

Promoting independence for people with disabilities

(scientific paper)

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Abstract: *The following post aims to present partial results from the ongoing research, which is based on the initiative of the Abakus Foundation. The main objective of the project is to map good practice in the system of support for the independence of young adults with disabilities in the Czech Republic. Supporting the independence of people with disabilities is one of the important areas that contributes to improving the quality of life. This concerns both the disabled individual and the person caring for them. In this paper, we will offer a brief insight into the issue of independence and partial results of the research carried out.*

Keywords: *independence, disability, intellectual disability, physical disability, deaf-blindness*

1 Introduction

The concept of independence can be viewed very broadly, in different ways and at different levels. For example, it is also referred to in the Convention on the Rights of Persons with Disabilities as one of the general principles of access to people with disabilities (MoLSA, © 2020). Independent living takes into account several areas, such as independence from family or institutional care, access to independent housing, food, the ability to find and keep a job, and the provision of sufficient financial resources to cover essential living costs. It also includes independence in activities of daily living such as transport, shopping, self-care, advocacy for individual rights and interests, provision of all essential needs, pursuit of hobbies and entertainment, participation in social life, starting one's own family or partnership (Jurkovičová, Růžicková, 2022).

Ensuring the highest possible level of independence for people with special needs is a key element in achieving the highest possible quality of life. Independence brings with it a greater level of satisfaction and happiness (Haigh et al., 2013). It is also a factor that helps the individual to work better with themselves, have control over their actions and be more self-sufficient (Sexton, O'Donovan, Mulryan, McCallion & McCarron, 2016). Thus, a number of studies speak of a lifelong process of education and support towards strengthening independence. All of this is done with the support of family and professionals who assist the individual with a disability (Hale et al., 2011; Young et al., 2012).

The very nature of a disability means that it restricts an individual in certain activities of their normal life. The degree and type of disability also determines the degree of dependence on the help of others. Particularly in the case of severe disabilities such as mental or physical disabilities, there is more support from parents, teachers, carers or other professionals who work with the individual. However, in the field of special education, the goal is to achieve the maximum development and possible degree of socialisation, which leads to support and independence for individuals with disabilities. However, it is not entirely impossible to achieve at least partial independence that is optimal and achievable for the individual (Sandjojo et al., 2018).

Below we describe a list of disabilities that are inherently considered some of the toughest severe forms.

Intellectual disability

According to the ICD-10, mental retardation is characterized as “A condition of arrested or incomplete development of the mind, which is especially characterized by impairment of skills manifested during the developmental period, skills which contribute to the overall level of intelligence, i.e. cognitive, language, motor, and social abilities. Retardation can occur with or without any other mental or physical condition.” Intellectual abilities and social adjustment can change over time and even disabilities can be improved through exercise and rehabilitation.

Independence and self-sufficiency will be affected by the degree of mental retardation. Individuals with a milder degree of mental retardation may achieve full independence in self-care and practical skills of daily living. Difficulties may occur particularly in managing more complex tasks and situations. With a higher degree of mental retardation comes a limited ability to perform self-care activities, manual tasks and self-sufficiency. They need support both in managing the household and in living independently. Individuals with the most severe degree of mental retardation already require constant supervision and support in all areas of life (Huang, 1997; Glidden, 2021).

Physical disability

Physical disability can be defined as a persistent or permanent impairment of motor skills with a permanent or significant effect on cognitive, emotional and social performance (Gruber, Lendl in Vítková, 1999).

Physical disability causes a reduction in independence and reinforces dependence on other people. Limited physical abilities can make self-fulfilment more difficult. The degree of self-sufficiency and independence is important and is related to the maintenance of acceptable motor function of the upper and lower limbs.

Deafblindness

Other severe disabilities undoubtedly include combined hearing and vision impairment, i.e. deaf-blindness. Vision and hearing are essential components in obtaining information, communication, orientation, self-care and education. The reduction or complete loss of both senses brings with it quite extensive problems not only in these areas, but in the overall life of such an individual. Limitations in hearing and visual perception entail a number of specific adjustments to the services provided which are to such an individual, as well as to the environment modifications, which are dependent on the degree of hearing and visual impairment, the time of onset of the impairment or the possible comorbidity of multiple impairments. Deafblindness, as this disability is also called, has a number of definitions. European Deafblind Union (EDBU, © 2014) defines deafblindness as follows: “Deafblindness is a unique disability caused by various combinations of auditory and visual impairments. It causes obstacles in communication and in social and practical interaction and it prevents full and inclusive participation in society.” Similarly deafblindness is also defined by NHS: “Deafblindness is a combination of sight and hearing loss that affects a person’s ability to communicate, access information and get around.” Setkáme se také s pojmy jako např. “dual sensory loss” or “multi-sensory impairment” (NHS, © 2022).

Even though both senses are affected, it does not mean that the person is completely deaf and blind. As a rule, one of the senses is more preserved than the other, but there is still a limitation to such an extent that it causes the individual problems in everyday life. Such problems include, for example, the need to turn up the television or radio, or poor orientation in communications where many people are talking at the same time. The individual also has problems if someone speaks to them from behind, quietly and too quickly. In the context of reduced visual perception, this includes problems with spatial orientation, self-care activities, and interaction with the environment. It is necessary to involve compensatory factors such as tactile or cognitive functions. In addition to education, it is also problematic to engage the individual in the work process at the same time (LORM, © 2015).

As can be seen, the combination of multiple disabilities at the same time also falls under the category of severe disability. The care of such individuals will be very specific. The needs towards the integration of the individual into society will vary according to the individual comorbidities and an individual approach will again be essential. Depending on the type and degree of disability and the level of the individual concerned, approaches and methods will be chosen that will lead to the highest possible level of independence and self-sufficiency, thus promoting independence.

The above forms of disability are key to the research within the ABAKUS project – Mapping good practice in the system of support for the independence of young adults with disabilities. The aim is to identify the most used and effective forms of treatment and rehabilitation for people with severe disabilities, which are aimed at developing the highest possible level of independence and self-sufficiency and thus lead to the improvement of the quality of life not only of these concerned, but also of their caregivers. The outcome is the creation of a comprehensive proposal of individual rehabilitation and therapeutic approaches, services and methods that lead individuals towards independence within the Czech Republic.

2 Methodology

On the basis of the ongoing research, it is a mapping of available or missing services and methods within the Czech Republic. The aim is to describe these services and methods and to find the most effective ones, as well as new services and methods that support independence of people with disabilities and have not been systematically described in the literature so far.

The project is implemented in several phases:

1. Mapping the current situation in the field of empowerment of individuals with disabilities towards independence by searching for systematic reviews.
2. Key interviews with people with disabilities, families (or caring persons) of people with disabilities and providers of services for people with disabilities.
3. Creation of good practice cards to offer a systematic overview of the most effective services, methods and approaches that assist in moving individuals with disabilities towards independence.

The first stage of the research searched already established systematic reviews for source material that could provide evidence-based information on promoting independence for people with specific needs. The search strategy involved searching the Epistemonikos and Cochrane databases based on predetermined keywords. Primary searches were for English-language articles whose title and abstract contained the

keywords. The date of publication was not limited in time. Keywords for the first search: independent living, people with special needs/disabilities and services. Keywords for the second search: housing, employment, assistance and disability. The next step was screening – reviews screened out or ranked according to predetermined criteria based on reading titles and abstracts. Included reviews were then assessed by reading the full texts. Data from the included reviews were extracted and organised into summary tables and the outputs helped define examples of good practice in the system of supporting independence for young adults with disabilities.

The systematic reviews identified in this study addressed supportive interventions within several domains. Three of the included systematic reviews dealt with personal assistance, two dealt with independent living support, two dealt with vocational rehabilitation support, and the remaining six reviews dealt with different types of interventions that promoted independence for people with disabilities in one or more areas of their lives or focused on their transition from childhood to adult life and services.

The second, and still continuing phase, is interviews focusing on mapping the area of services, methods and techniques provided to individuals with disabilities and their families or caregivers in the Czech Republic. The services sought should be aimed at supporting the independence of the individuals concerned through compensation or support services or compensatory aids/technologies. But we also include here the possibility of modifying or reducing the demands of the environment with the possibility of using a particular service or aid/technology.

The interviews were grouped into three categories, according to the position of the entity either using or providing the service. The first group of interviewees are families (or carers) of individuals with disabilities. Based on pre-determined questions and criteria, this group of individuals' experiences with the provision of services and methods leading to their child's independence are explored. Those that were most beneficial and effective for the group, according to the individual assessment, and helped the affected member to achieve the greatest degree of independence are sought. The ongoing research shows that individual attention, staff expertise, time and cost availability of the service/method, comprehensiveness, and a friendly and supportive environment are key to the use of services by families with a member with a disability.

We have similar experiences from interviews with individuals with disabilities themselves. Above all, the individual approach, the comprehensiveness of services, the expert staff and the all-round accessibility of services and methods are absolutely crucial for each individual. The interviews, however, focus on the individual specifications of these services and methods and, on this basis, the most effective ones are sought for the independence of the individuals concerned.

Interviews with service providers focus on their access to services or their processing technologies/tools. This information is also very valuable for the subsequent development of best practice cards. The expert perspective provides additional information about the service, method, technology and how it works in practice. They can complement the experiences of families and individuals with disabilities with expert insight into the effectiveness of the services and methods they provide. Because of their expertise, the worker can modify the service to carry the various elements according to the needs of the clients. Together they also plan how best to achieve a degree of independence. The staff position is also crucial to motivate and encourage the client and their carers. At the same time, the worker can also recommend which methods, technologies/aids and services can help the individual to become independent, which of these options are good to include at the beginning of rehabilitation and which options can be added to this care during further development according to the needs of the individual with a disability.

3 Results

It should be added that these are only partial outputs from the interviews and therefore it is not possible to create a comprehensive view of the services provided. However, we can already say that the above-mentioned aspects are, due to their frequency, essential for the project's outputs. The research investigation leads to the identification of the most effective and key methods, services and procedures that help to improve the lives of people with disabilities towards the highest possible level of development of independence. In order to make such an investigation effective in practice, so-called good practice cards will be created to describe the services, methods and aids. The content will be to adjust the environmental conditions to the extent that self-realisation, self-care and decision-making are enabled with the level of skills and abilities that the person currently possesses.

4 Conclusion

This contribution presented the main aim and partial results of the project stages implemented in the Czech Republic. We are now in the stage of data collection through interviews conducted with families of persons with severe disabilities, with persons with disabilities themselves and with providers of services to persons with disabilities. The last phase of the research will be the creation of good practice cards. These cards can be imagined as a systematic overview of the specific most effective services, methods and approaches that help in the empowerment of individuals with disabilities towards independence. The content of the cards will be based on the data collected from the interviews.

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