

**Respecting Dignity:  
“Subjective Wellbeing in People with Intellectual Disabilities”**

*Ihor Kornii*  
*Social Worker*

**Executive Summary**

A report of an action research project in one agency to identify and critically reflect on the factors and forces, which influence subjective well-being in people with intellectual disabilities. It explores whether the responses and attitudes of those who are working with people with intellectual disabilities respects their dignity and well-being.

**Introduction**

This action research project was carried out as part of the Double Degree Programme organised by interdiac (The International Academy for Diaconia and Social Action, Central and Eastern Europe) and accredited by Universities and the relevant authorities in Finland and the Czech Republic. The focus of the programme is on diaconal social services with an emphasis on community development and participatory approaches. As part of this programme, participants have to develop a specific project and also carry out a research project. In this case the project and the research are linked. This article introduces the project and research which I developed and carried out.

A key aim of the action research project was to search for and critically reflect on the factors and forces, which influence subjective wellbeing in people with intellectual disabilities. I was also particularly interested to explore whether those who engaged with people with intellectual disabilities took into account how their responses and attitudes respected the dignity of the people with whom they were involved. The evidence gathering used a narrative approach with the intention of critically hearing and recording the ups and downs in the life and lived experiences of the people with intellectual disabilities. This focused on grasping different views and perceptions on the issue of subjective wellbeing through listening to the experiences and stories of the selected group of people.

**Background and Context.**

The research and practice activities were carried out in cooperation with “Slezská Diakonie” (non-profit Christian organisation), and the therapeutic workshop “Eben-Ezer” in particular. This social therapeutic workshop is a part of “Slezská Diakonie”, and also it is a residential house for people with intellectual disabilities. Alongside, the accommodation, the agency provides service users with a diverse range of practical workshop experiences and activities.

---

The research adopted a qualitative research methodology, a narrative approach for data collection, and thematic analysis for the process of analyzing the data. Time constraints limited the extent of the number of people with whom, realistically, I could engage in the process of data collection. Eventually, a group of six individuals were selected on the basis that I had built up some previous contact with them through a “Peer Mentoring Project”, which I organized and facilitated a few months before current research initiative.

### **Explore the gifts of people**

The inspiration for the researching “subjective well-being” had its roots in my earlier practice experiences in the service agency. An identified concern in day to day activity was that consistently the service users were rarely encouraged to participate in any decision - making processes. This was happening in spite of the fact that the organisation expressed in its aims, that it is focused on the development of the independence of people with intellectual disabilities. In fact, the service users had very limited choice, either what to wear or on what day to clean the kitchen and so on. From my perspective, the “lived experiences “ of people in this centre had very little impact on what might be described as the “quality of their life experience” and it made little difference in their personal development and flourishing. Again, from my perspective, their dignity was barely respected at a personal level.

Another issue is that people with intellectual disabilities within this practice context lacked the chance to give or offer something back to society, they are taken only to be the “receivers”. In other words, no consideration was given to exploring the gifts of the people. In my view, the talents and strengths of the service users were not being fully discovered and utilized.

### **A “Peer-Mentoring Project” as a response to a negative experience**

Taking into account some of the above observations I negotiated with the agency to take in charge in developing and implementing a “Peer-Mentoring Project”. The vision of the initiative was that the participants would have the opportunity to develop and explore how they might use their own skills and talents for the benefit of each other. Furthermore, taking into account theories and ideas about co-design, co-creation and co-production, a strong emphasis was expressed that the project should be in the ownership of its members. This included the group being aware of my role being more facilitative, rather than leading or directing. The intention of my role was to keep a solid focus on the strengths and gifts of the participants of the project, instead of focusing on their disability. The intention and aim was that throughout the project participants would experience being appreciated and gifted enough to share their experiences and insights with other people, who are experiencing similar difficulties and challenges.

Another area I focused on was building up of the personal resilience of the project’s participants. Smith et al have illustrated from their research that through the developing

---

of personal resilience, the individuals may also improve their wellbeing (Smith et al., 2011).

### **A potential pathway for change?**

The outcome of this small scale “Peer-Mentoring Project” was that the participants became very motivated to go on with similar initiatives. The staff team in the agency acknowledged that the process had identified practice development opportunities in their facility and inspired efforts to relate to the user group in new ways.

From my perspective, a change was underway and, according to Lawrie (2010), it is very necessary feature of each project. The “Peer-Mentoring Project” raised some new challenges regarding my own perception and perspectives. This resulted in exploring the phenomenon of subjective wellbeing of people with intellectual disabilities.

### **Human Dignity and Diversity.**

McNaught (2011) argues that diverse people may hold opposing understandings of the systematic factors of the state of wellbeing. That’s why it is crucially important to let the people identify their own conception of the wellbeing within a particular context. Indeed, the studies have shown that what may be considered as positive for one, for others may be a disadvantage. Especially, this is connected to physical and intellectual abilities of people and their experiences, either positive or negative. According to Diener (1984) subjective wellbeing can be evaluated by capturing the information about how people experience their lives. Ideally, they are based on an individuals’ self-reports. Moreover, reflection on subjectivity, in accordance to Knight and McNaught (2011), creates an opportunity to make various interpretations of everyday circumstances.

It was discovered that the participants with more various positive life experiences, who are able to take care about themselves have higher self-confidence and resilience to various life challenges. The people with less social skills are limited to life either with the family or in the institution. Moreover, I explored the connection between the health issues and full participation in society. In fact, it was the reason why they are more dependent on their relatives or guardians. Also, research participants underlined supportive environment, as well as proper medication system as the factors for improved mental health, and, as a result, better subjective wellbeing. Finally, the research has demonstrated that the factors and forces making positive impact on subjective wellbeing of people with intellectual disabilities directly relate to the culture (e.g. watching hockey matches) and family traditions.

The conclusion which I have drawn from this action research project is that social workers and other workers in social services should learn more about and make more effort to create a positive impact on subjective wellbeing of people with intellectual disabilities. It should be addressed as the need of a person, not a ‘Western whim’. From my viewpoint, in the context of social services of Cesky Těšín (Czech Republic), those

involved in the work with people with intellectual disabilities have a focus mostly on physical needs (food, accommodation, clothes, hygiene etc.) of service users. This means relationships and activities with long-term impact are neglected or undervalued. In addition, the narrative approach can be used by the social workers with the therapeutic purpose, aimed at finding out what can make a positive impact by a particular social service on the subjective well-being of an individual. Still, it would require time and the aspiration by the social service to make a change.

### **Future application**

I have learnt many lessons from the research and made some suggestions for future practice, in connection to work with the phenomenon of intellectual disability.

Firstly, there is the necessity to create supportive and encouraging environments, which have massive influence on subjective wellbeing for everybody, not only intellectually disadvantaged people. According to White and Epston (1990), the stories which we tell ourselves or hear from others possess the power to make an impact on our wellbeing, either good or bad. They also suggest to that people with intellectual disabilities should be seen as people first, and as ‘handicapped’ in some way after that. This is why it is important do not underestimate what we communicate to people with intellectual disabilities, and what stories and thoughts we lead them to (as professional social care workers). In my opinion, it is essential in everyday communication, by words and actions, to underline the partnership and equal position of service users and social care workers. Practically, it means to reflect regularly on the language used and its possible effect on wellbeing of people with intellectual disabilities.

Secondly, I would suggest that it is important to pay close attention and underline every little effort of people with intellectual disabilities. As a matter of fact, what may seem as insignificant effort for ‘normal’ society members, may be hardly achievable for the others. Social services should aim at promotion of a good attitude towards people with intellectual disabilities. It can be done on the example of positive practice by “Mencap” (a British NGO, working with people with learning disabilities):

- provide special education;
- promote more positive attitudes via websites, leaflets and social media;
- challenge misconceptions by providing factual information;
- create film interventions to explain what intellectual disability is and show people with intellectual disabilities in positive roles, while also highlighting injustices they experience.

### **Enriching experience.**

This research made a great impact on my personal and professional growth. First of all, throughout the study I have managed to improve the understanding of the concept of intellectual disability, and, in particular, subjective wellbeing (which was very new topic for me). Furthermore, unexpectedly, I came to the outcomes and practical

suggestions for future use by other professionals in the field of social work and intellectual disability. To evaluate the process and the methods used in relation to the participants, the research project was empowering and supportive of different opinions and viewpoints. As for personal professional growth, I learned how to mute the voice inside myself, and give more space for the voice of people. An additional learning point was how we can deal with sensitive topics from the personal biography of interviewed individuals. The study also influenced me in the way that I see and respect the ‘truth’ of people and my own ‘truth’, without making any person or position ‘wrong or right’.

## **CONTACT**

Ihor Kornii  
“Relevant”  
Šmeralova 7  
Přesov  
Slovakia

Web Site: [www.relevant.sk](http://www.relevant.sk)  
Mobile phone: +421 0940 166 179  
Email: [ihorkornii@gmail.com](mailto:ihorkornii@gmail.com)

Relevant is a Christian NGO related to the Lutheran Church in Přesov

## **BIBLIOGRAPHY**

- Lawrie, A., 2010. Creating and managing a new project for volunteer organisations., Third Edition. London, Directory of Social Change.
- Diener, Ed 1984. Subjective Well-Being. Psychological Bulletin, 95 (3), 542–575
- McNaught, Allan 2011. Defining Wellbeing. In Knight, A. & McNaught, A. (ed.). Understanding Wellbeing: An Introduction for Students and Practitioners of Health and Social Care. Banbury, Lantern Publishing, 7-23
- Mencap, UK. Organization for People with Learning Disabilities. Accessed 1.09.2019 and available at: <https://www.mencap.org.uk/>
- Slezská Diakonie, the Czech Republic. Accessed on 1.09.2019 and available at: <http://www.slezskadiakonie.cz/>
- Smith, Amy, Humphreys, Simon, Heslington, Lorna, La Placa, Vincent, McVey, Dominic, & MacGregor, Ewen 2011. The Healthy Foundations Lifestage Segmentation. Research Report No. 2: The Qualitative Analysis of the Motivation Segments. London, Department of Health (DH)/National Social Marketing Centre (NSMC). Accessed on 20.12.2018 and available at: [http://thensmc.com/sites/default/files/HFLS%20Report%20No2\\_ACC.pdf](http://thensmc.com/sites/default/files/HFLS%20Report%20No2_ACC.pdf)
- White, M., and Epston, D. 1990. Narratives Means to Therapeutic Ends. W.W. Norton: New York.