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## Supporting the Development of Competences Necessary for the Independent Living of People With Profound Disorders of Intellectual Development: An Empirical Study

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### Abstract

**Objectives of the research:** The goal of the research was to identify the type and extent of activities that special education facilities engage in to teach and promote independence in people with profound disorders of intellectual development.

**Research methods:** Empirical material was collected using the author's original online questionnaire, which consisted of 30 questions measuring the extent to which students' needs for developing independent living skills are met. The survey was conducted among special education teachers (N=642) from seven European countries (Portugal, Spain, Belgium, Poland, Bulgaria, Romania, and Turkey).

**A short description of the context of the issue:** Independent living is widely seen as an immanent attribute of adulthood. Children and adolescents are prepared for independent living through the process of upbringing and socialization; people with disabilities are additionally prepared through rehabilitation. For people with a profound disorder of intellectual development, independent living is challenging but possible with the right support.

**Research findings:** The results indicate that in the course of developing independent living skills in people with profound disorders of intellectual development, efforts are mainly made to improve their self-management skills and democratic management methods in both team work and individual work.

**Conclusions and recommendations:** In the surveyed countries, there is a tendency to limit work for developing independent living skills to a single type of intervention. Rarely are two or three methods – not to mention four – simultaneously used to stimulate the development of independent living skills. It is therefore necessary to call for increased efforts to promote independent living among people with profound disorders of intellectual development and to focus this support on autonomy, self-determination, achieving quality of life goals, and, above all, the ability to make decisions – since this is what determines true independence in life.

**Keywords:** independent living, intellectual disability, quality of life, support, special education teachers

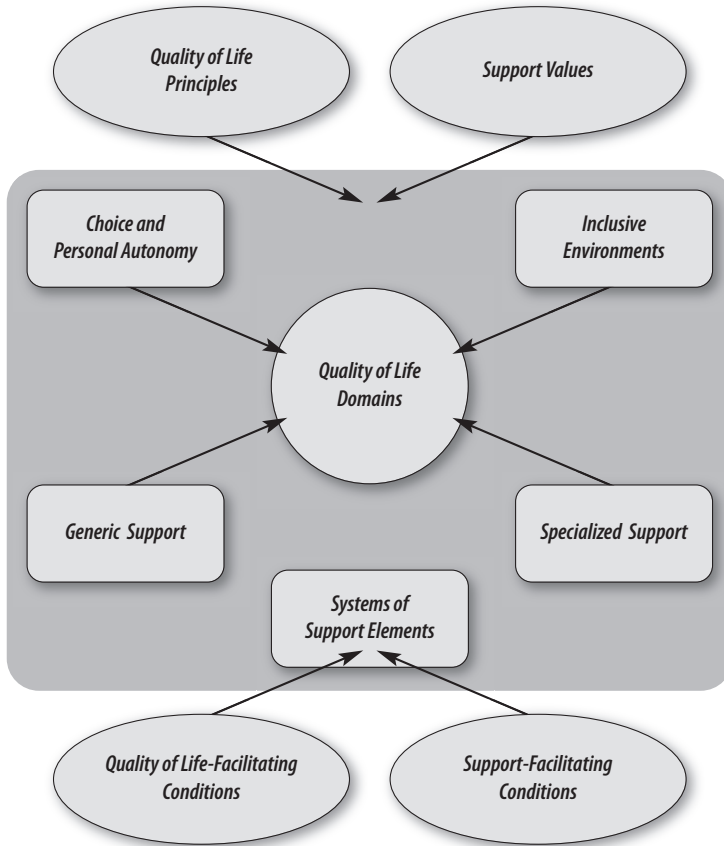
## Introduction

Independent living is widely perceived as an immanent feature of adulthood. Children and adolescents are prepared for independent living through education and socialization; people with disabilities are additionally prepared through rehabilitation. In the case of people with a profound disorder of intellectual development, achieving independence in life is more difficult, though no less important; it is possible thanks to appropriate support (Sandjojo et al., 2018, 2019). The term *profound*

*disorder of intellectual development* includes individuals with both moderate (6A00.1) and severe disorders of intellectual development (6A00.2). As can be seen from the description in the ICD-11 (WHO, 2022), many people with profound disorders of intellectual development require constant support in performing daily life tasks, thereby limiting their independence.

Independent living should be clearly distinguished from self-reliance (Fullana et al., 2020). Self-reliance is one of the elements promoting independence. On the other hand, an essential feature of independent living is the right to choose and to make decisions about one's affairs to the greatest extent possible. The issue is making choices to the best of one's ability and in accordance with one's own and others' safety and the rules of society. In other words, even if a person with a disability cannot do something on their own, they should be able to make choices about every aspect of their life, respecting these principles. The right to independent living and inclusion in a community is mentioned in Article 19 of the United Nations (2006) Convention on the Rights of Persons with Disabilities (CRPD): Living independently and being included in the community.

Thus, self-determination, inclusion, and the ability to make decisions are rights of all people, including people with disabilities (United Nations, 1948). They are important aspects of quality of life. In a hierarchical view of the basic dimensions of quality of life, both self-determination and social inclusion rank high (Schallock, 2000, p. 119). The contemporary paradigm for supporting quality of life in people with disorders of intellectual development integrates the key concepts of "quality of life" and "support" (Gómez et al., 2021). It is characterized by five essential properties: it has a precise theoretical background, it is ethical, flexible, adaptable, and it is evaluable. The model on which this paradigm is based is shown in Figure 1.

**Figure 1. Quality of Life Support Model (Gómez et al., 2021, p. 29)**

Supporting quality of life through planning and using appropriate action strategies fosters development and education and provides the conditions necessary to enhance individual functioning and well-being (Morisse et al., 2013). Through the essential elements of the model – namely, support and quality of life for people with disorders of intellectual development – it is possible to identify skills whose development can improve quality of life. These are democratic management, assertiveness, dealing with matters independently, and managing leisure time. All these skills fall into the areas of independent functioning of people with profound disabilities from the classic AAPEP (Mesibov et al., 1988), where the

main spheres related to independence are interpersonal behavior, adaptation to work, independent functioning, leisure skills, and communication and executive skills. Thus, it can be said that they are the main ways of increasing the level of independence among people with profound disorders of intellectual development (Sandjojo et al., 2019). Developing self-determination skills is equally important for people with intellectual disabilities (Kruk-Lasocka & Suchon, 2013, p. 15).

Previous research (Yıldız & Cavkaytar, 2020, p. 209) has shown that the main skills needed to build an independent life for people with an intellectual disability are personal care and hygiene skills, self-determination and interpersonal skills, employability, and safety compliance skills. Sex education is also needed. Studies that have utilized so-called “augmented reality” with smartphones and tablets (Bridges et al., 2020, pp. 5–9) indicate that video-based modeling increases the acquisition of skills necessary for daily living – such as ironing, making the bed, and setting an alarm clock – and ultimately contributes to improving the overall quality of life for people with intellectual disabilities. Characteristically, the level of independent living is largely determined by the ability to live on one’s own, with family and social support systems being of great importance. In turn, knowledge of safety rules and self-care are basic skills for people with intellectual disabilities. It is worth adding that such people usually prefer independent living, while their parents and educators prefer a more controlled environment under official supervision (Dimitriadou, 2020, p. 153).

There are still quite a few barriers in terms of enabling people with intellectual disabilities to live in natural settings that meet the requirements of social inclusion (Leach, 2016, p. 81). One way to reduce discrimination and increase real social inclusion is through *circles of support*. They support social inclusion and a “secure future” in the community for people with intellectual disabilities. The informal support that circles of support provide gives a voice and decision-making power to a person with a disability and their family. Support is shared and extended to the wider community. Participating in circles of support provides an opportunity to turn to others in different situations, which increases comfort and a sense of security in families and their adult children (Żyta, 2022,

p. 143). Even broader measures include comprehensive solutions for the social and professional activation of people with intellectual disabilities in the local community, actively involving local government; education, social welfare, and local employment services; business representatives serving as potential employers; and academic institutions in the region (Wolny, 2018, p. 675).

These issues closely relate to the adaptive behavior identified by the American Association on Intellectual and Developmental Disabilities as being fundamental to functioning.

Adaptive behavior is the collection of conceptual, social, and practical skills that have been learned and are performed by people in their everyday lives. Adaptive behavior is:

- (a) developmental and increases in complexity with age;
- (b) composed of conceptual, social, and practical skills;
- (c) related to the expectations of age and demands of particular contexts;
- (d) assessed on the basis of the individual's typical performance at home, school, work, and leisure, not their maximum performance; and
- (e) assessed in reference to the community setting that is typical for age peers. (Schalock et al., 2021, p. 2)

In general, adaptive behavior is defined as skills that are acquired and performed to meet everyday social demands. The number and complexity of adaptive behaviors needed to meet these demands increases with age. It can be concluded that higher levels of adaptive behavior are associated with more positive life outcomes and better quality of life (Tassé, 2021).

In summary, it can be pointed out that the core competences related to independent functioning are self-determination and interpersonal skills, skills necessary for daily life, and the ability to obtain and maintain employment (Wandry et al., 2013). It is also extremely important for people with intellectual disabilities to be able to live independently.

## Research methodology

In educational institutions, children and adolescents, including those with disabilities, are prepared for a democratic style of functioning, independence in dealing with various issues, assertiveness, and free time activities. This preparation is intended to help them find their place in the constantly changing world, in which they need to be ready to face challenges. However, what if we are dealing with people whose dysfunctions make it difficult to be independent from the very beginning? This question prompted the research questions: What is the level and type of support offered by special school systems in different European countries? Do the special school systems in various countries target the formation of independent and autonomous individuals, within the limits of their intellectual capacities? Do these systems more or less consciously shape obedient or assertive individuals?

The objective of the study was to characterize the work of the surveyed institutions aimed at teaching and supporting independence in people with profound disorders of intellectual development. In order to measure this, an original questionnaire was used, which included a set of questions for determining the satisfaction of students' needs in five key areas for learning independent living: partner relationships, including preparation for leading a sexual life; preparation for independent living; graduates' attempts to live independently; professional activity; and civic life. The study identified four essential ways to support the development of the necessary skills:

- 1) democratic management in group and individual work,
- 2) assertiveness,
- 3) dealing with issues independently, and
- 4) leisure time management.

A total of 642 teachers from seven countries took part in the survey, with the number of completed questionnaires varying from country to country depending on the response rate of the questionnaires. In all

countries, the project coordinators sent questionnaires to all the special schools available to them; however, the response rate varied greatly, as reflected in the data. The sampling was purposive. Because the respondents, teachers working in special education, represent only a small proportion of all professional teachers, it was crucial for the researchers to reach as many teachers as possible from very different sociopolitical backgrounds.

The respondents came from Bulgaria 31.2% (n=200), Portugal 20.6% (n=132), Turkey 15.3% (n=98), Poland 13.2% n=(85), Romania 8.1% (n=52), Belgium 7.9% (n=51), and Spain 3.7% (n=24). The gender distribution of the study population was 80.1% (n=514) women and 19.6% (n=126) men. More than half of the respondents held a master's degree 55.5% (n=356), 44.2% (n=284) had a bachelor's degree, and two respondents indicated that they had a doctorate. In terms of seniority, the largest group (37.7% [n=242]) were teachers who had worked for 0–10 years, followed by those working for 10–20 years (27.7% [178]) and those who had been in the profession for more than 20 years (34.6% [222]).

The research was conducted within the Erasmus+ project (KA226-9A6B05FC-PL) called "With a Little Help." The project started on March 1, 2021 and ended on February 28, 2023. It was implemented by seven organizations: Asturia vzw in Belgium, Embaixada da Juventude in Portugal, Asociació Educativa and Cultural Blue Beehive in Spain, ASOCIATIA EDULIFELONG in Romania, SISLI ILCE MILLI EGITIM MUDURLUGU in Turkey, Institute Perspectives in Bulgaria, and the Institute for Creative Integration in Poland.

In the statistical analysis of the collected material, the author created and used the Index of Methods Supporting Independence (IMWS), which was based on the question of how students' needs of developing competences for independent living are satisfied. In answering this question, the respondents were given a choice of four different categories of methods to support independence. Two points were awarded for each characteristic selected. Thus, depending on the number of characteristics chosen, each respondent received between 1 and 5 points. The MWS index is a synthetic indicator with values ranging from 1 to 5; the higher



the index value, the higher the level of support. The following scale was adopted: 1 point for no method applied, 2 points for one method applied, 3 points for two methods, 4 points for three methods, and 5 points for four methods. The study used a proprietary online questionnaire consisting of 30 questions, including open-ended questions, multiple-choice questions, and semi-open questions. The difficulty in developing the tool was preparing seven language versions of the tool so that the meaning of the questions remained the same despite linguistic differences.

### Research findings

According to the results, activities aimed at teaching independence to people with profound disorders of intellectual development are conducted in all countries. Only 7.8% of all respondents stated that such activities were not carried out in their institutions. However, strangely enough, methods for developing competences for independent living based on developing assertiveness (assertiveness training) were used least frequently. In contrast to other activities (democratic ways of managing group and individual work [47.7%], dealing with issues independently [52.6%], and managing leisure time [38.2%]), only 27.6% of all respondents indicated that assertiveness was taught. Is it true that out of all the methods applied, assertiveness (especially marking the individualism of each person) is used the least often? Is it a conscious, systemic activity, meaning that regardless of the country of origin of the surveyed teachers, a lack of interest in this method is visible?

For the purpose of this analysis, a hypothesis was put forward: that educational systems for people with profound disorders of intellectual development are geared toward shaping obedient rather than assertive individuals. To this end, the Index of Methods of Supporting Independence was created. The IMWS consists of four methods: democratic ways of managing group work and individual work, developing assertiveness, training in independent matters, and managing free time. Although there are many more methods to support and develop independence, it can be assumed

that the ones chosen for the purpose of this research are the most common (Mesibov et. al., 1988; Tassé et al., 2020; Giesbers et al., 2019; Leach, 2016; Fullana et al., 2020; Wandry et al., 2013; Dollar et al., 2021). The most important ones are the ability to determine one's own needs and the needs of others; to behave in a way that is not harmful to oneself and that respects the differences of others (the formation of assertiveness); the ability to cooperate and work individually (group and individual work); the ability to manage one's own affairs (independent handling of affairs); and, finally, the ability to plan one's leisure time. It should be recalled that the MWSI is a synthetic indicator ranging in value from 1 to 5 (the higher the index value, the higher the level of support).

The analysis of the data shows that independent living is not strongly promoted for people with profound disorders of intellectual development in the selected countries. A detailed breakdown of the data is presented in Table 1.

**Table 1. Methods of Supporting Independence Index (MWS)**

MWS Index		
	Frequency	Percent
No methods applied	50	7.8
1 method applied	331	51.6
2 methods applied	108	16.8
3 methods applied	93	14.5
4 methods applied	60	9.3
Total	642	100.0

According to the research, 51.6% (n=331) of all respondents use only one method to support the development of independence in people with a disability. Only one in ten (9.3%) applies all four methods, which indicates a low level of such support. The following data illustrate in detail which methods are utilized most frequently.

**Table 2. Catalogue of Methods Used to Develop Competences  
 for Independent Living**

Democratic methods of management in group work and individual work		
Country	Not present	Present
Poland	55.3%	44.7%
Spain	37.5%	62.5%
Portugal	40.2%	59.8%
Turkey	55.1%	44.9%
Belgium	78.4%	21.6%
Bulgaria	55.5%	44.5%
Romania	42.3%	57.7%
Assertiveness		
PL	54.1%	45.9%
ES	100.0%	0.0%
PT	68.2%	31.8%
TR	95.9%	4.1%
BE	94.1%	5.9%
BG	60.0%	40.0%
RO	82.7%	17.3%
Independently managing issues		
PL	7.1%	92.9%
ES	62.5%	37.5%
PT	22.7%	77.3%
TR	55.1%	44.9%
BE	58.8%	41.2%
BG	67.0%	33.0%
RO	67.3%	32.7%
Managing leisure time		
PL	31.8%	68.2%
ES	91.7%	8.3%
PT	74.2%	25.8%
TR	99.0%	1.0%
BE	70.6%	29.4%
BG	41.0%	59.0%
RO	67.3%	32.7%
Lack of satisfaction of self-reliance needs		
PL	90.6%	9.4%
ES	100.0%	0.0%
PT	93.2%	6.8%
TR	95.9%	4.1%
BE	94.1%	5.9%
BG	92.0%	8.0%
RO	80.8%	19.2%

Working on independent living skills connected with self-managing group and individual work or managing matters independently, without taking into account the ability to recognize one's own needs and to respect the needs of others (assertiveness), can lead to the danger of people with disabilities being completely subordinated and living in institutions that, while protecting them, indirectly isolate them from the community and limit their freedom through regulations and a hierarchical organization. The research confirms that learning to socialize is oriented toward submissiveness, passivity, and dependence.

### **Discussion and Concluding Remarks**

The results indicate that developing competences for independent living among people with profound disorders of intellectual development mainly involves activities which improve the skills of independently dealing with issues and developing democratic ways of managing group work and individual work. Activities for developing leisure time management skills are much less frequent, and the least attention is paid to developing assertiveness among people with profound disorders of intellectual development. Such an arrangement suggests that special educators focus on skills that facilitate independent functioning in everyday life, which is also relatively easy to observe and provides a kind of positive reinforcement for the participants (Yildiz & Cavkaytar, 2022). On the other hand, the social environment, especially those who are closest, is usually interested in the specific skills of a person with a disability and their independence as much as possible, reducing the need for their support. In turn, relatively advanced skills of democratically managing group and individual work seem to be justified by the requirements of the contemporary job market and societal expectations of functioning on democratic principles. It also prepares people with an intellectual disability for their role as citizens and for building partnerships and democratic relationships in local communities, in which social capital provides the basis for sustainable networks of social commitment of trust and reciprocity (Adamczyk, 2021, p. 91).

However, preparing people with intellectual disability for organizing and spending their leisure time arouses much less interest among educators. The reason for this may be that this skill is regarded as natural and not requiring special intervention, although special educators are aware of its importance in the rehabilitation process, as mentioned in the classic works on rehabilitation (Leland et al., 1967; Mesibov et al., 1988). Moreover, leisure time concerns time spent out of school, which may also explain the relatively limited interest of educators in preparing children and adolescents for it. What is worrying, however, is the low importance attached to skills of assertiveness; one might even say that there is a clear deficit in this area. This may be rooted in the way people with profound disorders of intellectual development are perceived as requiring the support of the social environment in many activities, and this in turn may result in an expectation of submissiveness rather than assertiveness in social relationships (McConkey, 2019). There is also a strong negative association of assertive practices with cooperative and loyalty-promoting practices of institutional collectivism. Thus, belonging to a group does not necessarily promote assertive behavior, as learned patterns of behavior of this type transferred to one's own environment may be shocking and perceived as aggressive or aggression-provoking. Moreover, politeness should be considered the opposite of assertiveness in terms of cultural interpersonal communication. Expectations of people with a profound disorder of intellectual development are more likely to approach the extreme of "politeness" than assertiveness, because they often require social support. This perhaps explains the relatively weak interest in developing these skills among such people. The greater support for the development of assertiveness in some countries, including Poland, Bulgaria, and to some extent Portugal, may be due to the fashion for assertiveness imported directly from individualistic cultures, where the "independent self" is manifested in low-context, direct communication and is expressed in an assertive style (Boski, 2009, pp. 144–237). On the other hand, a low level of assertiveness can pose a threat to one's rights and even physical safety.

In light of the MWSI values presented herein, the least favorable thing about the surveyed countries is that the activities for developing

independent living skills are usually limited to one type of intervention. Most frequently, this is a single type of training, either in self-management or in developing democratic ways of managing group and individual work. Rarely are two or three methods used to stimulate the development of independent living, and all four are only occasionally implemented. It is therefore necessary to call for more activities for developing independent living skills in people with profound disorders of intellectual development, not only in terms of increasing the training of a particular skill, but also with respect to broadening the spectrum of interventions in other areas. Referring to the paradigm of quality of life of people with an intellectual disability (Gómez et al., 2021), it is necessary to focus on autonomy, self-determination, support as a tool for achieving quality of life goals, and above all the ability to make choices, because this is what constitutes real independence in life. However, it is worth formulating recommendations for rehabilitation practice in order to better develop the somewhat neglected skills related to leisure activities and assertive behavior. In the case of the former, people with profound disorders of intellectual development should be prepared to initiate leisure time activities and be motivated to participate in activities organized by others. To this end, it is worth using interactive games, simple movement games, or art, music, and dance. All these activities should be conducive to performing an enjoyable and socially accepted activity (Mesibov et al., 1988, pp. 17–18). Assertiveness skills, on the other hand, can be developed in the course of social skills training or in a more targeted form in psycho-educational classes (Majewicz, 2017, p. 118). For people with intellectual disabilities, developing the ability to ask for help and to refuse to comply with, for example, blatantly inappropriate requests is very important. The development of assertive behavior contributes to a greater ability to defend one's rights and to stay safe.

## Limitations of the Research

An unquestionable limitation of the research presented herein is the highly variable number of educators from the different countries taking part in the project. While in Bulgaria there were 200 participants, in Spain there were only 24. Although the total number of participants in the research is significant, with 642 educators from seven countries, this wide variation limits our ability to generalize the results. Furthermore, the remote rather than face-to-face form of data collection also entails limitations (Durga Prasad Nayak & Narayan, 2019). With any online research, there is a danger of surveys being completed only by certain people, e.g. those interested in the topic, including fringe groups who are either very positive or very negative, or those who prefer to be contacted via multimedia. Thus, the representativeness of the results obtained through this methodology may be somewhat questionable.

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