students from kindergarten to high school. Follow-up results (collected from 6 months to 18 years post-intervention) show a positive improvement in children's development. Participants performed significantly better than the control group in social and emotional skills. The benefits were similar regardless of the students' race, socio-economic background or school location. The development of social-emotional skills after the intervention was the strongest predictor of well-being. SEL improved critical aspects of students' developmental trajectories. SEL helps students and adults to acquire and apply knowledge, skills and attitudes that enhance personal development, social relationships, ethical behavior and effective productive work. Skills educated in social emotional learning are connected with cognitive-behavioral competences important for life and success in school, such as: self-awareness, self-control, social awareness, responsible decision making, and relationship building skills (Taylor, Oberle, Durlak, & Weissberg, 2017). Long term researches have shown that SEL is associated with education, satisfaction and health later in life. Therefore, social and emotional skills are directly linked to positive adolescent development.

The research described in the article Follow-Up Effects of SEL Programs (Taylor, Oberle, Durlak, Weissberg, 2017) identifies five important findings. The first relates to the length of time students have been involved in the SEL program. It is shown that longer involvement shows more transparent results. The second important finding involves the positive and negative indicators of SEL well-being. The research shows that SEL interventions show to improve positive behavior, social behavior and academic performance in students. The third relates to how SEL impacts positive youth development for all demographic groups, different racial groups, or socioeconomic status. SEL supports young people from diverse family and diverse geographic backgrounds. A fourth important finding relates to the positive relationships between social and emotional relationships and well-being. They found that social skills, more than attitudes, create long-term impacts. The fifth and final set of findings includes positive effects on several additional important outcomes, such as: improving relationships, increasing grades, reducing risky behaviors.



Social skills develop gradually throughout childhood and adolescence (Bandura, 1986; Beauchamp & Anderson, 2010). In middle childhood (6-12 years), establishing and maintaining close friendships with peers is a key developmental task, as is learning and adapting appropriately to the rules of school and society (Eccles in Sørli, Hagen, & Berg, 2021). Learning and gathering of social skills, depends not only on social learning opportunities, i.e., what is obtained at home through modelling, reinforcement and imitation (Bandura, 1997), but also on school-related factors, i.e., relationships with peers and teachers (Ogden & Hagen, 2018). Social skills are learned through practice and environmental responses in a variety of situations. It is expected that children with well-developed social skills at some point will continue to score highly on later measures and that children will show increases in social skills in primary school.

Developed social skills depend on different developmental pathways. Children have different experiences of interactions, with parents, brothers, sisters, which will influence their interaction with peers and teachers. Children with well-developed social skills can more easily establish positive relationships with teachers and peers, which in turn influences their social skills (Sørli, Hagen, Berg, 2021). On the other hand, children who act inappropriately or awkwardly towards others are more likely to experience confrontation and rejection, thus losing out on positive interpersonal experiences. In the same way, a child's social functioning is influenced by the context in which he or she is placed, including the school context. Research (Sørli, Hagen, Berg, 2021) has shown that different aspects of the school system influence the development of social skills. The school context, the classroom, can have different effects on the course of children's social skills. Classrooms characterized by positive relationships between classmates create contexts that are more conducive to the development of positive skills. Positive classroom attitudes may be more important for those who show poorly developed social skills. This study (Sørli, Hagen, Berg, 2021) focused on whether and how student-student and teacher-student relationships, problem-solving behavior in class and teachers' collective efficacy influenced the social skills of students from 4<sup>th</sup> following until 7<sup>th</sup> grades. Evidence shows that children who have positive relationships with their teachers have better outcomes in the area of social performance, whereas, conversely, when student-teacher relationships are poor, negative outcomes are encountered in terms of poor academic performance, emotional insecurity, problem behavior and negative relationships at school (Split et al. in Sørli, Hagen, & Berg, 2021). When looking at the student-student relationship, they note that very little research has been done in this area. Despite a large literature on the importance and impact of young students' social relationships on their social functioning and educational achievement, surprisingly little is known about the predictive value of student-student relationships and whether they influence the growth of social skills over time. This study investigated whether the quality of self-rated relationships between students predicted different trajectories of social skills (Sørli, Hagen, & Berg, 2021). Problematic

behavior in the classroom has an impact on the classroom, but it is not clear to what extent this has an impact on the individual and their social skills. Safe and constructive classroom environments with lower prevalence of problematic behavior facilitate the increase and reinforcement of positive skills for teachers and their exhibition for students (Odgen, 2015 in Sørli, Hagen, Berg, 2021). Classrooms where problem behavior is more prevalent, on the other hand, form a challenging context in which students practice a wide range of social skills such as negotiation, cooperation, self-control, etc. In this study, the prevalence of problem behavior in the classroom and children's level and growth in social skills were investigated, as this has not been empirically investigated.

The data in the study (Sørli, Hagen, Berg, 2021) were obtained from a multi-cohort efficacy study involving pupils in grades 4<sup>th</sup> to 7<sup>th</sup> and school staff in 65 primary schools over five consecutive school years. The data obtained through the study show that the majority of children, 72%, follow a moderately stable path of strengthening or increasing social skills, that some children (14%) follow a high-declining path and an equally large group follow a high-increasing path. The high-declining group can be considered to be at high risk of social exclusion and other negative life consequences (Sørli, Hagen, Berg, 2021).

Table 1 Assessment of social and emotional learning in different research

Research	Positive effect of social and emotional learning	None or negative effects of social and emotional learning
<p>1.</p> <p>Jones et al, 2017: Promoting Social and Emotional Competencies in Elementary School</p> <p>Meta-analytic reviews. Large number of studies of school-based SEL (213 studies and 75 studies). Reviewed 11 widely used SEL programs for elementary schools.</p>	<ul style="list-style-type: none"> <li>- Students who participated in SEL programs had significantly better outcomes than students who did not.</li> <li>- The association between social and emotional competencies acquired in primary school is linked to positive academic, social, and mental health.</li> <li>- Classrooms function more effectively and students learn better when students are able to better focus their attention, manage uncomfortable emotions, navigate relationships with peers and adults, and persevere in the face of adversity.</li> <li>- Children with better developed social skills are more likely to form friendships and also persist in relationships, have more positive relationships with teachers, participate in class and engage positively in learning.</li> <li>- Get along better with others, do better in school, and have more successful careers as adults.</li> </ul>	<ul style="list-style-type: none"> <li>- Specific and concrete effects should be measured otherwise we limit our understanding - Social Development Research Consortium found no differences between group receiving SEL in the one who didn't.</li> <li>- Measuring SEL involved significant time commitment.</li> <li>- When using general measures, we are less likely to see effects.</li> <li>- When theory, evaluation plan and measurement are closely aligned, we do see effects.</li> <li>- Although the research reveals that there are strong reasons for making social and emotional learning skills a central feature of primary school, it also analyses that research on SEL mastery among students shows none or no significant effects. This is largely attributed to the difficulty in defining the objectives of the program or in defining the objectives of the program in detail.</li> </ul>

<p>2.</p> <p>Taylor, Oberle, Durlak, &amp; Weissberg, 2017: In-depth Meta-Analysis and follow-up</p> <p>Research reviewed 82 school-based social and emotional learning interventions, 38 of which were outside the US. It included 97.406 students from kindergarten to high school.</p>	<ul style="list-style-type: none"> <li>- Positive improvement in children's development.</li> <li>- Participants with the intervention of SEL performed significantly better than the control group in social and emotional skills.</li> <li>- The benefits were similar regardless of the students' race, socio-economic background or school location.</li> <li>- SEL is associated with education, well-being and health later in life.</li> <li>- Social and emotional skills are directly linked to positive adolescent development.</li> </ul>	<ul style="list-style-type: none"> <li>- For non-safe SEL programming it was not possible to evaluate whether there is any improvement or not.</li> <li>- It was hard to measure assessment of independent competencies.</li> <li>- Evaluation with youngsters, but not perspective of others (parents, teacher...).</li> <li>- Greater attention to the environment would allow a more complete understanding.</li> <li>- The effect of age is significant.</li> </ul>
<p>3.</p> <p>Sørli, Hagen, Berg, 2021: Development of social skills during middle childhood: Growth trajectory and school-related predictors.</p> <p>Study involving pupils in grades 4<sup>th</sup> to 7<sup>th</sup> and school staff in 65 primary schools over five consecutive school years.</p> <p>Research has shown that different aspects of the school system influence the development of social skills.</p>	<ul style="list-style-type: none"> <li>- Evidence shows that children who have positive relationships with their teachers have better outcomes in the area of social performance.</li> <li>- 72%, follow a moderately stable path of strengthening or increasing social skills, some children (14%) follow a high-declining path and an equally large group follow a high-increasing path. The high-declining group can be considered to be at high risk of social exclusion and other negative life consequences.</li> <li>- Children with well-developed social skills can more easily establish positive relationships with teachers and peers, which in turn influences their social skills.</li> </ul>	<ul style="list-style-type: none"> <li>- When student-teacher relationships are poor, negative outcomes are encountered in terms of poor academic performance, emotional insecurity, problem behavior and negative relationships at school.</li> <li>- Problematic behavior in the classroom has an impact on the classroom, but it is not clear to what extent this has an impact on the individual and their social skills.</li> <li>- When looking at the student-student relationship, they note that very little research has been done in this area.</li> </ul>

<p>4. Hukkelberg, Keles, Ogden, Hammerstøm, 2019: The relationship between behavior problems and social competence: a correlational meta-analysis</p> <p>518 studies were considered</p>	<ul style="list-style-type: none"> <li>- Poor social competence, which includes difficulties processing social information, difficulties adapting to situations and rejection by friends, can contribute to the development and maintenance of behavioral problems and vice versa</li> <li>- Lack of social competence leads to higher levels of behavioral problems, or high levels of behavioral problems undermine social competence.</li> </ul>	<ul style="list-style-type: none"> <li>- Not all children who show poor social competence show behavioral problems, and not all children who have problems are socially incompetent either.</li> <li>- Children with behavioral problems often lack problem-solving skills, regulate their emotions, communicate with other children in an aggressive and disruptive manner, and thus the likelihood of peer rejection and dislike increases over time.</li> </ul>
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Social and emotional learning has many positive effects on children, adolescent and later in life. Positive affect is shown in the field of social interaction, self-performing, well-being and academic achievement of students in a variety of socioeconomic and cultural contexts. On the other hand, we can see that lack of social competences can lead to social and emotional difficult behaviors, which can lead to peer rejections, aggression, academic failure and other negative pathways. The reviews also show that measuring social and emotional competences in some researches don't show any significant effect on pupils and therefore is a need to express precise measurement instruments that need to be used and long period of measuring.

**The Impact of Social Skills on Children With Emotional and Behavioral Difficulties**

For social pedagogy and reflection on children with emotional and behavioral difficulties, the contribution to research on the impact of social skills on children with pre-existing difficulties is particularly valuable. Social competence in relation to behavioral difficulties has been investigated in a Norwegian research Centre. They were interested in the link between social competence and behavioral problems in children and adolescents. The relationship between the two is inversely proportional, i.e. higher behavioral difficulties are thought to be associated with lower social competence and vice versa (Chen et al. 2014, Montroy et al. 2014 in Hukkelberg, Ogden, 2020).

Social competence plays a particularly important role for children with behavioral problems, both those that are externally visible and those that are internalized, such as dropping out of school and school failure, with other associated challenges. Definitions of social competence describe competence as an organizational construct that uses both external and internal resources to achieve its goals (Hukkelberg, Ogden, 2020, p. 81).

Over the last decade, many studies have reported an inverse relationship between behavioral problems and social competence in children. That is, high levels of problems seem to be associated with low levels of social competence and vice versa (Montroy, Skibble, Foster, 2014, in Hukkelberg, Keles, Ogden, & Hammerstøm, 2019).

Findings suggest that poor social competence, which includes difficulties processing social information, difficulties adapting to situations and rejection by friends, can contribute to the development and maintenance of behavioral problems (Hukkelberg, Keles, Ogden, Hammerstøm, 2019). However, the correlation is not clear. Not all children who show poor social competence show behavioral problems, and not all children who have problems are socially incompetent either. Social disability can manifest itself in different ways (Hukkelberg, Keles, Ogden, Hammerstøm, 2019, p. 2). Children with behavioral problems often lack problem-solving skills, regulate their emotions, communicate with other children in an aggressive and disruptive manner, and thus the likelihood of peer rejection and dislike increases over time. Deficits in social competences thus often limit the possibilities for future interactions and further skill development (Hukkelberg, Keles, Ogden, Hammerstøm, 2019, *ibid.*).

Behavioral problems in children and adolescents are considered a risk factor for successful functioning in a variety of domains. They are also associated with harmful future consequences, including antisocial behavior, social exclusion and severe psychopathology (Hukkelberg, Keles, Ogden, & Hammerstøm, 2019).

In the study the relationship between behavior problems and social competence: a correlational meta-analysis (Hukkelberg, Keles, Ogden, Hammerstøm, 2019), they focused on three different types of behavior problems: externalizing behavior, conduct problems and aggression. Social competence in childhood has therefore become an interesting area for both researchers and those working with children because of its negative correlation with behavior problems. 518 studies were considered according to the inclusion criteria. These were: 1) reporting on the correlation and sample size between social competence and problem behavior, 2) for children and adolescents aged 3 to 13 years, 3) social competence or social skills measured, 4) antisocial behavior, externalized behavior, behavioral problems or aggression measured, 5) parent and/or teacher reports included, 6) conducted between January 2008 and January 2018, 7) published in English, Scandinavian languages or Turkish. The result showed that intervention programs targeting behavioral problems should also promote social skills and social competence in addition to these problems (Hukkelberg, Keles, Ogden, & Hammerstøm, 2019). Lack of social competence leads to higher levels of behavioral problems, or high levels of behavioral problems undermine social competence.

## Conclusion

A review of scientific articles in the field of social and emotional skills shows that, especially in recent years, there has been a lot of in-depth analysis of the measurement of the effects of social skills. When measuring SEL, it is important to understand that there is a need for precision in measurement, a need to investigate the effects on pupils in the long term, and a need for a school environment that is conducive to this. The results also show a link between well-being, mental health and academic performance, and between social competence. Higher social competence means higher performance, better health and well-being, although the results are not so clear-cut and other aspects such as innate genetic characteristics and early socialization need to be taken into account.

It cannot be said with certainty that this type of learning will have an impact on all pupils, nor on the majority of pupils with emotional and behavioral difficulties, anxiety or aggressive behavior, but it shows some evidence that it has effect on pupils. There is the need for years of evaluation of the pupils and, on the other hand, for a school climate that is conducive to it, where the school staff is adequately educated in this field. Although we agree with the authors about the positive effects of social and emotional learning for all pupils, including those with emotional and behavioral difficulties, we also share their doubts, i.e. how, by whom and in what way social and emotional skills are introduced in schools, and in particular for work with children with emotional and behavioral difficulties, is an important success factor.

The implementation of social and emotional skills represents, on the one hand, a much-needed skill for students in concrete situations and, on the other hand, an investment in social and emotional skills for the future of the individual, i.e. when entering the labor market and beyond. It is also part of a preventive program for all pupils and particularly important for pupils with pre-existing problems such as anxiety disorders and behavioral and emotional difficulties. In the past we have provided social skills training for specific groups, most often excluded from the school curriculum, but today we are faced with the challenge of how to include a wider range of children in such learning, i.e. how to integrate SEL into the mainstream curriculum.

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Maria Groinig, University of Hildesheim  
groinig@uni-hildesheim.de

Martina Pokoj, German Youth Institute  
pokoj@dji.de

## Care Leaver Statistics (CLS): Ethical challenges and data protection in long-term research with marginalized and vulnerable groups

### SUMMARY

The CLS study is the first Germany-wide panel study on the “leaving care” of young people who were part of the child and youth welfare system. This study examines social participation of emerging adults during life course transitions. At the beginning of this long-term study, the participants ranged in age from 16 to 19 years old. The survey started with 2,000 young people (net sample) in foster and residential care. In addition to sociodemographic data, data on relevant participation dimensions were recorded, including institutional “pre-care-leaving-constellations”, opportunities for participation and complaints, social networks, housing, health, school qualifications and education, as well as employment and leisure time. Research on young people who have experiences in the child and youth welfare system (e.g., foster care, residential care) requires several preliminary considerations and must follow comprehensive ethical concepts. Therefore, diversity sensitive implications are kept in mind and reflected throughout the research process. The diversity concept of the CLS study is a unique guideline that reflects the possibilities and limitations of ethical principles in quantitative research. The vulnerability of the target group was also considered in the development of the research instruments and the research process. Additionally, this research study consists of participatory elements and an accompanying programme with a focus on peer support, community building, and resource strengthening elements.

**Key words:** *Care-leaving research, panel study, life course research, sensitivity to diversity, research ethics, data protection*

### Introduction

Research ethics is about social responsibility, should prioritize the accommodation of specific scientific methods, and goes beyond legal regulations. Every ethical framework should focus on raising awareness of ethical principles in research. This means that thinking about the ethical dimension of research work should be an integral element of training researchers, students and professionals (Rakebrand, 2019; von Unger, 2016). It is not enough to address

ethical challenges once, during an introductory event or the ethics committee review as part of the scientific work. Some areas of research, including medical research, intersect very directly with ethical issues, while in other areas awareness of certain problems only emerge during the research process. It is only possible to raise awareness to a limited extent about research ethics, privacy issues and data protection by reading the fundamental literature, developing conceptual considerations and following the legal requirements. Corresponding events must be included alongside discussion. This has not always been the case, especially in social research, except where individual researchers have consciously made it their focus. The necessities always have to be re-evaluated and negotiated during research processes with a view to the respective research content, research subjects, research methods and research questions (Schaar, 2022; Wagner, 2017; von Unger, 2012).

The term 'vulnerable' refers to people and groups who are at particular risk due to their personal conditions or certain circumstances and are therefore in need of increased protection, including in the context of scientific surveys and research. This applies to children, young people, adults and elderly people in emergency situations (e.g., subject to violence, sexualized violence, racism, and discrimination) or in dependent relationships and circumstances (e.g., people with different kinds of disabilities (cognitive or physical) and marginalized groups who cannot exercise their right to freedom of expression. Their social background can thus also mean they have special need for protection. The range shows that in every research process there is a need to address vulnerability, marginalization and ethical challenges. During research processes, reflection on this topic may be necessary in certain research fields (e.g., medicine, sociology, linguistics, theology, sports science, or nursing science). However, every research process needs to address the issue of whether there are inclusive or exclusive and violent research practices that need to be addressed. Social science research comes into contact with aspects of vulnerability and marginalization, for example research on (1) gender differences, (2) colonialism or (3) the representation of people of color in society and in cultural fields.

One way to respond to ethical challenges is to incorporate participatory elements into the research process. The participation of subjects and their representatives is one way to challenge and validate the researchers' point of view and to confront the scientific field with the subjects' perspectives. In interview situations, researchers need to be particularly sensitive with vulnerable groups, as there is always a risk of possible re-traumatization. For projects involving work with vulnerable groups, it is important to be in contact with advisory institutions that the researchers and participants can consult if necessary. It is also important to consider how the researchers or institutions deal with research subjects who seek contact after a project and want to share their personal stories or perspectives. It is not ethical for researchers or institutions to reject these people because the project funding has expired. The focus of participatory elements always needs to be set in the context of the research topic.

Vulnerable and marginalized groups and third-party data need to be protected. The ethics committee review is an important act before the research project starts. Every research ethics framework should focus on protecting the rights of the research subjects and encompass data access, data gathering and data processing. In this paper, we present the current panel study in the field of care-leaving in Germany, focusing on research ethics and data protection challenges during the research process with the vulnerable and marginalized group of care leavers.

## Ethical Rules, Guidelines and Laws in Germany and Europe

The discussion on research ethics procedures and legal standards regarding data protection has become more important in the social and educational sciences in German-speaking countries in recent decades. In Germany, ethical requirements for research vary strongly across research fields. Requirements are strict and legally binding in medical or biomedical research and more lenient in the social sciences. In the latter context, ethical questions are instead addressed within the framework of self-regulation by professional associations of sociologists or psychologists. More general standards are set out in the guidelines on good scientific practice established by the German Research Foundation (DFG). These guidelines encompass all fields of scientific research and focus strongly on questions of ethical behavior among researchers. The DFG recommended that universities establish their own guidelines on the basis of the DFG guidelines. In 1998, it decided that research institutions receiving funding from the DFG had to establish rules securing good scientific practice (Oellers & Wegner 2009). While ethic committees at the research institutions advise professional associations on ethical questions, it is in no way involved with approving research projects from an ethical point of view (RatSWD, 2017; Wagner, 2017; Oellers & Wegner 2009).

The only legal requirement to consider in the social sciences is that on federal data protection, which is based on the European General Data Protection Regulation (GDPR). This law addresses issues of consent, data gathering, storage and processing for all kinds of research. It sets out some general standards for data-related issues in scientific research, such as the duty to anonymize information. The GDPR does not apply to data that has been anonymized. In the course of effective anonymization, all personal references must be permanently removed. The requirements are stricter when particularly sensitive data is processed. The processing of personal data can be justified by the consent of the data subject (Art. 6, Para.1a GDPR) or a legitimate interest of the researchers (Art. 6, Para.1a GDPR). *"The guarantee of freedom inherent in the concept of academic freedom is affected by a restriction on the free use of data by researchers whenever researchers are unable to collect the data required for their research in full or are restricted in the collection process"* (Becker 2022, p. 110). There is a tension between these two fundamental rights. In the most favorable case, a balance can be found between the two fundamental rights - data protection and freedom of research - so

that both fundamental rights can be exercised (Metschke & Wellbrok 2002, p. 9ff).

During the planning and development of research projects, the first question to be asked is about scientific quality and the researchers' integrity, which is usually assessed from their academic qualifications. However, scientists at universities and non-university research institutions are embedded in structural balances of power and interdependence that are subject to economic and political conditions. Basically, the question arises as to who is interested in research (e.g., qualification work, contract research, evaluation research, third-party funded projects, public funding lines) and what consequences the research can have for the subjects or participants. It should be noted that there is no legally binding obligation to obtain ethical approval in the social and educational sciences, in contrast to the strict data protection laws that apply. Problems related to data protection law and research ethics arise in social and educational research, particularly when research is conducted on marginalized and vulnerable groups who are considered unable to adequately exercise and represent their rights themselves, or in the case of data belonging to third parties (e.g., teachers, social workers or classmates or information on sexual offenders or abusive family members). It is therefore particularly important to ensure that data protection rights and the parties' privacy are adequately considered.

## Care Leaver Statistics

Care Leaver Statistics is the first cross-organizational Germany-wide panel study on the transitions undergone by young people leaving out-of-home care (e.g., foster care and residential care). It examines participation across the life courses of 16–19-year-old adolescents and emerging adults. Based on the desiderata the problem is not meaningfully represented in general surveys on childhood, youth and emerging adulthood (e.g., AID:A, ALLBUS, NEPS, PAIRFAM, SOEP, KIJ statistics) and also—often—that categorizations of out-of-home care in the surveys need to be differentiated according to the development of child and youth welfare (Erzberger et al., 2019), the CLS study means that a Germany-wide data infrastructure on care-leaving will be set up for the first time. This record of participation across the life courses of care leavers in the Federal Republic of Germany is currently the most comprehensive study in the research field. For this purpose, the research network of the CLS study is developing a multidimensional survey instrument that will be adapted as the study progresses. The standardized survey is carried out by infas, the Institute for Applied Social Sciences, in a personal environment chosen by the adolescents. In the first wave of the survey, all the young people were interviewed in person (CAPI) or by telephone (CATI). Additional web-based surveys (CAWI) are planned for further survey waves. The first survey wave was carried out from January to June 2023. The findings from the first survey wave will be presented in January 2024 by the research network of the CLS study.

A survey instrument was developed that captures multidimensional data on opportunities for and barriers to participation, studying the young people's subjective and objective situations in life and individual aspirations. These have been operationalized as the pre-care-leaving constellation, co-determination, rights, complaints, agency, living place, qualifications, work, finances, social ties, health, social demographics, leisure time and satisfaction with life. In addition to the comprehensive public relations work and regular panel maintenance ('panel maintenance basic'), the CLS study offers the adolescents an accompanying program and chances to participate in the research process ('panel maintenance plus'). In order to maintain the response rate and to further build up the panel, elements of participatory research are integrated into the research process (panel maintenance plus) in addition to the proven panel maintenance measures (panel maintenance basic). Incentives, including monetary incentives, continuous contact, information offers and comprehensive public relations work are among the core elements of panel maintenance. Panel maintenance plus and the CLS accompanying program are intended to stimulate peer community-building among the participants and help them connect to existing care-leaving communities. The #CLS\_networkspace is a digital space for information, meetings, education and networking. It will take place weekly starting in August 2022. Participants can leave the panel (i.e., Article 7(3) EUGDPR withdrawal at any time), refuse to participate in the CLS accompanying program (panel maintenance plus) and/or withdraw from the accompanying program at any time (i.e., they can withdraw from the accompanying program but continue to participate in the study).

## **Conceptual Considerations on Research Ethics and Data Protection in the Context of Care Leaver Statistics**

Research ethics challenges and data-protection-related procedures can be divided into three levels: (1) research ethics when planning and beginning research projects, (2) research ethics during the research process and (3) research ethics relating to the dissemination of research findings, secondary analyses and the 'third mission'.

### **Research Ethics and Data Protection When Planning and Beginning a Research Project**

During the planning of the CLS study, a data protection manual was drawn up based on the General Data Protection Regulation. The manual comprehensively shows and documents the processing of study participants' personal contact details and address data. The data protection manual for the CLS study begins by documenting and discussing the fundamental approaches and content of the data protection declaration and informed consent to the CLS study, including information, data subjects' rights, options to refuse or withdraw from participation, and the deletion of personal data. A legal opinion by the German Institute for Youth Welfare and Family Law (DIJuF e.V.) assessed whether the study participants, all aged

16 or over, had given their informed consent in terms of their ability to understand the risks and consequences of participating in the CLS study.

In the context of the CLS study, we collect two forms of particularly sensitive data: (1) health data and (2) third-party data. Against this background, a comprehensive discussion had to be held as to how this data would be processed and anonymized. For example, we could not ask what disorders the participants had been diagnosed with or what medications they were taking, as other youth studies do. However, the questionnaire used in the study focuses on more general things that might affect their participation over their life course (e.g., if they have a disease and whether it affects their everyday life). The priority of the CLS study is to investigate how care leavers cope with transitions across their life course, not to compare them to their peers.

The CLS study is carried out by a research association. Therefore, cross-site activities involving the processing of personal data, and the institutions' technical and organizational measures, are documented and checked. The risk forecast and the data protection impact assessment are also documented in the data protection manual. The data protection officers of the associated institutions and the BMFSFJ (Federal Ministry of Family Affairs, Senior Citizens, Women and Youth) assessed the questionnaire, the data protection manual and the resulting information material for potential participants in the CLS study (including information material, an information brochure and an informational website), and whether participants had given their informed consent. In addition, ethical approval was obtained from the Ethics Committee of Department of Education and Social Sciences at the University of Hildesheim.

## **Research Ethics and Data Protection During the Research Process**

During the research process the CLS research association works according to a self-developed diversity concept, a code of conduct and participatory elements. These are briefly explained below. The surveys of the participants are conducted by interviewers from infas Institute for Applied Social Sciences. The interviewers are prepared for the interview situations in training courses. In interview situations, interviewers need to be particularly sensitive with vulnerable and marginalized groups, as there is always a risk of possible re-traumatization. Therefore, after each survey, each interviewer gives a postcard to participants with addresses where they can get assistance or advice if they wish.

### **Central Elements of the Diversity Concept and the Code of Conduct**

From the beginning, the CLS study team was engaged in a debate about how to deal with diversity, social exclusion, barriers to research participation, and research ethics. In the course of the discussion, a working group was initiated which went on to author a text recording the state of affairs. Initially, the aim of the document was to understand stances within the



project. To make this reflection on research ethics transparent, it has been published on the website of the CLS study<sup>1</sup>. Since this is the current status (autumn of 2022), the document and the concept have not yet been finalized, but are intended to offer interested parties key topics for discussion. The document consists of two parts: the diversity concept and the Code of Conduct. The initial focus is the diversity concept, in which we drafted how we view the responsibility of research in relation to social diversity, difference and inequality. The diversity concept of the CLS study contains four aspects or basic elements: (1) recognition of and openness to diversity and differences, (2) awareness of discrimination and aiming for inclusion, (3) reflection on relations of power, oppression and inequality, (4) transparency regarding boundaries and decisions. The specific application of the diversity concept is also described and documented in a Code of Conduct covering the following aspects: (1) text production and the reflective use of language, (2) developing research instruments, (3) participation, (4) awareness of experiences of violence, (5) interviewer training, (6) secondary analysis. The reflective application and further development of the research ethics elements, diversity concept and code of conduct will take place continuously during the research process and as required for specific contexts.

### Participatory Elements During the Research Process

Concerning the research subjects' participation, a comprehensive concept was developed for the 'panel maintenance plus.' It involves CLS study participants digitally and non-digitally by introducing elements of participatory research into the research process. As an element of participatory research, the #CLS\_networkspace provides a space for confidential information, meeting, networking and education. It is intended to create added value for everyone involved. By communicating with one another, researchers can validate their attitudes, perceptions and perspectives in relation to the research field and the research process. For the adolescents, the #CLS\_networkspace offers (1) a wide range of content and topics that can be talked about, (2) discussion with experts and peers and advice on leaving care, (3) information on the status and implementation of the CLS study, (4) complaints and crisis management relating to the CLS study, (5) socio-cultural animation and the stimulation of informal educational processes, (6) the creation of a joint experiential space for support and strength and (7) networking with peer communities in transition. The communities in this space always remain private and protected. That includes not using Facebook groups, Instagram stories or similar public relations formats. The adolescents are also not instrumentalized for the addressee-oriented development of practice or for political interests. However, there is an implicit outing about the identity of the young people, when they are participating in partic-



ipatory elements. It is ensured that the participants only connect using their first names, and the activation of the video function is optional. At the same time, participatory elements in the research process of the CLS study lead to a variety of barriers and dilemmas, since it is not possible to smooth out or influence biographical risks, socio-cultural conditions and structural inadequacies through the CLS accompanying program—even if an implicit connection to and identification with the CLS study is created by establishing trusting relationships during the study. Ethical and social political dilemmas must also be continuously reflected upon and discussed during the research process in order to achieve concrete measures to improve the adolescents' and emerging adults' opportunities for participation (von Unger, 2021; von Unger & Narimani, 2012). The final question is to what extent the accompanying program might positively influence the lives of the study participants and thus also the study results. Therefore, the study questionnaire asks how often participants take part in the accompanying program.

In addition to the above points, ethical and data protection issues must be continuously considered and discussed, since the confidential, protected context creates intimacy (von Unger & Narimani, 2012). Appropriate, professional self-care and reflective self-awareness should therefore be cultivated in research practice (e.g., individual supervision, team and peer-led supervision, further education and training). Against this background, in the context of panel maintenance, the concept includes referrals to counselling specialists. This is intended to offer support in the event of acute crises. Such support is also integrated into existing expert advice and initiatives and involves cooperation with existing care-leaving communities. The referrals and support are not only for panel participants but also for researchers and interviewers. They are applied not only during panel maintenance but also during the participatory processes itself.

## **Research Ethics and Data Protection Relating to the Results**

In social science, the discourse on diversity sensitivity and intersectionality has prevailed, which means that scientific findings should always be reflected upon in terms of intersectional difference. From an ethical point of view, it is essential to take into account how people would like to be addressed, especially in data analyses and when presenting results. Therefore, elements of participatory research can be inserted. In evaluation workshops before publishing the findings, it is necessary to align the interpretations of researchers and participants or research subjects. There should be a discussion about what the numbers mean and how to position them in the subjective and objective context. In this way, the researchers' and participants' perspectives can be irritated, which is an important ethical challenge during research processes.

In context of the CLS study, we are going to provide a scientific use file, so that the scientific community can use the CLS data. For researchers who are going to use data, it is customary

and necessary to sign a data use agreement under data protection law. However, this usually does not contain any binding regulations on the ethical principles according to which the data are to be handled. Therefore, new ethical challenges arise. The research association follows a diversity concept and a code of conduct. From an ethical perspective, it is important to note that results evaluated and published with CLS data should not be normative, engage in victim blaming or reproduce stigmatization. Social dynamics and survival strategies usually lead people to identify with powerful groups and individuals. This causes the phenomena of victim blaming and the exclusion of vulnerable and marginalized groups. Victim blaming can be defined as treating a person or group that has experienced harmful or abusive behavior as if that behavior resulted from something they did or said, instead of placing the responsibility where it belongs: on the people, institutions or groups who harmed them. Victim blaming can take the form of accusations, implications or actions. Against this background, the research ethics principle is about ensuring that social groups and individuals are not harmed by research processes, findings and public science activities. This includes an appropriate strategy for publication and the use of the data in science and journalism. It is even more complex if more groups of people have an interest in the data, e.g., policymakers, stakeholders and funding institutions. This is why the type of communication and the communication process used are essential during public science activities. Communication should be restrained and in no way exaggerated in terms of interpretations or recommendations. Simplification leads to distortion and undermines the credibility of science. Therefore, the complexity and intersectionality of the results should be taken into consideration. The results need to be placed within established empirical theories and the state of the art, whether or not they confirm them. Aspects that are not apparent from the data, and any limitations of the methods, should be stated openly, not concealed. In this way, the scientific discourse is advanced, new insights can be gained and trust in science does not suffer (Wagner 2019).

## Conclusion

Ethical challenges and data protection issues in research should be more present and discussed more regularly in research teams and generally at every level of the research process (e.g., when planning and beginning the research project, during the research project and in terms of the results of the research process). Research processes are always embedded in socio-structural and socio-cultural contexts that are characterized by hierarchical and meritocratic balances of power and interdependence. Against this background, a consensus has been established that procedures and discussion spaces are needed to deal with research ethics questions and data protection challenges before and during research projects, when disseminating results and during the 'third mission,' public science activities. However, the granting of ethical approval is recognized as a sign of the quality of research work, and most

German funding institutions (e.g., DFG, FWF, BMBF, BMFSFJ) now require ethics reviews. Scientific journals also require ethical approval when findings are to be published. Overall, it can be assumed that the conflicting fundamental rights of subjects and the interests of the researchers must be weighed against one other. The collection of special categories of personal data (Art. 9 DGSVO)—for example about uninvolved third parties and health conditions—is a frequent gray area when it comes to data protection issues in research projects. Therefore, the objection is raised that a ban on certain questions or survey methods is in conflict with the principle of freedom of research. Besides requiring ethical approval, the CLS research association works according to a self-developed diversity concept and a code of conduct during the panel study process. Concerning the research subjects' participation, a comprehensive concept was developed for the 'panel maintenance plus.' It involves CLS study participants digitally and non-digitally by elements of participatory research into the research process. In terms of the results of the research process, these elements will ensure that ethical challenges and data protection issues are continuously reflected upon.

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Katja Vrhunc Pfeifer, University of Primorska, Faculty of Education  
katja.VrhuncPfeifer@pef.upr.si

Mitja Krajncan, University of Primorska, Faculty of Education  
mitja.krajncan@pef.upr.si

## Self-harm as a phenomenon in various forms of out-of-home care

### SUMMARY

Self-harming behaviour without suicidal intent is defined as “an act by which an individual deliberately inflicts harm to him/herself without suicidal intent” (Kvas Kučič, Krajnik and Konec Juričič, 2012, p. 57), and as “deliberate, self-inflicted, low-level bodily harm that is socially unacceptable, while its objective is reduce psychological distress” (Vidmar, 2012, p. 64). Self-harming behaviour can be divided into three groups: acute self-harm, where a person inflicts injuries to their own body for less than one month and no behavioural disorders are present; chronic self-harm, where a person inflicts injuries to their own body for more than one month and no behavioural disorders are present; and chronic self-harm with behavioural disturbances, where a person inflicts injuries to their own body for one month or more and behavioural disorders are also present (Hawton et al., 1982, in McDougall, Armstrong and Trainor, 2010). Self-harming behaviour co-occurs with many mental disorders (Haw, Hawton, Houston and Townsend, 2001; Herpertz, Sass, and Favazza, 1997; Klonsky, et al., 2003; Zlotnick, et al., 1999, in Klonsky, 2007). Usually, self-harm is only one of the symptoms of profound mental distress. This study used a descriptive and causal non-experimental method of pedagogical research. The data were obtained through: questionnaires (for social pedagogues, institute managers, and counsellors - focus groups); semi-structured interviews with teachers, counsellors and principals (focus group); and documentation analysis. The results show that this is a very specific phenomenon (the proportion of which is constantly increasing), with a wide range of different execution styles as a consequence of very complex disorders and problems of the children placed in professional centres. Professional centres represent a non-stigmatising title for all forms of educational help (educational groups, residential groups, intensive groups, day centres, mobile services, social pedagogical work with families, farms, experiential pedagogy, and so on) along the entire continuum of help, from prevention to the most difficult cases. We will analyse approaches and crisis interventions, and conclude by formulating guidelines for working with the above-mentioned population.

**Key words:** *Self-aggressive behaviour, self-harm, residential treatment centres (residential care), children and adolescents with emotional and behavioural problems/disorders*



## Introduction

Residential treatment centres for children and adolescents with behavioural and emotional disorders or difficulties face complex challenges. In Slovenia, the entire network of educational institutions has been divided into 5 regional residential treatment centres, which provide regional assistance along the entire continuum, i.e. from preventive work, mobile work, various forms of educational assistance at the level of half-day and day centres, to educational residential groups with different concepts, farms and intensive groups for the most complex cases (Krajnčan 2019b). It is therefore a newly coined term that reduces stigma and represents a kind of superlative for all forms of out-of-home care. Specific crisis situations plague users of residential treatment centres, with self-harming, self-aggressive behaviour becoming increasingly common.

Self-harm is a behaviour in which an individual deliberately causes harm to his or her own body without intending to cause death. This behaviour can manifest itself in a variety of ways, such as cutting the skin, causing burns, hitting oneself or other forms of self-aggressive behaviour (Fliege, Lee, Grimm and Klapp, 2009).

Crisis interventions in residential treatment centres in the case of self-harm are extremely important, as self-harm can be seen as a sign of increased risk to an individual's well-being and safety (Krajnčan and Vrhunc Pfeifer 2021). In this article, we will present the issue of self-aggressive behaviour with a focus on self-harm in children and adolescents with behavioural and emotional disorders or problems, and focus on the scientific literature on crisis interventions in this context.

A number of studies have focused on research on self-harm in children and adolescents with behavioural and emotional disorders or problems and on effective intervention approaches. Research has focused on understanding the causes of self-harm, such as difficulties in emotion regulation, traumatic experiences, mood disorders, attachment disorders, and on identifying risk and protective factors. Methods and approaches used in crisis interventions, such as behavioural and cognitive-behavioural therapies, art therapies, family therapies, the use of pharmacological treatments and other approaches have also been explored (Nixon and Anderson, 2011; Cerar, Gaber, Kaliman and Knez, 2011).

Self-injurious behaviour can be divided into three groups: acute self-injury, where the person is injured for less than one month and no behavioural disturbances are present; chronic self-injury, where the person is injured for more than one month and no behavioural disturbances are present; and chronic self-injury with behavioural disturbances, where the person is injured for one month or more and behavioural disturbances are present (Hawton et al., 1982, in McDougall, Armstrong and Trainor, 2010). Self-injurious behaviour is common in

many mental disorders (Haw, Hawton, Houston and Townsend, 2001; Herpertz, Sass and Favazza, 1997; Klonsky et al. 2003; Zlotnick et al. 1999, in Klonsky, 2007). Usually, self-harm is only one of the symptoms that indicate deep mental distress or problems, often including mental health disorders.

The acute self-harm group usually includes people who express acute mental distress and resort to self-harm as a way to relieve their current pain or feelings of inner tension. This may include self-harm to gain attention, to seek help or to express despair. This group of people usually does not have a consistent pattern of self-harm and only self-harm occasionally over a short period of time. Behavioural disturbances are usually not present, but other mental disorders that contribute to self-harm may be present, such as depression, anxiety or post-traumatic stress disorder. It is important that people in this group seek professional help in a timely manner to prevent possible recurrences of self-harm and to learn effective coping strategies to deal with stress and negative emotions (Klonsky and Muehlenkamp, 2007).

Chronic self-harm is a behaviour that occurs in children and adolescents who self-harm for more than one month but do not have a behavioural disorder. In chronic self-harm, several patterns of behaviour can be observed, such as cutting, stabbing, tearing hair or nails, chopping and burning the skin (Walsh, 2007). This group includes adolescents who self-harm as a way of coping with their emotions, and some may also use this behaviour as a means of gaining attention. Adolescents who self-harm often suffer from mental health problems such as depression, anxiety, post-traumatic stress disorder, eating disorders, mood disorders, attention-deficit/hyperactivity disorder, personality disorders and other mental health problems (Walsh, 2007). Chronic self-harm can lead to serious consequences such as infections, scars, inflammation and other physical injuries. In addition, such behaviour can progressively worsen and can lead to an increase in the severity of injuries and, consequently, to life-threatening situations (Whitlock and Knox, 2007). Treatment for chronic self-harm includes individual and family psychotherapy, behavioural therapy, cognitive behavioural therapy, art therapy and pharmacotherapy. The aim of treatment is to develop new strategies for coping with stress, to teach more effective ways of expressing emotions and to help reduce impulsivity and aggression. Chronic self-harm with behavioural disturbances refers to a form of self-harm that has been present for one month or more and co-occurs with behavioural disturbances. Behavioural disturbances can include various forms of inappropriate or aggressive behaviour such as impulsivity, violence, vandalism, theft, rule-breaking and others (Whitlock and Knox, 2007).

For children and adolescents dealing with chronic self-harm and behavioural disorders, there are often family dynamics that contribute to their behaviour. For example, they may experience a lack of parental supervision or emotional support, family conflict, substance abuse

and other family problems (Whitlock and Knox, 2007). Treatment for chronic self-harm with behavioural disorders usually involves a combination of pharmacotherapy, psychotherapy and other forms of therapeutic support tailored to the individual's needs and circumstances. Psychotherapies such as behavioural therapy and cognitive therapy can help to manage inappropriate behaviour patterns, while art therapies can help with expressing emotions and managing stress. Family therapy can also help to address family problems that contribute to an individual's behaviour (Whitlock and Knox, 2007).

Characteristics that are often present in people who self-harm include: intense and accentuated experience of negative feelings, high scores on negative temperament scales, depression, anxiety, dissociative episodes, alexithymia, rumination, difficulty expressing emotions, self-criticism, intense anger, poor self-esteem, low experience of self-efficacy, feelings of chronic emptiness, alienation, isolation, childhood trauma, sexual or physical abuse, dysfunctional families, low frustration tolerance, incompetence in communication and interpersonal relationships, social vulnerability, repression and some neurobiological factors (specific characteristics of the genetic signature, serotonin system, dopaminergic system, etc.). Self-injurious behaviour can occur in a number of mental disorders such as depression, anxiety disorder, borderline personality disorder, post-traumatic stress disorder, schizophrenia, bipolar disorder, eating disorders, and others. In some cases, self-harm may be an attempt to self-manage anxiety, feelings of emptiness, despair or other intense emotions that the person is otherwise unable to cope with. In other cases, self-harm may represent an attempt to identify and release psychological pain on a physical level, which is associated with low self-esteem, an inability to express emotions and inadequate emotion regulation (Vidmar, 2012). Mladostnik, ki se samopoškoduje, čuti neko vrsto ujetništva. Čuti se ujetega, ker negativne emocije, še posebej obup, sovraštvo in bes, ne more izraziti. Zato so ta emocionalna stanja ponotranjena. Energije ne morejo usmeriti drugam, kot navznoter, proti sebi (Oblak, 2016).

Young people sometimes find it difficult to explain the reason for their self-harm, especially when it is a way of communicating distress that is not easily expressed in words or even thoughts (some people experience it as an internal scream). Self-harm serves as a way of expressing a very deep inner distress. After such acts, individuals temporarily feel able to cope with life. Self-harm can be a way for young people to deal with intense emotions such as anger, sadness, emotional emptiness, mourning, self-loathing, fear, loneliness, guilt (Nixon and Anderson, 2011).

Self-harm is not the same as attempted suicide, but some individuals who self-harm may be suicidal. It is important to understand that self-harm can become an addictive behaviour. During the act itself, the release of endorphins blocks pain and brings a sense of relief and comfort, similar to some narcotic analgesics. When endorphins reach opioid receptors in the

limbic system, especially in the hypothalamus, the individual feels relief, comfort and satisfaction. They may feel calm and more positive after such actions. Self-harm thus becomes a coping mechanism for intense negative emotions such as anxiety, guilt, depression, stress, emotional numbness, overwhelm, low self-esteem and pressure to be perfect. The body becomes dependent on the chemicals it produces during the act itself, similar to an addiction to illicit drugs. The link between self-harm and feelings of relief becomes entrenched in the brain, prompting us to seek to manage negative emotions through self-harm (Oblak, 2016).

The hypothesis of NSSI (self-injurious behaviour without suicidal intent) as an addictive behaviour is very important, but currently under-researched. Addictive behaviour is that behaviour which, despite negative consequences (in the case of NSSI, pain, body deformity, environmental aversion), stimulates the endogenous reward system strongly enough to cause a persistent desire to repeat the harmful behaviour. Craving is basically a strong psychological urge to repeat the effect of a psychoactive substance to which the individual has developed a dependence syndrome. Strong craving occurs during withdrawal symptomatology or, less frequently, during withdrawal (especially when exposed to specific triggers) (Bunderla and Gregorič Kumperščak, 2015, p. 719).

In the following, different approaches and techniques used in crisis interventions for self-harm in young individuals in residential treatment centres will be presented.

The treatment of self-harm in young individuals in residential treatment centres for children and adolescents with behavioural and emotional disorders or problems requires a holistic and tailored therapeutic approach. The following are some of the approaches and techniques that can be used in crisis interventions for self-harm (Vrhunc Pfeifer, 2021):

1. Cognitive Behavioural Therapy (CBT): CBT is one of the most commonly used therapeutic approaches for treating self-harm. It is based on an understanding of how thoughts, feelings and behaviours affect each other and focuses on identifying and changing negative patterns of thinking and behaviour. Therapists focus on helping the adolescent to develop healthier ways of coping with emotions and managing stress, which can reduce the need to self-harm.
2. Dialectical Behaviour Therapy (DBT): DBT is a therapeutic approach often used with adolescents with intense emotional problems, including self-harm. The therapy focuses on understanding and accepting emotions, and developing skills for stress management, communication and problem solving. DBT also emphasises building a therapist-youth relationship based on acceptance and respect for the adolescent's experiences and feelings.
3. Emotionally Focused Therapy (EFT): EFT is an approach that focuses on understanding and changing emotional patterns. Therapists help adolescents to identify and understand emotions that are associated with self-harm and to develop skills to manage emotions in a health-

ier way. EFT also emphasises the building of a trusting and secure relationship between therapist and adolescent, which can contribute to better coping with emotional difficulties.

4. Stress and emotion management skills: crisis interventions often focus on teaching adolescents stress and emotion management skills, which can reduce the need to self-harm.

In this context, the literature also focuses on the role of professionals in crisis interventions, including the need for a holistic approach involving professionally trained staff with different expertise and skills. The importance of an individualised approach that takes into account the specificities of each individual and the need to work with parents, carers and other relevant stakeholders in the treatment of a child or adolescent who self-harm is also emphasised (Krajncan and Vrhunc Pfeifer 2021). Approaches that emphasise the importance of understanding the context in which self-harm occurs and involving the parents or carers of the child/young person in the treatment process are also emerging in the literature.

## Objectives

The article pursues the following objectives:

1. To define self-aggressive behaviour, with a focus on self-harm.
2. To present the self-assessment of professionals in residential treatment centres on the frequency, intensity and complexity of self-aggressive behaviour, with a focus on self-harm.
3. To present the ways in which practitioners deal with self-harm behaviour in children/adolescents.
4. To present interventions in cases of self-aggressive behaviour, with a focus on self-harm, that practitioners consider effective.
5. To demonstrate the impact of auto-aggressive behaviour (with emphasis on self-harm) on other crisis situations in residential treatment centres.

## Research Problem

Self-harm, as a form of self-aggressive behaviour, is an increasingly common problem in residential treatment centres (Krajncan and Vrhunc Pfeifer, 2021). It represents a crisis situation for the individuals who are subjected to this type of behaviour, for the professionals who deal with it and to other users who are indirectly involved as observers. Self-injurious behaviour often serves as a way of expressing internalized emotions, stress, anger, sadness, loneliness or helplessness (Nixon and Anderson, 2011; Whitlock, and Knox, 2007; Oblak, 2016; Vidmar, 2012). Children and adolescents who are experiencing emotional as well as behavioural problems/anxieties in particular often lack the appropriate skills to verbally express their feelings, and therefore resort to physical actions. Self-injurious behaviour may therefore be one way

for them to release emotional tension. Self-harm releases this tension and makes them feel better for a while (Ferbežar and Vrhunc Pfeifer, 2023). Copying behaviour is also common in professional centres, and even more so for girls. In practice, this can mean that when one girl engages in self-harm, she may „pull“ five others after her, trying to integrate into a group or gain attention in this way, which puts additional strain on practitioners, especially educators, who spend most of their direct time with the girls (Balažic, 2017). Some users engage in this type of behaviour in order to gain control over their bodies and, at the same time, their lives. In this way, they create the feeling that they are in control of some segment of their lives (Jovanović, 2018). In addition to being a health hazard, self-harm behaviour also presents crisis situations for professionals, as mentioned above, especially educators, who must intervene appropriately when this behaviour occurs. As these are physical injuries, medical treatment is needed, or rather the appropriate skills of professionals to provide appropriate medical care and monitor injured individuals (Krajncan and Vrhunc Pfeifer, 2021). Understanding the causes of self-injurious behaviour is necessary, as this is the only way for the professional to identify which emotional problems or stressors are contributing to the behaviour. Practitioners also need to try to prevent the reoccurrence of self-injurious behaviour, which means extra attention to these individuals and, in some cases, ongoing supervision. In doing so, they need to develop individualised approaches that help individuals to manage emotional problems in a more constructive way. Support and therapeutic help, or guidance, is therefore needed for this type of problem, teaching individuals better ways and, above all, less harmful ways of dealing with their own emotions. Collaboration with other professionals is needed to ensure that individuals with self-injurious behaviour are treated in a holistic way. It is important to understand that each individual is unique and therefore the treatment of self-injurious behaviour needs to be approached in an individual and holistic way, which requires a number of competences from professionals that enable them to intervene effectively.

## Hypotheses and Research Questions

As part of the quantitative part of the research, the following hypotheses were formulated:

H1: Professionals in residential treatment centres self-assess self-aggressive behaviour, with an emphasis on self-harm, as very common.

H2: Professionals in residential treatment centres self-assess self-aggressive behaviour, with an emphasis on self-harm, as very challenging.

H3: Professionals in residential treatment centres self-assess self-aggressive behaviour, with a focus on self-harm, as very intense.

H4: Self-aggressive behaviour with a focus on self-harm does not affect the occurrence of other crisis situations in the residential treatment centres.

As part of the qualitative part of the research, we asked the following research questions:

1. In what ways do the educators of the residential treatment centres cope with self-aggressive behaviour (with emphasis on self-harm behaviour?)
2. Which interventions do they consider effective in dealing with crisis situations related to self-injurious behaviour?

## Methods

The survey, which took place between 15. and 30. September 2020, all Slovenian institutions for the education of behaviourally and emotionally difficult/moody children and adolescents were included in the survey in the following order (Mladinski dom Malči Beličeve Ljubljana, Zavod za vzgojo in izobraževanje Logatec, Educational Institution Kranj, Educational Institution Višnja gora, Youth Home Maribor, Youth Home Jarše, Educational Home Veržej, Educational Institution Planina and Educational Institution Frana Milčinskega Smlednik). For the qualitative part of the research, data were collected in focus groups involving the head teacher, two experienced educators and a counsellor. To process the data, the interviews were first transcribed and then processed using a descriptive method according to the principles of qualitative content analysis based on coding.

For the quantitative part of the study, we used a self-developed questionnaire that asked for self-assessment of the frequency, intensity and complexity of self-aggressive behaviour, with a focus on self-blame. The quantitative research also examined whether self-aggression is a predictor of other crisis situations in the professional centres. The questionnaires were distributed among all the educators working in the centres in Slovenia at the time. After reviewing the questionnaires in physical form, we transferred the questionnaire data into electronic form and used the SPSS computer tool to process the data. For the purpose of analysing the data obtained, we used: basic statistical parameters; non-parametric statistical test (Kruskal-Wallis H test); Cronbach's  $\alpha$ -coefficient (checking the reliability of the measuring instrument); and factor analysis in order to check the validity and reliability of the instrument and to extract common factors.

Personal folders were also used to look at the different phenomena in the field of auto-aggressive behaviour among children/adolescents in the centre, and all personal data was strictly protected.

## Results and Discussion

For the sake of clarity, we will first present the results of the quantitative part of the survey and then the qualitative part.

The main statistical population of the quantitative part of the survey is made up of educators from vocational training centres in Slovenia. According to the information obtained from the directors of the centres (as the Statistical Office of the Republic of Slovenia did not have this data), the total number of educators employed in 2020 was 271. In our sample, which included voluntary participation, 154 educators (representing 56.8% of the population). Among the educators surveyed, 91 were female (59.1%) and 61 were male (39.6%), while two participants (1.3%) refused to express their gender.

In the following, we show how the educators rated the frequency, intensity and complexity of dealing with auto-aggressive behaviour.

Figure 1 Educators' self-assessment of the frequency, intensity and complexity of self-aggressive behaviour

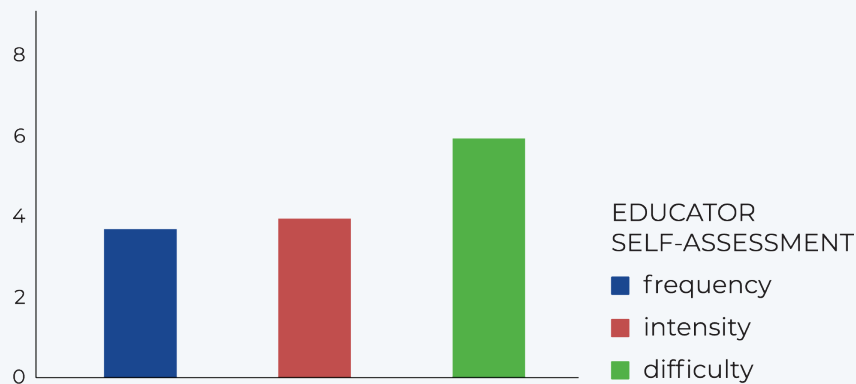


Table 1 Frequency, intensity and complexity of auto-aggressive behaviour

	$\chi$	S	Min	Max
Frequency of autoaggressive behaviour	5.19	2.25	1.00	10.00
Intensity of autoaggressive behaviour	5.52	2.15	1.00	9.00
The complexity of auto-aggressive behaviour	6.38	2.37	1.00	10.00



The frequency, complexity and intensity of self-aggressive behaviour were measured using a 10-point rating scale, where 1 is the least frequent and 10 the most frequent. Educators rate the frequency and intensity of self-aggressive behaviour similarly, while they find this type of phenomenon even slightly more challenging ( $\bar{x}=6.38$ ).

Educators rate self-aggressive behaviour as frequent and intense, while they rate it as slightly more challenging. Given the hypotheses, we thus reject hypothesis 1 and hypothesis 2, since we hypothesised that they rate crisis situations related to self-aggressive behaviour, in which we highlight self-injurious behaviour, as very frequent and very challenging, but rather as moderately frequent and intense. Hypothesis 3, that educators rate self-aggressive behaviour as very challenging, can be accepted, as they rate this type of behaviour as challenging rather than frequent and intense. A 2018 survey by Roh, Jung and Hong ranked Slovenia among the top ten countries with high rates of suicidal behaviour. This was particularly pronounced in the 10-14 and 15-19 age groups. Although the percentage of suicidal behaviour has decreased, the fact that the age limit for suicidal behaviour is getting lower and lower remains a cause for concern. In this context, it is worth noting that the proportion of suicidal behaviour is slightly higher in girls compared to boys (NIJZ, 2021; Jovanovič, 2018; Roškar, Jeriček Klanšček, Vinko et al., 2019). There has been a reduction in hospital admissions for self-harm behaviour. Among boys, alcohol poisoning is the most common method of self-harm, while girls are more likely to resort to the use of sharp objects and various substances. Minors in Slovenia are similarly more likely to think about self-harm compared to their peers in other countries, but in Slovenia they actually self-harm more often (Roškar, Jeriček Klanšček, Vinko et al., 2019).

As the research also covered other crisis situations in the residential treatment centres, we tested whether any of the crisis situations plays a decisive role or a predictor that influences the occurrence of other crisis situations. In estimating the regression models, we used the ENTER method, which included all selected variables and estimated the regression coefficients for all variables simultaneously. We used the constructed crisis variables.

The crisis situation of auto-aggression has emerged as a major factor in the differences in the ratings of individual crisis situations. In the following, we show results only for those crisis situations where autoaggression emerged as a significant predictor. We start by showing how the main predictor (autoaggression) behaved when included in the model together with the other independent variables (all other crisis situations) before focusing on it alone.

Table 2 Showing the behaviour of the main predictor (autoregressions) when included in the model together with the other independent variables (all other crisis situations)

	Auto-aggression	
	B	P
Abuse	0.224	0.003
Addiction	0.212	0.036
Combined disorders	0.225	0.004
Mental health problems	0.235	<0.001
Heteroaggression/violence/delicacy	-0.007	0.948

The table shows the regression coefficients (B) for the autoregression when all predictors are considered in the model and each crisis situation is analysed separately. The results show that there was no statistically significant association between autoaggression and the crisis situation heteroaggression/violence/divergence. The unstandardised regression coefficient (B) is (B = -0.007, P = 0.948), which means that the association is negative and not significant. However, in other crisis situations, self-aggression showed a statistically significant role, as confirmed by the values of the statistical significance (P), which are everywhere less than 0.05. The results thus provide quite interesting data indicating the severity of crisis situations associated with self-aggressive behaviour. This is because it also influences the onset of other crisis situations, such as addiction, mental health problems, comorbid disorders and abuse (probably in the opposite direction, i.e. abuse as a trigger for the onset of auto-aggressive behaviour). This is therefore a result that suggests a more introverted population in the residential treatment centres, which is to a large extent coping with mental health problems. Given that the specialist centre used to be considered an institution where emotional and behavioural problems/disorders predominate and users are extroverted with frequent escalations in behaviour, the population is clearly changing, as mental health problems predominate according to the survey results. This calls into question the competence of staff to deal with these issues.

Based on the results, we reject hypothesis 4, as auto-aggression proved to be a significant predictor of other crisis situations, i.e. abuse, mental health problems, comorbid disorders and addiction.

The quantitative research served as a guide for the qualitative research, as this way we were able to obtain information on which we could later focus when researching educators' coping with these issues.

During the focus group interviews we focused on the types of self-aggressive behaviour and the cases they face, and we were further interested in the ways in which they cope with the issue and which interventions prove to be effective.

We will present the forms, methods and ways of dealing with these issues in the residential treatment centres.

The most common forms are:

*„Cutting. Self-harm. This is very popular with girls. Cutting. And threats of suicide. And that they'll jump...“; „Self-harm, cutting. When you call an ambulance twice when you have a girlfriend, then within an hour they call you, come and look for her. Let's say there was a case where she, it's not self-harm, it's an overdose of insulin, a knife attack, and then I stopped her and knocked her to the ground. And that's when I was stabbed. She was taken away in an ambulance and she wasn't even examined by a psychiatrist. She went to the emergency room. They gave her a patch. It's not a good thing to sew. It's fine, come and get her.“; „The fact is that when girls cut themselves, they cut themselves in invisible places, if they cut themselves on the wrists, they even go so far as to go and paint over themselves with an alcohol marker so that you think that she has cut herself. Which is very fashionable now, that everybody is scratched, tattooed a little bit. And it can only be the luck of the situation that somebody else tells you, or she tells you anyway, or an educator detects it. So most of the time, it's actually things that the children, they cut themselves, but they come to say that they are in need. A lot of times it is. A lot of the time it's also that somebody else says that they have something. Then you don't call an ambulance, because they are already oak trees. You don't have any. Because you don't know when it's going to happen.“; „ We had a girl who cut herself all over her thigh, up to her knee. From top to bottom, cut. These wounds are not deep. But they're so deep that they're pale.“; „The most common is cutting, but more and more common is boxing into the wall. There is more and more of that now. At the moment there is more boxing than cutting. There are more types. There is also bone breaking. Destruction of inventory because of one's own aggression towards oneself...“; „Now at the moment it happens most often with girls. But we have had boys too. Shapes, I don't know...cutting with various implements, anything they can find basically. From sharp objects to broken cups to blades from a skewer, broken balls, geotriangles, whatever they can find that's sharp enough to hurt themselves. They poke at the wall, at the door, so that their knuckles are marked. Pulling their hair, say, they drink some kind of liquid. Even with sprays, with deodorant, in fact, they cause burns. If the injuries are superficial, they are treated by our medical technicians. If it's deeper, they go to a doctor.“*

Often, the phenomenon of self-harm behaviour spreads in a chain among other users, more often among girls: *Girls don't cut themselves. They cut themselves, we had that, let's say one season last year, last school year there was a lot of that in the hook. We had a girl who just provoked this behaviour or somehow made other girls to get into a cult, and I'm not talking about a cult, in the classical cult sense, but they were all suddenly depressed and they were all laughing at each other and it was a, ma, it was a horrible situation in the main.“*

So it is a self-aggressive behaviour, most often manifested in the form of self-harm, which is carried out by cutting the skin. The most common treatment for this type of behaviour is paedopsychiatric treatment: „*The paedopsychiatrist then also gives feedback on these assessments and. So we don't do it ourselves.*“ A risk assessment is carried out to indicate the level of severity of the problem: „*Only a risk assessment, we can say that it is done. We are told that it is a big science*“; „*Or self-harm call the doctor on call always, always, always. Because that's the expert who can decide and that's not the case now.*“; „*When the doctor was conducting the procedure and then she referred him to a psychiatric hospital because he was threatening, no. Let's say that they have combined this, we say no, we now assess that the police will also be needed.*“; „*Above all, in these dangerous, physical protection is necessary. Above all by calmness, but to help him physically to remove himself from these dangerous situations. And preventive protection.*“; „*We have for a long time that we cooperate with the health centre. With the mental health dispensary. We have a consensus with them that we basically involve our children with paedopsychiatrists, psychologists and all these psychological specialists.*“; „*Now I think that when these events, crises, happen. It is very good that a network has been created. Because these difficulties that we have now, these mental health problems.*“; *Involve in some treatment, therapeutic. Because he refuses. Because these therapeutic treatments, for primary school children, we involve them.*“; *Let's just stop, you keep her clean, you talk to her. She was referred to a paedopsychiatrist anyway, but. First, of course, you pick up, you protect the environment. She was using the rattlesnakes. Everything, sharp objects.*“; „*We then have prevention workshops on the subject.*“; „*We use harm minimisation techniques when we foresee that the person is going to hurt themselves when they have the chance, so we explain, I don't know, the anatomy of the hand, or we tell them here's the disinfectant.*“; „*You always have to give a suicide pact. We are protected by this officially. Then we also talk about it.*“; „*So I had a problem because it happened most of the time at night, that she came at about two or three in the morning and in the room she cut herself on her arms, legs, body with some kind of a thing, so then you are alone in the group and you see if it is really too deep or something and then you have to call an ambulance but yeah.*“; „*Yeah mostly, that they are being we take these youngsters to a psychologist for a check-up and a lot of pills no, these youngsters don't need them.*“ From the verbatim quotations of professionals, it can be seen that when dealing with self-aggressive behaviour, which is predominantly self-injurious, the most frequent methods used are paedopsychiatric treatment, emergency calls or on-call doctors, and in cases of severe escalation, police accompaniment is also used. There is a lot of preventive work, especially on awareness-raising and on removing opportunities for self-harm behaviour. They also produce a threat assessment or an anti-suicide pact in such cases. Professionals work together with the health care institutions that provide them with assistance, and users are

also involved in psychotherapeutic treatments. They are also familiarised with minimisation techniques, which are useful in the case of alternative ways of reducing harm and danger.

Most professionals rank attitudes as the number one effective intervention. A quality relationship between the child and the professional is a fundamental element of trust. Children/young people are more likely to open up and feel comfortable if they believe that the professional understands, respects and cares for them. This trust allows children to share their problems, fears and worries, which is crucial for effective help. Establishing a relationship enables the professional to better understand the child/young person's needs, wishes and abilities. Each child is unique and faces different challenges. Through a deeper relationship, the practitioner can better tailor their approach and support to meet the specific needs of the child. Children/young people need a stable and supportive framework to feel safe to explore their emotions and feelings, especially when they feel helpless. A quality relationship allows them to express their feelings, learn to cope with stressful situations and face challenges in a more constructive way. The relationship is a bridge between the professional and the child/young person and is the key to a successful helping process. Similarly, Krajncan and Bajzelj (2008), in their article, attribute a key role to the relationship. After establishing a relationship based on trust, the main focus is on addressing the causes of self-harm behaviour: *„Self-harm has very different dynamics, backgrounds, and it is important to know what they are. Whether it is family or traumatic, whatever, it is necessary to find out where the origins are and then help is offered. Depending on what the response is.“* Where relationship work is not sufficient and life is at risk as a result of self-injurious behaviour, emergency medical intervention is required, where the wounds are moderate and not life-threatening, the child/young person should care for them themselves, or with the help of a medical technician where available. The minimisation techniques already mentioned above have been found to be effective: *„A cold shower, otherwise listening to music, reading, putting on a box of with some of their things that mean a lot to them, talking to a friend, writing a letter - one that they can burn, that they can put all their feelings down on paper. Basically, there are, within this safety plan, at least 20 things that we can suggest. We give it to the child so that he can read it several times and find a more appropriate way. Anyone who self-harms gets a safety plan!.* As part of the medical assistance, individuals are later offered paedo-/psychiatric treatment (also emergency) or children/young people with such problems attend psychotherapy sessions. Most professionals point out that waiting lists for paedo-/psychiatric treatment are long and individuals do not receive treatment when they need it.

Also, as effective, professionals cite constant vigilance and supervision: *„We are on standby 24 hours a day. That's what I was studying before, you're on standby all the time. There are a few things you have to do. We would need two people on call 24/7, no, in those cases.“* and at the same time the need for an additional educator to allow more attention to be given to

individuals who are prone to self-harm behaviour. In addition, they recommend a de-escalation talk and increased preparedness, both in terms of an additional educator and in the removal of all potentially dangerous objects: *Yes, it is not the mirrors that are classic. Then of course, there are no razors, but there is a technician next to say when shaving boys or girls. All these dangerous objects are removed as long as it is not possible, so to speak. And when all these relaxation techniques are used, it is looked at that if it is walks, not to pick up some things and so on, in this way we try to keep it to a minimum, but there will always be some no's. That is to say, you have to work intensively with them in the direction of this prevention so that this does not happen.*" The effective intervention approaches mentioned above should not neglect the cooperation between all the staff who are in contact with a child/young person who is prone to self-harm behaviour: *„Now, again, this depends on the case. There is no systematic way of doing things, we basically work together so much all the time. The educators work together, or the teachers if there is something like that. Then we go in, but not yet. Some of the children, they are with me more permanently, they come for talks, or they come to the social worker, but some of them they get close to the educators and then they talk more about it. Each child chooses one important person for themselves. And we let them do that.*" So mutual cooperation across the continuum of support plays an important role. Only the joint work of all stakeholders can contribute to the success of a case.

Professionals from different residential treatment centres highlighted the issue of self-harm behaviour, which is a growing and frequent form of crisis behaviour. These behaviours take many forms, including more traditional and common ones such as cutting, scratching or scraping the body, causing wounds, hitting, causing burns, pulling hair, punching walls, breaking bones, consuming harmful substances and even swallowing objects. Sometimes, however, these behaviours manifest themselves in extremely specific and unusual shapes beyond imagination. They also pointed out that there are many different techniques online that allow individuals to do this undetected. It is also important to distinguish between those who imitate this behaviour, which is often a way of manipulation, and those who self-harm in secret, and do so mainly alone or in secret. When assessing the severity of an injury or crisis situation, we need to be aware of when to call for first aid. It is important to remain calm and to ensure the psychological and physical safety of the individual.

Different residential treatment centres use different measures to deal with this type of situation. Some hold emergency crisis meetings, while others may enter into a suicide pact with the individual, which also has legal implications. In addition, preventive measures such as unbreakable glass and mirrors are sometimes installed, as well as an emphasis on the use of only "safe objects". A variety of techniques are used, including harm minimisation, relaxation techniques, walking, music, reading, rewarding positive behaviour, distraction, cold showers and other techniques. The safety plan by Gregorčič Kumperščak (2019) describes self-harm as

a short-term way of coping with emotions. Preparing alternative ways of coping with stress, such as ice, elastic, running, or a punching bag, is crucial, and the individual should keep the safety plan with them at all times.

Some residential treatment centres are prepared to deal with such behaviour, including wound care, necessary medical attention in a facility or by a doctor. They also have the option of isolating the child or young person from the group and providing individualised treatment. Daily individual interviews, consultations with psychologists, social workers and the management of the institution are also an integral part of the measures to deal with these situations.

The results of the survey show that this is a fairly common phenomenon in residential treatment centres and needs to be seriously addressed, with a need for treatment across the whole continuum and good cooperation between all stakeholders. It is also interesting to note that self-aggressive behaviour is a predictor of the incidence of other crisis situations that occur in residential treatment centres, and that staff should be further trained in intervening with self-aggressive behaviour, which, according to the survey results, could reduce the incidence of other crisis situations.



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Natalija Lisak Šegota, UNIZG, Faculty of Education and Rehabilitation Sciences  
lisak.natali@gmail.com

Daniela Bratković, UNIZG, Faculty of Education and Rehabilitation Sciences  
daniela.bratkovic@erf.unizg.hr

Sonja Alimović, UNIZG, Faculty of Education and Rehabilitation Sciences  
sonja.alimovic@erf.unizg.hr

## The challenges of independent living from the perspective of persons with disabilities

### SUMMARY

The UN Convention on the Rights of Persons with Disabilities (UN, 2006) defines the Independent Living Movement in Article 19 as a concept that includes three key elements: the ability to make one's own decisions (to support self-determination), individualised services, and available and publicly accessible services that are equal for persons with disabilities. The Independent Living Movement of People with Disabilities empowers people to advocate for their rights. It also aims to achieve social inclusion through community development and support based on emancipation, autonomy, and the full participation of all citizens on an equal basis. As scientific evaluations and other reports show, there are many challenges along this path. This scientific study was conducted as part of the partnership project "Platform 50+" in cooperation with the Croatian Union of Associations of People with Disabilities. The aim of the study was to gain insights into the possibilities for independent living in different regions of Croatia from the perspective of individuals with disabilities, their parents, and professionals. The perspective of adults with different types of disabilities is presented using a qualitative approach. Data from the focus group interviews were analysed using thematic analysis. The data obtained from the perspective of people with disabilities shows that there continue to be many barriers to independent daily living and creating their own family - support/assistance is not available and it is not individualised, there is a need to develop more community resources and improve accessibility to support participation in daily community activities. However, the most important point is to ensure the right to make their own decisions and receive support. These findings also provide important insights and recommendations for improving disability policies and support systems based on the experiences of people with disabilities.

192 **Key words:** *independent living, persons with disabilities, social inclusion, community development*

## Introduction

As early as the late 1970s, when the transition from the medical model to the independent living model was proposed (DeJong, 1978), persons with disabilities (PwD) and their communities were creating policies and opportunities for independent living. Independent living became a philosophy that promotes and supports all aspects of life to support self-determination, equal rights, and self-esteem for all PwD regardless of the level of support needed (Parker & Clements, 2012; Ratzka, 2005).

To promote independent living, major world organisations have proposed the acts and strategies for countries to improve supports for PwD. According to Article 19 of the UN Convention on the Rights of Persons with Disabilities (UN, 2006), independent living means that people have the opportunity to make their own choices, have control over their lives, and achieve full participation in the community. The key role in promoting independent living in Europe is played by the ENIL - European Network on Independent Living (<https://enil.eu>). It advocates for the basic principles for independent living proposed by the Reclaiming our Futures Alliance (ROFA): accessibility of information, health and social care, transportation systems, environment, and housing; availability of inclusive education and training, independent advocacy and self-advocacy, peer counselling; adequate income, technical aids and equipment, personal assistants; and equal employment opportunities (ENIL, 2022; ROFA, 2019).

In parallel, there have been significant changes in legislation, definitions of disability, deinstitutionalization, and provision of support tailored to people's needs in recent decades (UN, 2006); World Report on Disability, 2011; Žganec, 2008). In 2017, the Government of the Republic of Croatia adopted the National Strategy for Equality of Persons with Disabilities from 2017 to 2020 as a strategic document for policy making for PwD (Nacionalna strategija izjednačavanja mogućnosti za osobe s invaliditetom od 2017. do 2020. godine, 2017). However, research from various countries shows that challenges still exist (Brennan et al., 2018; Legg et al., 2022). Bakula Anđelić's (2019) research showed that the most common challenges to independent living for individuals with physical disability in Croatia are in the areas of physical accessibility, formal and informal support, personal assistance, community participation, mobility, and universal design. In addition, Bratković, Mihanović and Lisak (2018) found many barriers to achieving independence and social participation that, despite the positive effects of deinstitutionalization, result in People with intellectual disability (ID) being socially isolated and discriminated against. Nevertheless, there is still a lack of information about different areas of independent living and the implementation of principles and strategies to improve independent living of persons with disabilities with different support needs in Croatia, so we conducted this study.

## Objective

The objective of this qualitative study was to analyse the challenges of independent living in different regions of Croatia from the perspective of persons with disabilities.

## Research Question

In accordance with the study objective, we defined the following question:

What are the challenges of independent living of persons with disabilities in different regions of Croatia from their point of view?

## Methods

Participants were selected based on purposive sampling. The inclusion criteria for participants were that they were well informed about the research topic, had practical experience, and had a variety of perspectives based on criteria explained and defined by authors Miles & Huberman (1994). The participants with disabilities (N=42) had different types of disabilities (in adulthood), were of both genders, and had different levels of education and socio-economic status. Most of them had physical disabilities (N=17), then chronic diseases (N=7), visual impairments (N=6), hearing impairments (N=5), deaf-blindness (N=3), two of them had autism spectrum disorder, and two people didn't provide information about the type of their disability. Most participants were employed (N=15), including 7 participants who worked in civic organisations and associations for PwD. Many were retired (N=12) and unemployed (N=8). There were also 4 students. The focus group method was used to collect qualitative data. The participants were diverse in terms of some characteristics and experiences of living with disability in different regions of Croatia, which was important in order to have a quality discussion about the research phenomenon (Rimac & Ogresta 2012). The protocol for the focus groups was developed and included questions about the challenges of independent living in the areas defined in Article 19 of the CRPD and Optional Protocol (UN, 2006): Housing and Partnership, Marriage and Parenting; Systematic Professional Support; Access to Public Spaces, Facilities and Services in the Community; and Self-Determination and Decision-Making. The study was conducted in December 2021 in four different regions of Croatia. The focus groups took place in Osijek (N=8), Rijeka (N=12), Split (N=10) and Zagreb (N=12). The research follows and implements the ethical principles of research as outlined in Article 2 of the Code of Ethics of the Commission on Ethics in Science and Higher Education (2006).

We conducted three thematic analyses: realist (participants' "meanings and experiences of reality"), theoretical (transition from theory to data), and semantic (not looking for meanings beyond what participants said, but trying to understand what people said, what their opin-

ions or thoughts were, and how they explained their experiences) (Braun & Clarke 2006, 9; p. 12 & 13). The open coding method was used in the analysis to summarise and structure the data. Prior to coding, the audio data was transcribed, and the transcripts were carefully read. Based on the open coding process, the initial themes and subthemes were created. Themes were expected to be based on the theoretical concept of independent living. Sub-themes may include some variety or specificity within a main theme (Braun & Clarke 2006). Nevertheless, the researchers were interested in finding some emergent themes that were raised by participants during the focus groups.

## Results and Discussion

Participants in this study *rarely achieve autonomous, independent living* defined as a basic human right to decide for themselves where and with whom they want to live (Ghanouni et al., 2021), mostly due to unemployment (e.g. *"It is a big problem that people cannot separate from their families because they are not independent, do not work, and do not have money to live on their own"*). They cite the lack of continuous and comprehensive employment support (e.g. *"The system should provide more employment support for PwD"*) and uncompetitive occupations in the open labour market as the cause of unemployment. There are still high school programmes recommended for PwD, for occupations that no longer even exist (e.g. *"Blind people aren't competitive because the problem is often in the choice of occupation, and again, it is a problem of the unreformed education system ..."*, *"I should... work either as a telephone operator or as a masseuse..."*). This shows us that the educational system does not match the requirements of the labour market since persons who have finished school stay at home and are unemployed. Sometimes PwD have difficulties finding a job because of many prejudices, especially deaf people because of communication problems (e.g. *"When they apply to be a housekeeper... ..they get a lot of rejections. He says, "See, communication." And why? Well, deaf people can see very well"*), and because doctors do not support employment, but incapacity (e.g. *"...the doctor writes article 17, incompetent, why?"*). WHO recommends the use of the International Classification of Functioning, Disability and Health (ICF) when assessing PwD in order to emphasize the person's functioning and abilities to participate with reasonable accommodations to the environment (WHO, 2013). Although ICF is widely used by professionals to determine the degree of disability and to determine the rights of different beneficiaries, we can conclude from this study that it is not used to support employment. Thus, we can conclude that the ICF is again used to determine disability and the need for social services, rather than to determine functioning and opportunities for participation.

Just as our participants perceived low income as a major barrier to independent living, Conder and Mirfin-Veitch (2020) concluded that people with learning disabilities who make inde-

pendent living decisions are sometimes constrained by their income in choosing where to live and who to live with. Economic independence supports independent living. Participants who are unemployed cannot achieve independent living, even with government support because they perceive this financial support to be insufficient.

Another barrier to independent living is that *housing is not accessible and suitable for PwD*. In the case of a deaf person who got a city apartment in a suburb of the city where there is no adequate public transportation and no access to school. In addition, the process for obtaining state or municipal housing is very slow, takes a long time, and the disability must be proven over and over again (e.g. *"I have right on a city apartment, I am on the priority list... but it takes too long to wait 10 years for an apartment", "I have to keep submitting new documents"*). Some countries have developed social rental housing but still face problems. Anderson, Theakstone, and Lawrence (2020) therefore provide recommendations for housing policy and practice on how to improve the accessibility of apartments and houses for PwD. To improve housing accessibility for PwD, inventors are developing smart houses that could be of great help to people with all types of disabilities, but the problems lie in implementation and affordability (Ahmed et al., 2016). Although the Croatian government is implementing the strategic goal of deinstitutionalization described in the national strategy (Nacionalna strategija izjednačavanja mogućnosti za osobe s invaliditetom od 2017. do 2020. godine, 2017), participants from Rijeka reported that the only place of residence currently available for PwD is an elderly care home, which is not accessible and lacks services and content for PwD (e.g. *„...and what can be currently planned in our region is an option that is not acceptable for the vast majority of PwD, and that is the retirement homes for the elderly...“, „... also in most parts of Croatia, where PwD are mostly without parents and end up in a home... So you can live in a home, but is that a life?... for most of us it is not, but there is no other option...“*). Organized supported living is primarily a service for PwD who do not have family support and need to be cared for by the system; PwD who need personal assistance to work and live independently are not eligible for organized living services (e.g. *"When I called there to ask for a place for me, the woman said, 'Do you have someone to take care of you?'.... ...'If they have sufficient income and are willing to take care of you, you do not have a place in our center.' It is the center for social cases, for those who have no one to take care of them."*).

From the perspective of PwD from all regions, *parents and other family members are over-protective* when they want to live independently, start their own family, have a partner, get married, or become parents (e.g. *"the parents, the mother is overprotective, ... there are many parents who do not think about our future ... they are afraid"*). Perhaps families of PwD from our study have a similar problem, which Dimitrova and Goncharova (2023) represent by a hypothetical question: "Who will take better care of him than me?". This prevents independent living but is often a consequence of the lack of support from the state and local authorities.

In the context of *systemic professional supports and services*, PwD emphasize the unsupportive and discriminatory relationship of staff in the social and health care systems (e.g. *"...I had bad experiences, very, very bad. It's like they want to take advantage of our rights ... to take them away from us", "I did not get any concrete information from them"*). Kritsotakis et al. (2017) found poor attitudes toward persons with physical and ID among medical, nursing, and social work students, and our participants had similar experiences with professionals who finished similar studies. Therefore, we need to rethink the educational system that prepares professionals to work with PwD in order to provide better support to those in need.

Biškup, Buljevac and Leutar (2009) wrote about the importance of personal assistance in achieving independence for PwD. However, the participants of this study emphasize the problem of continuous funding for personal assistance and sign language interpreters/communication mediators, which is not solved systematically, but is based on *projects of the non-governmental sector* (e.g. *"The government should be more understanding of associations for PwD and support them financially", "Associations are not profit-oriented, they depend on projects", "Thank God for non-governmental associations, otherwise we would have nothing, nothing at all"*). The authors of the 2019. study found similar problems with personal assistance. So, although everyone is aware of this problem, nothing has changed in the last four years (Bakula Anđelić, 2019). Even if the problem of funding is solved, the availability of services remains insufficient because the implementation of the right to personal assistance is only four hours per day, which is not enough for most people to live independently (e.g. *"It is not nearly enough to have 4 hours of personal assistance, I would need it 24/7"*). Individuals with hearing impairments may receive assistance from sign language interpreters or communication mediators only once a week (e.g. *"It is very difficult to find a good communication interpreter who is motivated and knows how to convey all relevant information. We do not have enough support, sometimes only for a few hours a week"*). In addition, the problem also lies in the regulation of the personal assistance/sign language interpreter profession and the motivation and quality of their work. The participants in the study from the United States of America who suffer from spinal cord injury, as well as their personal assistants, were dissatisfied with overly restrictive policies regarding this service and also with reimbursement for the work of personal assistants (Matsuda et al., 2005). Participants in Croatia also recognised the need for financial regulation, continuous systematic training, and supervision (e.g. *"Personal assistants leave when they find a concrete, well-paying job, ... these people need to be paid adequately, then they will stay," "...we feel that these personal assistance projects put pressure on the hard-to-employ women, and then these beneficiaries are no longer important for PwD, and the question is, what do these people actually know, they need to be trained systematically, ... it is still a difficult job, not well paid, and people apply for it when there's nothing else, and then they're not motivated..."*). Considering the above points and



the importance of personal assistance services, it is crucial to organise these services at the state level. The service must be well regulated and not simply left to the “people with heart” as Matsuda et al. (2005) called it. Meanwhile, Croatia adopted the Law on Personal Assistance (NN, 71/2023), a service that is now financed from the state budget rather than EU funds and is defined as a social service that assists PwD in everyday activities at home and outside the home, in communication and in acquiring information, so that the person has greater autonomy and is on an equal footing with the typical population. We expect that the first effects will be seen in practice, depending on the legal acts and the delivery of the service.

Another major problem is that the system is not flexible, and people cannot combine the services they need within the system or between systems (e.g. “...Those who have a salary of more than 530 EUR lose the right to the personal disability allowance... PwD are just sluggish, they lose, they are not motivated to continue their education, they have a hard time finding a job. We are creating a group of very, very socially dependent people”, “Because of this inflexibility of the system, PwD cannot assert their rights at multiple levels, so they often choose to be dependent on other people”). Many authors wrote about the need of PwD to have flexibility in choosing and receiving services (Fisher, Parker & Purcal, 2009; Helgøy, Ravneberg & Solvang, 2005). Helgøy, Ravneberg & Solvang (2003) also mentioned in their work the need for flexibility of caregivers who sometimes insist on routine-domination in their work.

The right to *assistive and digital technology* needs to be much more widely implemented, especially in adapting the workplace and technology to support the independent and efficient work of PwD (e.g. “People with visual impairments...we need special software and accessible environments to work efficiently...”). Assistive technology increases the level of independence of PwD (Kan & Wang, 2021). Therefore, it needs to be accessible to them. However, according to the participants in our study, the implementation of the right to assistive technology takes too long, and the technology funded and provided by public health insurance is of low quality and does not last long (e.g. “The evaluation just takes too long, at least a year, and it has not been changed for years”). The price of assistive technology is very high (e.g. “The price of the products is just too high and the quality is not good if we do not have technology... it's like a requirement to be independent”). Assistive technologies with better performance are too expensive, so many PwD cannot afford them. Therefore, many authors now recognise the importance of developing and providing affordable and effective assistive technologies (Khasnabis, Mirza & Maclachlan, 2015).

*Accessibility of public spaces, facilities, and services* needs to be improved, especially in the Dalmatia region around the city of Split. There are some differences between Zagreb and Split in terms of accessibility of public transport and public buildings where services are located, especially in the health and social sectors (e.g. “We can say that here in Zagreb we



are lucky, we have a lot of public transport, e.g. trams that are accessible, and platforms in buses... but in other cities the problem is much bigger", "The social centre has stairs, and the service is on the fourth floor."). While there are standards for the construction of new buildings or the renovation of old ones, these are rarely put into practice, and there are no penalties for not implementing adaptations and accessibility. For example, "platforms in front of the entrance are often not accessible because they are too steep, so they cannot be used and have no function", "there are no penalties for ineffective adaptations, the people who make them are not competent, it's all about form..."). Another major problem is that even when conditions for accessibility are met, such as elevators or platforms, they may be inaccessible or "locked" for safety reasons (e.g. "At the health centre there is an elevator that is locked and no one knows where the key is, or you have to call 911 and go there, call someone and wait two hours for it to be unlocked.", "But I also understand the other side, do not get me wrong, people are cattle and would tear it up in two hours."). Accessibility of public space is a necessity for all people, so universal design principles must be applied. To achieve this, people with different perspectives and needs must be consulted to find the best possible solutions for all (Barnes, 2011; Church & Marston, 2003; Lid, 2014). There is also a human factors issue when it comes to ensuring public transportation, as public transportation employees do not know enough about how to ensure accessibility and what is required (e.g. "I have turned to the experts in this field and asked if drivers are required to open the ramp if there is a disabled person at the bus stop... There are still buses in Rijeka that are not accessible or have not been adapted, ... and the answer is that the driver is not obliged to do so... so it all depends on good will.", "... and they very often do not follow the rules"). Wilson (2003) also recognises several barriers to using public transportation in her report, including "staff attitudes," as PwD feel that transportation staff are not sufficiently aware of their needs. Participants recognized the need for adaptation and accessibility of sports facilities and content, as it is very important for their quality of life as a leisure activity (e.g. "I am the only one who participates in mountain climbing as a blind person and has the support of sighted people..."; "Yes, you said that this should be normal, but it is not..."; "I have never seen or heard that any club organizes something specifically for PwD..." "If there are sports facilities for PwD, you still have to pay for transportation and assistance..."; "...the sports club exists for 10-11 years, they still haven't adapted the entrance for wheelchair users."). This was especially emphasised in the Split, Zagreb and Rijeka regions. It is a common opinion that PwD are less likely to participate in recreational activities. However, according to Devine (2013), just as the respondents of this study expect sporting activities to be, the "right fit", i.e. they must meet their personal needs, be adapted to their needs in order to be accessible, and correspond to their leisure interests. Accessibility of cultural and public life content needs to be improved, as PwD need sign language interpreters and also text recordings, e.g. in cinemas or theaters (e.g. "Deaf people still

*have no adaptation in the theater. We have to beg for every performance... Deaf people do not have a chance to attend a comedy or theater if there is no interpreter... we need subtitles and sign language.*“). Attending cultural events is not a necessity for anyone, but it enhances the quality of life. According to various authors, several factors are important for access to cultural events, theaters, cinemas, museums, etc. Person has to have the information beforehand, venues must have accessible environments and guidelines, and staff must be aware of the different needs of PwD. People who are blind must have access to audio description during the performance, and people who are deaf must have sign language interpreter. As Richardson and Thompson (2018) write, “Signing gives access” (Blok & Westerlaken, 2022; Cavallo, 2015; Richardson and Thompson, 2018). It is a major annoyance that PwD are not included in the design of adaptations and implementation of accessibility based on their wishes and experiences (e.g. *“No one asks you about quality and accessibility,” “Yes, there is no such thing, they do not ask us,” “With some political intent, we are present in the media, but not otherwise... “It’s a state level issue, you are not really involved in anything...”, “I think it’s definitely important on a societal level and especially on a national level to encourage PwD to advocate for themselves.”*).

*PwD do not have the opportunity to actively participate in planning activities for the individual plan or in the evaluation of services or professionals (e.g. “You did not ask for an evaluation,” “You do not ask us...”, “Nobody asks you about the quality...”, “There is no such thing in general. They do not ask anyone that...”, “...that’s the absurdity of it. We revolve around this issue all the time. How are services supposed to be appropriate and of high quality if the user is not asked what they need?”*). Nor do they have any way to influence the decisions that affect them. Many countries are now developing programs to empower PwD to advocate for their rights as they should (e.g. *“PwD should be better informed about their rights and advocate for them, to learn more about them”, “We are invisible people because no one can see us...we need to show ourselves in public as often as possible”, “...and I think that the political participation of PwD themselves is very important, they should be encouraged to advocate for themselves.”*). Empowerment programs for PwD should be implemented at an early age to empower the person to make decisions (Algozzine et al., 2001; Cmar & Markoski, 2019; Wehmeyer et al., 2000)

## Conclusion

Independent living is a philosophy based on the basic human right of PwD to participate in the life of the community and to have the possibility to choose where and with whom they want to live, to have access to a range of support services, and to receive community services that address their needs. The results of our study, based on the statements of persons with

exercise their basic human rights. Persons with disabilities cannot choose their place of residence because they cannot afford it; they do not have a range of support services because there is no continuous funding; and the community does not address their needs because they cannot even approach to public institutions due to inaccessibility. This study identifies numerous obstacles to the realisation of the rights and basic principles of independent living: unemployment due to inadequate education for occupations that do not exist in the open labour market and due to the emphasis on the person's incapacity; inadequate and/or non-continuous financial support for non-governmental institutions that have a hard time providing the support and personal assistance services they need; an overprotective attitude towards PwD; non-supportive and discriminatory attitudes of social welfare staff; barriers to accessing public spaces, facilities, services and even public transportation; inflexibility of regulations and the system that should be supportive; unavailability of assistive technology and other technical solutions due to high costs and slow delivery procedures. Moreover, the voices of persons with disabilities are almost never heard, and they have no influence on the necessary changes. For all these reasons, they call for a serious rethinking of the existing system and for improving public policies through the mandatory inclusion of persons with disabilities in decision-making processes.

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Franja Želimorski, UNIZG, Faculty of Education and Rehabilitation Sciences  
franjca.zelimorski@gmail.com

Ksenija Butorac, University of Applied Sciences in Criminal investigation and Public Security  
ksenija.butorac@gmail.com

## Dose' of intervention: How much is enough?

### SUMMARY

'Problem drug use' is defined by the European Monitoring Centre for Drugs and Drug Addiction (EMCDDA, 2012) as 'injecting drug use or long duration or regular use of opioids, cocaine, and/or amphetamines'. This definition specifically includes regular or long-term use of prescribed opioids such as methadone, but does not include their rare or irregular use, nor the use of ecstasy or cannabis. Drug-using lifestyle is associated with significant collateral damage, including high rates of premature death, as well as physical and mental health problems, criminal records, unemployment, poor housing opportunities, and damaged relationships for survivors. In response to the complexity of the problem, drug addiction treatment often requires parallel or successive application of different therapeutic activities/procedures, both medical and psychotherapeutical, sometimes over a long period of time. International studies have reported that drug treatment, covering different types of drug problems, using different treatment interventions, and in different treatment settings, can positively impacts the levels of drug use and overdose risk. There is a lack of evidence on what intensity or dose of psychosocial interventions is required by different groups of drug users, as well as by whom and at what stage of the recovery process they should be administered. Therefore, it is clear that further research is required in this area. However, the main concern remains on the emerging evidence of delivering poor 'doses' of psychosocial interventions. Consequently, the aim of this study was to fill the knowledge gap by conducting a systematic review of interventions in order to improve the process of a radical shift in a lifestyle that includes drug use.

**Key words:** *problem drug use, drug addiction treatment, medical and psychosocial interventions, recovery process*

### Introduction

Opioid dependence is a problem that exacts a significant toll on public health and generates criminal, health and economic costs quantifiable in the billions (Reimer, Wright, Somaini,

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Roncero, Maremmani, McKeganey, Littlewood, Krajci, Alho, and D'Agnone, 2015). Insight into the problems associated with addiction is beyond necessary, but often difficult to achieve. The addict must realize that they have a problem with taking the substances. Strong denial, minimizing the problem or rationalizations need to be overcome in order to achieve the patients' cooperation in treatment programs. It is often necessary to cooperate with family members, friends, employers and others, in order to overcome pathological defense mechanisms. The addict often needs to be confronted with the possible loss of career, family and health (Buljan, Bundalo-Vrbanac and Gelo, 2013).

Pharmacological approaches are the primary treatment option for opioid misuse, with psychosocial interventions providing an important element of the overall treatment package (National Institute for Health and Clinical Excellence, 2007). Methadone and buprenorphine, two opioid substitution pharmacotherapies, are WHO essential medicines. Opioid substitution treatment (OST) medications such as methadone and buprenorphine are controlled drugs for medical (and scientific uses) and can be obtained only by doctor's prescription. Opioid substitution therapy with methadone or buprenorphine greatly improves survival of individuals with opioid dependency who are in treatment by reducing mortality risk, especially for mortality due to fatal opioid-related overdose (Kimber, 2015). Depending on the country, specialized doctors (e.g. psychiatrists or accredited medical doctors) or non-specialized doctors (e.g. general practitioners) can prescribe these medications (European Monitoring Centre for Drugs and Drug Addiction (EMCDDA), 2019).

Psychotherapy is the method of choice for addiction treatment. There are a number of psychotherapeutic methods for treating addiction to psychoactive substances, the most used are brief interventions, motivational therapy, cognitive-behavioral therapy, behavioral therapy (including contingency management and psychosocial approach), relapse prevention and the 12-step program. It is more successful when it focuses on the reasons for taking addictive drugs, rather than on vague psychodynamic issues. Individual, marital, family, group psychotherapy and the psychotherapy community are just some of the procedures which are used in the treatment of addiction diseases (Buljan et al, 2013).

## **Opioid Substitution Treatment (OST)**

At the start of opioid substitution treatment, initial treatment goals are generally aimed at enabling clients to control opioid withdrawal symptoms and cravings, addressing any medical or psychosocial crisis faced by clients, and establishing a rapport with clients and educating them about the treatment process (Reimer et al, 2015). After the initial stage, goals generally focus on maintaining clients on adequate doses of OST medication, addressing other substance use by the client, if any, and preventing clients from shifting to use of an-



other substance; motivating clients and referring them to other services, including HIV and hepatitis C virus diagnosis and treatment; helping clients in regaining occupational, financial and familial stability; retaining clients in treatment and helping them to adhere to the treatment regime; and helping clients to prevent relapse to opioid use (Reimer et al, 2015). In the treatment of addiction, pharmacotherapy also aims to prevent and reduce intoxication symptoms of abstinence crisis, reduce the craving for an addictive substance or even cause an aversion to it (Buljan et al, 2013). It is estimated that nearly half of the 1.3 million problem drug users in the European Union are receiving this treatment, a considerably higher rate than in most other world regions (EMCDDA, 2019).

However, there is no specified duration for clients to be maintained on OST, it may last for months or years. The end point is generally reached when the client achieves the treatment goals decided mutually by the client and the service provider during the initiation of OST. The treatment goals are not limited to the client stopping drug use; they also include successful reintegration of clients into their family, society and work (EMCDDA, 2021). The achievement of these outcomes depends greatly on the motivation and circumstances of each individual and on the quality and effectiveness of the treatment delivered, as well as on the wider treatment, health and social services supporting the recovery of the client in OST. It is important to acknowledge that pharmacological treatment by itself will not enable an individual to achieve a full range of outcomes (Advisory Council on the Misuse of Drugs (ACMD), 2015)

### **Illicit Drug Use - Diversion and Misuse**

Due to the agonist nature of OST medication, it can be diverted or misused for recreational, self-medication or other purposes. Diversion is defined as the intentional transfer of a controlled drug from legitimate distribution and dispensing into illegal channels, while misuse is defined as the use of a medication other than as directed or as indicated, whether willful or unintentional, and whether it results in harm or not (Reimer et al, 2015). Although abstinence may be one of the long-term goals of treatment, it is not always achieved. The wide use of substitution treatment is supported by scientific evidence accumulated over recent decades regarding the benefits of this treatment in treating drug dependence and in ameliorating its associated health and social consequences. In spite of these clear benefits, recent years have seen increasing debate about the worrying levels of diversion and misuse of substitution treatment medications in Europe, which appear to be playing an increasing role in the European drug problem (EMCDDA, 2021). A rise in overdose deaths associated with methadone and buprenorphine, although not necessarily diverted, has also been observed in recent years in Europe (EMCDDA, 2019). These deaths currently represent a substantial proportion of overdose deaths in some European countries. In the USA, with over 70,000 opioid-related deaths in 2020 and evidence of increasing overdoses involving a synthetic opioid fentanyl

amidst the COVID-19 pandemic (Wen & Sadeghi, 2020; Ahmad, Rossen, & Sutton, 2021), the opioid epidemic remains a critically important and dynamic public health issue. Currently there is a fourth wave of the opioid epidemic which involves a shift toward poly-substance use and a surge in stimulant-involved (cocaine and methamphetamine) in fatal overdoses, exceeding those from prescription opioids (Seth, Scholl, Rudd, & Bacon, 2018; Kariisa, Scholl, Wilson, Seth, & Hoots, 2019). The opioid epidemic has taken a huge toll both in terms of morbidity and mortality in the US, with evidence that the opioid epidemic may only be continuing to evolve and worsen across the country (Mukherjee & El-Bassel, 2020; Silva & Kelly, 2020).

Diversion of OST medicines has been associated with increases in crime, has had a negative impact on prescribers' practice, has threatened the reputation of treatment services and has compromised public acceptance of the long-term treatment of opioid-dependent individuals (Alho et al., 2015; Wright et al., 2016; Reimer et al., 2016). While it is clear from individual sources of evidence that the impact of misuse and diversion of OST includes a broad range of negative outcomes for the individual and for society, there is no clear definition in quantitative terms to support a significant change in treatment delivery and opioid dependence care (Reimer et al., 2015). The scale of diversion and misuse of OST medications becomes particularly worrying when it reaches levels at which prescription OST medications become the drug of choice among the majority of high-risk opioid users in a country (EMCDDA, 2021). However, the demand for specialized treatment related to the misuse of OST medications and the number of deaths associated with these medications have been increasing over the past decade. This growing problem requires close monitoring and adequate interventions. For this reason, it is important to describe and understand the national contexts, groups and drivers behind these observed increases (EMCDDA, 2021). First, it is important to clarify the terminology pertinent to such analysis and to draw a distinction between prescription opioids and prescribed opioids. Prescribed opioid medications, such as methadone and buprenorphine, are prescribed by a physician to a patient and dispensed by a pharmacy. Prescription (or prescribable) opioids refer to opioid medications that are intended to be prescribed as medicines and that can be diverted anywhere in the system without necessarily being prescribed (Scholten, 2017). For example, it is estimated that about 75 % of fatal overdoses from prescription opioids in the United States (primarily opioids used for pain relief) occur in people who have not been prescribed opioids during the 3 months preceding their deaths (Scholten and Henningfield, 2016). The majority of these people probably obtained these prescription opioids on the illicit market. Thus, the diversion of prescription opioid medications, such as buprenorphine and methadone, refers to the act of redirecting these medications from legitimate sources to illegitimate or illegal ones (EMCDDA, 2021). Friends and relatives are the most common and predominant source for high-risk opioid users to obtain these medications in an illegitimate manner (EMCDDA, 2021). These are generally gifted rather than traded

or sold. High-risk opioid users regularly socialize with other users in OST programs with ready access to medications (a legitimate medical source). Within these communities, informal medication sharing occurs and is often driven by altruistic motives or the desire to help another who may be experiencing the effects of withdrawal or have no access to treatment. The exchange of OST medications for money (and other medications or illicit drugs) may also take place between high-risk opioid users. Diversion, in this case, occurs when friends and relatives who have access to legitimate OST medications divert their own medications (EMCDDA, 2021). Drug dealers are also a common source for obtaining OST medications, which are most often part of a wider range of products on offer to potential consumers (pharmaceuticals and illicit drugs) (Rigg et al., 2012; Vuolo et al., 2014). Little is yet known about where drug dealers are obtaining their supplies of OST medications. Investigations have revealed that organized crime groups in Finland are operating through large-scale cross-border trafficking of buprenorphine medications, which supplies the national illicit market. Legitimate medical sourcing is also a relatively common channel for end users to obtain prescription OST medications for non-medical use. Medications are obtained legitimately by the end user (e.g. in the context of a treatment program), but partial or excess supplies of medications are not used according to clinical guidance (e.g. injected) or are stockpiled for later use (EMCDDA, 2021). Studies have also shown the occurrence of diversion of supervised OST doses such as methadone, whereby clients have removed all or part of their dose at the time of administration (Larance et al., 2011). This is commonly done for the purpose of saving medications for later personal use (Larance et al., 2011), but it has also been documented that others may coerce treatment clients to share or sell their doses (Green et al., 2013; Allen and Harocopos, 2016; AMCD, 2015). For example, individuals with legitimate access to treatment in France sell their doctor prescriptions to individuals called 'collectors'. They also use stolen health insurance cards to collect buprenorphine prescriptions. These collectors collect up to 10 prescriptions a day, which can amount to over 1000 buprenorphine tablets daily (112 tablets per prescription). Strips of seven tablets are then being sold for 10 EUR each to wholesalers who then sell them to smugglers for 15 EUR each. These smugglers then resell them to dealers at the retail level for 35 EUR per seven tablets. The final price in the capital region around Helsinki is between 30 and 50 EUR per tablet. In December 2017, a Europol-supported operation dismantled a trafficking ring that had smuggled high-dose buprenorphine tablets (Subutex) from France to Finland in significant quantities (EMCDDA, 2019). Economic motives are also reported to play a role in the non-prescribed use of diverted methadone or buprenorphine, when these are available at lower prices than heroin on the illicit market (Schmidt et al., 2013; AMCD, 2015) or when they are used as a replacement for heroin during heroin shortages, namely when heroin prices are high or when it is difficult to access a supplier (Rettig and Yarmolinsky, 1995; AMCD, 2015). In this context, the reason for the misuse of OST medications

may be to avoid withdrawal symptoms induced by the absence of heroin or potentially for euphoric purposes. The main difficulty for patients who use non-prescribed OST medications is that it is not possible for doctors to accurately predict equivalent therapeutic doses in most cases at the start of the treatment (EMCDDA, 2021). This is especially true for street methadone or buprenorphine, as the purity is variable, or when past dosages are unknown. It is also problematic to convert the dosage from one medication to another when the half-lives are not equivalent (e.g. between methadone and buprenorphine). Clinicians must therefore apply careful clinical judgement and monitor the progress of treatment carefully, especially during the early stages of treatment. The initial OST dose should aim to achieve an effective level of comfort, both physical and psychological, while minimizing the likelihood of overdose (EMCDDA, 2021). Evidence shows that supervised consumption of methadone or buprenorphine can ensure that patients take the dose prescribed. This reduces diversion and can prevent overdose (Strang, Hall, Hickman and Bird, 2010; ACMD, 2015).

### **Evidence Based Psychosocial Interventions in Drug Treatment**

There has been a breakthrough in the development of evidence-based psychosocial treatments for problem drug users in recent years. Overall psychosocial interventions have proven to be effective. Some interventions such as cognitive behavioral therapy, motivational interviewing and relapse prevention appear to be effective for many problem drug users (Jhanjee, 2014). Likewise, psychological treatment is more effective when prescribed together with substitution therapy than when pharmacological therapy or psychological treatment alone is used, especially in opiate users. Psychosocial interventions can be used in a variety of treatment settings either as stand-alone treatments or in combination with pharmacological interventions. They can be carried out individually or in groups, and are carried out by a number of health professionals. Psychological treatments can be short or intensive and specialized. They are considered the basis of drug and alcohol addiction treatment, especially for substances for which pharmacological treatments alone are not sufficient. The main criterion for effectiveness is that psychological therapy leads to reductions in substance use or abstinence and improvements in a wide range of areas of functioning, including physical and mental health, hepatitis, interpersonal relationships, employment, and criminal behavior (Jhanjee, 2014). Psychosocial interventions should be aimed at understanding the special situations in which the patient takes an addictive substance, finding alternative ways of managing these situations, changing inadequate behavior and improving interpersonal communication. The goal of these interventions is to encourage abstinence, teach patients new skills to cope with stress, strengthen motivation to resist addiction and improve quality of life (Buljan et al., 2013). However, the main question, relevant to doctors and policy makers as well as patients, is how much therapy is enough (to ultimately achieve permanent abstinence).

## Motivational Interviewing

Motivational interviewing is one of psychosocial techniques that helps people explore and resolve their ambivalence about substance use and begin to make positive behavioral as well as psychological changes. Principles of motivational interviewing include expressing empathy through reflective listening, developing discrepancies between patients' goals or values and their current behaviors, avoiding arguments and direct confrontation, accommodating client resistance, and supporting self- efficiency and optimism (Jhanjee, 2014). Cochrane (2011) also concludes that MI can reduce the extent of drug abuse compared to that which exists without interventions.

Motivational interviewing is also considered most effective when combined with other standard psychosocial interventions (Rohsenow, Monti, Rubonis, Gulliver Colby, Binkoff & Abrams, 2001). Therefore, Motivational Interviewing can be offered both as an independent treatment and in combination with pharmacological treatment.

## Cognitive-Behavioral Interventions

Cognitive-behavioral interventions include a range of approaches based on learning principles with a theoretical approach on behavior that is influenced by cognitive processes (Epp & Dobson, 2010). Standard cognitive behavioral treatment (CBT) is a time-limited, structured psychological intervention, derived from the cognitive model of drug abuse (Wright, Beck, Newman & Liese, 1993). Emphasis is on identifying and modifying irrational thoughts, managing negative mood, and post-abuse interventions to prevent full relapse. Typical cognitive strategies used are recognizing and challenging dysfunctional thoughts and recognizing seemingly unimportant decisions that lead to relapse. Common behavioral strategies used are coping with substance craving, fear exposure, promoting non-drug activities, relaxation training, emergency preparedness, and coping with relapse. Other elements of CBT include social skills training (effective communication, refusal skills) and problem-solving skills. CBT is often rated as the most effective treatment approach in drug and alcohol populations (Weisner, Matzger, & Kaskutas, 2003), and is well received by clients (Ellis & Smith, 2002).

Evidence for the effectiveness of CBT exists for a range of substances including alcohol, cannabis, amphetamines, cocaine, heroin and intravenous drug use. Magill and Ray (2009) conducted a meta-analysis of 53 studies examining the effectiveness of cognitive-behavioral treatment in adults with alcohol or drug dependence disorders. They found a small but statistically significant effect compared to conditions when CBT was not administered. 58% of people in CBT achieved a greater positive shift than those who were not in treatment. Regarding other treatments in combination with CBT, the best result was manifested in combination with some other psychosocial treatment, in relation to the combination with pharmacological treatment or carried out separately.

Furthermore, through a meta-analysis of studies on the effectiveness of CBT on the population of adolescents addicted to psychoactive drugs, Barrett Waldron and Kaminer (2004) concluded that this type of therapy significantly affects the reduction of drug use and related problems. CBT has also been shown to reduce illicit drug use among substitution therapy users, as well as other behaviors that lead to the risk of relapse (Teesson, Hall, Lynskey, & Degenhardt, 2000). Therefore, the cognitive-behavioral treatment of addiction to psychoactive substances has numerous advantages because it provides the user with knowledge and means that can help him overcome the craving for drugs and is an important means of intervention and occupies an important place in the psychosocial treatment of substance addiction disorders.

### Relapse Prevention

Relapse prevention is an approach that focuses on learning to recognize triggers for taking drugs and learning alternative behaviors in response to those triggers. This approach was originally designed as a maintenance program after treatment for addiction-related disorders; although it is also used as a stand-alone treatment program. An individual or group relapse prevention program should include identifying high-risk situations and triggers for craving, developing skills to manage cravings and other painful emotions without using substances, learning to cope with problems, and achieving lifestyle balance (Wanigaratne, Davis, Pryce, & Brotchie, 2005). It also includes techniques such as questioning the user's expectations about the positive effects of the drug, and psychoeducation whose goal is to make the user more informed when choosing their own behavior in challenging or problematic situations (Vindiš, 2019). A meta-analysis of 26 studies examining the effectiveness of this approach found that relapse prevention did reduce drug abuse, but not significantly (Irwin, Bowers, Dunn, & Wang, 1999). On the other hand, it has been shown to have a significant effect on the improvement of general psychosocial functioning. Relapse prevention is an effective psychosocial treatment, and can be improved by adding pharmacological therapy. There is evidence that abstinence rates can be improved when psychosocial treatments such as Relapse Prevention and Cognitive Behavioral Therapy are combined with acamprosate (Feeney, Young, Connor, Tucker & McPherson, 2002). This intervention is based on the theory of operant learning and includes the awarding of concrete rewards as positive reinforcement for meeting treatment goals (Vindiš, 2019). Such a treatment approach is aimed at encouraging positive behavior by providing positive reinforcement when the patient is making progress toward treatment goals (e.g., no drug use) or by withholding positive reinforcement or providing punishment when the patient engages in undesirable behavior (e.g., continued drug use, urine positive for substances). In the field of addiction treatment, vouchers that can be exchanged for goods or services are often offered as a reward if a negative drug test in the urine is shown. When someone enters the program, they have to submit a urine sample



every week, and if it is negative, they get positive reinforcement in the form of a reward. What is important in its implementation is that the size, i.e., the value of reinforcement, must grow in proportion to the length of abstinence (Petry, 2010). There is strong evidence that CM is an effective strategy in the treatment of drug abuse, especially opioid, tobacco and polydrug use. A large amount of empirical evidence points to the effectiveness of reward and punishment systems (Petry, 2010). A meta-analysis by Griffith, Rowan-Szal, Roark, and Simpson (1999) examined its effectiveness based on 30 studies of outpatient methadone addiction treatment and its effects. Interventions based on a system of reward and punishment have been shown to be effective in reducing positive findings of illegal drugs in urine. The effect is small to moderate, but still significantly large for clinical and practical applications.

### **Contingency Management (CM)**

This intervention is based on the theory of operant learning and includes the awarding of concrete rewards as positive reinforcement for meeting treatment goals (Vindiš, 2019). Such a treatment approach is aimed at encouraging positive behavior by providing positive reinforcement when the patient is making progress toward treatment goals (e.g., no drug use) or by withholding positive reinforcement or providing punishment when the patient engages in undesirable behavior (e.g., continued drug use, urine positive for substances). In the field of addiction treatment, vouchers that can be exchanged for goods or services are often offered as a reward if a negative drug test in the urine is shown. When someone enters the program, they have to submit a urine sample every week, and if it is negative, they get positive reinforcement in the form of a reward. What is important in its implementation is that the size, i.e., the value of reinforcement, must grow in proportion to the length of abstinence (Petry, 2010). There is strong evidence that CM is an effective strategy in the treatment of drug abuse, especially opioid, tobacco and polydrug use. A large amount of empirical evidence points to the effectiveness of reward and punishment systems (Petry, 2010). A meta-analysis by Griffith, Rowan-Szal, Roark, and Simpson (1999) examined its effectiveness based on 30 studies of outpatient methadone addiction treatment and its effects. Interventions based on a system of reward and punishment have been shown to be effective in reducing positive findings of illegal drugs in urine. The effect is small to moderate, but still significantly large for clinical and practical applications.

### **Twelve Steps Program for Addiction Recovery**

This approach views addiction as a relapsing disease with complete abstinence as the sole goal of treatment and is based on behavioral, spiritual and cognitive principles. As part of the process toward recovery, individuals must acknowledge to themselves (and other people) the harm that substance use has caused to themselves and others, acknowledge that they are powerless over drug use, and surrender to a higher power for recovery (Jhanjee, 2014).

The three basic ideas that permeate the 12 steps are as follows (NIDA, 2018):

- 1) Acceptance i.e., understanding that addiction is a chronic and progressive disease that the patient cannot control; that life has become unbearable due to taking a psychoactive substance; that the willpower is insufficient to solve the problem; that abstinence is the only alternative;
- 2) Surrendering oneself to a higher power, accepting the leadership and support of other group participants and following the activities necessary for recovery;
- 3) Active participation in 12-step meetings and related activities.

Despite its many limitations, the 12-step program appears to be extremely successful in maintaining abstinence from both alcohol and drugs for participants who remain in such treatment long-term. Reviewing the works of Donovan et al. (2013) found that the program mostly has positive outcomes in maintaining abstinence, sometimes truly long-term - up to 16 years. Furthermore, it improves general psychosocial functioning and perceived self-efficacy. As the most valuable finding, the authors state that it has been shown that positive outcomes are indeed related to participation in the program, because indirect effects such as “good prospects” for recovery, the participants themselves, the amount of motivation, the existence of comorbid psychopathology or the severity of problems related to addiction are excluded. Regardless of its limitations and specifics, the 12-step program is one of the most widespread approaches in the treatment of addiction even after almost 90 years since its introduction. This is certainly supported by numerous evaluation studies that confirm its long-term effectiveness or sustainability. Another important advantage is the fact that it is free, which initially opens the door to a wide population of users. For this reason, regardless of its unconventional methods and the limited possibility of adapting the program to the individual, this approach is an extremely important link in the addiction treatment chain.

### **MATRIX Model**

The matrix model of outpatient addiction treatment was developed in the 80s of the 20th century, after a rapid increase in the abuse of psychostimulants, especially cocaine, and an increase in the demand for adequate treatment of addiction to psychostimulant drugs (Rawson et al., 1995). Scientists from the Matrix Center, after which the model was later named, developed a set of techniques that they called the neurobehavioral model from the beginning. The premise of this approach was to create a model that would directly respond to the needs of the target group, cocaine addicts, while at the same time creating a structured protocol according to which the evaluation could be carried out. A pilot study of this model showed early potential. A significant effect was found to reduce cocaine use after 8 months of program participation (Rawson et al., 1995). The authors later conducted a series of research projects to evaluate the Matrix model in different versions, with different populations and



measurement methods. This model has been shown to be associated with a statistically and clinically significant effect on reducing cocaine intake. Moreover, all conducted studies have shown these results. Also, the psychosocial functioning of the users recorded a significant improvement. Shoptaw, Rawson, McCann, and Obert (2008) conducted a study of the effectiveness of this treatment on psychostimulant users after 6 months of involvement. Previous findings on the effectiveness of the program to reduce drug use were confirmed, the level of which is equivalent to the amount of involvement in the program, that is, the number of program activities in which the user participates. An important discovery was also the knowledge that efficiency increases in parallel with adapting and responding to changes in the user population. This research also showed that methamphetamine addicts participate in individual meetings longer and have better abstinence results, but considering their relatively limited number and different reasons for primary involvement in the program, the authors state that this finding should not be considered relevant.

### **New Approaches - Immunotherapy**

In addition to established, widespread psychoactive drug addiction treatments, there are many others that are still in the process of being developed, tested, and implemented. One of such treatments is immunotherapy. For a long time, vaccines have been one of the basic tools in preventive medicine for the purpose of suppressing disease, but their use in the field of treatment of addiction to psychoactive substances (which has only relatively recently been accepted as a medical disorder or disease) has only recently been discussed. Vaccines work by stimulating an immune response to an ingested (weakened) microorganism or some other substance that represents a disease. After a certain period of time, a sufficient number of antibodies are created which subsequently block or reduce the effects of the ingested organism or other substance and thus prevent the development of the disease. Such vaccines are called prophylactic. Immunotherapy for drug addiction, on the other hand, is being developed primarily as a therapeutic vaccine. Unlike the classic ones, it is applied to people who have already developed the disease. However, it is assumed that prophylactic drug addiction prevention will be available in the future (Kosten & Owens, 2005).

### **Discussion and Conclusion**

Of all existing approaches, the simplest form of treatment is pharmacological substitution therapy, which is mainly used in opiate addiction. The premise is to replace the harmful substance to which a person is addicted with another, which does not have so many negative consequences, and in this way reduce the addiction syndrome. However, in practice the situation is often quite different. The biggest drawback is that this therapy actually replaces one type of addiction with another (also opioid), so the person still has a similar problem, only

with fewer direct negative effects on psychophysical health. When the user, in addition to pharmacological therapy, is also involved in some other form of psychosocial treatment, the possibilities for recovery from addiction increase, along with an improvement in general psychosocial functioning (Vindiš, 2019). Much evidence is available on the effectiveness of psychosocial interventions in drug addiction disorders. For substance-abusing clients, any form of psychological treatment leads to better treatment outcomes, but there is no general consensus that one form of psychological treatment is better than another. Some interventions, such as cognitive-behavioral therapy, motivational interviewing, and relapse prevention, appear to be effective for many drug users. Psychological interventions are an essential part of treatment regimens, and efforts should be made to integrate evidence-based interventions into all substance abuse treatment programs (Jhanjee, 2014).

McLellan et al (1993) compared methadone alone with no other services with the methadone service, i.e. methadone plus, and enhanced methadone services with psychosocial interventions, on-site medical/psychiatric access, family therapy and employment help. Outcomes including the cessation of heroin use and less use of emergency rooms were greater with more psychosocial input (McLellan, Arndt, Metzger, Woody and O'Brien, 1993; ACMD, 2015). A follow-up study on cost-effectiveness showed that the intermediate service with psychosocial interventions was the most cost-effective (Kraft, Rothbard, Hadley, McLellan and Asch, 1997; ACMD, 2015). There is also some evidence from qualitative studies on the benefit of psychosocial support in OST. The Dutch study by de Maeyer et al (2011) says: "A number of participants mentioned methadone's limited impact on achieving a meaningful life, stating that they experienced methadone purely as a substitute for their heroin use." They cited the importance of psychosocial counselling, alongside their pharmacological methadone treatment, to support them in achieving a meaningful life (De Maeyer, Vanderplasschen, Camfield, Vanheule, Sabbe, and Broekaert, 2011; ACMD, 2015). Pierce et al. (2015) state that psychosocial treatment is best provided as an additional, not an alternative, component of the treatment response. A large evidence base exists for the health and cost benefits of OST, especially when it is combined with psychosocial and other interventions. These benefits include reductions in the risk of HIV and other blood-borne infections (in particular when combined with needle and syringe exchange interventions), risky sexual behaviours, the risk of overdose, participation in criminal activity and illicit drug use. The evidence also indicates that OST is associated with increased levels of retention in treatment and social reintegration (Mattick et al., 2004; Amato et al., 2005, 2011; Gowing et al., 2008, 2011; Lawrinson et al., 2008; ECDC and EMCDDA, 2011; Havnes et al., 2012; MacArthur et al., 2012). Understanding the impact of OST misuse and diversion is key to defining strategies to address these issues (Reimer et al, 2015). All countries have a dual obligation with regard to these medicines based on legal, political, public health and moral grounds. The dual obligation is to ensure that essential medicines

such as methadone and buprenorphine are safely accessible and available for medical purposes while protecting populations against the harms derived from the abuse and misuse of, and dependence on, these medicines (WHO, 2011; EMCDDA, 2021). All things considered, effective interventions for opioid dependence are available. The best treatment outcomes are achieved when a comprehensive multidisciplinary approach such as opioid substitution treatment (OST) is offered, including opioid-substitution medicines and integrated health and social care interventions to respond to individual patient needs (WHO, 2008; Reimer et al, 2015). However, it is necessary to carry out a larger number research to further examine the ways in which psychosocial interventions can be applied together with pharmacotherapy in order to optimize results for both methods of treatment. Providing incentives for abstinence, longer stay in treatment, regular intake of therapy as well as dealing with the side effects of medications, are just a few from the potential applications of psychosocial therapies..

The evidence base for psychological treatment needs to be expanded and should also include research on optimal combinations of psychological therapies and any particular matching effects, if any. There is a need for research on psychosocial interventions in special populations such as adolescents, polydrug abusers and in people with psychiatric comorbidity. More research is needed on the intensity and duration of these interventions for people with more severe addiction problems.

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Alexander Jensen, Brigham Young University  
alexjensen@byu.edu

Jasmina Stošić, UNIZG, Faculty of Education and Rehabilitation Sciences  
jasmina.stosic@erf.unizg.hr

Ana Wagner Jakab, UNIZG, Faculty of Education and Rehabilitation Sciences  
ana.wagner.jakab@erf.unizg.hr

## Support in adulthood: Perspectives of adults on the autism spectrum, parents, and siblings

### SUMMARY

Adults on the autism spectrum (AS) face many challenges in striving for a safe and happy future (Hendricks & Wehman, 2009). The parents and siblings of adults on the AS with intellectual disabilities (ID) often play an important role in helping them achieve a happy life (Holmes et al., 2018; Orsmond & Fulford, 2018). A vast majority of the research in this area, however, is focused on populations in North America. Empirically, little is known about these processes in other regions, including Croatia. This presentation will report on data from 25 Croatians. The participants included adults on the AS with ID, their parents, and siblings. Data were collected in Autism centres in two major Croatian cities, Zagreb and Split. The data has not been analysed yet. Quantitative analysis, however, will explore differences amongst the perspectives of different family members, and different perspectives based on demographic factors (education, marital status, and so on). The findings of this study can contribute to an understanding of how family members perceive the likelihood of adults on the AS with ID having a safe and happy future in association with their perception on the availability of resources and support. This presentation will highlight connections with the scientific literature and provide implications for practitioners.

**Key words:** *autism, adults, families, parents, siblings, support, Croatia*

### Introduction

Adulthood is often marked by growth in independence and transitions into new roles (Arnett, 2007). Transitions and intrapersonal growth in adulthood are challenging for most individuals (Arnett, 2007; Reifman et al., 2007), but even more so for adults diagnosed with autism spectrum disorder (ASD; Hendricks & Wehman, 2009). In particular, many adults diagnosed with ASD struggle to obtain education, establish employment, and enter romantic relationships (Wei et al., 2015). The depth of those challenges likely varies from one individual to another, connected to characteristics of their traits and support available to them (Waizbard-Bartov et al., 2023).

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Family often plays an essential role in supporting adults on the spectrum to help them achieve their goals and ensure a happy and safe future (Burke et al., 2012; Orsmond & Seltzer, 2009). For many individuals on the spectrum, primary support comes from a parent (Burke et al., 2012). However, many parents believe that their adult child diagnosed with ASD will require ongoing support throughout their lives (Anderson et al., 2018; Huang et al., 2020). As parents age, concerns arise about who will be able to assist their child when they are no longer able to do so (Burke et al., 2012; Holmes et al., 2018; Myers et al., 2009). In many families, this involves including siblings of the adult (Orsmond & Fulford, 2018; Tozer & Atkin, 2015; Tozer et al., 2013). Thus, typically developing sibling(s) often play crucial roles in supporting adults on the spectrum (Tozer & Atkin, 2015; Tozer et al., 2013).

Providing support unsurprisingly presents both benefits and challenges for parents and siblings of adults diagnosed with ASD (Jensen & Orsmond, 2019; Orsmond & Seltzer, 2009). When family members receive support and feel supported, including the utilization of community resources, they are more likely to offer quality support. Although this pattern has not been tested in autistic samples, it has been observed in related areas of research (Meyer et al., 2022). For instance, caregivers of older adults with dementia report feeling more rested and physiologically capable of handling caregiving stress when utilizing community resources such as adult daycare services (Klein et al., 2016).

The existing literature on this topic, however, has important limitations, with a primary focus on North America in most research (e.g., Orsmond & Fulford, 2018). Cultural and structural components of support for adults with disabilities vary between countries and cultures (Allison & Strydom, 2009; Gupta et al., 2011). Therefore, it is imperative to examine the experiences of families with an adult child/sibling with AS in different countries. In the current study, we specifically focused on families in Croatia, partly because the cultural emphasis on familial obligation is much stronger than in North America.

## Objective

The current study aimed to explore the experiences of Croatian families with an adult child/sibling on the spectrum. The study sought to examine the quality of support for adults diagnosed with ASD and their families, and to quantitatively assess the confidence of family members in the adult with AS having a safe and happy future, as well as their satisfaction with autism services in their community. The following research questions were developed:

1. What is the perspective of adults diagnosed with ASD, their parents, and siblings on the informal and formal support that they receive?
2. What are their support needs?
3. How confident are family members that adults on the spectrum will have a safe and happy future?



## Method

### Participants

Participants for this study were recruited from autism centers in the two largest cities in Croatia, Zagreb and Split. Eligible participants needed to be a parent or sibling of an adult diagnosed with ASD or the adult diagnosed with ASD (18 years or older). In the fall of 2021, directors of the autism centers and NGOs informed eligible family members about the opportunity to be interviewed. Interested participants visited the autism centers and NGOs on scheduled days for the interviews. After confirming eligibility and obtaining informed consent, participants completed a brief quantitative survey. Subsequently, they were asked a series of questions in a semi-structured interview format. The interviews were recorded and later transcribed. At the conclusion of the interview, participants were offered 120HRK as a token of appreciation for their participation. Apart from one interview (where the participant requested to be interviewed in English), all interviews were conducted in Croatian. Interviewers were native Croatian speakers, and the English-language interview was conducted by a native English speaker.

In total, 25 participants were interviewed across the two cities, comprising parents, siblings, and adults with AS. Table 1 provides detailed demographic information about the participants.

Table 1 *Demographic Information of Participants by Member of the Family*

	Parent mean (standard deviation) or proportion	Sibling mean (standard deviation) or proportion	Adult diagnosed with ASD mean (standard deviation) or proportion
Number of participants	18	5	2
Age	57.56 (10.87)	29.60 (11.72)	35.5 (3.54)
Male	.24	.40	1.00
Married	.89	.00	.00
Employed	.39	.60	.00
Number of children	2.06 (.73)	.00 (.00)	.00 (.00)
Income (monthly in HRK)	10438.89 (4037.05)	11250.00 (8539.13)	.00 (.00)
City			
Zagreb	.61	.40	.00
Split	.39	.60	1.00

HRK = Croatian Kuna in 2021; ASD = Autism Spectrum Disorder

## Data Collection and Analysis

Quantitative measures in the study comprised two items. The first item was phrased as, "I am confident that my loved one with autism will have a safe and happy future" (rated on a scale of 1 = very unconfident, 2 = unconfident, 3 = neither unconfident nor confident, 4 = confident, and 5 = very confident). The second item was phrased as, "I am satisfied with the autism services in my community" (rated on a scale of 1 = very dissatisfied, 2 = dissatisfied, 3 = neither dissatisfied nor satisfied, 4 = satisfied, and 5 = very satisfied).

The semi-structured qualitative interviews were tailored to the individual being interviewed. Questions concerning support were integrated into a broader interview that explored the experiences of family members and adults diagnosed with ASD.

To assess family members' confidence in the future well-being of adults diagnosed with ASD and their satisfaction with community services, a series of independent samples t-tests were conducted using the open-source software R, version 4.2.3 (R Core Team, 2023). Furthermore, a bivariate correlation analysis was conducted to explore the relationship between confidence in a safe and happy future and perspectives on community resources.

For qualitative data analysis, a thematic analysis approach was employed, utilizing the realistic method within it. Specifically, inductive thematic analysis was applied, involving the coding of data without attempting to fit it into an existing coding framework (Braun and Clarke, 2006). The data analysis in this research unfolded through several sequential steps.

Initially, researchers familiarized themselves with the data by transcribing the audio recordings of interviews. Then, interesting features of the data were systematically coded. In the third step, the obtained codes were organized into potential subthemes and themes, and all relevant data was collated under these identified themes. After establishing the themes and subthemes, they were scrutinized to ensure their efficacy in capturing the coded features and representing the entire dataset. The fifth step involved further refinement and specification of the themes. The final step of thematic analysis encompassed a comprehensive examination and presentation of selected excerpts from the data, providing a nuanced understanding of the identified themes.

## Results

We will start by presenting the quantitative results, followed by the qualitative findings.

Results for confidence in a safe and happy future (see Figure 1) showed that parents ( $M = 3.28$ ,  $SD = 0.96$ ) and siblings ( $M = 4.00$ ,  $SD = 1.41$ ) reported similar levels of confidence in the future for adults with AS ( $t(21) = 1.35$ ,  $p = .19$ , Cohen's  $d = .56$ ). Similarly, siblings ( $M = 4.00$ ,  $SD = 1.41$ ) and adults with AS ( $M = 5.00$ ,  $SD = .00$ ) also reported similar levels of confidence ( $t(5) = 0.94$ ,  $p =$

.39, Cohen's  $d = 0.71$ ). However, parents ( $M = 3.28$ ,  $SD = 0.96$ ) and adults with AS ( $M = 5.00$ ,  $SD = .00$ ) reported different levels of confidence in the future ( $t(18) = 2.48$ ,  $p = .02$ , Cohen's  $d = 1.11$ ). Results for satisfaction with community resources (see Figure 2) showed that parents ( $M = 3.11$ ,  $SD = 1.10$ ) and siblings ( $M = 3.20$ ,  $SD = 1.08$ ) reported similar levels of satisfaction ( $t(21) = 0.16$ ,  $p = .87$ , Cohen's  $d = .07$ ). Similarly, siblings ( $M = 3.20$ ,  $SD = 1.08$ ) and adults with AS ( $M = 5.00$ ,  $SD = .00$ ) also reported comparable levels of satisfaction ( $t(5) = 2.20$ ,  $p = .08$ , Cohen's  $d = 1.66$ ). However, parents ( $M = 3.11$ ,  $SD = 1.10$ ) and adults with AS ( $M = 5.00$ ,  $SD = .00$ ) reported different levels of satisfaction ( $t(18) = 2.42$ ,  $p = .03$ , Cohen's  $d = 1.08$ ).

Figure 1 Means with the same subscript do not differ at  $p = .05$

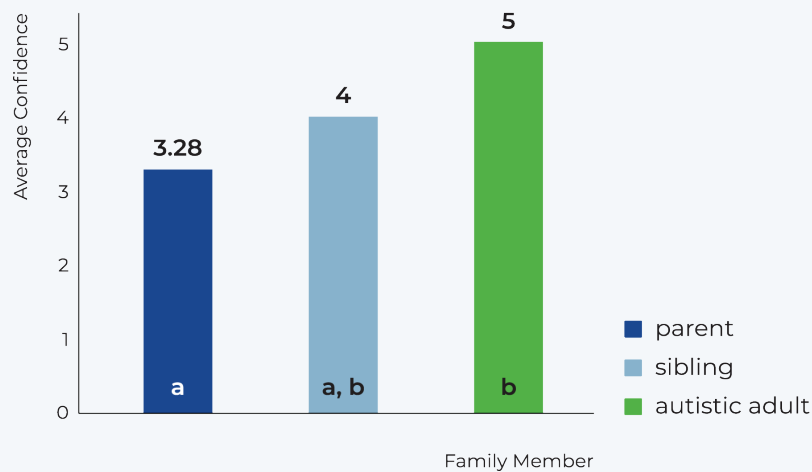
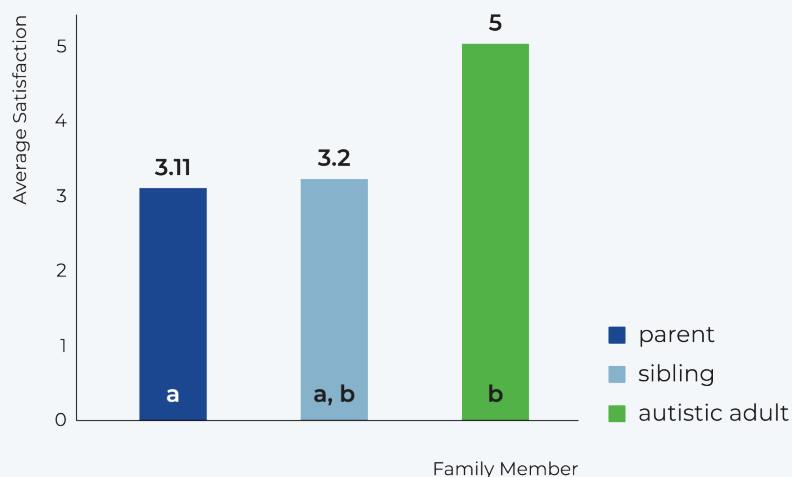


Figure 2 Means with the same subscript do not differ at  $p = .05$



The bivariate correlations indicated that individuals who reported higher satisfaction with community resources and services also reported greater confidence in a safe and happy future for adults with AS ( $r(23) = .69, p < .001$ ).

Thematic analysis has yielded three main themes and nine subthemes. The results are presented in Table 2.

Table 2 Overview of the thematic analysis of confidence in a safe and happy future and satisfaction with community resources

Main Themes	Subthemes	Codes
INFORMAL SUPPORT	Different sources of support	<ul style="list-style-type: none"> <li>• Support from grandparents</li> <li>• Emotional and practical support from partners</li> <li>• Support from brother and sister (daughters and sons)</li> <li>• Support from parents</li> <li>• Support from other parents of persons with disabilities</li> <li>• Support from friends and members of wider family</li> <li>• Finding support in activities for themselves</li> </ul>
	Unavailable and insufficient informal support	<ul style="list-style-type: none"> <li>• Unavailable support from partners</li> <li>• The lack of support from friends and family</li> <li>• Understanding for the lack of support from friends</li> </ul>

FORMAL SUPPORT	Satisfaction with formal support	<ul style="list-style-type: none"> <li>• Satisfaction with the support received in the institution where the child is enrolled</li> <li>• Great satisfaction with the services provided by the association</li> <li>• Satisfaction with the work of the ombudspersons</li> </ul>
	Unavailability and poor quality of formal support	<ul style="list-style-type: none"> <li>• Dissatisfaction with the support in the institution or NGO</li> <li>• Dissatisfaction with integration into mainstream schools</li> <li>• Dissatisfaction with the ministries and with the whole support system in Croatia</li> <li>• Unavailable services for adults</li> </ul>
	Support from professionals	<ul style="list-style-type: none"> <li>• Unmotivated professionals</li> <li>• Good and bad experiences with professionals</li> </ul>
	Advocating for better formal support	<ul style="list-style-type: none"> <li>• Fighting for support</li> <li>• Unwillingness of other parents to join and advocate for support</li> </ul>
NEEDS FOR SUPPORT	Hopes and fears for the future	<ul style="list-style-type: none"> <li>• Worrying about the support in the future</li> <li>• Hope that other children will take responsibility to support their sibling</li> </ul>
	Needs for formal support	<ul style="list-style-type: none"> <li>• Residential services</li> <li>• Day programs and services</li> <li>• Psycho-emotional personal, partner and family support for all family members</li> <li>• Support in the local community</li> </ul>
	Raising awareness in the community	<ul style="list-style-type: none"> <li>• Need for education and raising awareness in the community</li> <li>• Reducing stigma with raising awareness</li> </ul>

Within the main theme of “Informal Support,” two subthemes were identified: “Different Sources of Support” and “Unavailable and Insufficient Informal Support.” Participants highlighted various sources of informal support, including family members, friends, and other parents of children with disabilities. Grandparents were notably recognized as a valuable and

significant source of support by most participants.

When M was younger, there was tremendous support from grandma and grandpa, whether it involved caregiving, assistance, practice - anything he could or couldn't do.

From the parents' perspective, sisters and brothers played a crucial role in everyday situations with the child on the spectrum.

She (the sister) is absolutely incredible for him; she manages to calm him down in a way we can't. She is great with him.

Parents recognize the importance of sharing responsibilities as partners, emphasizing that it is wrong to place the burden solely on one parent.

Now, if the mother takes 100% of the burden, it's over. If the father takes 100% of the burden, it's over. If the mother takes around 50% and the father 50%, that's ideal then. So, it's one scale, one balance where both must be as close to 50% as possible.

Parents also emphasize the significance of being connected to other parents of children with disabilities. They feel most understood by parents who share similar experiences.

Parents help each other the most in those situations through conversations, through talking, through motivating, I don't know, just trying to relax the other parent a bit, encouraging him to calm down, trying to get him to breathe, and then trying to look at it from a different perspective. You share your life story with them, they tell you, and then you try it that way. In this way, yes, we are each other's best support.

While some parents feel very supported by partners, extended family members, and friends, there are others who feel alone in supporting their child.

My cousin's wife made that so normal, she told her three sons he is, like he is, this is him, and he is your cousin, and children accepted that and even now when they meet, all 4 of them, you can see that bond they share. They are a great support.

...but I don't have support... I don't have any support as a person in the sense that someone will also love him... that kind of support is desperately needed for me... for someone else besides me to love my son, that's because family is the first to distance themselves, and friends also disappear when there's trouble... because it's difficult, and nobody likes shouting, and no one likes aggression.

Parents have also learned to accept and show understanding for the lack of support from friends.

No... I mean, I don't blame any of these people because I believe if one of my friends had an autistic child, I would feel the same... like he does towards my child. I mean, it's not exactly like talking to a wall, but something similar, so sometimes, I'm always surprised by people when they complain that others don't understand their child, but they wouldn't understand

if someone else had such a child and they didn't, so that's it.

Experiences with "Formal Support" vary. Some parents express high satisfaction with the work of the ombudsperson for people with disabilities and with the support their child receives in institutional or NGO services.

I find this truly inspiring. For example, I... I am all for this daily program at the NGO... they learn new skills... he is there among people from his world. Someone who is like him. Somewhere where he doesn't stand out from others. And I think this... There should be more of these kinds of things.

However, most parents express the sentiment that the system has failed them and their children.

So, for us in Croatia, if something destroys families, if something destroys us, it's the system that simply prioritizes form over substance.

Support is either unavailable or of poor quality, particularly in adulthood. Most parents report on the inadequate quality of services in specialized institutions and NGOs, spanning from childhood to adulthood. Additionally, they express significant dissatisfaction with the integration of their children into mainstream schools.

This integration did more harm than good. I requested for him to be transferred to a special class because I saw that it wasn't working. Integration is like pulling a sardine out of the sea and putting it in a river and expecting that sardine to survive there. The environment is not good for these children to learn.

Parents also shared mixed experiences with professionals who worked with their child, including variations in their motivation and effort towards the well-being of the children.

So, when my son enters this mix of professionals, everything is fine if he ends up with the good, very good, and excellent ones. But if he ends up with someone who is bad, it's a catastrophe.

They are not the majority, but some just don't care. They are indifferent to the problem, indifferent to knowledge, indifferent to children...

Parents frequently found themselves in the position of persistently advocating and fighting for the necessary support for their children.

Here, you can't achieve any success, for instance, if you don't raise your voice, if you don't shout.

They often encountered officials who were completely indifferent and acted as barriers to obtaining necessary support.

And there are state officials who lack any, any, any soul, heart, or intelligence. I mean no soul,

no heart, no intelligence. So when you seek help from them, you know what that means? It's like hitting a Chinese wall you can't cross...

Within the main theme of "Need for Support," three subthemes emerged: "Hopes and Fears for the Future," "Needs for Formal Support," and "Raising Awareness in the Community." All participants expressed fears about the future, particularly concerning a time when parents will no longer be able to care for the adult on the spectrum.

Our health is already bad, our son has his family, I don't know what the future holds.

We have had nightmares for 15 years, thinking about what will happen to him when we are gone.

Furthermore, as they lack confidence in the provision of formal support, they place reliance on their other children, hoping they will support their sibling on the spectrum.

So, it's more important to me that my younger daughters feel a sense of responsibility and attachment towards her. I hope that tomorrow, if I fall ill or pass away, they will understand that it's not some sort of punishment, but simply that they are responsible for their sister.

Regarding services, they emphasized the need for the development of residential services, day programs, and services in the local community. Additionally, they expressed the need for support for the whole family, including psycho-emotional, personal, partner, and family support.

Now that we are already in our senior years, support in the direction of finding a place for her is important, so that we have some security when we are no longer here.

The state should provide daily and half-day care facilities that will be available, let's say, for 10 hours a day...

Participants also expressed the need for raising awareness in the community, which they believe would eventually reduce the stigma they face. Some mentioned that this was more important to them than having specific services.

I think there should be education provided to people in our community so that they understand, umm, what children with autism are like. Because I have issues with certain neighbors, when I am on a walk with my child... So, I believe it's more important to educate them than to provide assistance to us, in my opinion.

Maybe more socialization with other people, rather than some kind of psychological help, again, it's not about him, it's about the community. In my opinion, the problem lies not in M and our family but in the community.



The challenges faced by Croatian adults with AS in establishing independence, employment, and forming romantic relationships are likely comparable to those encountered by individuals in other regions (Hendricks & Wehman, 2009; Reifman et al., 2007). In response, family members are identified as crucial sources of support for these individuals (Orsmond & Fulford, 2018; Tozer & Atkin, 2015; Tozer et al., 2013). This study employed a quantitative approach to assess family members' confidence in the future well-being of the adult on the spectrum and their satisfaction with autism services in the community. Additionally, qualitative methods were utilized to explore family members' perspectives on the informal and formal support they receive, along with their identified needs for support.

The findings indicate that Croatian parents and siblings of adults on the spectrum express a sense of uncertainty regarding the future well-being of their family members. The qualitative data reveals a lack of belief among parents that systematic support and community resources will be available for their adult child on the spectrum. Nevertheless, they harbor hope and reliance on their other children to assume the responsibility of caring for their sibling in the future. This reliance on sibling support after parents are no longer able to provide care aligns with findings from other studies (Orsmond & Fulford, 2018; Tozer & Atkin, 2015). Interestingly, adults on the spectrum themselves exhibit a notably higher level of confidence in their future compared to their parents.

On average, parents and siblings of adults with AS expressed a neutral stance in their satisfaction with the available ASD resources in their community. However, higher satisfaction with resources was associated with greater confidence that the adult diagnosed with ASD would have a safe and happy future. While the study cannot establish causation, it suggests a potential link between satisfaction with community resources and the perception of facing future challenges.

Qualitative data revealed diverse experiences among parents regarding both formal and informal support. Some feel supported by family members, friends, and partners, while others feel isolated and unsupported. Some authors in Croatia emphasize grandparents as playing a significant role (Klepici & Laklija, 2018) in supporting children, particularly those with disabilities, and their families (Rob, 2022; Buljevac, 2019). Informal support is found to be crucial for family quality of life, contributing to better parental health and family resilience (Fong et al., 2021; Marsack & Hopp, 2019). Similarly, some families report positive experiences with formal support from institutions and NGOs, but a significant number cite poor quality or unavailability of services for their adult child.

Research on the availability of adult services for individuals on the spectrum in the European Union by Micai et al. (2022) suggests a gap in autism services provision, with many participants from various countries facing challenges in accessing services like residential or employment support. Parents emphasize the importance of raising awareness and foster-

ing acceptance in the community. Both adults on the spectrum and their family members encounter stigma, which can impact their well-being (Turnock et al, 2022).

## **Conclusion**

Parents and siblings play vital roles in supporting adults with AS. Unfortunately, formal support and community resources that could enhance the support for the adult on the spectrum and their family members are either unavailable or of poor quality. In many cases, parents rely solely on informal support, where grandparents often play a crucial role, and they depend on siblings to assume full care for the adult on the spectrum when they are gone.

To address the diverse needs of adults diagnosed with ASD and their families, there is a pressing need for a range of support options. The development of varied and specialized employment, residential and social services for adults on the spectrum should be prioritized. Recognizing the significance of informal support, it is essential to provide support to parents, siblings, and grandparents through counseling, support groups, education, and training.

Advocacy efforts should focus on supporting and encouraging self-advocates to promote awareness and acceptance of individuals on the spectrum. This can be achieved through community panels, lectures, workshops, campaigns, and media presence.

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Ana Katušić, UNIZG, Faculty of Education and Rehabilitation Sciences  
ana.katusic@erf.unizg.hr

Ana-Marija Bohacek, UNIZG, Faculty of Education and Rehabilitation Sciences  
ana-marija.bohacek@erf.unizg.hr

Tomislav Gojmerac, Children's Hospital – Srebrnjak

## The complexity of motor behaviour in infancy is related to minor neurological dysfunction at 2 years of age

### SUMMARY

**Aim:** Preterm infants show a higher incidence of neurodevelopmental disorders (NDD). The Infant Motor Profile (IMP) is a clinical, qualitative assessment that evaluates the complexity of early motor behaviour. The aim of this study was to evaluate the association between motor behaviour in infancy and neurological outcomes in terms of minor neurological dysfunction at 2 years of age.

**Method:** This study is part of a prospective cohort study on the development of infants born preterm. The study group consisted of 74 children (42 males, 32 females) with a median gestational age of 28.2 wks (range 26-32.3 wks). Motor behaviour was assessed with the Infant Motor Profile at 6 and 12 months corrected age (CA). Neurological outcome was evaluated at 2 years with the Hempel examination.

**Results:** A clear relationship was found between total IMP scores and outcomes of the neurological examination (Kruskal-Wallis  $p < 0.001$  at all ages), particularly in terms of minor neurological dysfunction.

**Interpretation:** Early motor behaviour assessed with the IMP is strongly associated with middle-term neurodevelopmental outcomes. In particular, low scores on the variation domains at 6 and 12 months CA were important indicators for minor neurological dysfunction.

**Key words:** *preterm infants, variation, motor behavior, minor neurological dysfunction*

**Abbreviations:** *CA, corrected age; GMs, general movements; IMP; Infant Motor Profile; MND, minor neurological dysfunction; TEA; term-equivalent age; VPT, very preterm*

### Introduction

Follow-up studies on very preterm (VPT) born children without obvious neurological deficits have revealed high rates of multiple, co-occurring subtle neurological impairments, such as difficulties with fine motor functions, coordination, and learning abilities (Arnaud et al., 2007).

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It has been suggested that one-third of four-year-old VPT children demonstrate more than one neurodevelopmental impairment in motor, cognitive, and behavioral domains (Woodward et al., 2009). When comparing VPT children with and without motor impairments, those with motor difficulties more frequently exhibit co-occurring social, behavioral, and attentional impairments (Bolk et al., 2018). This outcome can occur even in the absence of significant brain lesions and may be related to subtle alterations in brain development (Ment et al., 2009).

Recognizing the importance of the interdependence of all developmental domains in early childhood, it becomes crucial to identify the manifestation of risk behaviors. One cornerstone of evaluating infant development is the assessment of motor behavior, and its early emergence suggests a pivotal role in subsequent development. Infant motor behavior can be assessed through milestones and the evaluation of movement quality. It has gradually become evident that the quality of motor behavior in infancy serves as a significant predictor of developmental outcomes (Wu et al., 2020).

Within this framework, the video-based assessment, the Infant Motor Profile (IMP), examines the quality of motor behaviors in infants aged three to 18 months (Heineman et al., 2013). The IMP evaluates motor behavior in four qualitative domains: variation, adaptability, symmetry, and fluency, along with one quantitative milestone domain - performance. Two domains - variation and adaptability - are grounded in the Neuronal Group Selection Theory. Variation indicates the size of the motor repertoire, while adaptability refers to the ability to choose efficient strategies from this repertoire (Hadders-Algra, 2018). These traits are indicative of typical human motor development and can be used for diagnostics in infants at risk for more subtle developmental disorders (Kwong et al., 2018).

Developmental outcomes often manifest as minor neurological dysfunction (MND), which can be categorized as simple (s-MND) or complex MND (c-MND) based on the number of dysfunctional domains. Simple MND holds limited clinical significance, while complex MND is considered an extensive form of brain dysfunction associated with learning, cognitive, motor, attention, and behavioral problems (Hadders-Algra, 2002). MND is identified in 64% of very preterm (VPT) children (Niutanen et al., 2022). The same study confirmed the accumulation of multiple minor impairments among VPT children at six years, emphasizing the need for support and timely interventions for VPT children and their families throughout childhood and preschool age.

During infancy, predicting which children are at risk for the development of minor neurological dysfunction (MND) is challenging. However, the debate persists regarding the identification of the appropriate diagnostic instruments to be used at the right time (Rizzi et al., 2021). Several studies have indicated that the spatiotemporal variation and complexity of spontaneous general movements (GMs) during early postnatal life can serve as predictors of

minor neurological disorders (Groen et al., 2005; Bruggink et al., 2008). These GMs gradually diminish after 4-5 months post-term age, making way for new complex intentional goal-directed movements. This prompts the question of whether the complexity of this novel motor behavior across infancy is related to the neurological profile at toddler age.

## Objective and Hypotheses

The aim of the present study was twofold. The main objective was to assess whether the complexity of motor behavior in infancy is related to the presence and severity of MND at 2 years of age in a cohort of children born very preterm. Furthermore, we wanted to study the prevalence of MND at 2 years of age in the same cohort.

As the IMP assesses several parameters of neurological integrity, we hypothesized that reduced complexity of motor behavior in infancy would be correlated with the MND profile at 2 years of age. Also, we expected that the prevalence of MND in VPT-born children would be high.

## Methods

The study group comprised 74 children (42 males, 32 females) born very preterm between January 2018 and December 2020 and admitted to the neonatal intensive care unit of University Medical Center Zagreb. These children were part of a larger group of 102 infants included in a prospective study on the development of preterm-born infants. Inclusion criteria were a gestational age below 32 weeks. Infants with severe congenital anomalies and those with high-grade brain injury on MRI at term-equivalent age (TEA) were excluded from the analysis (Figure 1).

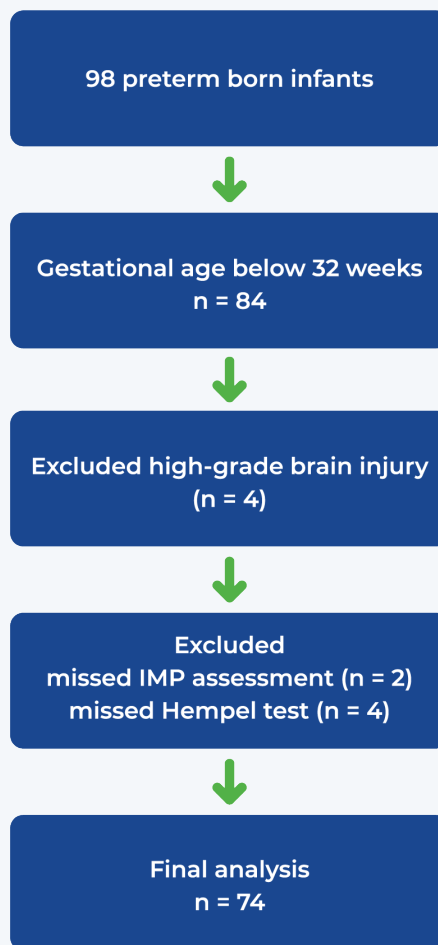
The study design received approval from the ethics committees of the University Medical Center Zagreb and the School of Medicine, University of Zagreb. Parents provided written informed consent for their child's study participation.

Motor behavior in infancy was assessed with the IMP at 6- and 12-months CA. The assessment involved evaluating self-produced and elicited movements in various conditions (supine, prone, sitting, standing, walking, reaching, grasping, and manipulation), depending on the child's age and functional capacities. Domain scores were individually obtained by calculating the percentage of the raw score relative to the maximal score. The total IMP score was calculated as the mean of the five domain scores. All scores were expressed as percentages, with 100% as the maximum.

The neurological profile was evaluated at a median age of 2 years and 6 months with the Hempel examination. The Hempel assessment is a neurological tool used to evaluate MND at preschool age, i.e., from 18 months up until the age of 4 years. It comprises a significant portion of standardized free play, allowing for the assessment of the quality of gross and fine motor behavior (Hempel, 1993).



Figure 1 Flow diagram of participants



The Hempel examination assesses five domains of functions that can be scored as typical or deviant: fine motor function, gross motor function, posture and muscle tone, reflexes, and visuomotor function. Children were classified as neurologically normal, having s-MND or c-MND, and abnormal (indicating the presence of cerebral palsy). Neurologically normal implies the absence of neurological dysfunction. Simple MND indicates the presence of one deviant domain (except the domain of reflexes). Complex MND indicates the presence of more than one domain of dysfunction.

The IMP assessments were conducted by trained early intervention professionals, and the Hempel neurological examination was administered by a pediatrician neurologist.

The potential relationship between early motor behavior and neurological condition was analyzed using Spearman's rank correlation and linear regression. The interpretation of Spearman's correlation coefficient was as follows:  $\rho < 0.25$ , weak relationship;  $0.25 < \rho < 0.50$ , fair relationship;  $0.50 < \rho < 0.75$ , moderate relationship; and  $\rho > 0.75$ , strong relationship. The relationships between the total IMP score and agespecific neurological examination (Hempel) were graphically rep-



resented with boxplots and tested for the total IMP score and the variation and adaptability domain separately using the Kruskal-Wallis test. Differences and correlations with a  $p$ -value of  $<0.05$  were considered statistically significant. Analyses were performed using SPSS 20.0.

## Results and Discussion

The clinical characteristics according to the MND profile group are presented in Table 1. The median gestational age of included infants was 28.2 weeks (range 26.0–31.3), and the median birthweight was 925g (range 630–1080). Fifty-two (70.3%) of the infants had a normal neurological profile, 16 (21.6%) children were classified as having simple MND, and six (8.1%) had complex MND. Previous studies reported a similar prevalence in very and extremely preterm-born children. Specifically, in the EPIPAGE study, which used the simplified version of the Touwen examination, the prevalence of complex MND was 5% (Arnaud et al., 2007). More recently, Broström et al. (2018) reported a prevalence of 28% for simple MND and 7.5% for complex MND. It is noteworthy that very and extremely preterm birth carries a risk of MND, even in the absence of high-grade brain injury.

Table 1 *Clinical characteristics of the study cohort*

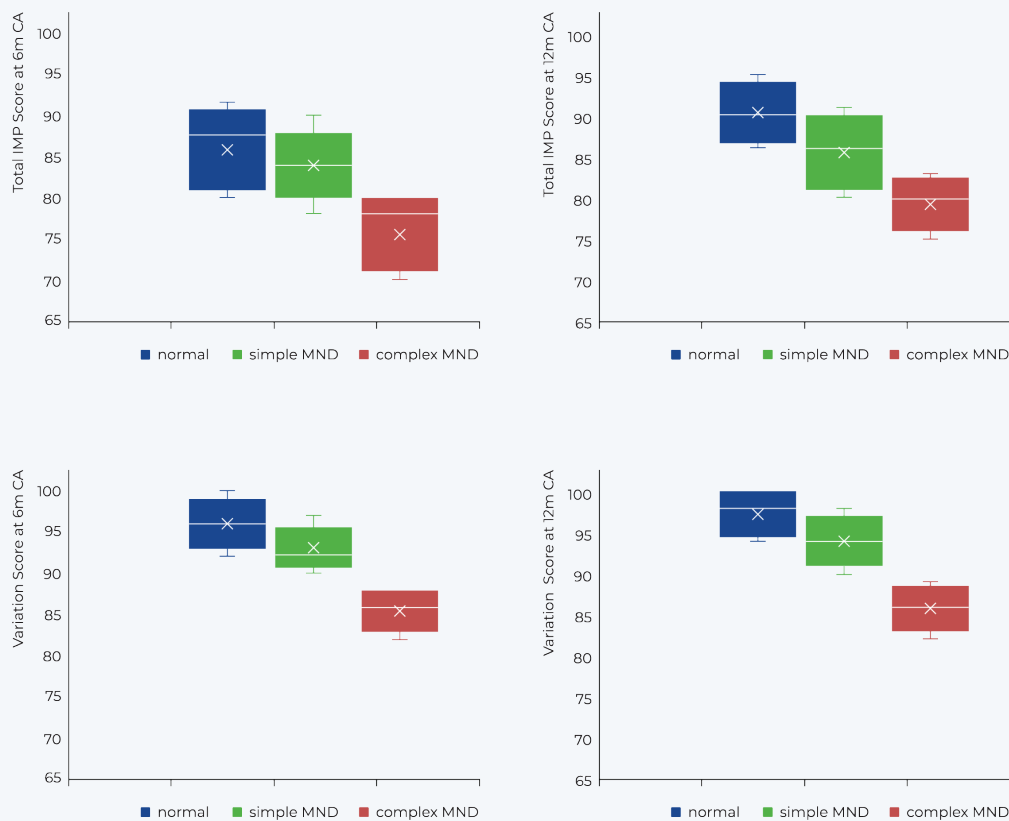
Characteristic (n = 74)	Median
Male sex, n (%)	40 (54%)
Median birthweight (range), g	925 (630 – 1080)
Median gestational age at birth (range), wks	28.2 (26 – 31.3)
Small for gestational age, n (%)	23 (31%)
Multiple pregnancies	10 (14%)
Median Apgar score at 5 min	7 (5 – 8)
Sepsis, n (%)	20 (27%)
Necrotizing enterocolitis, n (%)	12 (16%)
Bronchopulmonary dysplasia, n (%)	18 (24%)
Retinopathy of prematurity, n (%)	Grade 0 21 (28%)
	Grade 1-2 53 (72%)
Mild abnormality at Term MRI, n (%)	32 (43%)

Among children with simple MND, six exhibited dysfunctions in fine motor skills, four in visual-motor integration abilities, and two in each of the following domains of the Hempel examination. In the complex MND group, five of them had dysfunction in fine motor and visual-motor integration skills, three in the posture domain, and two in gross motor abilities and reflexes. Male sex was associated with the degree of MND ( $p=0.027$ ), consistent with previous studies (Arnaud et al., 2007; Skiold et al., 2014; Broström et al., 2018), emphasizing that males born very preterm are at a higher risk factor for developing MND.

We observed a clear relationship between the total IMP score and the outcome of the neurological examination (Hempel examination). Children with MND had lower total IMP scores in infancy than children with optimal neurodevelopment (Fig. 2; Kruskal–Wallis  $p < 0.001$  at all ages). They also scored lower in the domain of variation than children with a normal neurology profile ( $p = 0.016$  for simple MND,  $p = 0.005$  for complex MND). Given that variability in motor behavior is already indicated as a marker of the integrity of the infant’s brain (Prechtl, 2001; Bruggink et al., 2008; Hadders-Algra, 2008), we presume that reduced variation also reflects dysfunctions reflected in the MND profile. All six infants with complex MND scored  $\leq 85$  on the total IMP score at 12 months CA, indicating a high probability of developing an aberrant neurological profile in multiple developmental domains, which aligns with previous studies (Heineman et al., 2013).

Linear regression analyses revealed that the total IMP score was a significant predictor of complex MND ( $p = 0.003$ ,  $r^2 = 0.62$ ).

Figure 2 Infant Motor Profile (IMP) scores at the corrected ages of 6 and 12 months in children with normal neurology and simple MND or complex MND profile at 2 years of age. (a) Total IMP score. (b) Variation domain. Bold horizontal lines indicate median values, boxes represent 25<sup>th</sup> and 75<sup>th</sup> centiles, and vertical lines indicate range. At all ages, differences in total IMP scores and variation scores between the three neurological conditions were significant (Kruskal–Wallis  $p < 0.001$ ).



This study explored the prevalence of MND in a cohort of VPT-born children and analyzed the association between the complexity of motor behavior in infancy and the neurological profile in terms of MND at the age of 2 years and 6 months. In addition to the clinically relevant prevalence of MND in VPT-born children, the present study indicates that the quality of motor behavior is related to the MND profile at the age of 2 years and 6 months. We found significant differences in the complexity of motor behavior in infancy between children with optimal neurodevelopment and those who developed simple and complex MND. Difficulties in fine motor and visual-motor skills were the prevalent dysfunctional domains in both groups. This aligns with previous studies that emphasized an increased risk for subtle visuomotor and visuospatial processing impairments in very preterm infants (Ferrari et al., 2012; Pugliese et al., 2013). We assume these dysfunctional clusters result from complex alterations in white matter microstructure in motor pathways, often found in VPT-born children with subtle motor impairments (de Kieviet et al., 2014; Groeschel et al. 2014). Furthermore, impaired visuomotor function might reflect cerebellar and dorsal-visual pathway disturbances in preterm-born children (Van Braeckel and Taylor, 2013).

During early infancy, predicting which children are at risk for the development of MND, particularly c-MND (Groen et al., 2005), is challenging. In addressing this concern, our study aimed to investigate the association between the complexity of motor behavior in early infancy and later neurological profiles. Several studies have already indicated that the General Movement Assessment (GMA) and the quality of the motor repertoire at 11 to 16 weeks post-term are related to MND at school age (Bruggink et al., 2008; Ferrari et al., 2012; Groen et al., 2005; Hadders-Algra et al., 2009).

The lack of early identification in the context of MND means that these children completely miss out on vital input during critical periods of development when interventions provided may improve outcomes (Hutchon, 2018).

Our findings align with the study by the Groningen group, demonstrating that MND can be reliably determined in infancy (during the first 18 months of life). Moreover, the Hempel neurological examination is effective in detecting neurological signs of MND at 2 years of age (Hadders-Algra et al., 2010).

MND among VPT-born children may be associated with widely distributed disturbances in normal brain development (Kostović & Judaš, 2006), including inadequate cortico-striato-thalamo-cortical and cerebello-thalamo-cortical circuits in the brain (Hadders-Algra, 2002; Kikkert et al., 2013). These children are susceptible to altered brain maturation (Volpe, 2009; Back, 2015), and impaired growth of brain structures (de Kieviet et al., 2012; Matthews et al., 2018; Dewey et al., 2019) that are linked to MND (Hadders-Algra, 2002; Setänen et al., 2016). It's interesting to note that cerebellar growth can be affected in the preterm brain, resulting in

smaller volumes (Limperopoulos et al., 2005; Katušić et al., 2020). This observation aligns with existing research that suggests the importance of the cerebellum not only in motor skills but also in cognition (Noroozian, 2014).

The study by Setänen et al. (2016) explored the association between alterations in brain volume, particularly in the thalamus, basal ganglia, and cerebellum, and the occurrence of MND in preterm infants, suggesting there may be a link between the size and development of these brain regions and the manifestation of MND in preterm infants. However, it's important to note that the relationship between brain structure and function is complex and multifaceted. Further research is needed to fully understand the mechanisms underlying these associations.

The strengths of this study include its longitudinal design, the use of standardized, age-specific, and sensitive measurements, and a low attrition rate. However, a limitation was the absence of long-term follow-up, which reduced the power to establish predictive validity, as the clinical picture of MND may not be fully expressed at the age of 2 years and 6 months (Hadders-Algra, 2002). Acknowledging that outcomes at 2 years may have limited predictive value for school-age outcomes, this cohort will be continued to be followed up, enabling exploration of longer-term outcomes and trajectories.

In conclusion, the complexity of motor behavior in infancy is associated with the profile of MND in children born very preterm. The reduced variability of motor behavior hampers an infant's ability to explore and interact with the environment, resulting in fewer opportunities to vary and adapt motor strategies, ultimately leading to alterations in neurodevelopment (Bruggink et al., 2008). Thus, neuromotor assessments reflecting the quality of motor behavior in infancy may serve as early markers of neurologic integrity and function, enhancing the ability to identify, among VPT-born infants, those at the highest risk for MND.

Our results underscore the importance of close monitoring of children born very preterm, even in the absence of high-grade brain lesions. It is paramount to identify infants at risk for MND as early as possible, as MND is associated with behavioral and neuropsychological impairment across multiple neurodevelopmental domains, leading to challenges in academic and social life.

## **Concluding Remarks**

The demonstrated relationship between the complexity of motor behavior in infancy and MND suggests that the quality of motor behavior can serve as a predictor of neurological profile. Specifically, the reduced variability of motor behavior in infancy poses a risk for the development of MND. This highlights the importance of utilizing age-specific and detailed measurements of neuromotor function in the follow-up practices of preterm infants.

Further studies in larger populations are necessary to determine the precise value of IMP assessment for the early detection of clinically relevant forms of MND.

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Sanja Narić, Neuropsychiatric Hospital "Dr. Ivan Barbot"  
sanja.naric@gmail.com

Roberta Matković, Public Health Institute

Ajana Löw, UNIZG, Faculty of Education and Rehabilitation Sciences  
ajana.low@erf.unizg.hr

Martina Lotar Rihtarić, UNIZG, Faculty of Education and Rehabilitation Sciences  
martina.lotar.rihtaric@erf.unizg.hr

Katarina Marušić, University Psychiatric Hospital Vrapče

## Development and validation of The Phubbing Scale – partner and self-assessment in Croatia

### SUMMARY

The extent to which smartphones have invaded everyday life has changed the norms of human behaviour, especially in intimate relationships. Research shows that partner phubbing, i.e., using the smartphone in the presence of the romantic partner and thus ignoring the partner, affects relationship quality.

In this paper we present the stages of development and validation of the Croatian Phubbing Scale – partner and self-assessment. This is the first partner phubbing scale developed in Croatian and, to our knowledge, the first validated partner phubbing scale that includes both a partner and a self-assessment form. Two studies were conducted with adult respondents, one for the development of the final partner assessment form (N=308; 80.84% female) and the second for the validation of the metric characteristics of both forms (N=273; 61.90% female). Based on the results of the exploratory factor analysis of the second study, both forms of the scale were reduced to 7 items, which showed very good internal consistency with  $\alpha = 0.86$  for the partner assessment and  $\alpha = 0.85$  for the self-assessment form. The one-factor structure explained 47.37% of the total variance for the partner assessment form (item loadings .64-.77) and 46% of the total variance for the self-assessment form (item loadings .61-.80). Discriminant validity analyses showed a significant moderate positive correlation between self-assessed partner phubbing and fear of missing out and nomophobia. The data also confirm previous research findings on the negative correlation between partner phubbing and relationship quality. The results of these studies have yielded a valid and reliable scale for measuring phubbing in a romantic relationship.

**Keywords:** *partner phubbing, scale, fear of missing out, nomophobia, intimate relationship quality*

## Introduction

With the emergence and extensive use of mobile phones, it has become unimaginable to leave home without them. Moreover, as these communication devices have evolved into smartphones, they have taken an irreplaceable place in all aspects of daily life (Al-Saggaf & MacCulloch, 2018). According to some data, about 85% of the world's population now owns a smartphone, and it is estimated that the number of users will reach 6.8 billion in 2023 (Statista, 2023). In 2022, there were more mobile device users than residents in Croatia (Kemp, 2022). Social networks are used by 59.4% of the world's population, while the average internet user spends 6 hours and 37 minutes online every day, of which 92.3% of users use their smartphones (Kemp, 2023). Finally, the social changes caused by the COVID 19 pandemic contributed to the global increase in smartphone use, with the frequency among existing users almost doubling and even people who did not need them in the pre-pandemic period starting to use them (Solano et al., 2021).

One of the consequences of such a penetration of smart devices into our everyday lives is the emergence of phubbing, the phenomenon that Roberts and David began to explore in 2016. The word phubbing originated from the combination of the words phone and snubbing and emerged in 2012 as part of a campaign for an Australian English dictionary in which linguists, writers and poets were asked to find a new word to describe the behaviour of ignoring others in favour of a mobile phone. On this occasion, Australian student Alex Haigh came up with the word phubbing, and the "Stop Phubbing" campaign was launched to raise awareness of the problem (Ducharme, 2018). Prior to the wider use of the word phubbing, McDaniel and Coyne (2016) used the word technoferece, exploring the interference of technological devices in partner relationships, but today the term technoferece is used to refer to distraction by technological devices in general (tablets, laptops, televisions, etc.).

Although the aforementioned social phenomenon has only been researched for the past seven years, Capilla Garrido et al. (2021) already list 11 definitions in their review paper. "Phubbing is an act in which mobile devices cause people to ignore the person they are talking to, thus interrupting communication" (Cizmeci, 2017, p. 364), which is a type of social exclusion and interpersonal neglect, leading to a disruption of social relationships through smartphone use. This is clearly a negative concept with multiple dynamics involving disrespect and neglect of the person(s) we are with, showing more interest in virtual than real interactions, but it also refers to a problematic relationship with a mobile phone with the possible development of addiction to a certain application or internet addiction (Karadağ et al., 2015). Phubbing is therefore researched from several perspectives. The first is research into the predictors of phubbing, with a smartphone, the internet or an use/gaming addiction seen as the main predictor (Karadağ et al., 2015; Chotpitayasunondh & Douglas, 2016). Other predictors

of phubbing or even possible mediators between phubbing and the above-mentioned addictions are the so-called fear of missing out (FoMO, Fang et al., 2020; Schneider & Hitzfeld, 2019; Franchina et al., 2018), nomophobia (Mendes et al., 2022), certain individual traits such as neuroticism (Balta et al., 2018; Błachnio & Przepiórka, 2018), boredom and loneliness (Bolkan & Griffin, 2017; Dayapoglu et al., 2016) and partner's attachment style (Bröning & Wartberg, 2022). The second aspect of research is the impact of phubbing on decreasing the quality of interpersonal relationships in general (Guazzini et al., 2019; Miller-Ott et al., 2017; Chotpitayasunondh & Douglas, 2016; Karadağ et al., 2015), in partner relationships (Wang et al., 2017; Roberts & David, 2016; Miller-Ott et al., 2015) and in business relationships (Roberts & David, 2017) and more recently in parent-child relationships (Wang et al., 2022).

A growing body of research shows that phubbing has become a widely accepted phenomenon in everyday interactions (Chotpitayasunondh & Douglas, 2016; Karadağ et al., 2015). People are often undecided about whether to pay attention to their conversation partners while being accessible to others via the smartphone (Miller-Ott & Kelly, 2017). Data from 2014, for example, shows that 89% of mobile phone owners surveyed used their phone during their last social interaction (Ranie & Zickuhr, 2015), and furthermore, the possibilities offered by smartphones today are countless. More than 70% of married or cohabiting women reported that smartphones interfere with their interactions with their partners (McDaniel & Coyne 2016). It has also been shown that people tend to use a mobile phone themselves when someone close to them (e.g. their partner) is using a mobile phone (Chotpitayasunondh and Douglas, 2016), further explaining the prevalence of the phenomenon.

In terms of gender, it has been shown that women tend to perceive smartphones as facilitators of social interactions, while men focus more on their instrumental function (Chotpitayasunondh & Douglas, 2016). The same can be seen when comparing participants of different age groups. Namely, younger participants are more likely to use a mobile device for the purpose of socialising (Kim et al., 2014), while for older people, mobile phone use is more instrumental and almost exclusively for the purpose of voice calls (Berenguer et al., 2017). Accordingly, younger participants show more understanding by accepting the use of a smartphone in informal (café, restaurant, etc.) or social group interactions (Miller-Ott & Kelly, 2017; Kadylak et al., 2018), but when it comes to formal settings or two-person communication, the majority of participants perceive phubbing as rude and offensive behaviour towards the interlocutor (Ranie & Zickuhr, 2015). Since informal and group interactions require a lower level of commitment to the interlocutors, a possible poor quality of communication in such a setting is less threatening to the interlocutors' feelings and the intimacy of the relationship.

Some of the most intimate relationships a person enters into during their lifetime are those with romantic partners. A romantic relationship is defined as a mutual, enduring and volun-

tary interaction between two people characterised by specific expressions of affection, intimacy and mutual support (Collins et al., 2009). The personal assessment of feelings towards the partner and the relationship constitutes romantic relationship satisfaction (Cepukiene, 2019; Cizmeci, 2017), which is influenced, among other things, by the feeling of connectedness with the partner in the way that partners are open and focused on each other in mutual interaction without being distracted by other things (Rossouw & Leggett, 2014). Clearly, the use of a mobile phone during interaction with a partner threatens the closeness, trust and intimacy that such a relationship assumes. However, sharing technology during romantic partners' leisure time (on a daily basis) has been shown to be a positive predictor of leisure time and relationship satisfaction (Drouin & McDaniel, 2021; McDaniel et al., 2021; Coyne et al., 2014), while using technology separately when a partner is present is a predictor of conflict and lower relationship satisfaction (McDaniel et al., 2021; Halpern & Katz, 2017). Thus, it is not the issue of time spent on the mobile phone, but the use of the mobile phone in a way that neglects the partner with whom we interact directly, that increases the likelihood of conflict (Beukeboom & Pollmann, 2021; Coyne et al., 2014). Conflict, in turn, reduces satisfaction with the romantic relationship and ultimately personal well-being through lower life satisfaction and increased depression (Roberts & David, 2016).

In partner phubbing, the perception of social interaction by the individual plays an important role, who may perceive their partner's smartphone use as problematic or not take it personally, suggesting that the line between beneficial and constructive use of smart devices and harmful and destructive use is not universal. Therefore, phubbing research needs to focus on both actors of social interaction, especially in the context of the partner relationship, considering how phubbing affects the quality and satisfaction of the partner relationship.

In Croatia, research on partner phubbing is modest. On a sample of 116 couples, Čurlin (2020) examined, among other things, the difference in relationship satisfaction and quality of communication as a function of partner phubbing and found that partner communication quality increases inversely proportional to the frequency of phubbing. As expected, the same was found for relationship satisfaction.

## Objective

Since partner phubbing can have a significant impact on relationship quality and satisfaction, it is important to develop and validate an instrument that examines the behaviour of both partners. A review of the existing literature shows that there is only one scale that can be used to assess perceptions of partner's phubbing behaviour. This is the 9 item Partner Phubbing Scale (Roberts & David, 2016). Chotpitayasunondh and Douglas (2018) developed the Generic Scale of Phubbing (GSP) and the Generic Scale of Being Phubbed (GSBP) as

two independent scales, the first containing 15 items and the second containing 22 items, to assess phubbing in general rather than partner phubbing. As far as the authors are aware, there is no existing scale that examines partner phubbing, and also provides the possibility of assessing one's own behaviour.

The aim of this study is therefore to develop and validate the Phubbing Scale – partner and self-assessment (PS), which consists of two forms – partner assessment form (PAF) and the self-assessment form (SAF). To achieve this goal, two studies were conducted – the first to select the items for the partner assessment form, and the second to validate the final version of both forms of the scale.

### Phases of scale development

The scale development process was conducted in three phases according to current scientific guidelines (Boateng et al. 2018; Carpenter, 2018; DeVellis, 2017; King et al., 2012) incorporating the recommended phases for scale development (DeVellis, 2017).

Table 1 Phases of Phubbing scale – partner and self-assessment (PS) development

Phase	Actions
I	Review of literature about the construct Definition Defining situations and behaviours for instrument Items pool creation Review by experts
II	Study 1 data collection (N=308) Data processing Reduction of no. of items Switch to 1 <sup>st</sup> person
III	Selection of constructs for discriminant validity testing Study 2 data collection (N=273) Data processing Optimizing scale length Finalization of PS (both forms each with 7 items)

The three-phase process of scale development (Table 1) began with a review of the available literature (consideration of the definitions of the construct and existing measurement instru-

ments). Since the applied scales tend to cover the whole construct in order to make accurate predictions (King et al., 2012), and the set of statements should cover the core of the construct (Flynn & Percy, 2001), after selecting the initial definition, the situations in which partners spend time together (with the possibility of using a mobile phone at the same time) were defined. According to the situations, a set of items was compiled, in such a way that for each of the situation a certain number of items describing phubbing was generated. Three types of time together were defined – at home (meals together, 6 items; watching TV, 7 items; and time in the bedroom before sleep, 6 items), outside the home (in a café or restaurant, 5 items; shopping, 3 items; and walking or spending time in nature, 3 items) and during a partner conversation, regardless of where the conversation takes place (11 items).

Individual behaviours related to the mobile phone were also defined – holding the mobile phone; checking the screen and possible messages even though there was no signal to do so; browsing content and responding to the signal without interrupting the current activity.

Using the deductive method described (Boateng et al. 2018), an item pool was created that contained 41 items for assessing partner phubbing after review by the independent experts.

After the item pool was designed, in the second phase the first study was conducted with the aim of selecting items for the final version of the scale. DeVellis (2017) advocates the use of shorter scales in terms of achieving effectiveness, as they are generally less burdensome for respondents. Therefore, 14 items were selected based on the results of the data analysis. Finally, 14 items were transferred to the 1st person to obtain a self-assessment scale (PS-SAF).

The third phase was conducted to test the possibility of additional shortening of the scale and to test the metric properties of the scale on another sample. In addition, the dimensionality of both forms of the scale was checked. The final version of the Phubbing Scale consists of two forms, with both forms containing 7 items with the same content. The methodology and results of the two studies are presented below.

## Study 1

### Method

Data for the first study were collected from a convenience sample of 308 participants (80.84% female). The inclusion criteria for participants were age and being in a romantic relationship for at least 6 months. The average age of the participants is  $M=39.07$  years ( $SD = 9.93$ ), they mostly have four years of education (42.21%) and are permanently employed (81.82%). On average, they have been in a relationship for 14.74 years ( $SD = 10.19$ ,  $Min=6$  months,  $Max = 43$  years), living with their partner (85.39%) for an average of 12.13 years, and living with a child/children as additional household member(s) (64.61%).

Data were collected through an online questionnaire using Google Forms employing the snowball method. Prior to administering the questionnaire, participants were informed about the purpose of the study and that participation was voluntary and anonymous. It was emphasised that all data would be analysed collectively, and they were provided with the author's email address in case they had any questions about the study or data. The participants gave their assessments on 41 items. Their task was to estimate on a 5-point scale (0 – never, 1 – very rarely, 2 – sometimes, 3 – often, 4 – almost always) how often they observed the described behaviours in certain situations. In addition, they were asked questions about socio-demographic characteristics (gender, age, education level, work status, duration of the relationship, cohabitation, and number of household members). The duration of the partner relationship and the duration of cohabitation were given by the participants as years and months, which were then converted into years.

Statistical analyses were carried out using the IBM Statistical Package for the Social Sciences (SPSS) 23. A descriptive analysis and an exploratory factor analysis were conducted on the collected data for the initial set of items.

## Results and discussion

Data analysis of the initial item pool showed that participants responded between 0 and 4 for all items, with the mean response for each item ranging from 0.27 to 1.57, and the most frequent responses for all items were 0 – never or 1 – sometimes, showing a tendency towards a floor effect.

To check the dimensionality of the items and to exclude those with lower saturation, an exploratory factor analysis was conducted including all items. Using the Keiser–Meyer–Olkin test  $KMO = .970$  and Bartlett's test for sphericity ( $\chi^2 (820) = 11300.962, p < .001$ ), it was determined that the data were suitable for factor analysis (Tabachnick & Fidell, 2013). Cattell's scree plot showed that only one factor was significant and explained 53.06% of the variance, with factor saturations ranging from .53 to .83.

In selecting items for the final version of the scale, statements were excluded according to the following criteria: 1. saturation less than .40 (DeVellis, 2017), 2. statements with the lowest inter-item correlations, 3. statements with the lowest item-total correlations, and 4. Cronbach  $\alpha$  remains the same or increases when the item is eliminated (Flynn & Percy, 2001). The results showed that this was a fairly homogeneous set of items, with saturations ranging from .53 to .83, and that the removal of an item had no effect on Cronbach  $\alpha$ . It was therefore decided to retain two statements for each phubbing situation described. Preference was given to items with the least tendency to have a floor effect and those with the least dispersion in order to increase the sensitivity of the scale (DeVellis, 2017).



The described procedure resulted in a scale with 14 items PS-PAF. Exploratory factor analysis was again conducted and based on Cattell's scree plot; it was found that there was one significant factor explaining 56.57% of the variance of the measured construct. The saturation of the individual items with the factor is between .65 and .82. The internal consistency, of the scale is high (Cronbach  $\alpha = .94$ ).

## Study 2

### Method

The second study was conducted online on a sample of 273 (61.90% female) adult participants who have been in a relationship for at least 6 months. The mean age is  $M = 34.73$  years ( $SD = 10.71$ ). Most participants have completed graduate studies (37.73%) and are permanently employed (57.14%). Participants have been in a relationship for an average of 10.56 years ( $SD = 9.63$ ), 68.13% have been living together in average for  $M = 7.73$  years ( $SD = 9.40$ ), of which 41.76% also have children in the household.

In terms of measurement tools, two forms of the Partner Phubbing Scale were used – the Partner Assessment and Self-Assessment Form, the Fear of Missing Out Scale, the Nomophobia Questionnaire and The Marriage Quality Index.

The Fear of Missing Out Scale (FoMOS, Przybylski et al., 2013) examines the extent to which participants feel fear and worry about missing out on experiences and events from their friends' lives and wider social environment. The scale consists of 10 items on one dimension. Participants rate the extent to which each item applies to them on a 5 - point scale from 1 – does not apply to me at all to 5 – applies to me completely. The total score is calculated as an average of the responses. A higher score means that the fear of missing out is more pronounced. Research shows satisfactory reliability of this scale,  $\alpha = .87 - .90$  (Przybylski et al., 2013). The scale was translated into Croatian and validated on a Croatian sample, with Cronbach's reliability  $\alpha = .84$  (Omejec, 2020), while in this study it is  $\alpha = .81$ .

The Nomophobia Questionnaire (NMP-Q, Yildirim, 2014) contains 20 items that measure anxiety and fear due to the unavailability of a smartphone and the inability to communicate via virtual networks. The items are grouped into four dimensions 1. Not being able to communicate (6 items); 2. Losing Connectedness (5 items); 3. Not being able to access information (4 items); and 4. Giving up convenience (5 items). Participants are asked to rate their level of agreement with each item, from 1 – I completely disagree to 5 – I completely agree. The total score on a particular subscale and on the whole questionnaire was formed as the sum of the scores on the items of the corresponding dimension, with a higher score indicating a stronger expression of a particular dimension of nomophobia. The questionnaire was translated into



Croatian and validated on a Croatian sample, with the reliability of the individual subscales ranging from  $\alpha=.67$  to  $\alpha=.91$  (Bodrožić Selak, 2020). In this study, the reliability of dimensions ranges from  $\alpha=.88$  for Not being able to communicate to  $\alpha=.97$  for Losing of Connectedness.

The Quality of Marriage Index (QMI, Norton, 1983) consists of 6 items on which participants rate their satisfaction with their marriage and/or relationship. Participants indicate their agreement with the first 5 items on a scale from 1 (very strong disagreement) to 7 (very strong agreement). The last item relates to the rating of overall satisfaction with the relationship, and the response is given on a scale of 1 to 10, with 1 representing very unhappy and 10 representing very happy in the relationship. The author proposed the formation of two results. The first result, the quality index, is expressed as the sum of the responses to the first 5 items and the second result is the response to the 6<sup>th</sup> item, i.e. it represents a global self-assessment of relationship quality. The total score is the sum of the responses to all 6 items. The questionnaire was validated on a Croatian sample where the internal consistency was Cronbach  $\alpha=.97$  (Salkicevic et al., 2014), while the reliability of the whole scale in this research is Cronbach  $\alpha=.92$ .

## Results and discussion

Exploratory factor analyses were conducted with the aim of testing the dimensionality of the two forms of the PS-PAF. The Keiser-Meyer-Olkin test ( $KMO = 0.935$ ) and Bartlett's sphericity test ( $\alpha^2 (91) = 2127.200$ ,  $p < .001$ ) for the partner assessment form indicated that the data were suitable for further factor analysis (Tabachnick & Fidell, 2013). Based on the Cattell's scree plot, it was found that there was one significant factor explaining 49.33% of the variance with factor saturations ranging from 0.70 to 0.78.

In addition, the self-assessment form was also tested. The Keiser-Meyer-Olkin test  $KMO = 0.918$  and Bartlett's sphericity test ( $\alpha^2 (91) = 2253.062$ ,  $p < .001$ ) for the self-assessment form also confirmed that the data were suitable for factor analysis (Tabachnick & Fidell, 2013). The results of the factor analysis showed that there is one significant factor explaining 49.25% of the variance, with factor saturations ranging from .61 to .83. The self-assessment form also shows high internal consistency Cronbach  $\alpha=.93$ .

With the aim of further shortening the scale, it was decided that one item from each situation described, which had better metric properties, should be retained. Since all remaining items had a saturation greater than .40 and Cronbach's  $\alpha$  did not decrease below .70, items whose exclusion would be less detrimental to internal consistency and which had less response dispersion were excluded (DeVellis, 2017).

In order to implement the initial idea of creating the phubbing scale with two forms (PAF and SAF), data from both forms were considered when truncating the number of items for final

version. In this way, both forms of the scale contain items with the same content.

A factor analysis was conducted for the final version of the Phubbing Scale – partner and self-assessment. For the partner assessment form, a significant factor was found to explain 47.37% of the variance with factor saturation ranging from .64 to .77, as shown in Table 2. The internal consistency is  $\alpha=.86$ . It is concluded that the shortening of the scale is justified as the scale still has good metric characteristics.

Table 2 *The final version of both forms of the Phubbing Scale – partner and self-assessment*

PS-PAF / Partner assessment form		PS-SAF / Self-assessment form	
While we are talking, my partner is using the mobile phone at the same time.	.70	While I am talking to my partner, I am using the mobile phone at the same time.	.72
I feel like I am watching a movie alone because my partner is using a mobile phone.	.64	I use the mobile phone while my partner and I watch a movie together.	.65
While walking, my partner is carrying a mobile phone in a hand.	.69	I carry a mobile phone in my hand while I go for a walk with my partner.	.61
While I am choosing groceries in the store, my partner is using a mobile phone.	.64	When we are in the store, I am using the mobile phone while my partner is choosing groceries.	.66
I feel like I am sitting alone in a café because my partner is using a mobile phone.	.77	While we are sitting together in a café, I am not paying attention to my partner because I am using the mobile phone.	.80
When a notification arrives on the mobile phone, my partner responds immediately, even if we haven't finished eating.	.71	When I get a notification on my mobile phone, I react immediately, even if my partner and I haven't finished eating yet.	.64
While in bed, before going to sleep, my partner uses a mobile phone excluding me.	.65	While in bed, before going to sleep, I use my mobile phone excluding my partner.	.65

For the self-assessment form, the results of the factor analysis of short version with 7 items confirmed a significant factor explaining 46% of the variance. The saturations, as in the case of the partner assessment form, are quite high, ranging from .61 to .80 (Table 2). The internal consistency is  $\alpha = .85$ .

The total score on the Phubbing Scale – partner and self-assessment is calculated as the sum of the responses to all items. Table 3 shows the results of the descriptive analysis of the total score for both forms of the scale. It can be seen that, on average, participants achieve lower

total scores on the scale ( $M_{PS-PAF} = 6.74$ ,  $M_{PS-SAF} = 6.22$ ), but they achieve both the minimum and maximum possible sum of responses (Min = 0, Max = 28).

Table 3 *Descriptive statistics and Pearson's correlation of Phubbing Scale – partner and self-assessment and other constructs included in the study for testing discriminant validity*

	Mean	SD	1	2	3	4	5	6	7	8
1 PS-PAF	6.74	5.30	1							
2 PS-SAF	6.22	4.73	.457**	1						
3 FOMO	20.68	6.51	.277**	.301**	1					
4 Not being able to communicate	21.04	11.05	.203**	.275**	.359**	1				
5 Losing connectedness	10.59	7.14	.175**	.386**	.425**	.616**	1			
6 Not being able to access information	13.22	6.73	.158**	.316**	.361**	.517**	.555**	1		
7 Giving up convenience	14.22	7.31	.209**	.390**	.396**	.636**	.634**	.723**	1	
8 QMI	39.40	7.89	-.359**	-.279**	-.152*	-.016	-.093	.037	-.080	1

\*\*p< .01; \*p< .05

Note. PS-PAF = Phubbing Scale – partner assessment form (score), PS-SAF = Phubbing Scale – self-assessment form (score), FOMO= Fear of missing Out Scale (score), Not being able to communicate, Losing connectedness, Not being able to access information, Giving up convenience= Dimensions of The Nomophobia Questionnaire (NMP-Q), QMI= Quality of Marriage Index (Score)

Finally, since partner phubbing affects relationship quality, the correlation of both forms of the scale was tested with The Quality of Marriage Index (Norton, 1983). The correlations show a significant moderate positive correlation between the responses of participants who are more exposed to phubbing by their partner and those who tend to phub more ( $r=.457$ ,  $p < .001$ ). These results can be interpreted by the fact that participants who are phubbed more often tend to phub themselves, as shown in research by Chotpitayasunondh & Douglas (2016). Furthermore, it is evident that there is a low negative and statistically significant correlation between relationship quality and both forms of phubbing. This means that respondents who are phubbed more often or tend to phub their partner more often report lower relationship quality, which is consistent with previous research (McDaniel et al., 2021; Przybylski & Weinstein, 2012).

The process of development and validation the Phubbing Scale – partner and self-assess-

ment resulted in a reliable and valid instrument that has high internal consistency, good discriminant validity and the expected dimensionality. Nevertheless, further testing of the scale is needed. To gain insight into other measurement characteristics of the scale, it would be desirable to determine test-retest reliability in future research. In addition, the sample in this study may be considered a limitation of the research as it is predominantly female, especially in the first study. Although the proportion of males in the second study is higher than in the first, female participants still make up the majority of the sample. As men show a lower willingness to participate in online research, such a ratio between men and women is not surprising. A recommendation for future research refers to the use of the scale in a paper-pencil survey to more easily ensure an equal ratio of men and women. Finally, both studies presented were conducted on a convenience sample, so it is advisable to conduct further research on one of the probabilistic samples.

## Conclusion

Roberts and David (2016), authors of The Partner Phubbing Scale, emphasise the need for further development of new instruments for research the phubbing phenomenon in order to provide new perspectives. In this effort, the Phubbing Scale – partner and self-assessment was developed.

This research makes a significant scientific contribution to research of phubbing in the Croatian scientific context. The Phubbing Scale - partner and self-assessment is the first partner phubbing scale developed in Croatian language validated on a Croatian sample. To the authors' knowledge, this is the only scale with two forms, partner assessment and self-assessment, and the scale with the smallest number of items. The developed scale has high internal consistency and discriminant validity.

The negative influence of phubbing leaves its mark on both the intrapersonal and interpersonal levels. Since phubbing significantly affects relationship quality and satisfaction, it also affects the quality of family life more broadly. Therefore, it is necessary to study and clarify the mechanisms of phubbing in order to raise awareness of its negative consequences and prevent possible social resignation and general acceptance of phubbing as an inevitable and necessary evil that comes with technological progress.

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Mila Puljiz, Elementary School Kajzerica  
milapuljiz.st@gmail.com

Matea Luburić, UNIZG, Faculty of Education and Rehabilitation Sciences  
matealuburic@gmail.com

Kristina Rašić, Center for preschool education in Travno  
kristina.rasic89@gmail.com

## Challenges of the teaching assistant workplace in an inclusive environment

### SUMMARY

Teaching assistants are an example of an acceptable modification in the context of inclusive education. They help pupils become independent in the school by offering immediate support and working in partnership with the teachers, other professionals, and parents of children with developmental disabilities. However, there are many questions surrounding this practice, which are becoming the focus of a growing number of scientific investigations and media appearances due to inadequate legislative restrictions. The purpose of this study was to learn more about how teaching assistants view their jobs, needs, and difficulties that they encounter in the regular education system. Data was collected through an online questionnaire with open and closed questions, and the questionnaire was posted on Facebook groups intended to connect teaching assistants in the Republic of Croatia. Two hypotheses were examined in this study, taking into consideration the evaluation of scientific literature and practical work experience: 1. It is expected that teaching assistants with more experience will perceive their employment as less difficult than those with less experience; 2. It is expected that teaching assistants who receive additional education will find their job to be less difficult than those who do not receive additional education. According to the results, teaching assistants must motivate students to work, control the challenging behaviour of students with developmental disabilities, communicate with parents of students with developmental disabilities, and support students as they learn subject matter. Also, participants mentioned the need for group meetings to build cooperation with other teaching assistants and school staff members, as well as define their work status, and acquire further professional training.

**Key words:** *inclusion, teaching assistants, students with disabilities, workplace needs and challenges*

## Introduction

Within the regular education system, one of the most significant challenges emerges – namely, how to provide effective, universal, and least restrictive services to students with disabilities (Yates et al., 2020). The increasing number of students with disabilities in the regular education system requires a growing support staff that assists them (Alston & Kilham, 2004). This, in turn, necessitates the assessment and evaluation of the effectiveness of such support (Giangreco & Broer, 2005). Teaching assistants represent one of the key roles in ensuring support for inclusive education, a sentiment shared by both teachers and parents (Stockall, 2014). They have become the primary tool for facilitating the inclusion of students with disabilities in accordance with their individual needs (Howes, 2003).

However, while performing various roles for which they are often inadequately trained (Blalock, 1992), and considering the complexity of their job, teaching assistants face various challenges and needs. Research shows that teaching assistants do not undergo adequate education for performing their tasks effectively (Breton, 2010). This, in addition to compromising the quality of services for students with disabilities, gives rise to legal, ethical, and programmatic problems and challenges (Chopra & Giangreco, 2019). They typically undergo brief training, with the expectation that they will be effective in their roles afterward, even though the success of their work depends on various factors (Jurković et al., 2020). Groom and Rose (2005) emphasize the need to focus on the education that teaching assistants receive, given the mismatch between their education and the demands of their roles (Russell et al., 2005).

Over the past decades, the role of teaching assistants has undergone constant changes and development, offering an opportunity for the development of skills and attributes that support students with disabilities (Groom, 2006). The author mentioned earlier states that this ensures a framework for continuous professional development, which can contribute to reducing challenges in the teaching assistants' workplace. Therefore, examining their perception of the workplace is crucial for understanding their experience and, accordingly, improving support for students with disabilities.

## Objective

The aim of this research is to gain a deeper understanding of teaching assistants' perceptions of their workplace, needs, and existing challenges within the regular education system. Additionally, it seeks to determine whether the perception of the workplace changes based on the length of tenure and the number of additional educations attended by teaching assistants.

## Research Problems and Hypotheses

From the aforementioned research objective, the following two research problems emerge:

1. To determine if there are differences in the subjective experience of the challenges of the teaching assistants' job based on their length of tenure as teaching assistants.
2. To determine if there are differences in the subjective experience of the challenges of the teaching assistant's job based on the number of additional educations attended by the teaching assistant in the last year.

Based on the defined research problems, the results of foreign and domestic research, as well as personal experience, the following hypotheses have been formulated:

H1: It is expected that teaching assistants with longer tenure rate their job as less challenging compared to teaching assistants with shorter tenure.

H2: It is expected that teaching assistants who undergo additional education perceive their job as less challenging compared to teaching assistants who do not pursue additional education.

## Methods

The research was conducted online using the "Google Forms" platform. The survey questionnaire was posted on the social network Facebook, specifically in groups aimed at connecting teaching assistants from the Republic of Croatia. Therefore, it represents a non-probabilistic convenience sample. Completing the survey questionnaire took 15 minutes, and it was available for completion over a period of 15 days (from March 27, 2023, to April 11, 2023). Before beginning the questionnaire, participants were informed about the research's purpose, the way to complete the questionnaire, anonymity, as well as the voluntary nature of participation in the research and the option to withdraw from participation at any time during the completion of the survey questionnaire without any consequences. Additionally, participants were provided with information about the research leaders and contact information to reach out to researchers with any questions related to the research process or results.

A total of 197 participants completed the survey questionnaire, initially categorized into four groups based on the classroom settings in which they provide support to students with disabilities: regular mainstream classroom, partly regular and partly special classroom, special classroom, and special education group. Given that the aim of this research pertains to teaching assistants within an inclusive environment, the final sample included teaching assistants from regular mainstream classrooms as well as those from partly regular and partly special classrooms, totaling 168 participants.

The collected data were processed using the SPSS statistical software program. In order to address the research hypotheses, both descriptive and inferential statistical methods were

employed. Skewness and kurtosis z-values were used to test the normality of distributions based on the criteria established by Kim (2013). Since all tested distributions exhibited a normal distribution, parametric tests such as Analysis of Variance (ANOVA) and independent samples t-tests were used for further testing of group differences.

Out of 168 participants, two (1.2%) were male, while the remaining portion of the sample, comprising 166 individuals (98.8%), were female (see Figure 1). The participants ranged in age from 20 to 60 years ( $M_{age} = 37.98$ ,  $SD_{age} = 10.291$ ) (see Table 1). Further distribution pertains to the level of education. Out of the 168 participants, 89 (53%) had completed secondary education, 66 (39.3%) had completed college or university education, and 13 (7.7%) had completed a master's or doctoral degree (see Figure 2).

Figure 1 *Distribution of teaching assistants by gender*

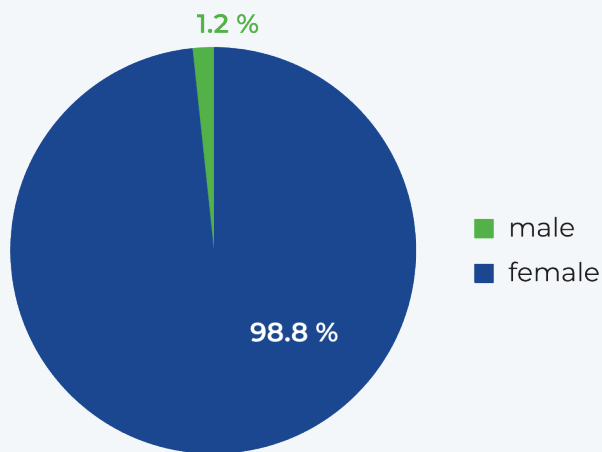


Figure 2 *Distribution of teaching assistants by level of education*

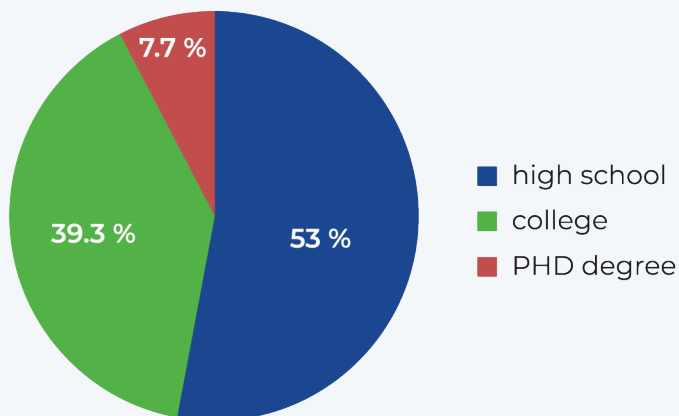


Table 1

Age	
Mean	37.98
Standard Deviation	10.291
Minimum	20
Maximum	60

A questionnaire was constructed, consisting of a total of 35 open-ended and closed-ended questions. The first nine questions pertained to sociodemographic information (age, gender, and education level) as well as data related to length of tenure, basic education, the classroom in which the teaching assistant provides support, the number of students they support, whether their institution employs a specialized educational rehabilitator, and the number of additional education they have attended in the last year. In the following 25 questions, participants expressed their level of agreement on a Likert scale ranging from 1 to 5 with statements related to the perception of the challenges in their job. The final question was open-ended, where participants shared their own opinions on necessary changes they believe would contribute to a reduced perception of the challenges in their job.

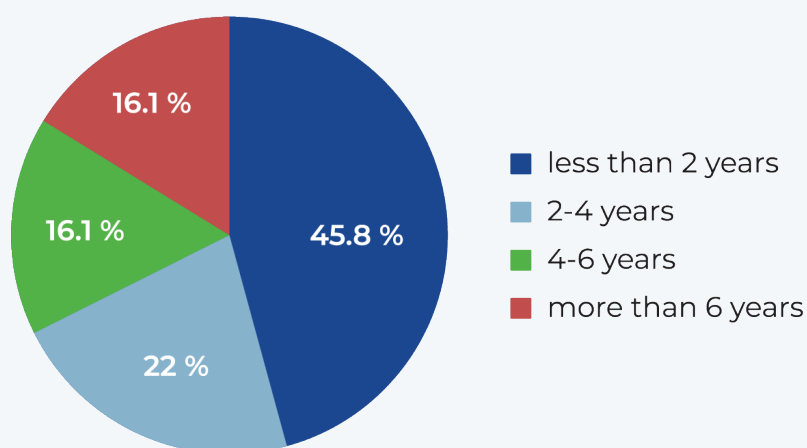
## Results and Discussion

The first hypothesis posits that teaching assistants with longer tenure are expected to rate their job as less challenging compared to teaching assistants with shorter tenure. The total number of participants on whom this hypothesis was tested is  $n = 168$ . The average tenure of teaching assistants is 3 years and 4 months ( $M_{\text{tenure}} = 40.31$ , expressed in months,  $SD_{\text{tenure}} = 32.573$ ). Participants in this study had a minimum of 2 months and a maximum of 12 years and 7 months of tenure (see Table 2). Participants were grouped into four categories based on their length of tenure. The largest number of participants in the teaching assistant role had less than 2 years of tenure, with 77 participants (45.8%), 37 participants (22%) had 2 to 4 years of tenure, 27 participants (16.1%) had 4 to 6 years of tenure, and another 27 participants (16.1%) had over 6 years of tenure in the teaching assistant role (see Figure 3).

Table 2

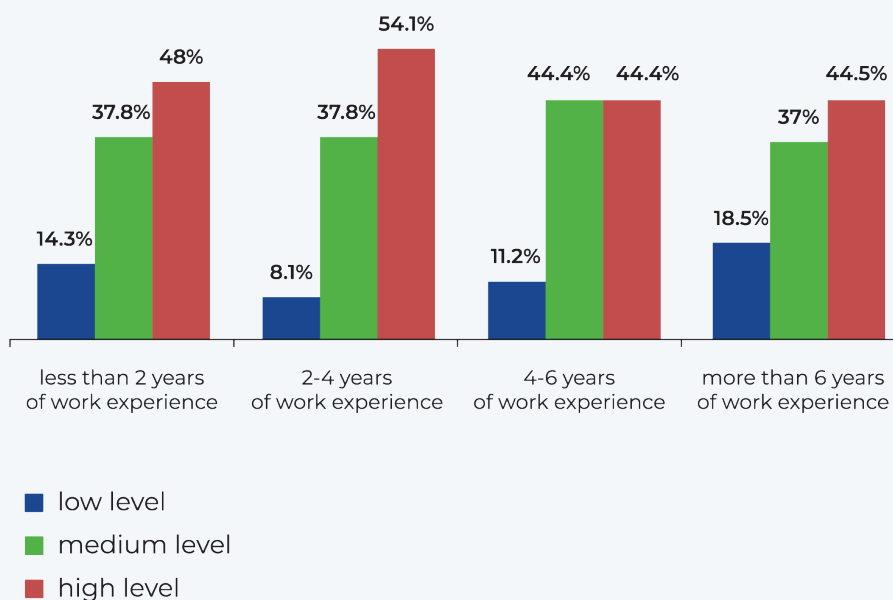
Work experience as TA	
Mean	3 years and 4 months (40.31 months)
Std. Deviation	32.573
Minimum	2 months
Maximum	12 years and 4 months (151 months)

Figure 3 Distribution of working experience as a teaching assistant



In Figure 4, it is visible that among the group of participants who have been working for less than 2 years, the highest level of perceived challenge is experienced by 37 of them (48%). In the group of participants who have been working for 2 to 4 years, the highest level of perceived challenge is experienced by 20 of them (54.1%). In the group of participants with 4 to 6 years of experience, 44.4% (12 participants) perceive a moderate to high level of challenge. Among the group of participants who have been working for more than 6 years, the highest level of perceived challenge is experienced by 12 of them (44.5%).

Figure 4 Distribution of teaching assistants' perceived challenges



As previously mentioned, the normality test of distribution (z-values for skewness and kurtosis) for all tenure categories showed that they were normally distributed according to the criteria established by Kim (2013). Parametric statistics, specifically one-way ANOVA analysis, were employed to test the stated hypothesis. The results of the ANOVA test  $F(3,164) = 0.511$ ,  $p = 0.675$ ,  $p > 0.05$ , indicate that there is no statistically significant difference in the results on the challenge test with respect to the length of teaching assistant tenure (see Table 3). Thus, hypothesis H1 is rejected.

Table 3

ANOVA			
	df	F	Sig
Between Groups	3	.511	.675
Within Groups	164		

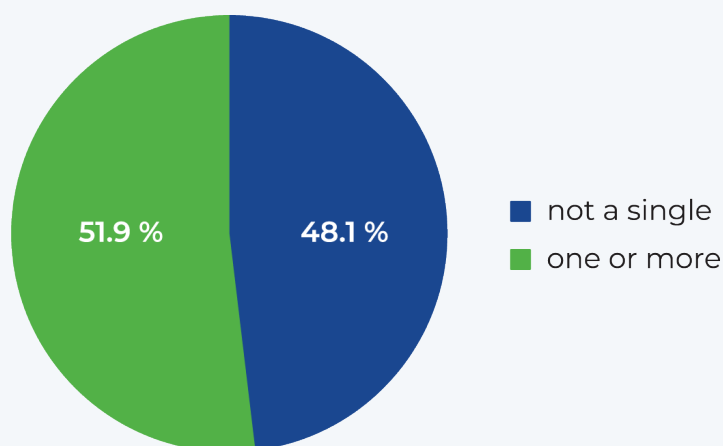
The second hypothesis suggests that teaching assistants who undergo additional education are expected to rate their job as less challenging compared to teaching assistants who do not pursue additional education. To test this hypothesis, participants were divided into two groups based on the number of additional educations they attended in the last year. Out of the total 168 participants, 39 (23.2%) had less than one year of experience and were not included in further data processing for this hypothesis. Data for this hypothesis were tested on a total of 129 participants, of whom 67 (51.9%) participated in one or more education, and 62 (48.1%) did not participate in any education in the last year (see Figure 5). The highest number of educations attended by participants in the last year was 5. The average number of educations attended by participants in the last year is 0.78 ( $M_{edu} = 0.78$ ,  $SD_{edu} = 1.186$ ) (see Table 4).

Table 4

Number of Additional Education	
Mean	0.78
Standard Deviation	1.186
Minimum	0
Maximum	5

Figure 6 illustrates that in the group of participants who did not attend any education in the last year, the highest number of respondents, 33 of them (53.2%), experience the highest level of challenge, while in the group of participants who attended at least one education in the last year, the highest number of respondents, 32 of them (47.8%), also experience the highest level of challenge.

Figure 5 *Distribution of teaching assistants' additional educations in the last year*



The normality test of distribution (z-values for skewness and kurtosis) for all education indicated that they were normally distributed according to the criteria set by Kim (2013). Parametric statistics, specifically an independent samples t-test, were used to test the stated hypothesis. The results of the independent samples t-test showed that  $t(127) = -0.029$ ,  $p = 0.977$ ,  $p > 0.05$ . Therefore, we conclude that there is no statistically significant difference in the results on the challenge test between teaching assistants who attended one or more additional education in the last year and teaching assistants who did not attend any additional education in the last year (see Table 5). Thus, hypothesis H2 is rejected.

Figure 6 *Distribution of perceived challenges by teaching assistants who did not attend any education in the last year*

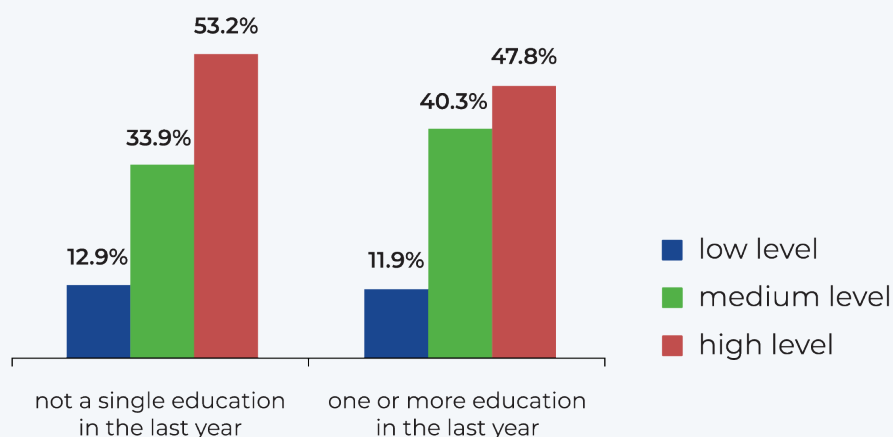




Table 5

Independent Samples Test			
	t	df	Sig
Equal variances assumed	-.029	127	.977

The results of this study indicate that there is no statistically significant difference between the number of education and tenure and the subjective perceptions of teaching assistants regarding the challenge of their job. However, certain aspects in the survey showed the highest average scores, representing areas where teaching assistants find their job most challenging.

One of these aspects is related to the inability to meet their basic needs with their current salary, a concern supported by the findings of other studies since teaching assistant positions are among the lowest paid in the education system (Gist et al., 2022). Research conducted by Fisher and Pleasant (2011) suggests that respondents mention the possibility of a salary increase depending on the experience and skills of teaching assistants, which could be one of the solutions and incentives for employment.

In today's context, many educational institutions face a shortage of teaching assistants, and in addition to the previously mentioned challenges, the participants in this study also express frustration with the yearly contract termination, i.e., the inability to obtain permanent employment. Glashan et al. (2004) emphasize that teaching assistants with more experience provide more effective support to students, but due to the lack of support in terms of employment practices (Fisher & Pleasant, 2011), they are forced to seek other jobs with better working conditions, leaving students with disabilities without the optimal conditions assumed by the inclusive environment.

Despite the numerous difficulties affecting job satisfaction, teaching assistants continue to play a crucial role in supporting the education of students with disabilities (Mirenda, 2014). Besides work experience, continuous professional development plays a significant role in enhancing the quality of their work (Koegel et al., 2014). The participants of this study report attending a limited number of educations during their work experience, and almost half of them have not received any education in the past year. This raises questions about the reasons for this and how to improve the situation. Similar results are reported by Webster and Blatchford (2015), emphasizing that one-third of teachers and teaching assistants have not received education on the specific educational needs of students with disabilities. Authors Giangreco and Doyle (2007) believe it is essential to define the education of teaching assistants and their roles in education. Furthermore, to enable students with disabilities to progress and receive adequate support, clear rules should be assigned to teaching assistants.

Given the research results and the raised hypotheses and concerns of teaching assistants, mainly regarding monthly earnings and contract signing, it is advisable to investigate intrinsic motivation in future research, as teaching assistants provide support to the most vulnerable groups of students (Carter et al., 2008). Intrinsic motivation can play a crucial role in an individual's willingness to develop an interest in work content (Maslić Seršić & Trkulja, 2009). When teaching assistants are intrinsically motivated, they are more likely to seek opportunities for further development, skill improvement, and knowledge enhancement (Knowles et al., 2022). Feelings of disrespect and inequality are reported by a higher number of participants when it comes to collaborating with other educational professionals. Mason et al. (2020) emphasizes similar findings and mentions that such relationships lead to workplace stress and reduced self-efficacy. Moreover, such feelings of inferiority and lack of recognition by colleague's impact job satisfaction negatively (Brown & Stanton-Chapman, 2017). Collaboration with teachers, specialists, and other educational professionals is essential for a coordinated approach to providing support to students (Florian & Black-Hawkins, 2011). Bagawan et al. (2023) highlight the importance of teacher support because through collaboration, active listening, and guidance, teachers and teaching assistants together create a supportive environment that fosters intrinsic motivation and, therefore, increases job satisfaction for both parties. Additionally, research confirms that the effectiveness of the teaching assistant role depends on the leadership of the teacher and their ability to integrate teaching assistants into their work (Biggs et al., 2018).

## Conclusion

The results of the conducted study are in line with previous studies that show how teaching assistants do not consider additional education useful for their role (Symes & Humphrey, 2011). Since the participants in this study undergo very little additional education, future studies should examine the impact of the Dunning-Kruger effect, a phenomenon in which people with less experience or knowledge may overestimate their abilities and fail to recognize the need for further improvement (Dunning et al., 2003).

Metcalf (2009) emphasizes that the tendency to exaggerate one's own knowledge can demotivate individuals and deter them from learning in areas they believe they already possess knowledge in and consider important. In this case, it would be valuable to investigate whether the cause of the limited number of educations is a lack of awareness of the potential benefits that such education could provide. Research suggests that well-trained teaching assistants can effectively perform their tasks (Brock & Carter, 2016). According to Jurković et al. (2020), it is sometimes not essential what people know at a given moment, but their ability to recognize gaps in their own knowledge that will encourage them to learn.

tors influencing the role of teaching assistants is the implementation of qualitative research aimed at providing evidence that can be used to inform practice by examining relevant participants (Brantlinger et al., 2005). However, the obtained results should be viewed with caution since there are certain limitations. Due to the sampling method, the results of this study cannot be generalized to the entire population of teaching assistants. Furthermore, the study was conducted online, and the participants who took part may represent a specific subset that is computer literate. It would be advisable for future studies to include participants outside of an online context.

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## Women's Rights in Institutional Correctional Rehabilitation in the Republic of Croatia: A Blueprint for Research

### SUMMARY

The aim of the research is to find out the possibilities, challenges and peculiarities in the realization of women's rights in penal rehabilitation and underage girls in institutional treatment of a correctional institution. The research focuses on reproductive health, parenting, and training for employment. The research aims to answer the following questions: To what extent do women in penal institutions and underage girls in correctional institutions in the Republic of Croatia understand their rights, have information about them, and describe the challenges they face in implementing them? What do the treatment staff/medical staff/heads of correctional institutions say about the challenges they face in their work and realization of the rights of women and minors? The research methodology is mixed. All women and girls currently in institutional penitentiary rehabilitation and education facilities in the Republic of Croatia who volunteered to participate as well as all treatment staff/medical staff/heads of correctional institutions who volunteered to participate are taking part in the research. The instruments are the questionnaire "Non-discrimination and equality with regard to the right to health and safety" by Penal Reform International, a survey on prison quality or "moral performance" prepared by researchers from Cambridge University Prison Research Center (referred to as MQOL in English Prison Service), guides for semi-structured interviews and focus groups with female prisoners, and guides for semi-structured interviews with treatment staff / medical staff / heads of correctional institutions. Analysis of the results consists of descriptive statistics procedures, analysis of normality of distribution, and, consistent with this, analysis of differences. The empirical material collected through qualitative analysis procedures will also be summarized, structured, interpreted and explained according to the principles of the phenomenological approach. The research results presented in this way are intended to provide suggestions for improving the protection of the rights of girls and women in the penitentiary system of the Republic of Croatia, focusing on the areas of reproductive health, parenthood and education for employment.

**Key words:** *prisoner's rights, women's rights, institutional correctional rehabilitation*

## Prisoner's rights

Human rights represent the inalienable rights of all members of the human family and are accessible to everyone, regardless of differences in race, gender, language, religion, political or other opinions, national or social origin, property status, birth, or other legal status (Universal Declaration of Human Rights, 1948). The mere belonging to the human species grants each individual inalienable rights that other members of the society in which the individual lives are obliged to respect. Among the most crucial human rights are the right to life, freedom, and equality (Charter of the United Nations, 1945).

Achieving equality between women and men and eliminating all forms of discrimination against women are fundamental human rights and values of the United Nations. However, challenges in achieving equality have spurred efforts to realize women's human rights as universal human rights, even though they have not always been a priority, despite the fact that women around the world regularly experience violations of their human rights. Achieving equality between women and men requires a comprehensive understanding of how women experience discrimination and denial of equality to develop appropriate strategies for eliminating such discrimination (MacKinnon, 1989; Connell, 1987; Yuval-Davis, 1997).

The United Nations has a long history of addressing women's human rights, and despite significant progress in securing women's rights worldwide in recent decades, there are important gaps. The realities women face are constantly changing, with new forms of discrimination regularly emerging. Some groups of women face additional forms of discrimination based on age, ethnicity, nationality, religion, health status, marital status, education, disability, and social status, among other grounds. These interconnected forms of discrimination must be considered when developing measures and responses to combat discrimination against women (United Nations, 2014).

By going to serve a prison sentence, an individual loses the right to personal freedom. Prisoners thus become an extremely vulnerable group susceptible to potential violations of fundamental human rights and freedoms (Garland, 1990; Christie, 2000; Davis, 2003; Coyle, 2005).

The rights of prisoners are guaranteed by numerous conventions, laws, and subsidiary regulations. Among the universal legal documents, the most important are the Charter of the United Nations (1945) and the Universal Declaration of Human Rights (1948).

For the conditions of serving a prison sentence, the most crucial documents are the Standard Minimum Rules for the Treatment of Prisoners (UN, 1957), International Covenant on Civil and Political Rights (UN, 1966), Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (UN, 1984), Convention on the Transfer of Sentenced Persons (UN, 1983), and the United Nations Rules for the Treatment of Women Prisoners and Non-custodial Measures for Women Offenders – Bangkok Rules (UN, 2010). The Bang-



kok Rules are particularly significant in protecting women from discrimination in the judicial system, and their development is based on 30 years of advocacy for recognizing the specific risks and needs for the protection of women prisoners.

The rights of prisoners are also guaranteed by European Union regulations, such as the European Convention on Human Rights (Council of Europe, 1950), European Minimum Rules for the Treatment of Prisoners, 1973 (CoE, 1973), European Prison Rules (CoE, 1987, 2006), and the European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CoE, 1987).

The Standard Minimum Rules for the Treatment of Prisoners (UN, 1957) apply to all prisoners without discrimination. The specific needs and realities of all prisoners, including female prisoners, should be considered in their application. However, with the increasing number of female prisoners worldwide, the importance and urgency of developing clearer guidelines related to the treatment of female prisoners have become more pronounced. The standard rules were not sufficient to protect women from discrimination while serving a prison sentence, considering the specific needs and vulnerability of women (Lempert, 1997; Richie, 2001; Petersilia, 2003; Chesney-Lind, & Pasko, 2004).

## **Women's rights in institutional correctional rehabilitation**

Special requirements for addressing the situation of female offenders have been emphasized in various United Nations contexts over the past 30 years. For instance, in 1980, the Sixth UN Congress on the Prevention of Crime and the Treatment of Offenders adopted a resolution on the specific needs of female prisoners. It recommended that, in countries where it had not yet been done, programs and services used as alternatives to imprisonment be made available to female offenders on an equal basis with males. The United Nations, government and non-governmental organizations with consultative status with the UN, as well as all other international organizations, were urged to ensure that fair and equal treatment was accorded to female offenders during arrest, trial, sentencing, and imprisonment. Special emphasis was placed on the unique challenges faced by female offenders, such as pregnancy, childbirth, and childcare (UN, 1980).

In the Vienna Declaration on Crime and Justice: Meeting the Challenges of the Twenty-First Century, adopted at the Tenth United Nations Congress (UN, 2000), member states committed to taking into account and addressing, within the UN crime prevention and justice program and national crime prevention and justice strategies, any disproportionate impact of programs and policies on women and men. They also pledged to develop action recommendations focused on the needs of women as prisoners and offenders. The action plans for the implementation of the Declaration include a separate section dedicated to specific

recommended measures that should follow the commitments. This involves the analysis and assessment and, if necessary, amendments to legislation, policies, procedures, and practices related to criminal matters, in a manner consistent with their legal systems, to ensure fair treatment of women in criminal justice.

The United Nations General Assembly, through its resolution 58/183 titled "Human Rights in the Administration of Justice" (United Nations General Assembly, 2003), called for greater attention to be paid to the issue of women in prison, including the children of women in prison. The aim was to recognize key issues and ways in which these problems could be addressed.

With its resolution 61/143 dated December 19, 2006, titled "Intensification of efforts to eliminate all forms of violence against women," the UN General Assembly defined "violence against women" as any act of gender-based violence that results in, or is likely to result in, physical, sexual, or psychological harm or suffering to women, including arbitrary deprivation of freedom, whether it occurs in public or private life. The resolution urged states to amend or abolish laws, regulations, policies, practices, and customs that discriminate against women or have a discriminatory effect on women. By accepting it, member states committed to taking positive measures to address the structural causes of violence against women and to strengthen efforts to prevent discriminatory practices and social norms, including those related to women requiring special attention, such as women in institutions or custody. It also called for training and capacity-building on gender equality and women's rights for law enforcement officers and the justice system. The resolution recognizes that violence against women has specific implications for women's interaction with the criminal justice system, as well as their right to freedom from victimization during imprisonment. Physical and psychological safety are crucial for ensuring human rights and improving outcomes for female offenders (UN General Assembly, 2006).

The European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT) has, on several occasions, identified specific groups that need special consideration, including imprisoned mothers with children, adolescents, and vulnerable prisoners due to health or social conditions. In prisons where women, mothers with children, or minors are housed, the healthcare team should possess additional skills and specific knowledge to meet the special needs of these populations. This involves providing gynecological and obstetric care, as well as pediatric care. Team members should be trained to work with these special groups to ensure tailored and attentive healthcare. In cases where women are allowed to have their young children stay with them in prison, regular pediatric care should be available, with the possibility of pediatric examinations in the presence of the mother while preserving confidentiality to ensure appropriate child health care (CoE, 2018).

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Recognizing the need for global standards regarding specific aspects related to female

prisoners and offenders and considering a series of relevant resolutions adopted by various United Nations bodies, which call on member states to provide an appropriate response to the needs of female offenders and prisoners, the United Nations Rules for the Treatment of Women Prisoners and Non-custodial Measures for Women Offenders – Bangkok Rules were adopted on December 21, 2010 (UN General Assembly, 2010).

The Bangkok Rules (2010) do not replace the Standard Minimum Rules for the Treatment of Prisoners (1957). All relevant provisions contained in these two sets of rules continue to apply to all prisoners and offenders without discrimination. While some of the Bangkok Rules (2010) further clarify existing provisions in the Standard Minimum Rules for the Treatment of Prisoners (1957) and their application to female prisoners and offenders, others cover new areas. The Bangkok Rules are inspired by principles contained in various United Nations conventions and declarations, and therefore, they are in line with the provisions of existing international law. They are addressed to the prison authorities and criminal justice agencies (including policymakers, legislators, prosecutors, the judiciary, and parole authorities) involved in the implementation of non-custodial sanctions and measures in the community (UN, 2010).

Like the Standard Minimum Rules for the Treatment of Prisoners (1957), given the significant diversity in legal, social, economic, and geographical conditions worldwide, it is evident that the Bangkok Rules (2010) cannot be uniformly applied in all places and under all circumstances. However, they should encourage a continuous effort to overcome practical challenges in their implementation, recognizing that they represent, overall, global aspirations that the United Nations has deemed guiding toward the common goal of improving outcomes for female prisoners, their children, and communities. Some of these rules address issues applicable to both male and female prisoners, including those related to parental responsibilities, some medical services, search procedures, and the like, although the rules are primarily focused on the needs of women and their children. However, since the focus was put on the children of incarcerated mothers, it is necessary to recognize the crucial role of both parents in the lives of children. Therefore, some of the Bangkok Rules (2010) would equally apply to male prisoners and offenders who are fathers (Murray, & Farrington, 2008; Geller, Garfinkel, Cooper, & Mincy, 2009; Poehlmann-Tynan, 2018).

In the Republic of Croatia, significant documents protecting human rights, as well as the rights of prisoners, include the Constitution of the Republic of Croatia (1990) and the Execution of Prison Sentence Act (1999). The rights of prisoners are also regulated by the Family Act (2015) and a series of accompanying sublegal acts such as the Regulation on Prisoners' Benefits (2010). The principles of imprisonment execution and the rights of prisoners in the Republic of Croatia are governed by the Execution of Prison Sentence Act (1999). This is a key act that prescribes rules

for the execution of imprisonment in the Croatian legal system. Among the rights of prisoners covered by this law are the right to accommodation, dignity, and protection from inhumane and degrading treatment, the right to legal aid and access to legal remedies for the enforcement of rights, the right to letters and visits in accordance with the rules of the institution, the right to work and education corresponding to their abilities and interests, the right to health-care, freedom of religion and the practice of faith, participation in cultural and sports activities, and political elections, as well as the right to file complaints if they believe their rights are being violated. The rights of prisoners are further detailed in sublegal acts and regulations related to the execution of imprisonment in specific institutions (Babić, Josipović, Tomašević, 2006).

The fundamental purpose of the execution of imprisonment in Croatia is rehabilitation with the aim of preparing the person serving the sentence for life in freedom in accordance with the law and social rules. This process should take place with respect for humanity and dignity, as stated in the Basic Principles of Imprisonment Execution (Articles 11 and 12) in the Execution of Prison Sentence Act (1999). To achieve the conditions for respecting these rights, the classification of prisoners is important, along with the corresponding accommodation methods, forms of shared sentence execution, and program activities in which prisoners participate in the development and implementation (Execution of Prison Sentence Act, 1999).

Based on the Report on the State and Operation of Penitentiaries, Prisons, and Correctional Facilities and Centers in the Republic of Croatia for 2021, it is evident that women constitute a share of 6.43% of the prison population. This trend has remained relatively stable over the years. At the end of 2021, there were a total of 207 women in the penal system of Croatia - 135 serving a prison sentence, 57 in pre-trial detention, 4 punished for misdemeanors, and 11 with educational measures. There were no girls in the juvenile detention center. The Women's Prison in Požega is the only women's penitentiary in Croatia. Women serve sentences longer than six months (shorter sentences are served in prisons according to the place of residence), representing a specific context where challenges of the judicial system and human rights care intersect. It has a capacity for 165 women, including ten places for minors, and consists of closed, semi-open, and open departments adapted to different levels of security and freedom of movement. The most common criminal offenses for which women are incarcerated are property-related, with an average prison sentence length of five years. The Report on the State and Operation of Penitentiaries, Prisons, and Correctional Facilities and Centers in the Republic of Croatia for 2021 does not include the percentage of the female population based on age and type of offense. However, it provides data on the share of women in the application of security measures, with 26 cases of women out of a total of 640. The most prevalent measures include mandatory treatment for addiction, mandatory psychiatric treatment, and mandatory psychosocial treatment.

Supervision over the treatment of prisoners in penitentiaries and prisons, as well as juveniles in correctional facilities in the Republic of Croatia, in accordance with the laws, is carried out by the Central Office for the Prison System of the Directorate for Prison System and Probation of the Ministry of Justice and Public Administration, the Ministry of Health, the Ministry of Science and Education, the competent execution judge, the Ombudsman, the Ombudswoman for Gender Equality, the Ombudswoman for Children, and the Ombudsman for Persons with Disabilities, non-governmental organizations dealing with the protection of human rights, and, periodically, the European Committee for the Prevention of Torture, Inhuman or Degrading Treatment or Punishment of the Council of Europe and the Mission Board of the European Commission for justice and internal affairs (Babić, Josipović & Tomašević, 2006).

Specific challenges faced by female prisoners are highlighted in some of the reports mentioned in the treatment supervision. According to the Ombudswoman's report for 2021, problems with family contacts have been reported. Due to health protection measures during the COVID-19 pandemic, the scope and duration of visits have been reduced, and calling costs pose a communication barrier for some prisoners. However, the report does not specify whether these are complaints from male or female prisoners and whether the possibilities for contact with minor children have been significantly reduced in this way (Ombudswoman of the Republic of Croatia, 2022).

According to the reports of the Ombudswoman of the Republic of Croatia for 2018 and 2021, as well as the Report on Visit to Croatia, in which the European Committee for the Prevention of Torture, Inhuman or Degrading Treatment or Punishment warned in 2014, the conditions in the women's penitentiaries in Croatia do not comply with legal and international standards and may be degrading (Ombudswoman of the Republic of Croatia, 2019, 2022). In January 2024, new renovated parts of penitentiaries were opened, in compliance with standards (Ombudswoman of the Republic of Croatia, 2022). The Report on the Work of the Ombudswoman for Children for 2019 also speaks about the problems of exercising the rights of parents for a meeting in a suitable environment and points to individual reports of violations of the right of a child to contact a parent serving a prison sentence (Ombudswoman for Children of the Republic of Croatia, 2020).

A special situation exists for pregnant women or mothers with a child born during the serving of a prison sentence, which is regulated by Article 111 of the Execution of Prison Sentence Act (1999). A pregnant woman and a mother with a child born during the serving of a prison sentence are provided with comprehensive healthcare in relation to pregnancy, childbirth, and motherhood. A pregnant woman is placed in the maternity ward six weeks before giving birth, and afterwards in the mother and child department, where she stays until the child reaches three years of age. A pregnant prisoner and a mother with a child have the right to weekly visits from family members.

In this regard, the Ombudswoman for Children of the Republic of Croatia, in the Report for 2019, emphasizes that there is still inequality among children born just before the mother is sent to prison because they do not have the opportunity to stay with her. The Ombudswoman highlights the improvement in protecting the rights and interests of children of prisoners by the Directorate for Prison System and Probation, particularly in the arrangement of separate spaces for visits designed to encourage the relationship and communication between the child and the parent, as well as the introduction of video visits. In June of each year, a pan-European campaign for the protection of the rights of children whose parents are in prison is held under the slogan "Not my Crime, Still my Sentence," in which representatives of the Republic of Croatia actively participate (Ombudswoman for Children of the Republic of Croatia, 2020).

The European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT) visited the Croatian prison system in 2012, 2017, and 2022. The published reports (for 2012 and 2017) emphasize the need to improve spatial capacities and living conditions, ensure access to healthcare, provide more activities, education and critically address the implementation of disciplinary procedures and confidentiality related to prisoners' complaints (CoE, 2014, 2018).

### **Research on the rights of women in institutional correctional rehabilitation - emphasizing reproductive health, parenting, and education for employment**

Scientific research on the complexity of numerous challenges faced by women in serving prison sentences reveals varied results from different perspectives. However, it consistently emphasizes the insufficient representation of research and the lack of a female perspective in existing studies (Chamberlain & Moore, 2002; Covington, 2002; Chesney-Lind & Shelden, 2004; Batchelor & Burman, 2004; Šučur & Žakman-Ban, 2005; Bloom, Owen & Covington, 2005; Jeđud, 2010). The fact that women are less involved in committing crimes and engage in less harmful criminal activities results in a narrower scope of research on their issues. Simultaneously, the challenges women face in serving prison sentences are specific and warrant more attention (McQuaide & Ehrenreich, 1998).

Women in prison confront complex emotional, social, and health challenges, including economic difficulties, unemployment, mental disorders, and social exclusion (Farkaš & Žakman-Ban, 2006). According to Špadijer Džinić, Pavičević, Simeunović-Patić (2009), six factors of prison deprivations for women include deprivation of motherhood, autonomy, individuality, human attention and compassion, and the role of women and friendly relationships. Belknap (2001; as cited in Blanchette & Brown, 2006) mentions enduring issues related to the incarceration of women, such as significant geographical distance from loved ones due



to the remoteness and isolation of women's prisons, limited opportunities for education and employment in prisons, a lack of specialized treatment programs, and insufficient success in separating mentally ill and serious offenders from less severe ones.

In the United States, incarcerated women encounter numerous barriers to achieving reproductive health. When viewed in the broader context of racial bias in the criminal justice system, economic disparities, gender discrimination, and the extensive scope of imprisonment, it becomes apparent that incarceration in the US is a matter of reproductive justice. Many women in custody have significant reproductive healthcare needs, which are often neglected or not acknowledged as crucial medical requirements (Sufrin, Kolbi-Molinas, & Roth, 2015).

In a qualitative study involving incarcerated women in Canada, participants describe their healthcare access and reproductive healthcare experiences. The information presented highlights three components within a reproductive justice framework: limited healthcare access for incarcerated women, attitudes toward pregnancy and contraception influenced by reproductive safety and dignity, and an expressed desire for improved reproductive healthcare. The participants frequently mentioned discrimination, stigma, favoritism, prison conditions, power hierarchies, and experiences of violence in the context of seeking reproductive healthcare (Liauw, Jurgutis, Nouvet, Dinely, Kearney, Reaka, Fitzpatrick-Lewis, Pierson, & Kouyomdijan, 2021). A literature study conducted on UK prison research aimed to investigate the current knowledge regarding women's access to reproductive rights. The study specifically identified notable gaps in the existing literature, focusing on three key research questions: 1) How women access reproductive healthcare in UK prisons, 2) The experiences of imprisoned women with reproductive healthcare, and 3) Their encounters with pregnancy within the prison system, including diagnosis, carrying to term, unintentional miscarriage/stillbirth, and intentional miscarriage/abortion.

The synthesis of papers across three research questions reveals a fragmented and uneven understanding of imprisoned women's access to reproductive rights. The literature predominantly concentrates on pregnancy and childcare within prisons, particularly on maternity care provision and the experiences of separation from infants in Mother and Baby Units. Fewer studies delve into women's experiences of pregnancy in prison, some relying on the perspectives of prison staff and healthcare professionals. Notably, there is scant research on women's experiences of ending pregnancies while incarcerated, including abortion, miscarriage, or stillbirth. Knowledge gaps also persist in other areas of women's reproductive health, such as incontinence, cervical screening, fertility services, and menstruation. Overall, the literature highlights the necessity for more comprehensive research to address these gaps in understanding and advocate for improved reproductive healthcare for incarcerated women (Quandt & Wang, 2021).

In the realm of education for both youth and adult prisoners, a global perspective reveals common challenges across diverse regions, such as Central Asia, North Africa, South America, and Europe. Issues identified include:

- Lack of a well-established legal framework that delineates the fundamental distinctions in the organization of the educational process between general education and vocational schools in penitentiaries compared to regular schools.
- State educational standards do not adequately consider the psychological characteristics of the beneficiaries and the unique circumstances of educational institutions in prisons.
- Absence of a unified state system for prison teacher education, leading to a shortage of qualified teachers who can effectively address the challenges faced by prisons. Additionally, a state system for training prison staff is non-existent.
- The logistical infrastructure in prisons is evolving slowly, with general and vocational schools often lacking sufficient textbooks. Budgetary constraints hinder the allocation of funds to update or create a modern means database for training, including computer classes, multimedia systems, software, television, video equipment, and other educational tools (Czerwinski, König & Zaichenko, 2016).

In most European countries, the provision of education and training requirements encompasses all prisoners. However, in some cases, specific groups may be targeted for educational opportunities, and certain groups are given precedence, such as juveniles or women prisoners lacking basic literacy skills. Additionally, some countries specify particular types of education to be provided, limiting it to primary-level education exclusively (Hawley, Murphy, & Souto-Otero, 2013). Existing resources in prisons are frequently directed toward enhancing protection, safety, and order, rather than investing in prison workshops, vocational training, educational tools, and recreational activities. The prevailing approach appears to prioritize security through restrictive and disciplinary measures rather than by improving the overall prison environment, fostering constructive employment of prisoners, and encouraging positive relationships between staff and inmates (Czerwinski, König & Zaichenko, 2016).

## Research Design and Methodology

This research is part of the TEMIDA project, which focuses on assessing the possibilities and realization of reproductive health, motherhood, and as addition education for future employment rights for incarcerated women in the Republic of Croatia, specifically in the Požega Penitentiary and girls in the Požega Correctional Facility. These two institutions are the only penal facilities for women in Croatia. The project is carried out in partnership with the Association for Creative Social Work, the RODA Association, KUN - Centre for Equality and Diversity,



Nordfold, Norway, the University of Zagreb, the Faculty of Education and Rehabilitation Sciences, and the Study Center for Social Work at the Faculty of Law, University of Zagreb. The project is financially supported by the Active Citizens Fund – Iceland, Liechtenstein, Norway, and its duration is from October 1, 2022, to December 31, 2023, extended until March 1, 2024.

The project's objective is to analyze the possibilities and implementation of incarcerated women's rights to reproductive health, motherhood, and education for future employment in Croatia. Through its activities, the project aims to contribute to the improvement of the protection of the human rights of girls in correctional facilities and women serving prison sentences by strengthening and networking civil society organizations, government agencies, relevant ministries, and other stakeholders. In addition, the TEMIDA project envisions the design and implementation of a series of advocacy activities to continuously empower incarcerated women and girls in correctional facilities to actively raise awareness in the broader community about the importance of respecting the human rights of vulnerable groups and promoting tolerance.

This is the first research in Croatia on the rights of women serving prison sentences and girls in correctional facilities. Additionally, the research considers the perspectives of both women and girls as well as professional prison staff.

All attempts to measure the quality of institutional correctional services typically consider three broad dimensions critical to prison life: Relationships, Personal Development, and Order and Organization. These dimensions are closely linked to humanitarian, rehabilitative, and custodial goals, and they often overlap (Liebling, Hulley & Crewe, 2011). They encompass various empirical dimensions such as respect, humanity, fairness, well-being, professionalism, organization, consistency, and more. The process of identifying relevant dimensions and translating them into measurable items is an ongoing effort (Liebling et al., 2011).

The purpose of this study is to examine the opportunities, challenges, and characteristics of realizing the rights of women and girls in institutional rehabilitation while serving their sentences in a correctional facility. The perspective of all participants in the rehabilitation process is considered. The research specifically focuses on the areas of reproductive health, parenting, and education for employment. The research methodology is mixed, incorporating an exploratory approach to deepen our understanding of the "hard to measure" aspects of correctional treatment, such as rights, humanity, and fairness.

The assessment topics are based on several key documents, including:

- Bangkok Rules (2010) for ensuring the healthcare of women in penal institutions: 7, 8, 10, 11, 12, 15, 16, 23, 26, 28, 33, 42, 28, 29, 51, 52.
- Bangkok Rules (2010) for ensuring the rehabilitation of women in penal institutions - Education, Work and Social Skills Training: 37, 46, 54.

- Standard Minimum Rules for the Treatment of Prisoners (1957): 29, 96-103.
- UN Convention on the Rights of the Child (1989), Article 3.

The goal of the study is to answer the following research questions:

- To what extent do women and adolescent girls in correctional institutions in the Republic of Croatia know their rights?
- How do they describe the challenges in implementing these rights?
- What do the treatment staff, medical staff, and heads of correctional institutions say about the challenges they face?

The research utilizes the following quantitative and qualitative instruments:

1) Questionnaire for woman and girls: Survey on Non-Discrimination and Equality with Regard to the Right to Health and Safety (Penal Reform International, 2015).

Aligned with its designated duties, the UN Working Group dedicated to addressing discrimination against women in both legal frameworks and practical implementations, known as "the Working Group," has developed this survey to gather information on how laws and practices demonstrate discriminatory tendencies against women concerning health and safety entitlements. Furthermore, the questionnaire aims to underscore effective strategies and insights acquired in advancing equality between women and men in the realm of the right to health and safety. The survey is focused on three key aspects: preventing gender-based discrimination in exercising the right to health and safety, identifying and remedying potential instances of gender discrimination in practical applications within health and safety domains, and highlighting commendable practices in these areas.

2) The HM Prison Service questionnaire, "Measuring the Quality of Prison Life," aims to assess participants' self-perceived satisfaction with the quality of life. The questionnaire consists of a total of 136 items divided into 12 subscales that measure the sense of autonomy, safety, relationships within the prison, contact with the outside world, content and amenities, and mental health. Additionally, the questionnaire includes several open-ended questions, providing space for additional explanations (Liebling, et al., 2011).

3) Guidelines for semi-structured interviews with women and girls – designed for this research

The interviews encompass open-ended, individual questions about experiences during imprisonment. They address the following areas:

- Reproductive health care (adequate nutrition, medical check-ups, therapy, monitoring, accessibility of contraception, the right to make personal decisions).
- Pre-natal and post-natal care for pregnant individuals (adequate nutrition, giving birth in a hospital without restraints, the best interests of the mother and child).

- Childcare (adequate nutrition, the best interests of the child, positive mother-child contact, cohabitation in facilities without prison-like features equivalent to nursery/preschool; collaboration among mothers, staff, and professionals, the child's contacts with family members outside the prison/correctional facility, and transitioning the child into the community with preparation, monitoring, and the mother's involvement in ongoing parenting).

- Education, acquiring skills, and knowledge for post-release employment opportunities and possibilities (desires, motivation, prior knowledge) to facilitate successful reintegration into society.

4) Guidelines for semi-structured interviews were created for this research, targeting treatment and medical staff as well as prison managers – designed for this research.

Interviews with staff members involve open-ended questions about their attitudes, opinions, professional experiences, and knowledge regarding the rights of women and girls in institutional correctional rehabilitation, along with the possibilities for their realization. Experts will have the opportunity to discuss the challenges they face, their views on necessary changes, and ideas for their implementation. The emphasis is on the current state and opportunities for improving reproductive health rights, parenting rights, and education for employment, taking into account all current circumstances in the penal system of the Republic of Croatia.

In the research, the entire population will be approached, including all women serving prison sentences at the Požega Penitentiary and all girls at the Požega Correctional Facility. All participants will receive an invitation letter with information about the goal, purpose, stated principles, and the implementation of the research, and will be asked to participate. Consequently, it can be defined that the research participants will be all women and adolescent girls in the institutional penitentiary system in the Republic of Croatia, who are willing to participate in the research.

The same principle will be applied to all professional staff at the Požega Penitentiary and the Požega Correctional Facility. Therefore, it is possible to state that the participants will also include all treatment and medical staff, as well as institutional managers (all participants involved in the treatment of women and girls in correctional institutions in the Republic of Croatia willing to participate in the study).

Data will be collected in three stages: in the first stage through questionnaires, in the second stage through individual interviews with women and girls, and in the third stage through interviews with professionals and management.

The research adheres to ethical standards in social science research. All participants are guaranteed awareness of the research, anonymity, voluntary participation, the option to withdraw at any time, and data verifiability (European Commission, 2021).

In the quantitative analysis, selected discriminant and predictive variables will be utilized. Consistent with previous quantitative studies, the focus will be on variables such as contact with the outside world, relationships with children and family, relationships within the prison, and mental health.

The empirical data gathered through qualitative analysis procedures will be summarized, organized, interpreted, and explained following the principles of the phenomenological approach. The intention is to provide detailed information about the understanding and realization of the rights to reproductive health, parenthood, and education among girls and women in Croatian institutional correctional rehabilitation. The data analysis is in progress.

The research results presented in this manner are intended to offer suggestions for enhancing the protection of the rights of girls and women in the penitentiary system of the Republic of Croatia, focusing on areas of reproductive health, parenthood, and education for future employment.

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