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SYMPOSIUM SERIES

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Experiences of Croatian parents-caregivers: The meaning of caregiving and employment in the context of raising a child with developmental disabilities

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The part of our work with parents of children with (developmental) disabilities

Slišković, A., Tokić, A., Šimunić, A., Ombla J. i Nikolić Ivanišević, M. (2022). Dobrobit zaposlenih roditelja djece s teškoćama u razvoju: pregled dosadašnjih spoznaja, smjernice za daljnja istraživanja i praktične smjernice. [**The Well-Being of Working Parents of Children with Disabilities: A Review of Current Knowledge, Guidelines for Further Research, and Practical Implications].** *Suvremena psihologija, 25 (1).* 47-69.

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Statistics

- According to the report of the Croatian Institute of Public Health (2024), in the Republic of Croatia persons with disabilities make up 17.0% of the total population.
- Of the total number of persons with disabilities, **12.3%** are **children aged 0–19 years**.
- The data are collected from several official state records:

►the most relevant for statistics related to children is the institute responsible for disability assessment, vocational rehabilitation, and employment of persons with disabilities

According to the relevant procedures, in the Republic of Croatia the severity of impairment (the impact of the impairment on functional ability) is classified as follows:

1st degree - no impact or a mild impact on functional ability.
2nd degree - moderate impact on functional ability (need for occasional and/or moderate support)
3rd degree - more severe disability
4th degree – very severe disability.

Being a parent of a child with (developmental) disabilities

...there are days when you cry, scream, both emotionally and physically

- Parents as primary caregivers
- Demanding role
- Long-term care
- *Exceptional* care
- Time consuming
- Financial burden
- Physically challenging
- Psychologically exhausting
- ...

Exceptional care differs from regular child care responsibilities in several ways: the time spent in care is longer, parental care obligations persist through childhood into young adulthood and beyond, and the care demands themselves are pronounced and frequent, with a greater likelihood of additional intensification in (frequent) health crisis situations

! Formal and Informal Support

Being a parent of a child with (developmental) disabilities vs. typical parenthood

- The ***caregiver career=*** parents' perception of the demands of their own involvement in caring for a child with developmental difficulties, as a continuous investment of effort and resources directed toward the child's well-being.
- Parents as **therapists**
- **Managing an unexpected life**
- Constantly **advocating for the child's rights** while experiencing **difficulties in exercising these rights**

(bureaucracy, slow procedures, disorganized information system regarding social rights, centralization of services, unrecognized needs,high prices of services in private health sector)

- **Loss of social network** and **reduced opportunities to participate in leisure activities**

*(...) when I think about it, actually, we were going to a lot of therapy, but it was all worthless if we didn't work with him for hours every single day. And I don't think we would have ever gotten to this point if we hadn't worked like that. But I absolutely agree with *, a parent really shouldn't be a therapist... I see how hard it is for parents and how many families fall apart...*

(...) this fight with everything simply requires a lot of strength and perseverance... parents become doctors and lawyers... you have to read all the laws and constantly question everything...just to know exactly what rights you have...

... something that gives me the feeling that I'm leading a normal life... trip to the cinema, a trip to the theatre, a small trip that is not related to the child's health or care.

Coping demands

- The loss of an image of *ideal* child
- Guilt and a sense of responsibility for the child's condition
- Social withdrawal
- Feeling of loss of control
- Chronic grief
- Parental burnout
- The *continuous journey of coping*...

Parenting children with developmental disabilities is neither expected nor planned.

One becomes a parent-caregiver the moment the system diagnostically characterizes a child as having (or likely to have) a health and/or developmental disability.

- Low socioeconomic status
- Unbalanced distribution of responsibilities within the family

… And if you didn't work that one day or that month with your child, or the child regresses in some way, you can't move away from that feeling of guilt.

I’m shutting down from other people. I don't have time anymore, we don't have time to go for a coffee with a friend. Then somehow, I started ignoring my friends

I’ve lost myself as a person...

Family dynamics

Ombla et.al.(2024) : Parent caregivers who experience greater social support also have better mental health, are they are more satisfied with life, while they experience less parental stress.

- Serious disruption of family dynamics and structure
- Siblings with normal development as a source of strength, but also a source of additional guilt
- Constant balancing of obligations
- ! The importance of social support
- ! Targeted empowerment of siblings and parents themselves, especially in the initial stages of adjustment to the diagnosis

Unfortunately, at some point, other children suffer, no matter how much we don't want them to

..mutual support where you support each other. It's not just my child, or just my husband's, it's our shared child, our shared care, our shared love.

I feel like I'm stretched out a lot and then you know, when you're stretched to the limit, wherever you touch it hurts. That's how it is - my day is fragmented, torn apart, stretched out all over and when you try to squeeze something in there - it hurts.

Caring for an adult child with a disability

- Diminished employment opportunities
- Extreme physical care demands
- Cumulative effects of stressful life
- Coping with parents’ own impaired health
- Care (exclusively) within the family
- Fear about child’s future (when parents can no longer provide care and nurturing)?

- ! The extreme importance of social support

Ombla (2023): Croatian parents caring for adult children with disabilities feel left to their own; they are overwhelmed by fear for their children's future lives and care issues.

When formal education is completed, children are left to their parents, who are getting older and „worn out" due to their lifestyle. There is no systematic, ongoing support.

As a parent, I am deeply troubled by the question, "What happens when I'm gone?" There is almost no adequate accommodation for people with intellectual disabilities, which is the biggest fear of parents.

Adaptive coping mechanisms

- Positive refocusing
- Acceptance (as a process)
- Post-traumatic growth

- ! First aid for parents is instrumental support

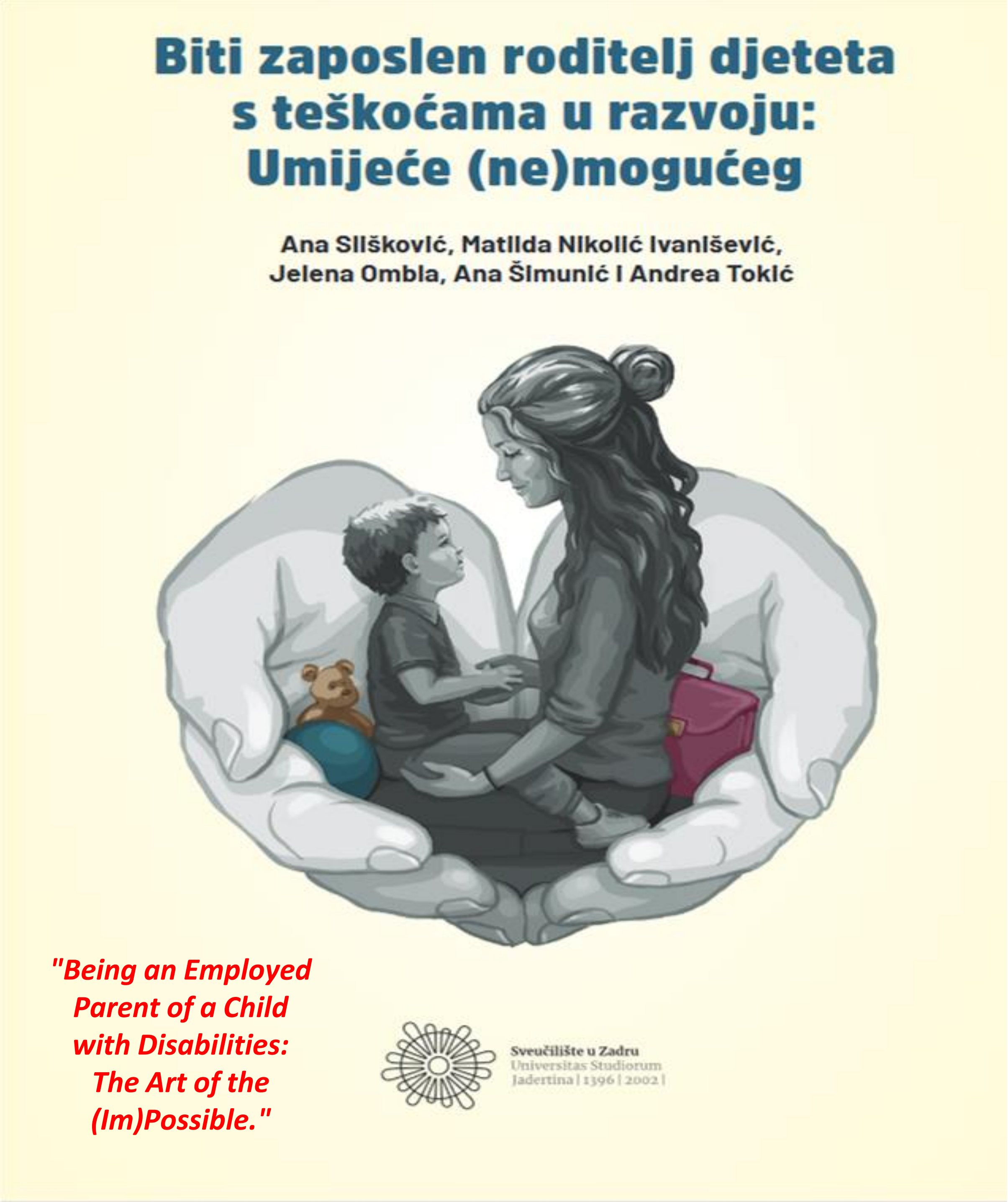
Adapting to life with a child with developmental disabilities should be viewed as a continuous process, primarily because of the child's development itself. Parents experience „good” and „bad” days, they sometimes adapt more successfully and sometimes less successfully.

...the first thing is acceptance, which was hard for me before. When you accept that it's like that, it somehow gets easier. A person comes to terms with the fact that as long as it's not getting worse, it's good.

...you have to look at it from the other side. That not everything in life is so dark. That you have to give them special love, special treatment, special everything and fight for that child.

...as hard and demanding as it is, it's worth it in the end because in the process you grow as a parent and as a person

I say there always can be worse, it can be harder. There are people who don't have what we have, I'm fine with that.



Biti zaposlen roditelj djeteta s teškoćama u razvoju: Umijeće (ne)mogućeg

Ana Slišković, Matilda Nikolić Ivanišević,
Jelena Ombla, Ana Šimunić i Andrea Tokić

Sveučilište u Zadru
Universitas Studiorum
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"Being an Employed Parent of a Child with Disabilities: The Art of the (Im)Possible."

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Experiences of Croatian parents-caregivers: The meaning of caregiving and employment in the context of raising a child with developmental disabilities

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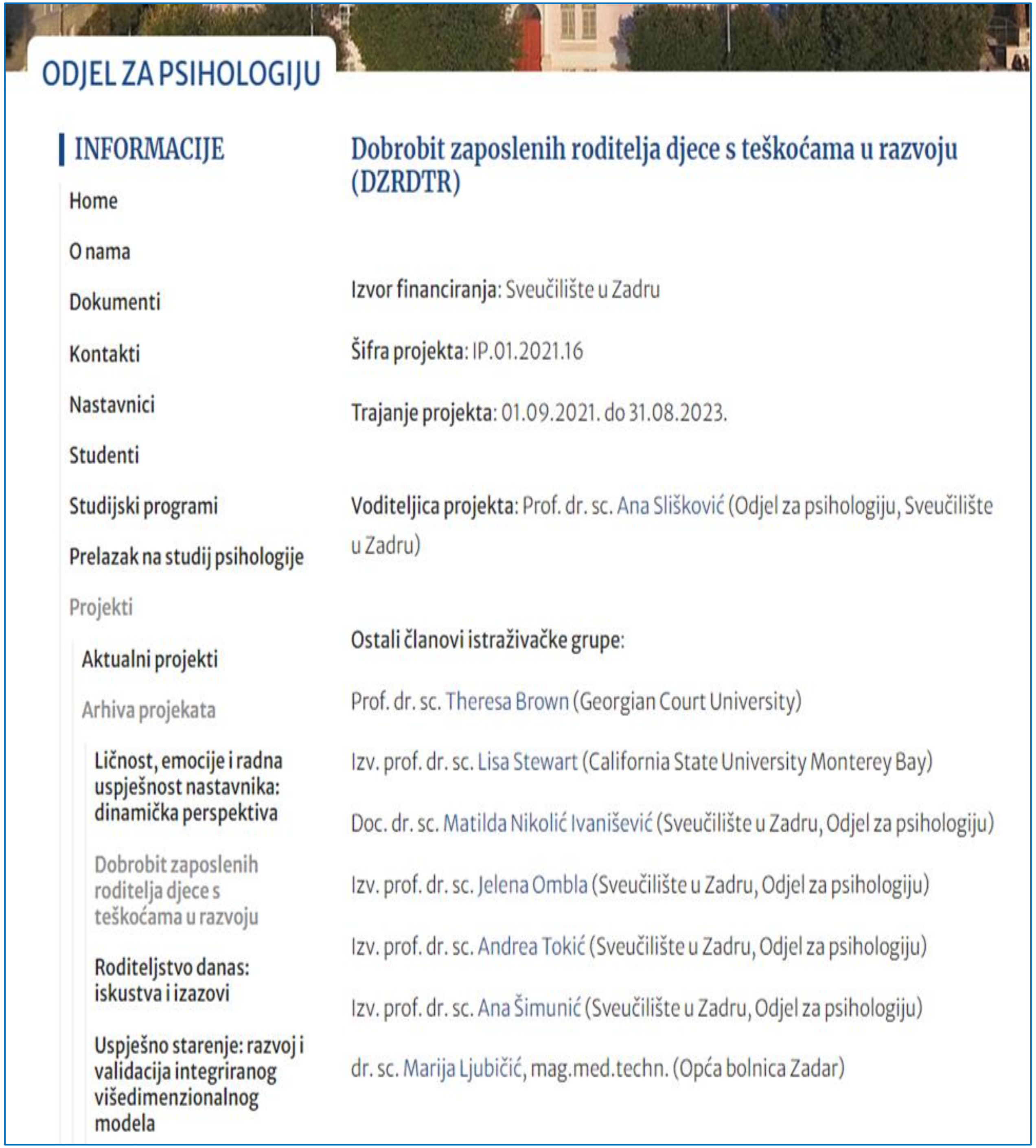

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- Home
- O nama
- Dokumenti
- Kontakti
- Nastavnici
- Studenti
- Studijski programi
- Prelazak na studij psihologije
- Projekti
  - Aktualni projekti
  - Arhiva projekata
    - Ličnost, emocije i radna uspješnost nastavnika: dinamička perspektiva
    - Dobrobit zaposlenih roditelja djece s teškoćama u razvoju
    - Roditeljstvo danas: iskustva i izazovi
    - Uspješno starenje: razvoj i validacija integriranog višedimenzionalnog modela

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General info about the project

"Well-being of Employed Parents of Children with Developmental Disabilities"

Premise (1):
Parents of children with developmental disabilities

- ❑ **High demands and challenges in the parental role:** quantitatively and qualitatively different compared to parents of children with typical development (physical, emotional, psychological, financial, educational, etc.).
- ❑ **Vulnerable group:** more susceptible to negative outcomes regarding parental stress, burnout in the parental role, subjective well-being, and mental and physical health.

- ✓ Caring for a child with an atypical developmental trajectory
- ✓ Learning about the specific disability
- ✓ Finding the right approach to treatment
- ✓ Coordinating various diagnostic, therapeutic, and intervention procedures
- ✓ Advocating for the child’s rights within the social, health care, and educational systems
- ✓ Paying for intervention and therapeutic services not covered by health insurance

Premise (2):
Challenges in the work domain

❑ Lack of research attention, especially in the Croatian context

- **Employment opportunities:** Parents of children with developmental disabilities (especially mothers) are often not formally employed due to the lack of adequate childcare during working hours
- **Work–family balance:** Parents of children with developmental disabilities face more difficulties in balancing family and work roles
- **“The other side of the coin”:** Employment may have a protective function for this group of parents

Premise (3):
Combined professional and personal motives of the research team

Aim and research approach

- **General project aim:**

  To explain the well-being of **parents of children with developmental disabilities*** by including relevant personal, family, work-organizational, and social factors.

- **Mixed-method design:**

- ✓ In-depth interviews (N = 25 employed parents of children with developmental disabilities; 15 mothers and 10 fathers)
- ✓ Survey study (N = 1103; 92% women)

  Employment status: 52% employed, 18% unemployed, 17% formal caregivers

  Degree of disability: 44% – level 4, 25% – level 3, 10% – level 2, 5% – level 1

*** Sample inclusion criterion:** Parents of children with objectively diagnosed developmental disabilities residing in Croatia.

Main results of the project research

SOCIAL DOMAIN

→ Formal care for children with developmental disabilities
→ Rights of children with developmental disabilities and their parents/families
→ Awareness and attitudes of the broader community
→ Informal support

WORK-ORGANIZATIONAL DOMAIN

FAMILY DOMAIN

→ Type and degree of the child's disability
→ Child's age
→ Presence of typically developing siblings
→ Overall family functioning
→ Support from immediate and extended family

PERSONAL DOMAIN

→ Personality traits
→ Coping styles
→ Attitudes toward family and work

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(I.) Does the well-being of parents of children with developmental disabilities depend on their employment status? *

- ✓ ***Employed parents*** (full-time and part-time) have **higher levels of subjective well-being** — better physical health, greater life satisfaction, and more social support.
- ✓ The **work role** contributes positively to a sense of fulfillment and provides a “break” from family obligations.
- ✓ **Part-time work** allows parents to stay engaged in employment while preserving well-being — equally effective as full-time work.

- ✓ **Unemployed parents and formal caregivers** show lower levels of well-being and have fewer sources of social support.

- ✓ **Social support** (from family, kindergarten, school, employers) is crucial for maintaining employment and work–family balance.
- ✓ The **formal caregiver status** does not adequately protect parental well-being — there is a need to develop **respite care** services.

*****Comparison groups:* (1) employed, (2) formal caregivers, (3) unemployed.

(II.) Work-related factors that facilitate the reconciliation of work and family roles*

**Results of qualitative research*

Organizational support: Organizational policy and supervisors

In my team, I experience maximum respect from colleagues and my supervisor, which is great — maybe it's just my individual situation, but really, the relationship is **fantastic**. Also, the company provides **financial support** — for example, HRK 20,000 gross per year for parents of children with developmental disabilities, which is about HRK 10–11,000 net annually. That's roughly HRK 1,000 monthly. But above all, that **flexibility of working hours** suits me immensely. And let's be honest — we have a lot of **vacation days**. I have 29 days off, you know…

The supervisor decides whether exceptions can be made… sometimes they can, but it's not always understood that they can. Sometimes I don't have the strength to look at the schedules, juggle things around for hours… you get tired of it. That's why I say, if it were legally regulated to accommodate such cases… Because **I don't see the point of my four-hour shift if I don't see my child all day.** I start work at two, she comes home at one-thirty, and I'm back at six-thirty — she's already tired and done for the day. I can only check her homework and see if she's ready for tomorrow, but nothing more.

Flexibility of working hours

- The possibility to adjust working hours and work from home facilitates caregiving (limitation: not applicable to all jobs)
- Negative side: “bringing work home” can disrupt family life

> “Flexible working hours don’t mean you can work all eight hours whenever you want, but it does allow you to adjust. For instance, whether you work from nine to three, or from seven to three, or ten to six — depending on your agreement with your supervisor — that helps a lot. It enables me to go on a school trip with my child or attend frequent medical appointments and meetings at school. Knowing I don’t have to work strictly from eight to four gives me flexibility.”

Support from colleagues

My colleagues are **wonderful** — I really have nothing but praise. They’re understanding, supportive, and always help when I need to take sick leave. We always find a solution together.

They’re understanding, sure, but with „don’t touch my shift”. I’ll help you if needed, but don’t swap my shift. They never said anything mean, but they made it clear — okay, you have a child, just let us know in advance if you’ll need to change things.

Job demands

The ability to balance family and work depends on the level of job demands.

Here, one can relax more — you don’t have to prepare as much for the lower grades; it’s all material you already know by heart.

What makes it harder is definitely my job — **the shifts, lots of overtime, being away from home a lot** — that really complicates family life.

Income

Financial stability is crucial for family well-being → higher income enables additional help and services for the child.

To be honest, money makes things easier. Finances solve everything. When you have money, you can have help — a housekeeper, a farmhand… When you don’t, you can’t manage anything. If you can work, you can make your child’s life easier, maybe pay for therapy, a spa stay, or something fun — because if you’re unemployed, the income isn’t much.

What frustrates me most is that my job is higher paid, and then my boss and regional manager keep ‘playing games’ with my salary. They’re reluctant to give me what I deserve, even though I do in four hours what others do in eight, with excellent results — results that affect their own profits.

I’m not satisfied because these are among the lowest-paid jobs with the least social prestige, even though I have a higher degree — I expected at least a bit more.

Autonomy at work

Greater control over one’s work increases flexibility and satisfaction and allows better adaptation to the child’s needs.

I set my own **schedule — location, appointments, working hours, everything. I have a company car, phone, and laptop 24/7, and I plan my workdays myself.**

So, if my child has a hospital check-up tomorrow, I just adjust my day accordingly

What helps me a lot right now is that I’m **my own boss.** I don’t know how I’d coordinate things if I had to work in a team. It’s much easier this way — for the child too. We can go to therapy at 9 a.m., when it’s less crowded, instead of during peak hours.

(III.) Well-being of employed parents of children with developmental disabilities: The role of work-related factors*

- Well-being was operationalized through measures of **life satisfaction**, **self-assessed general health**, and **mental health**.

- Significant relationships were confirmed between well-being and the following work factors:
  - Job demands
  - Work autonomy
  - Support from colleagues and supervisors
  - Financial satisfaction

** Results of quantitative research*

(IV.) Interaction between family and work roles among parents of children with developmental disabilities

● Most previous studies have focused on the **negative aspects** of role interaction, such as:

- Family → work conflict
- Work → family conflict

➞ Both **negatively** affect well-being.

● Our approach also included the **positive dimension** – *facilitation* = positive interaction between roles, where one role strengthens the other:

- Positive spillover work → family
- Positive spillover family → work

➞ Contributes **positively** to well-being.

→ **FACTORS contributing to role facilitation:** personal, family, organizational, and social resources.

Practical implications of the research findings

PRACTICAL IMPLICATIONS OF THE PROJECT RESEARCH

→ Need to **empower parents and families** of children with developmental difficulties:

- **General guidelines for coping with parenting challenges.**
- **Guidelines related to employment and work–family balance.**

→ Need to strengthen **formal professional support** for children with developmental disabilities, their parents, and families as a whole:

Guidelines for professionals in formal support systems

→ Need to strengthen **informal support** through community awareness and sensitization:

Guidelines for members of extended family, friends, neighbors, NGO leaders, and the broader community

→ Need for greater **support** for parents of children with developmental disabilities **in the workplace:**

Guidelines for employers, supervisors, and colleagues

General guidelines for parents of children with developmental disabilities

- ✓ Accepting the reality of the developmental disability
- ✓ “A small circle of great people”
- ✓ Seeking information and support
- ✓ Building partnerships with professionals
- ✓ Supporting and strengthening the family
- ✓ Taking care of one’s own health
- ✓ Embracing challenges and celebrating successes

Guidelines for parents of children with developmental disabilities related to the work domain

💼 **To work or not to work?**
➔ What should be considered when deciding about employment?
🔍 Searching for a job that allows a balance between work and private life.

⚖ **How to further balance the work role with the parental and other life roles?**
- ✓ Disclosure at work and dealing with fear of discrimination
- ✓ Maintaining and strengthening personal resources
- ✓ The importance of family support, but also reducing household demands
- ✓ Planning ahead and setting clear boundaries
- ✓ Ensuring time for rest and recovery from work and caregiving
- ✓ How do other parents do it?

IMPORTANT

- These guidelines are **not a universal “recipe.”**
- Every child and every family is **unique and specific.**
- The list of guidelines is **not final** — it allows for **personal choice and adaptation.**

“A parent must be well in order to provide adequate care for their child — so that their child can be well.”

Guidelines for professionals in the health, education, and social welfare systems*

- ✓ Build **a partnership relationship with parents**, respecting their knowledge and experiences regarding their child.
- ✓ Provide **objective and specific information** about the child’s condition, along with encouragement and support.
- ✓ Show **empathy and warmth** in communication with parents.
- ✓ Address parental mistakes **tactfully and clearly**, with understanding and support.
- ✓ **Inform parents** about all available formal and informal forms of support.
- ✓ Accept and handle **parental criticism** constructively.
- ✓ **Adjust service schedules and support** for employed parents to facilitate work–family balance.
- ✓ Promote and develop **programs and services** that support families of children with developmental disabilities.

- **NOTE:** Research results showed moderate parental satisfaction with professionals, but lower satisfaction with the overall functioning of the system and related legislation. Most problematic aspects: lack of professionals, long waiting times, high costs, complex administration, centralization, inclusion issues, poor coordination between systems, and insufficient care services that would allow employment. ➞ **BIG CHANGES are needed.**

- These guidelines are focused on **“small but significant improvements.”** The formal system should **strengthen parental competencies** and **support entire families**, respecting individual differences.

Guidelines for employers, supervisors, and colleagues of parents of children with developmental disabilities

- ✓ **Information and support:** Provide education about labor rights and create a supportive work climate without stigma.
- ✓ **Open communication:** Encourage empathetic, professional dialogue and joint problem-solving with continuous evaluation.
- ✓ **Flexibility:** Enable adjustment of working hours, remote work, and other forms of flexibility based on individual needs.
- ✓ **Additional support:** Provide practical help at work, task adjustments, substitutions in emergencies, and develop additional programs or benefits.

Goal:

To create an **inclusive work environment** that supports work–life balance, enhances employee well-being, and benefits the organization as a whole.

Guidelines for extended family members, friends, neighbors, association leaders, and the entire community:

👂 **Be there for them:** Offer presence and support, ask how you can help, listen, and assist in ways that are currently meaningful to them.

📰 **Learn about the developmental disability:** Educate yourself about specific conditions to better understand and provide quality support.

🎈 **Include children with developmental disabilities in social activities:** Encourage participation in birthdays, trips, gatherings; adapt the environment and raise awareness about inclusion.

💬 **Support parents as individuals, not only as caregivers:** Prevent isolation, include them in social activities, and show interest in them beyond their parental role.

💞 **Show empathy, not pity:** Respect both the child and the parents, emphasize the child’s strengths, avoid pity and insensitive comments, and talk openly about challenges and needs.

The project and the handbook aim to contribute to the development of a more inclusive society at all levels — including the work–organizational level.

Thank you for your attention!