

ABSTRACTS

Conceptualization, Measurement, and Application of Quality of Life for Persons With Intellectual Disabilities: Report of an International Panel of Experts

In this article a number of issues involving the concept of quality of life as applied to persons with intellectual disabilities are summarized, and a number of agreed-upon principles regarding its conceptualization, measurement, and application are presented. We realize that the concepts and models presented in this article will vary potentially from country to country, and even from area to area within countries. The cross-cultural understanding of the concept of quality of life is in its infancy, and we hope that the discourses resulting from the material presented in this article will facilitate both cross-cultural understanding and collaborative work. The article reflects current thought about the conceptualization, measurement, and application of this increasingly important and widely used concept in the field of intellectual disabilities and sets the stage for its continuing development.

Anikó Sándor: “You have to treat them as if they were real adults...” The possibilities and limitations of the self-determination of persons with high support needs

The paper presents the possibilities and limitations of self-determination for adults with high support needs in Hungary, based on a qualitative, participatory research in the theoretical field of Disability Studies. Through the research question – “What support is provided in Hungary for persons with high support needs to be self-determined, in the areas relevant for them?” – it examines the theories of self-determination and suggests a concept, that can include every human being, regardless of their support needs. The research was based on semi-structured interviews and participant observations in different living arrangements (community-based living, group homes, residential homes and living with parents). The qualitative content analysis of the interviews has shown, that the most important barrier of a self-determined life is that the support persons interpreted self-determination as independence, self-reliance and self-sufficiency. The results also indicate that the anomalies in the social system and the oppressive structures disempower the non-disabled supporters, so they cannot provide effective assistance. Goal of the research is to learn about the understandings of self-determination in different living arrangements, to detect the relevant and meaningful ways of performing it, and also to gain initial experiences about par-

ticipatory research with the group, so that further development can be done together with them, rather than for them.

Virág Katalin Bognár: Partners – analysis of support needs of adult men with severe and multiple disabilities. A biographical approach

Background: The goal of the research was to explore the key points through which people with severe and multiple disabilities are connected to the world. What their goals and desires are that adult support services can reveal by interviews. Communication was adapted by means of augmentative and alternative communication via several communication channels.

Method: 15 semi-structured interviews were conducted in three families about the complex support needs. Semi-structured interviews were conducted with the adult family member with severe and multiple disabilities, their parents, friends and neighbours, as well as with one professional.

Results: During the first step of the analysis case studies were prepared about the individual support needs. In the second step three overall themes emerged from the content analysis of the interview texts: The 'Multifaceted communication: considering them as adult partners' theme; 'Complex support needs of managing one's life' and the 'Roads of independence and the family support' theme, the latter contained three sub-themes: 'breaking the closed family environments', 'transmitting and assuming the male role' and 'out of the family towards independence and a residential home'.

Conclusion: Besides the common support needs the analysis revealed the importance of 'individual support need packages' which can serve as the basis of the service organization. Lacking services were the provision of daily activities outside the family, programs with peers, help in the transition process towards the supported independent living or a residential home, and finally ensuring mental health.

Sándor Gurbai: “We love it, because we have to”. Residential institutions for persons with intellectual disabilities are under Ombudsman’s scrutiny

Persons with intellectual disabilities are often deprived of their freedom of movement and their right to free choice of residence and are placed in large residential institutions providing long-term care. This paper summarizes the findings of the Ombudsman’s inquiries based on on-site inspections carried out in 2015 in three institutions located in different geographical parts of Hungary (Trans-Danube area; area between the Danube and the Tisza rivers; Trans-Tisza area). The article draws systemic conclusions and makes comments based both on personal experiences of persons with intellectual disabilities living in the inspected institutions and also on personal accounts of institutional staff. In addition, the paper presents critical remarks on the Ombudsman’s reports.

**Marianna Kopasz: Costs and outcomes of residential services for adults with intellectual disabilities in institutional and community living.
A methodological review of the literature**

The quality and costs of residential support for people with intellectual disabilities in institutional and community living are important issues for countries at the outset of the deinstitutionalization process, such as Hungary. The aim of this study is to review the research on the quality and costs of residential alternatives conducted mainly in the U.S. and UK during the deinstitutionalisation process. Taking a problem-oriented approach, we discuss the methodological challenges researchers face when studying the costs and quality outcomes of living arrangements for people with intellectual disabilities. Also, we look at how different client and setting characteristics influence the quality of life and the costs of care for persons with intellectual disabilities.

