Faktory ovlivňující proces osamostatňování u osob se zdravotním postižením

Factors Impacting the Process of Independence for People with Disabilities

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Abstract

Empowering people with disabilities to become independent and autonomous is crucial to their fulfilling life. Studies and background search show that crucial factors in this process include personal assistance, support for independent living and programmes aimed at vocational rehabilitation. What is also important is the development of skills for everyday life. In addition, support for the families caring for these people is key to successfully coping with the challenges. In general, the development of independence for people with disabilities requires a multidisciplinary approach and respect for individual needs. This article provides an overview of different forms of support and interventions aimed at helping these individuals reach their full potential for independent and quality living.

Keywords: Gaining independence. Disability. Young adults. Support. Intervention. Qualitative research.

Introduction

Identifying pathways to independence and autonomy for people with disabilities is a complex task that requires a systematic approach and a firm grounding in relevant data and information. There is a wide range of services and interventions available to provide the support needed to enable them to live full and independent lives.

Studies and background search provide insights into different aspects of supporting people with disabilities. Personal assistance, which enables people with disabilities to remain independent and active in their everyday lives is one of the key elements. Another important factor is the promotion of independent housing, which provides a suitable and accessible environment for them to live in. In the area of employment and vocational rehabilitation, there are various

programmes, such as supported employment, helping people with disabilities to find and keep their jobs. The development of skills for everyday life also plays a vital role in the independence and self-esteem of these individuals. In addition, it is obvious that support for families caring for people with disabilities is crucial to the successful management of everyday challenges. Programmes and services that respect the individual needs of families can contribute significantly to the overall quality of life and independence of everyone involved.

In general, the development of independence for people with disabilities requires a complex and multidisciplinary approach. In this article, we take a closer look at the different forms of support and interventions that can help these individuals reach their full potential for a fulfilling life.

Persons with Disabilities

There are several definitions for categorising people according to their disability. However, in terms of their approach to independent living, the used terminologies can be seen as identical. An individual with a disability is independent until they encounter an obstacle preventing them from doing so. These may be internal or external barriers preventing them from developing independence. At this point, the individual, in order to overcome the obstacle, becomes dependent on the assistance of another person and is therefore affected by their disability. The medical model sees medical care as the main solution of the problem. On the other hand, the social model works with integration as much as possible. It does not perceive the limiting factors for full independence as characteristics of the individual, but rather as a picture of the whole society, which deepens or even creates these limitations (MKN-10, 2001; Act No.108/2006 Coll. on Social Services, 2006). However, if these limiting internal or external barriers can be modified, the boundaries of independence for people with disabilities can be pushed significantly. The fact is that their needs are not any special or specific – as the terminology used may mislead. People with disabilities have the same needs as the majority society and can be characterized by the Maslow's well-known hierarchy of human needs. What prevents them from meeting these needs in the common way set by society is a physical disability, chronic illness, sensory impairment, reduced intellectual level or mental illness (Novosad, 2009). Thus, individual conception of a value system may not be consistent with the societal setting of these values (Maslow, 2014). The basic set of values remains the same from the beginning, but higher order values may rank differently for each individual (e.g. the importance of the value of one's own life). A disability therefore imposes physical or mental health limitations that can be detrimental to full participation in common life and achieving optimal health condition.

Specifics that can negatively affect the life of persons with disabilities include:

- **Physical limitations** leading to reduced or restricted mobility and the ability to perform specific physical activities; these can be manifested in the individual's independent movement (walking, handling objects, everyday tasks);
- **Impairment of cognitive abilities**, including intellect and mental capacity; manifestations can be found in thinking, memory, attention, imagination, perception or speech and communication skills;
- **Limitations in the communication area**, namely problems in speaking and expression, as well as comprehension; alternative or augmentative communication systems can be learned and used;
- **Limitations of sensory functions**, i.e. reduced or fully impaired perception using one or more of the senses (sight, hearing or touch); the issue may be manifested in the field of communication, spatial orientation, independent movement, self-service activities or information acquisition;
- **Limitations in the emotional area**, when the individual is unable to adequately regulate and work with their emotions; problems may be manifested in the area of self-awareness, self-assessment, self-regulation, etc.; health problems may have direct impact on the psyche of the person with a disability leading to states of anxiety, stress, deprivation, etc;
- **Specificities in the area of social relationships and inclusion**, where health conditions can lead to social isolation; also includes prejudices, stereotypes and misinformation of mainstream society in relation to people with disabilities (Fischer & Škoda, 2008; Slowík, 2016).

Determination of the Stages of the Independence Process

Independence and autonomy are key concepts in human development and social integration. These concepts, defined and discussed by various authors, are crucial to an individual's ability to manage their own life and make decisions about themselves. Independence, often understood as self-sufficiency or self-reliance or even autonomy, is associated with freedom of choice and personal decision-making. It thus forms the fundamental pillars of individual development and quality of life, not only for people with disabilities. Various authors approach the independence concept slightly differently. For example, Pacovsky (1994) conceptualizes autonomy as the capacity for self-sufficiency, while Maddux et al. (1982) include self-determination, self-direction, and the perspective of personal control. According to Zavázalová (2001), the idea of self-sufficiency is extended to include the ability to take care of oneself and the household, and she also attributes importance to it in everyday activities. These activities can be personal, i.e. related to biological needs, or instrumental, involving more complex activities in the domestic and social environment. Autonomy is closely linked to freedom and individual choice and is a key factor influencing an individual's quality of life. Thanks to autonomy, a person has

the ability to influence their actions and environment, which brings them a certain responsibility and freedom of choice. This concept promotes not only a sense of control over one's own life, but also the individual's active participation in planning and directing their activities (Reed & Sanderson, 1999).

For an individual with a disability, the very process of becoming independent is a crucial step towards self-reliance and autonomy. The individual learns to deal with common life situations and to plan their life according to their needs and preferences. This process requires an inclusive approach by society, technological support and coordinated work by professionals. As stated by Jovanović et al. (2022), the carers can play a key role in supporting an individual's autonomy, providing the necessary help and support and maintaining their decision-making abilities.

The process of becoming independent for people with disabilities is complex and involves several key stages. These stages are accompanied by different emotional and psychological reactions and require support and help from a variety of sources, especially family, friends, therapists and specialist disability services. Individual stages of the independence process can be specified as follows:

- **Increasing sensitivity and awareness of one's own needs:** The individual is aware of their need for independence and recognises their own abilities and limitations in the context of their disability.
- **Planning and preparation:** The person starts actively planning and preparing for independence. They seek information about available sources of support and services that can help them achieve independence.
- **Acquiring skills:** A person with a disability actively develops the skills necessary for independent living – self-care, household care, financial literacy, communication development and other practical skills.
- **Implementation of plans:** At this stage, the person with a disability actively applies their skills and plans to achieve independence and self-reliance as much as possible.
- **Adaptation and coping with obstacles:** During this process, obstacles and challenges may arise that require adaptation and coping with new situations and environments.
- **Maintenance and further development of independence:** After reaching a certain level of independence and self-reliance, the individual works to maintain these achievements and can continue to learn and develop skills.

All of these stages are dynamic and individual; therefore it is important and crucial to provide the individual with support and resources appropriate to their needs and abilities.

Factors Impacting the Process of Independence

An individual's health and type of disability have a significant impact on their ability to achieve independence and autonomy. Physical disabilities or chronic illnesses can mean mobility limitations, making everyday activities difficult even with the use of special aids. People with sensory impairments, such as hearing or vision loss, may have limited ability to communicate or navigate, which affects their ability to participate fully in common activities. People with intellectual disabilities or learning difficulties may have problems understanding information and learning new skills. The severity of the disability can also affect the social support an individual receives. It can lead to prejudice, discrimination or social exclusion. According to Pei et al. (2016), individuals who need help with everyday activities can feel abandoned and isolated from society, therefore maintaining their independence in these activities is a key factor in their quality of life.

The support of family and friends plays an irreplaceable role in the process of becoming independent. Close people, such as family, friends and loved ones can provide the individual with crucial emotional and practical support. Emotional support includes encouragement, understanding and acceptance, which can be essential for maintaining motivation and overcoming difficulties possibly arising in the process of gaining independence. In addition, family and friends can provide practical help in everyday life (household care, transport, health care, etc.). This practical support can make routine tasks for people with disabilities easier, enabling them to focus on their goals of independence and autonomy. And with the support of family and friends, individuals feel empowered and are more likely to successfully achieve their goals (Wagner, 2004). Vymětal (2003) adds the necessity of emotional response in a positive sense, especially from loved ones, as well as the necessity of social placement, encouraging the growth of the individual's self-esteem.

The availability and quality of support services have a major impact on the ability of individuals with disabilities to achieve independence and self-reliance. Quality rehabilitation programmes are key to providing people with the necessary skills and tools to manage their daily activities and maximise their potential. It is crucial for these programmes to be accessible and to provide the professional support and training needed to develop skills and independence. Additional important services include personal assistance that can provide practical help in everyday life, whether it is help with hygiene, meal preparation or transport. The availability and quality of these services can significantly affect the ability of individuals with disabilities to successfully integrate into society and achieve their goals of independence. Special education programmes are also key to providing the necessary resources and support to educate individuals with disabilities and prepare them for a successful transition to working life and full participation in society. Improving the availability and quality of these services is therefore essential to support the independence and

autonomy of people with disabilities (Garwood et al., 2023; Patton & Polloway, 1992).

Financial status plays a key role in the ability of individuals with disabilities to achieve independence. The availability and quality of services and support available to these individuals often depends directly on their financial means. Some services, such as rehabilitation programmes, personal assistance, or special education programmes, can be expensive and may not be completely affordable for individuals with disabilities. This can lead to a lack of access to essential services and limit their ability to achieve independence. In addition, financial constraints can cause stress and uncertainty, which in turn negatively affects an individual's overall well-being and mental health. It is therefore crucial to ensure that funding is available for those who need it, and that appropriate financial supports and subsidies are available to help individuals with disabilities gain access to necessary services and supports. Such measures can significantly contribute to their ability to achieve independence and fully integrate into society (Anderson et al., 2018; Braddock et al., 2008).

Social and environmental barriers can form significant obstacles to the process of gaining independence for individuals with disabilities. Insufficient accessibility of public buildings such as schools, workplaces or public transport can make it difficult or impossible for people with disabilities to fully participate in life. It is important to identify and remove these barriers through appropriate policies and measures. This can include improving the accessibility of infrastructure, educating the public about the needs and abilities of people with disabilities, and reinforcement of legal protection against discrimination. Eliminating these barriers can significantly improve the chances of individuals with disabilities to achieve independence and full participation in society.

Personal motivation and self-esteem are key factors in the process of gaining independence by individuals with disabilities. Individuals who are unable to perform activities of everyday life tend to be demotivated, which also affects their self-confidence. This impact is manifested in the wider environment of the individual. These are the aggregate activities everyone needs to be an independent member of society. Therefore, instrumental ADLs include activities such as managing finances, raising children, caring for family or pets, managing the household, shopping, and preparing meals. Task performance consists of three stages: starting the activity, continuing and completing it. Motivation and the ability to plan and manage one's own life can empower individuals to overcome obstacles and achieve goals. At the same time, it is important for them to have a positive relationship with themselves, which can encourage them to actively seek opportunities and solutions. Ensuring access to support services and resources promoting the development of motivation and self-esteem is key to successful independence and full participation in life (Krivosiková, 2011; Hartigan, 2007; Rogers et al., 2003).

Methodology, Working Procedure

The investigation based on which this paper was written focuses on two basic areas – background search of foreign research followed by the research among users of services (family or persons with severe disabilities themselves) aimed at increasing the independence of individuals with severe disabilities as well as among providers of these services. Bellow, we would like to present the results of foreign background search.

Background Search

In the research preparation phase, we conducted two searches. First, we analysed the literature and sources to define the terms used within the study. This analysis allowed us to identify specialist terms that are relevant to the research brief and are clearly and accurately described. To ensure accurate use of terminology, we searched electronic and print sources published in August and September 2022 in both Czech and English. This literature search also provided us with a basis for developing questions for subsequent interviews. The second part of the background search consisted of searching for existing systematic reviews. What we focused on were the studies providing information on empowering the people with disabilities for independence and, in particular, their eventual transition to independent lives.

Search Strategy

The search process was carried out in several steps.

First, the Epistemonikos and Cochrane databases were searched. The initial search was carried out using keywords:

- Independent living,
- People with special needs/disability,
- Services.

Due to the very low number of results (10 systematic reviews), additional sets of searches were conducted using keywords based individual interventions:

- housing, employment, assistance and disability.

What followed in the next phase was the screening of studies. At this stage, the publications found were included or excluded based on the reading of titles and abstracts according to predefined criteria. The included publications were then assessed by reading the full texts. Data from the included publications were extracted and organised into summary tables. The results helped to define examples of best practice in the system of supporting the independence of young adults with disabilities.

Inclusive and Exclusive Criteria Defined Using the PICOS Tool:

- Population: Young adults with special needs aged 16 and over (studies involving people aged 0–18 or adults aged 18 and over were also included)

- Intervention: any supporting procedures connected with the process of independence (personal assistance, digital assistance, transition programmes, supported housing, employment assistance, community living, etc.)
- Outputs: any degree of independence in any area of life for people with disabilities
- Design of the study: Secondary research – systematic review or evidence synthesis
- Studies focused on children with disabilities or older people with disabilities, as well as systematic reviews looking at people without disabilities were excluded. Studies dealing with hospital or other institutional care and systematic reviews dealing with any type of medical intervention (drugs, treatments, therapies, etc.) were also excluded. Studies in languages other than English were excluded as well.

Results

Our criteria were met by 13 systematic reviews from which data extraction was performed. The included systematic reviews provided us with an overview of interventions empowering people with high levels of support needs for independence and the scientific evidence of their effectiveness or impact on the participants' self-reliant living. Even though all the included studies deal with interventions provided abroad, most of them are present in the field of support in the Czech environment as well. An overview of the included studies is provided in Figure 1.

Figure 1. Overview of All Included Studies

Support area	Intervention	Author, title of article
Personal assistance	Personal assistance	Mayo-Wilson E., Montgomery P., Dennis J.A., 2008. Personal Assistance for Adults (19-64) with Physical Impairments.
	Personal assistance	Mayo-Wilson E., Montgomery P., Dennis J.A., 2008a. Personal Assistance for Adults (19-64) with Both Physical and Intellectual Impairments.
	Personal assistance	Mayo-Wilson E, Montgomery P., Dennis J.A., 2008b. Personal Assistance for Children and Adolescents (0-18) with Intellectual Impairments.
Housing	Design, placement, environment	Wright, C.J., et al., 2017. What housing features should inform the development of housing solutions for adults with neurological disability? A systematic review of the literature.

	Dispersed community housing	Mansell J., Beadle-Brown J., 2009. Dispersed or clustered housing for adults with intellectual disability: a systematic review.
Employment	Supported employment	Kinoshita Y. et al. 2013. Supported employment for adults with severe mental illness.
	Job preparation, transition programme	Suijkerbuijk Y.B. et al. 2017. Interventions for obtaining and maintaining employment in adults with severe mental illness, a network meta-analysis.
Development of skills	Training and practice of life skills	Tungpunkom P., Maayan N., Soares-Weiser K.,2012. Life skills programmes for chronic mental illnesses.
Complex intervention	Individual and group programmes, interconnection of social skills and work experience	Gross J.M.S., Monroe-Gulick A., Davidson-Gibbs D., Nye C. 2020. Multifaceted interventions for supporting community participation among adults with disabilities.
Case management	Intensive case management	Dieterich M. et al. 2017. Intensive Case Management for Severe Mental Illness.
Transition intervention	Education, therapy, mentoring, self-managed programmes	Lindsay S. et al. 2018. A systematic review of post-secondary transition interventions for youth with disabilities.
Transformation of services	Transition care models	Campbell F., O'Neill P.M., While A., McDonagh J., et al. 2012. Interventions to improve transition of care for adolescents from paediatric services to adult services.
	Transition care models	Jacobs P., MacMahon K., Quayle E., J., 2018. Transition from school to adult services for young people with severe or profound intellectual disability: A systematic review utilizing framework synthesis.

Results of the Initial Background Search

The initial search was conducted as a preliminary research strategy aimed at finding systematic reviews that looked at how to support the independence of

people with disabilities, particularly those with severe physical, intellectual or combined disabilities whose level of independence is severely limited and who require extensive support due to the extent of their special needs.

The research was based on the selected services supporting independence provided pursuant to Czech laws under the responsibility of the Ministry of Labour and Social Affairs – Act No. 108/2006 Coll., on Social Services (MoLSA, 2006, as amended), Act No. 435/2004 Coll., on Employment (as amended), and relevant decrees. These services include social services and Services of vocational rehabilitation. Social services are designed to help people achieve mental and physical self-reliance in order to integrate them into their natural social environment and daily life as much as possible. In relation to the issue of persons with disabilities and the support of their independence, we consider the following services to be particularly important: personal assistance, outreach and outpatient care services, support for independent living, day service centres, day and weekly residential homes, homes for persons with disabilities, for persons requiring regular assistance from another person, and social therapy workshops (MoLSA, 2017; Decree No.505/2006 Coll.).

The aim of the systematic review search was to find evidence-based services that participants in various research studies identified as effective in the process of empowering the people with disabilities for independence.

The systematic reviews identified in this study addressed supportive interventions in several areas. Three of the included systematic reviews focused on personal assistance, two focused on support for independent living, two on support for vocational rehabilitation, and the remaining six focused on different types of interventions to support the independence of people with disabilities in one or more areas of their lives or their transitioning from childhood to adulthood in terms of services. The total number of participants in all included studies was 34,219, including those in the control groups. The reviews looked into interventions for people across a wide range of ages and disabilities, whereas our focus was primarily on outcomes for people aged 16–30. It was this group of people who fell within the age range stated in the individual studies. The following text describes the results connected with individual interventions.

Personal Assistance

Three of the systematic reviews found dealt with personal assistance services, two of them with services for people aged 19-64 and one with services for people aged 0-18. According to the review results, the personal assistance service is preferred over other services, regardless of age groups, for people with both physical and intellectual disabilities. The use of personal assistance services has a positive impact on the quality of their lives and the satisfaction of both users and carers. Personal assistants help clients manage activities of everyday life and meet their needs.

The specific results of the systematic review state the following: *Even though PA was generally preferred over other services, some people do prefer other care models. PA can provide certain advantages for some recipients and can be also beneficial for the carers* (Mayo-Wilson et al., 2008; 2008a; 2008b). The main findings confirm the impact of the use of personal assistance services on the overall quality of life and satisfaction of users with disabilities, and on the lives of caregivers as well.

Some evidence suggests that *personal assistance can reduce unmet needs*. For carers, personal assistance increases satisfaction *with overall care arrangements* (Mayo-Wilson et al., 2008b), with this service having little effect on their emotional burden or leisure time.

Support for Independent Housing

Two included studies (Wright et al., 2017; Mansell et al., 2009) look at supporting independent housing in different areas. The first of the studies focuses on dispersed and clustered housing and the comparison thereof, the second one deals with the necessary elements related to the promotion of inclusive housing.

Dispersed housing is developing rapidly in Scandinavia, USA, UK, Ireland, Australia, and New Zealand as a substitute for residential care for people with intellectual disabilities (Mansell, 2006, in Mansell, 2009). It can be defined as housing of the same type and size as the majority population. Units are located in residential areas. These may be small group homes owned by a service organisation with paid support staff for residents, or the so called supported housing, which is not as common. People with disabilities in need of a higher level of support have the same housing rights as other citizens; they can rent or own a house or flat and, if they wish, share it with someone of their choice. They receive the necessary personal support as an in-home service from the agency of their choice (Mansell, 2009).

Clustered housing is defined as multiple housing units that form a community separate from the surrounding population. These are usually village communities, such as Camphill communities, of which there are about 100 in Europe, North America, southern Africa, and India, which support people with intellectual disabilities (Mansell, 2009). Residential complexes are another option, partly based on the principles of village communities, however, serving people with higher levels of support needs and employing staff to provide support to complex residents. They were established after the closure of institutions, mainly in the UK, the Netherlands, and Belgium, on the sites of institutions run by health service providers. Usually, they consist of a small number of housing units that may form the background of a larger community. Inclusive housing requires consideration and adherence to certain principles in terms of design, location and surrounding environment.

According to research, the following principles are important for design. The housing should:

- *Facilitate physical access* (e.g. physical accessibility, easy access to household items and resources, technological features) both inside and outside the home;
- *Create a cosy environment;*
- *Increase the safety, security and privacy of the person* (without compromising the cosy environment);
- *Improve the comfort* of users, the health and *safety* of clients and carers in the workplace, and the *accessibility and efficiency of the care provided*;
- Provide *access to rehabilitation and exercise facilities* (Wright et al., 2017).

In terms of location, housing should be in good proximity to local amenities, social networks and local services (Wright et al., 2017).

In terms of environment, it is important that the housing was established in neighbourhoods that:

- Support *physical access to public places and areas*;
- Provide *suitable community services* and resources for adults with neurologically based disabilities;
- Enable the development of positive social networks, thereby facilitating social support (Wright et al., 2017).

Vocational Rehabilitation and Supported Employment Services

Two systematic reviews dealing with vocational rehabilitation were included in the overview. Kinoshita (2013) monitored the effectiveness of supported employment for people with intellectual disabilities, and Suijkerbuijk (2017) compared the effectiveness of different types of vocational rehabilitation interventions and attempted to rank these interventions according to their effectiveness in facilitating competitive employment for adults with severe mental illness. Results have shown that supported employment can increase the level of obtaining and retaining any employment (Kinoshita, 2013).

Suijkerbuijk (2017) compared supported employment and extended supported employment with transitional employment, pre-vocational training and psychiatric care for people with severe mental illness. Supported employment *refers to programmes aimed at helping people with severe mental illness quickly gain competitive employment and provide ongoing support to maintain employment* (Bond, 2001a, in Suijkerbuijk, 2017). Extended supported employment is *enriched with additional interventions to increase employment outcomes, such as cognitive skills training with supported employment, etc.* (Loveland, 2007; McGurk, 2004; Tsang, 2009, in Suijkerbuijk, 2017).

Transitional employment refers to segregated programmes designed *to help people with disabilities who are not (yet) able to work in a competitive environment;* it can also be used *as a first step towards more gainful forms of employment.* They are usually operated by non-profit organisations that receive funding from state or federal sources (Boardman, 2003; Krainski, 2013). In our

conditions, social therapy workshops are the closest to this programme. Known as "*train, then place*" or "traditional vocational rehabilitation", pre-employment training is a *step-by-step approach in which participants are trained prior to employment.* This procedure applies *training courses, workshops, assessments or counselling, training general work skills or personal development such as self-esteem, assertiveness and stress management* (Corrigan, 2001; Loveland, 2007). Some specific training programmes may focus on *improving social or cognitive skills* (Corbière, 2009).

One study found that *people in supported employment needed shorter time before getting their first job in the open labour market in the long term* (Kinoshita, 2013).

As part of the comprehensive approach, psychiatric care is described as a complement to the aforementioned programmes and is defined here as routine care for people with serious mental illness without a specific professional component. This includes meditation, support psychotherapy and case management.

Extended supported employment, supported employment and pre-vocational training were found to be more effective than psychiatric care alone. Extended supported employment has been more effective than supported, transitional employment, and pre-vocational training.

Supported employment has been more effective than transitional employment and pre-vocational training (Suijkerbuijk, 2017).

Programmes Supporting the Development of Skills for Everyday Life.
The six studies included in this overview defined a specific group or individual programme to support independent functioning in everyday life (e.g. training in money management, household organisation and management, domestic skills, self-care and social skills).

So-called multi-component programmes, i.e. programmes with comprehensive focus containing several related and interconnected interventions, were reported to be more effective. Although the studies varied in terms of duration, length and number of sessions or form of provision, all reported *improvements in at least one area* (e.g. transition planning from residential care to independence, self-determination, career exploration, readiness and transition skills; social effectiveness, knowledge of disability in relation to career planning; enrolment for higher education, self-determination, self-confidence, transition and independent living skills, autonomy, social support, self-advocacy) (Lindsay et al., 2018).

When evaluating interventions aimed at supporting the transition from childhood to adulthood services, the findings were as follows: *Intervention may slightly improve young people's readiness for transition, enabling them to better self-manage and adapt to the use of adult health services* (Tungpunkom et al., 2012).

Little or no difference was found between the intervention and control groups (Tungpunkom et al., 2012) for interventions that could be described as short-term, one-off or telephone-based (Campbell et al., 2012). In such comparison, what was important were the results showing that long-term programmes focusing on multiple training, comprehensive approach, and linking multiple areas of support had a positive impact on users' acquired skills (Lindsay et al., 2018).

Programmes directed at supporting families and young people with disabilities had an overarching theme of *discrepancy in relation to the family's experience and the young person's needs and to wider ecological levels.* Policy and societal values emphasizing a young person's independence and self-determination seemed to stand in contrast to their lifelong high dependency (Jacobs et al., 2018).

Findings on selected topics related to interventions:

1) Family: *Prevailing support from parents as primary carers; only a minority living in supported housing or residential facilities* – little data on assessment of types of accommodation and quality of services.

2) Changing support networks: the end of a child's or young adult's education is perceived as a loss by parents. Similarly, differences can be seen in the perception of adult services, where there is a clear discrepancy between standards and parents' perceptions. According to parents, the ideal *placement for adults* would be *in a centre with small groups of the same age, which facilitates learning and skills and which is available 4-5 days a week, with caring and qualified staff.*

3) Decision-making and collaboration: parents perceive *a lack of accessible local services* to provide them with clear information about their choices. This includes *advisory services, financial security services.*

4) Organisational context: parents perceive *a lack of coordination of services*, budget, and funding (Jacobs et al., 2018).

Conclusion

The vision of autonomy and independence from family care tends to be the goal of most adolescents, as well as their parents. If a person's disability affects the independence from the family and its care, it is advisable to think about possible alternative or augmentative forms of independent living to help fulfil this goal. Both the aforementioned background search and the follow-up research in the Czech Republic have shown that for an individual with severe disabilities there is not only a single way to achieve independence. There are indeed multiple supports that can be used, offered both in state departments and in non-profit, non-state departments. In the stage of preparation for independence, elements of support have been shown to include:

- Functional communication, including the use of the AAC system,
- Training and development of skills needed for everyday life,

- Personal assistance,
- Parent support groups,
- Educational programmes and activities focusing on parents,
- Early care,
- Homesharing,
- Multi-day stays, residential summer camps, sports convalescent stays.

During the stage of gaining independence as such, the research identified the following areas supporting the independence of a person with severe disabilities:

- Various forms of supported housing and programmes supporting independence in the housing area,
- Social-therapeutic workshops,
- Human-centred planning,
- Case management,
- Educational activities for parents, however, aimed at promoting specific skills for the children's own independence (ABA, PBS therapy),
- Support aimed at developing the competences of young adults with disabilities themselves (ergotherapy, empowerment and self-advocacy, crisis plan, peer mentoring).

All of the above forms a very essential part of the lives of families caring for individuals with severe disabilities, as well as the individuals themselves. At the same time, all the energy of the options, services and strategies described above would be wasted if the family or the person with a disability did not want them. It is therefore important to listen to these voices and develop options that support and saturate their needs.

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