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Equal Treatment

Supporting Access of People with Intellectual disabilities to Secondary and Tertiary Healthcare Services

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Literature Review

Institutions participating in the project:

European Platform for Rehabilitation, Belgium; **Kaunas College**, Lithuania; **EEA Margarita**, Greece; **Research Center of Biopolitics of Panteion University**, Greece; **Girona Biomedical Research Institute**, Spain; **Arnau d’Escala Campus Foundation**, Spain; **Tampere University of Applied Sciences**, Finland

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Introduction

Equal Treatment is an ERASMUS+ funded project with the aim to improve the access of people with intellectual disabilities to secondary and tertiary health care through inclusive European policies in healthcare services; training of healthcare staff on interacting with patients with intellectual disabilities and; stronger collaboration between healthcare staff and professional supporters. Project duration 2022-2024 year. Project will focus on one main objective: **supported rights and access of people with intellectual disabilities to secondary and tertiary healthcare services.**

Results

1. More effective policies on people with intellectual disability inclusion in HealthCare services.
2. Lower barriers for people with intellectual disability to access HealthCare services.
3. More effective training of HealthCare Staff to interact with people with intellectual disability.
4. Stronger and better collaboration between HealthCare Staff and other professional supporters.

Target Groups and project beneficiaries: Doctors, Nurses, Administrative staff in secondary and tertiary HealthCare services (HealthCare Staff); Educators, Psychologists, Social workers, etc. supporting people with intellectual disability (Professional Supporters); People with intellectual disability (people with intellectual disability).

Articles on people with intellectual disability (people with intellectual disability) health issues and ensuring equality and providing health care services for people with intellectual disability were searched in the Medline and Google scholar electronic databases using the key words "Intellectual Disability mental, physical health problems, medical staff communication with people with intellectual disability, health care services for people with intellectual disability " between 15 June 2022–31 August 2022. Literature review was prepared by analyzing scientific articles and textbooks about people with intellectual disability in Europe and the world.

Not all European countries can boast of comprehensive research on the accessibility of health services for people with intellectual disabilities. In the presented review of the literature, we rely not only on the experience of the participants in the project, presented in scientific sources, but also on the experience of other countries of the world. Examples illustrating this fact.

”*There is very little data available in Spain on the group of people with ID in terms of health people with ID in terms of their state of health, given that disability does not appear explicitly as a variable in general health surveys (Macho etc.,2018*)”.

Analyzing the scientific experience of the countries participating in this project in the articles presented, it is clear that there is little research on adults with intellectual disabilities. In particular, there is a lack of research on health care professional preparation and professional performance challenges when working with people with intellectual disability. Representatives of social sciences study this phenomenon more widely from the point of view of social services and provision. A lot of research is being done on children with autism spectrum disorder. However, there is little research focusing on the preferences of adults with intellectual disability.

Literature review consists of two parts. The first part presents the most important scientific facts about people with intellectual disability people with intellectual disability statistics, causes, symptoms. The phenomenon of disability is analyzed in medical (clinical) and social inclusion approach, which is also important for health care institutions. Presents scientific facts about people with intellectual disability health problems - mental and physical. In this way, we will pay a big attention to communication with people with intellectual disability and the conditions for ensuring their safety and access to quality health care services.

The second part presents and analyzes legal documents related to equal opportunities for people with intellectual disability in receiving healthcare services in Europe. Equal opportunities are central to the functioning of people with intellectual disability in society.

Literature review made: *Assoc.prof. Viktorija Piscalkiene, Lecturer Evelina Lamsodienė, Gerda Bukauskaitė Žiūkienė (Kaunas University of Applied Sciences, Faculty of Medicine, Lithuania).*

Information sources were provided by the project “Equal treatment” partners:

- *European Platform for Rehabilitation, Belgium (project coordinator)*
- *Kaunas University of Applied Sciences (KUAS), Faculty of Medicine, Lithuania*
- *Tampere University of Applied Science“, Finland*
- *Vocational Training Center MARGARITA“, Greece*
- *Research Center of Biopolitics from Panteion University, Greece*
- *Girona Biomedical Research Institute (IDIBGI), Spain*
- *Fundació campus Arnau d’ Escala (FCAE), Spain*

1. The phenomenon of intellectual disability

1.1. Statistics, causes, features of intellectual disability (ID)

- Disability is a complex, evolving and multi-dimensional concept.
- Intellectual disability (ID) – partial or insufficient development of mental capacity, which reaches 2 percent.
- There are four types of ID factor: biomedical, social, behavioral and educational.
- There are four grades of severity of ID: mild, moderate, severe, very severe.

According to the data of the World Health Organization (World Health Organization, 2015), approximately 15 percent of all the world's population have some form of disability. 2-4 percent of them experience significant functional difficulties (World Health Organization (2015).

Disabilities impact on people's lives in many areas, for example in terms of: mobility and the use of transport equipment; access to buildings; participation in education and training, the labor market and leisure pursuits; social contacts and economic independence (Eurostat Statistics Explained, 2021).

A person with a disability is a person with long-term impairments (physical, sensory, mental, intellectual) that may prevent them from fully and effectively participating in society on an equal basis with other persons (United Nations Convention on the Rights of Persons with Disabilities, 2010). Disability is divided into groups:

- Visual disability (visual impairments from partial blindness to complete blindness);
- Hearing disability (hearing disorders from partial to complete deafness);
- Disorders of motor functions (physical disability) (from mild limping to movement in an electric wheelchair);
- Disorders of intellectual development (from learning difficulties to the inability to respond adequately to various situations);
- Psychosocial diseases (schizophrenia, depression, anxiety disorders, etc.);

When a person has symptoms of all or several types of disabilities, it is referred to as a complex disability.

According to the World Health Organization (2010), intellectual disability (ID) is a partial or insufficient development of mental abilities. Individuals with an intellectual disability have neurodevelopmental deficits characterized by limitations in intellectual functioning and adaptive behavior. It is characterized by a disorder in the formation of skills (cognitive, language, motor and social) that constitute a certain level of intelligence at various stages of development (Lee et al., 2022).

According to the American Psychiatric Association, ID is a disorder that causes changes in a person's thinking, emotions, behavior, or all of the above (American Psychiatric Association, 2018).

According to the international classification of diseases, mental retardation is a state of delayed or incomplete mental development, when the skills that appear during development and determine the general level of intelligence are disturbed, like cognitive, language, motor and social abilities. Intellectual disability may or may not be accompanied by any other mental or somatic disorder (ICD, 2011; Daniel etc., 2003).

Other synonyms of intellectual disability are also used: mental disability (eng. Mental handicap), intellectual disability.

Kalasiuniene (2014) presents concepts that are no longer in use. It can be seen that these concepts are slightly different in the world. Summarizing the data from 147 countries, the most commonly used terminology was found: mental retardation - 76 percent out of 147 countries, intellectual disability – 57%, mental disability – 40%.

Concepts of intellectual disability

Kalasiūnienė, 2014

Geographic location	The concepts used now	Historical terms that are no longer used
USA	Mental retardation Intellectual disability	Mental subnormality Mental deficiency Mental retardation Oligophrenia Stupidity An imbecile Idiocy
UK	Learning disability	
WHO	Learning/developmental disability Intellectual disability	

About 10% of the world's population has some form of disability, of which 2-4% experience severe functional difficulties. The overall prevalence of mental retardation or intellectual disability (ID) is 2-3% (Boardman et al, 2014).

Interesting data can be found in the presented report on the IQ of the world's population. Based on these data, it can be said that 4.1% of the world's population has scores below 70 and can be classified as a group of people with intellectual disability.

IQ classification

Boardman, L., Bernal, J., & Hollins, S. (2014)

IQ test range	IQ Classification	% of World Population
130 and above	Very Superior	2.1%
121-130	Superior	6.4%
111-120	High Average	15.7%
90-110	Average	51.6%
80-89	Low Average	13.7%
70-79	Borderline	**6.4%**
Scores under 70	**Extremely Low**	**4.1%**

In other sources, it can be found that between 1 – 3 % of the population has an intellectual disability. Mental retardation is usually 1.5 times more common in men than in women. Some studies report a male to female ratio of 3:2 (Maulik, 2011).

The causes of ID can be various. It is one of the most complex disorders due to its heterogeneous etiology.

According Carlier, Roubertoux (2014) there are four types of ID factor: biomedical (genetic disorders, nutrition, intrauterine and neonatal insults), social - environmental (social and family interaction, child abuse, acute and chronic psychological stress, physical abuse, exposure to family violence behavioral, and educational (availability of educational support). It is assumed that in approximately half of intellectual disability cases, there is no known cause.

Studies show that 2/3 of ID causes are genetic, but their diagnosis is difficult. Molecular karyotyping is significantly superior to other cytogenetic research methods in that it is possible to determine quantitative chromosomal changes with high resolution during one study. This new diagnostic technique was successfully applied to the diagnostic investigation of intellectual disability. Diagnostic yield of this analysis is over 15 % in cases people with intellectual disability iopathic intellectual disability (Čiuladaitė et al, 2012; Carlier M., Roubertoux, 2014).

Chromosomal anomalies (mainly, new micro deletions) are found in some 20% of cases. Alongside monogenetic disturbances of dominant or recessive inheritance (ca. 30–40%), polygenetic disturbances have been described as well. There are now 1222 known primary genes for ID that have been definitely clinically associated with a developmental disorder, and a further 1127 candidate genes with a possible association (Sappok, Diefenbacher , Winterholler, 2019, cit. Zweier C., 2018).

Phenylketonuria (PKU) is one of the inborn errors of metabolism that occurs in approximately 0.01% of the newborn. The consequent accumulation of phenylalanine is the culprit of intellectual disability (Bayat, 2015).

From a social and psychological point of view, it is the lack of a full-fledged environment that can be the cause of intellectual disability. A full-fledged social environment guarantees an abundant flow of signals to the brain, so not only biological, but also social environmental factors are important in the etiology of mental disability. A child's development can be blocked by an antisocial environment at home: due to neglect in the family, poverty, parental abuse of alcohol, drugs (Kalasiuniene, 2014).

Intellectual functioning is commonly measured by the intelligence quotient. IQ test determine whether a person has an intellectual disability. IQ test score has a median of 100 and a standard deviation of 15. A score of 70 or below indicates intellectual limitations (Lee, 2022).

Mild intellectual disability: Most people with intellectual disability experience a mild to moderate form. They can learn practical life skills and function daily with minimal help from the environment. However, they might struggle to understand how things work and develop social skills. IQ range of 50 to 69.

Moderate intellectual disability: IQ range of 35-49. The ability of these individuals to learn and acquire academic skills is limited. They experience difficulties in social communication, interpersonal relationships.

Severe intellectual disability: Persons with severe ID need more support than persons with mild intellectual disabilities and have limited communication skills. IQ range of 34 to 20.

Profound intellectual disability: Persons with profound intellectual disability often find it especially difficult to communicate and have difficulty performing life activities. They typically require round-the-clock care and support. IQ range is 20 and bellow. Reduced cognitive function affects ability to use conventional language; these individuals may communicate through non-verbal expressions and body language, and idiosyncratic communication is dominant (Boat, Wu, 2015; Gjermestad, 2017).

Grades of severity of intellectual disability (ID): definition, features, and frequency among persons (people with intellectual disability)

Sappok T, Diefenbacher A, Winterholler M. (2019)

Severity of ID	IQ	Cognitive reference age	Features	%
Mild	50–69	9–12 years	Slow learning performance, often delayed speech development, cultural techniques can be learned, independent living is possible, occupational training is possible	80%
Moderate	35–49	6–9 years	Delayed language development, often with a reduced vocabulary, often delayed motor development, independent living may be possible with support as needed, work in a protected workplace or on a simple task is possible, cultural techniques can be learned with certain limitations	12%
Severe	20–34	3–6 years	Marked impairment of language comprehension, has no active language or can only produce individual words, needs comprehensive support in the activities of daily life	7%
Very severe	<20	0–3 years	Verbal communication impossible or nearly so, needs comprehensive support in self-care and in the activities of daily life, often incontinent, somatic comorbidities (e.g., epilepsy) are	1%

			common	

Sappok et al. (2019) present four severities of intellectual disability: mild (IQ 50–69), moderate (IQ 35–49), severe (IQ 20–34) and very severe (IQ <20). Most people have mild intellectual disability (80%). Intellectual disability is classified according to learning performance, speech development, cultural techniques, independent living and self-care.

Intellectual disability is an object of interdisciplinary research, which is analyzed by representatives of biomedicine, health care and social sciences. The known people with intellectual disability statistics show how important it is to identify and provide support and empowerment for these people.

1.2. Persons with intellectual disabilities social participation: from the theories to the practice

- There are several models of disability that describe the nature of disability and the place of a person with a disability in that society.
- The integration of people with intellectual disability into society is limited, posing huge challenges for persons with disabilities.
- Persons with mental disabilities lack a positive public attitude towards them.
- According to principal of social integration disabled persons should be offered the same possibilities to use health care services.

It is worth remembering L. S. Vygotsky's principled approach to disability of any nature in childhood, as an outstanding pioneer of special pedagogy and psychology. He saw one crucial point: the much more harmful thing is not the original biomedical disability of the child, but the inadequate attitude of adults and the unfavourable reaction to it. A secondary "social disability" is created, which is more dangerous than the primary biological disability due to the consequences limiting education and socialization (Piscalkiene, 2008. cit. Vygotsky, 1978; Merkys, 1996).

Several models can be found in the literature describing the nature of disability, its significance in society and the place of a person with a disability in that society.

The oldest model of disability is the religious/moral model. The mentioned model of disability is based on punishment for sins committed in the past. Disability is equated with a right punishment for past sins or even behavior of ancestors that went against the truths of religion. There is no easy way to determine which moral rule was broken, or even who in the family or lineage violated it, but more "severe" disabilities (such as total blindness or quadriplegia) are believed to be the result. Persons with disabilities are separated from society, their marginalization takes place (Jensen, Zuber, 2020).

The medical model focuses on a health condition — a disease, illness, injury or health problem — of an individual which directly causes the disability of that individual, potentially impacting on that individual's quality of life. The clinical model treats disability as a problem caused by a disease in the individual. This problem must be solved by medicine, i.e. to treat the individual, promote adaptation and change behavior. In the case of the clinical model, the focus is on the disorder, the individual who needs treatment, correction, is evaluated from the prism of the disorder.

Another model – social, treats disability as a social problem, as a person's involvement in society. The social model focuses on socially-created barriers.

These barriers may be physical or concern attitudes and other social features that do not accommodate the variety of abilities of the population. Based on the social model, the difficulties of the person are solved by focusing on the powers and abilities of the disabled person, and the resources of not only the individual, but also the surrounding environment are used. Thus, in this model, the social environment is particularly strongly emphasized and plays an important role (Piscalkiene, 2008, cit. Ruskus, 2002; Eurostat Statistics, 2021).

Historically people with an intellectual disability have been excluded from society and many continue to live separately in institutions, group homes and segregated campuses (Murphy, White (2019). Disability began to be viewed through a medical prism around 1800. In the application of the medical model, disability was viewed as a certain consequence of the disease, which was sought to be cured, and people with disabilities themselves were treated as weak, poor and having undesirable traits. 20th century in the second half, disability began to be based on the social model of disability, when a person is considered to have a disability, taking into account not his disease, but the obstacles to social integration, which are determined by attitude and environmental factors, i.e. the problem is transferred from the individual to society (Rupsiene et al., 2021).

The growing interest in disability issues at the international level led to the UN declaring 1981 the International Year of Disabled People. Prior to the 1970s, apart from one or two notable exceptions, academic interest in disability was limited almost exclusively to conventional, individualistic medical explanations (Watson, Vehmas, 2019).

Since the end of the 20th century, the European continent and many parts of the world have abandoned the medical approach to disability and increasingly focused on the rights of people with disabilities (World Health Organization & World Bank, 2011). This document shows a new approach, which is based on social inclusion, which led to a growing tendency to look at disability as a human rights issue and to take care of the rights of people with disabilities.

The Economic Model describes by the expression *“Nothing is more important than your health . . . except your money”* (Jensen, Zuber, 2020, cit. Ferengi Rules of Acquisition 1993, 23). According to this model, disability is seen as an economic problem that has to be solved, and the solution is work, the key is work. It is treated that only working persons are valued and "contribute their part" to the welfare of the society. According to the economic model, the money lost by the disabled person not working or working less is calculated. The economic effect is overestimated and little attention is paid to the disabled person.

Researchers in the fields of sociology and educology present their insights on the features of social participation of persons with disabilities. Individual activity and an open society are the main conditions for successful social participation. It is also important that disabled persons can make their own decisions, live as independently as possible, and participate in the activities of the local community, certain organizations, and associations. Every member of society, regardless of their mental or physical deficiencies, must be guaranteed the same opportunities and conditions to participate in collective life as a person without a disability (Rupsiene et all., 2021, cit. Ebersold 2019: 6).

Various stereotypes about people with mental disabilities are one of the obstacles to achieving their harmonious integration into society. Different disabilities of people lead to different social images. The physical inability of people forms a sufficiently favourable image, because it is based on the feeling of the desire to survive. The social image of intellectual disability is not clear. Intellectual disability forms a "Mongolian" face, behavioral disorder, segregation, relationships, emotional images (Ruskus, 2002).

Socialization is the development of a person throughout his life, interacting with the environment, assimilating social norms, cultural values, improving and realizing himself in the society he belongs to. The socialization of an individual in society takes place under different conditions, which are often characterized by one or other dangers that negatively affect human development. Whole groups of people appear who become victims of unfavourable socialization circumstances. Persons with mental disabilities can also be assigned to them (Piscalkiene, 2008).

Social and economic changes in the world and modern theoretical concept of disability interpretation influenced education, social and nursing services concepts. According to principal of social integration disabled persons should be offered the same possibilities to use health care services (Piscalkiene, 2009).

Discrimination is the main problem that prevents a people with intellectual disability from getting involved in the life of society. A person with a mental disability is partially or completely unable to control his personal or social life, perform his duties and exercise his rights due to a congenital or acquired mental disability. Different countries of the world have different attitudes towards people with disabilities, policies, economic differences, and assistance options. Western countries are leaders in the inclusive and social participation processes of persons with disabilities (Staponkute, Rackauskiene, 2019).

Social inclusion is associated with improved well-being and quality of life for both the general and ID populations. Social inclusion may comprise social roles and participation in community and interpersonal relationships. It is a social construct, which is subjective and dynamic and which may vary depending on the personal and environmental circumstances of individuals (Causland, 2021).

People with intellectual disability who have generalized or extensive support needs constitute a particularly vulnerable group that has traditionally experienced situations of exclusion in Spain (Verdugo, 2018). Disability in Greece lack of independent living skills, and face limited chances for independence, and that social isolation and insufficient quality of life are being enhanced by poor interpersonal relations (Kartasidou, 2013).

Several main manifestations of discriminatory behavior are distinguished: bullying, harassment, ignoring equal rights, creating exceptional conditions, violence and exclusion. Indirect discrimination occurs when a person is told that they are not hiring because of their education, but actually because of their disability. Direct discrimination is when a person is directly evaluated negatively because of their disability. Society denigrates people with disabilities by using inappropriate terms to describe them. Poor knowledge of disability and communication skills with disabled persons has been identified among health care staff (Staseviciene, Fatkulina, 2017).

According Murphy, White (2019) people with intellectual disability were not regarded as citizens capable of full inclusion in society but rather experienced daily restrictions on their lives. The findings emphasized the need to ensure human rights are at the core of service delivery.

People with more severe ID may experience difficulties when asserting their interests, desires and personal goals. They have been pointed out by many of the organizations that offer support and services to this group, among which are (PMLD Network, 2003):

- Limited possibilities of choice derived, in part, from their communication difficulties and other complications that they can exist on a physical level; chances still diminishing more so if it is not involved in providing support to parents and professionals who really know the forms of communication of these users.
- Scarce representation in groups of self-advocates.
- Scarce representation in the development of social policy.
- Difficulty managing support resources with greater control.
- Difficulties in accessing alternative forms of communication, difficulties that are increased by the poor training of the professionals about them (Verdugo, 2018).

Persons with disabilities constitute a vulnerable population group in Europe, systematically exposed to high levels of poverty and social exclusion, with adverse effects on their health and well-being. An important pillar in the planning and implementation of integrated state health care interventions for people with disabilities should always be a key element in the implementation and systematic participation and involvement of people with disabilities. Participation of people with disabilities and their organizations (participation) through consultation to define implementation measures and mechanisms for their evaluation (Alexiadou, 2020).

When it comes to the social participation of persons with intellectual disabilities, equal rights in society, and decision-making, cultural matters must also be kept in mind. By Sánchez etc. (2018) firstly, we need to know the beliefs and cultural aspects associated with self-determination in professionals, family members and people with disabilities in the Spanish context, as the knowledge they have and the importance they attach to self-determination can condition the degree to which the specific components of self-determination (e.g., decision making, problem solving) are contemplated and worked on in the problem-solving) in different contexts (family and organizations). The construct of self-determination carries certain cultural nuances that may condition its definition and promotion depending on the cultural frame of reference which is why it is necessary to investigate the beliefs about self-determination that are held by professionals and family members in specific contexts.

A list of 19 strategic actions relating to service policies and procedures, and 11 indicators of health disparities were created through interviews with staff from the Special Olympics and validated by an advisory group of 6 people embodying a range of international expertise. Then an online questionnaire was sent to Special Olympics staff and health personnel who were asked to rate all items in terms of relevance for making health systems more inclusive for PWID and feasibility of their implementation. All the actions and indicators were rated as highly relevant to create inclusive health systems, with median scores of 8 or above. The highest rated actions focused on practical and awareness training for staff working with people with intellectual disability, explicit policy statements, active support to people with intellectual disability in decision making (e.g. consent to treatments) and available easy-read information (McConkey, 2020).

Social restrictions and service closures from COVID-19 have negatively impacted social inclusion and well-being for some people with intellectual disability. COVID-19 has adversely impacted the health and wellbeing of people with intellectual and developmental disabilities (IDD). During the early stages of the COVID-19 pandemic, many older people with intellectual disability stayed connected with family and reported rates of contact higher than were reported by others before COVID-19. This connection may have been supported by a significant increase in technology use during the pandemic (Causland, 2021). Participants described significant challenges to their health and wellbeing related to the pandemic and public health measures, but also demonstrated remarkable resilience in the face of this new adversity. (Lake et al., 2021).

Autism Europe (2020) conducted an online survey among its members across Europe, with the aim to investigate the effect of the Covid pandemic on people ASD in all aspects of their lives. The sample was 392 with a formal clinical diagnosis of ASD. 56% of the respondents were not aware of them, and among them 63% had a negative experience, mainly due to communication difficulties. When it comes to access to testing, 53% of respondents stated they didn’t get reasonable adjustments for autism-specific needs.

Review of policies from 15 European member states, published in March–July 2020 identified the following barriers for accessing COVID-19 services for autistic people: (1) a lack of accessibility to testing, including failure to prioritize and provide adequate adaptations to swab procedures; (2) lack of access to outpatient and inpatient treatment, largely due to differences in communication needs (eg, difficulty using telephone, lack of preparatory materials), which can also lead to difficulties describing and identifying symptoms; (3) ICU triage protocols that may directly or indirectly exclude individuals from lifesaving treatment; and (4) abrupt interruptions to standard health and social care, including mental health interventions, without appropriate interventions measures (Oakley, 2021).

In healthcare, WHO stresses the need to address physical, financial and attitudinal barriers such as social stigma, to disseminate information among health workers about the potential consequences of Covid for people with disabilities and to deliver information in alternative formats to suit different needs (WHO, 2020). 52% of respondents said that they were denied or deprived of healthcare for Covid. Triage guidelines in many cases discriminated against people with intellectual disability. Almost 30% of respondents didn't have access to medication. Also access to general and specialized healthcare was restricted, with people with intellectual disability being on the waiting list or treated in non-specialized places (COVID-19 Disability Rights Monitor (2020).

The growing interest in disability phenomenon since the 1980s in the world. Social inclusion is associated with improved well-being and quality of life for both the general and ID populations. Aspiration is a social model that is particularly opposed to the medical model. Based on the social model, the difficulties of the person with disabilities are solved by focusing on the powers and abilities of the disabled person, and the resources of not only the individual, but also the surrounding environment are used. Studies identified the following barriers for accessing COVID-19 services for people with intellectual disability and people with ASD.

2. The most common challenges for healthcare professionals in the face of people with intellectual disability and conditions for ensuring equality of health services

2.1. Mental and physical health challenges of people with intellectual disability

- People with intellectual disability have high rates of mental and physical health problems.
- People with intellectual disability do experience fear and anxiety, have epilepsy.
- People with intellectual disability are more often hospitalized compared to the general population.
- Prevalence of being overweight and obese among adult's people with intellectual disability is high.
- People with intellectual disability often experience sensory impairment.
- People with intellectual disability are less likely to receive preventive health care.
- People with intellectual disability had substantially higher risk of death from pneumonitis, influenza/pneumonia and choking.

Persons with intellectual disability are more vulnerable to mental ill-health for a number of complex reasons which range from biophysical to psychosocial (Whittle, Fisher, 2018). People with intellectual disability do experience fear and anxiety, at increased rates compared to the general population. Specific phobias (e.g., of dogs or elevators) are often can be seen in patients with intellectual disabilities. About half of children and young people with intellectual disability have a specific phobia compared with less than 5% in the typically developing population (Williams, 2018; Sappok, 2019; Moskowitz, 2019).

Symptoms of depression are common among people with intellectual disability. 14.5 percent of the home care clients with intellectual disabilities and 41.7 percent of the clients of the services for persons with intellectual disabilities had symptoms of depression (DRS>3). In the whole data of the home care services and services for persons with intellectual disabilities, the factors increasing the likelihood of symptoms of depression included female gender, withdrawal from activities of interest, conflicts with family or friends, experiencing pain every day, challenging behavior, and place of residence (Sohlman, 2021).

Dementia for people with intellectual disability five times more often than the general population. The frequency of dementia is particularly elevated in persons with Down syndrome. Characteristic features include memory impairment, loss of practical abilities in everyday life, and the early appearance of behavioral abnormalities (Sappok, 2019).

Research shows that people with intellectual disability does not differ in gender expression - they also have sexual needs. Findings revealed awareness of rights to sexual expression, protection, and enjoyment, but also of consequences when not following the social or legal rules. Analysis indicated issues of morality along with positive feelings toward intimate relationships like love, companionship, and mutual understanding. Finally, although participants expressed some uneasiness to talk about sexuality in general, there was great interest in getting appropriate knowledge and being prepared for the future (Karellou, 2017).

People with intellectual disability are the most vulnerable groups in society. They are more likely to be victims of sexual crimes and experience violence at home and in society. The majority of sexual crimes are committed against women with intellectual disabilities, and there are also a number of violent cases (Aker, Johnson, 2019).

Recent studies show that persons with intellectual disabilities are at risk of experiencing cyberbullying. The findings showed that 15.2% have been cyberbullied, 9.7% are currently being cyberbullied. Those who were cyberbullied reported more inadequate use of mobile phone and Internet (Jenaro et al., 2018).

30–50% of persons with severe and 15% with mild intellectual disability have epilepsy. Epilepsy adds both additional morbidity and mortality. The morbidity includes the physical trauma of the seizures leading to fracture and soft tissue injury, hospital admission, the impact on learning and development through seizure activity and the complex social impact of seizures (Sappok et al., 2019; Health Guidelines for Adults with an Intellectual Disability, 2022).

People on the autism spectrum disorder may have more physical and mental health conditions in midlife and old age compared to the general population. Many physical and mental health conditions, including immune conditions (70.6%), cardiovascular disease (49.0%) and its risk factors (46.2%), sleep disorders (85.3%), gastrointestinal disorders (49.7%), neurologic conditions (55.9%), and psychiatric disorders (72.0%) were highly prevalent in the group of people with autism spectrum disorder who participated in the study (Fitzpatrick, Rubenstein, 2019).

People with intellectual disability often experience sensory impairment. Deafness and visual impairment are the heterogeneous conditions that significantly impacts cognitive and social development. Adults with intellectual disability aged 30 years and over, especially those with Down syndrome, are at risk for early age-related hearing loss. The prevalence rates of those who are deaf and hard-of-hearing range between 30% to 46% in ID adult population samples. 50–60% of people with intellectual disability have a hearing impairment and about 40% of people with intellectual disability will have problems with their sight. Visual impairment at least 7 times higher than in the general population. Adults with Down syndrome aged 30 years and over are at risk for premature age-related cataract (Boardman et al., 2017; Fellinger et al., 2020; Health Guidelines for Adults with an Intellectual Disability, 2022).

People with intellectual disability complains various types of dental disease, particularly periodontal disease, oral mucosal pathology, and moderate to severe malocclusion, were up to seven times as frequent compared to the general population. In a population study of adults with an intellectual disability, Beange et al (1995) found that Dental disease was the most frequent health problem, occurring in 86% of people with intellectual disability (Health Guidelines for Adults with an Intellectual Disability,2022).

People with intellectual disability are more often hospitalized compared to the general population. People with intellectual disability were more frequently hospitalized at a younger age and less frequently at old age. The main reasons for hospitalization among people with intellectual disability is injury, poisoning and other consequences of external causes, whereas for the general population it is diseases of the circulatory system (Skorpen et al., 2016).

Gastro-esophageal reflux disease (GERD) and Helicobacter pylori is a major clinical problem in people with an intellectual disability. Predisposing factors are scoliosis, cerebral palsy, use of anticonvulsant drugs or other benzodiazepines, IQ<35. Symptoms indicative of reflux are vomiting, hematemesis, rumination and depressive symptoms. Helicobacter pylori infection can cause peptic ulcer and gastric carcinoma (Health Guidelines for Adults with an Intellectual Disability, 2022).

Verdugo (2018) noted that for the overall population with ID, overweight and obesity are generalized situations, affecting more than half of this population.

Persons with intellectual disability have a high prevalence of obesity and low physical activity levels, which are risk factors for hypertension. Studies show that people with intellectual disability have problems with being overweight and this is associated with a higher prevalence of diabetes (Aras, 2021).

Prevalence of being overweight and obese among adults with intellectual disability is reportedly 28%-71% and 17%-43%, respectively. Factors increasing the susceptibility of being overweight or obese have been identified as female gender, increasing age, having a certain diagnosis, mild intellectual disability, as well as living independently/with family, consuming certain prescription medications, and non-participation in physical activities (Ranjan, 2018).

Compared with the general population, persons with intellectual disability had 1.6–3.4 - fold higher age-adjusted odds of having a registered diagnosis of obesity or diabetes mellitus, with the exception of diabetes among men with Down syndrome. A registered diagnosis of hypertension was only more common among men with intellectual disability than in the general population (Flygare et all., 2018).

People with intellectual disabilities, despite the fact that they play sports and are an active part of society, face health problems. Oral disease is an unresolved problem among athletes with ID in these Mediterranean countries. According Rojas et al. (2021) therefore efforts should be directed to meet their treatment needs and to prevent oral disease. Among the main findings, the prevalence of untreated decay was 57.0% in Greece, 48.8% in Italy and 41.7% of the Spanish athletes. The prevalence of signs of gingival disease was 61.1% in Greece, 60.6% in Italy and 66.1% in Spain. While the majority of the athletes were in need of dental treatment.

A total of 33,122 individuals aged ≥18 years with intellectual disability who participated in Special Olympic events from 2014 to 2018 had their brachial blood pressure, BMI, and self-reported physical activity assessed. It highlights the similarity in prevalence to the general population. The results emphasize the importance of population-wide screening, increasing physical activity, and reducing obesity in decreasing cardiovascular risk in this population (Schroeder et al, 2020). Oral disease is an unresolved problem among athletes with ID in these Mediterranean countries. Therefore efforts should be directed to meet their treatment needs and to prevent oral disease.

People with intellectual disability are less likely to receive preventive health care such as cancer screening. Results highlighted individual, interpersonal, and community/institutional influences on screening, emphasizing the individual effects of social inequity on this population (Armin et al, 2022).

People admitted for cancer were 8 times more likely to die within the study period compared to people not admitted for cancer (Reppermund, 2019). Cancer people with intellectual disability were less likely than those without ID to have at least one visit in specialist inpatient and outpatient health care, during their last year of life. Older cancer people with intellectual disability were less likely to be assessed or treated by a specialist. This may suggest that people with intellectual disability have unaddressed or untreated distressing symptoms, which strongly contributes to a decreased poor quality of life (Segerlantz et all., 2020).

One research done in Scandinavian countries shows the need for the health professionals' teamwork, need for inter-professional support and need for education in gynecological-obstetric practice. Midwives strived to enhance informed choice and maintain a neutral attitude. The goal of counseling was to provide the most suitable contraceptive method balanced against any risk of long- term use and side effects. A few times midwives had to make the choice on the client's behalf (Höglund, Larsson, 2019).

Research has been done on mortality rates and common causes of death in people with intellectual disability. The standardized mortality ratio in the ID population when compared to the general population was 3.18, with life expectancy being 19.7 years lower (Glover, 2017).

People with intellectual disability, regardless of the severity of the disability, had substantially higher risk of death from pneumonitis, influenza/pneumonia and choking. Adults with mild/moderate ID also had higher risk of death from diabetes mellitus. The leading cause of death for people with intellectual disability indicated on their death certificate was heart disease (Landes et al, 2021).

Review of 27 articles to analyze trends of life expectancy, mortality rates and causes of death of people with intellectual disabilities showed the similar facts. People with intellectual disabilities die 20 years younger than the general population in high-income countries, with respiratory disease and circulatory disease being the most common underlying causes of death, and likely to be preventable in some cases (O'Leary, 2020).

Risk factors included ageing, medication, obesity, demographics, but also non-participation and specifically the lack of face-to-face appointments with clinicians. The study recommends specific guidance for people with intellectual disability as existing MLTC strategies are not always applicable to this group and may increase health inequalities (Mann et al.,2022).

Adam et al. (2020) study revealed specific problems in providing equitable palliative care for adults with intellectual disabilities. Identified needs included physical needs, psychosocial and spiritual needs, and information and communication needs. Barriers and facilitators were associated with education (e.g. staff knowledge, training), communication (e.g. staff skill), collaboration (e.g. importance of sustained multidisciplinary approach) and health and social care delivery (e.g. staffing levels, funding and management support).

Persons with intellectual disability have a high prevalence of mental and physical health problems. Health screening, mental, physical health interventions, inclusion of people with intellectual disability in health policy and improved health care are needed to meet the needs of this population.

2.2. Ensuring equality and providing health care services for people with intellectual disability

- People with intellectual disability are in poorer health and experience health care access problems.
- People with intellectual disability form a vulnerable group within the healthcare system, whose needs can be poorly understood due to their cognitive and communicative challenges.
- The treatment and nursing of people with intellectual disability is complex, needed interdisciplinary approach and special knowledge and skills of healthcare professionals.

People with intellectual disability experience poorer health and healthcare access issues. Vulnerability can also stem from the lack of competences and not knowing how to work with this group of people, poor access to services and professional stigmatizing attitudes. A lack of understanding, misdiagnosis and poor communication contributes to poorer health and increased incidences of hospital visits and stays (Doody et al., 2022).

One study aim was to identify the communication skills of a population of adults (40+ years) people with intellectual disability and explore relationships between individual and environmental factors and communication skills. Over 57 % of a population sample of people with intellectual disability reported communication difficulties. Interventions to enhance interaction and quality of life of people with intellectual disability should consider communication opportunities, needs, and barriers (Smith et al, 2020).

Social and economic changes in the world and the modern theoretical concept of disability interpretation influenced education, social and nursing services concepts. According to principal of social integration disabled persons should be offered the same possibilities to use health care services (Piscalkiene, 2009).

Health accessibility in relation to people with an intellectual disability have identified several common deficits in mental health services, including a lack of training for practitioners, a lack of specialized services, and ineffective service collaboration (Whittle et al., 2018).

Nurses research showed that they incline to evaluate lower their knowledge about disabled persons nursing, there no enough qualification courses on this subject. Qualitative results represent the fact that only small number of Lithuanian nurses have inclusive approach to disabled patients (Piscalkiene, 2009). Greek health and social care students showed poor attitudes towards people with physical and intellectual disability. Regarding intellectual disability (CLAS–ID scores), nursing students had slightly less positive attitudes in ‘Similarity’ but more positive attitudes in ‘Sheltering’ subscales. Previous work and contact was related to more favourable and higher age to less favourable ‘Similarity’ and ‘Sheltering’ attitudes. Males had higher ‘Exclusion’ scores (Kritsotakis et al., 2017).

Moloney et al. (2021) study highlights the need to involve people with intellectual disability and their advocates in healthcare professional design and to promote collaborative working. It also stresses the lack of evidence about the actual implementation or evaluation process of reasonable adjustments for people with intellectual disability.

Person-centered care in this context demands sensitive, passionate and effective staff who listen to and try to understand and interpret the meaning of individuals’ non-verbal expressions (Gjermestad, 2017, cit. Horgen et al., 2010). A study highlights the need to involve people with intellectual disability and their advocates in healthcare professional design and to promote collaborative working. It also stresses the lack of evidence about the actual implementation or evaluation process of reasonable adjustments for people with intellectual disability.

The majority of European countries nursing education still lacks courses on this specific patient group, as opposed to the UK (Appelgren et al., 2018). Carulla et al. (2015) reported that modules and contents on intellectual disability for health care specialist are equally scarce in European countries. Within the health sector, ID programmes focus mainly on psychiatry and psychology. The study underlines the existence of good training practices and experiences from other world regions that could help developments. Poor availability of ID training in health sciences is a matter of concern.

Research shows that treatment and care of patients with intellectual disability in the world has certain weaknesses. The main challenges in the care of persons with intellectual disability include the changes in the mental care system. At the moment there are no special services either in the inpatient hospital system or in the outpatient care (Krysta et all, 2019).

Whittle et al (2018) systematic search was carried with the aim of answering the following research question: “*What are the key barriers and enablers to accessing mental health services for people with an intellectual disability currently identified in the literature*?”

Results show that people with an intellectual disability can face substantial barriers to access mental health services, data are insufficient to address the specifics of those barriers and further work in the area is imperative. Organizational barriers were perhaps the most significant, while lack of services and a lack of consensus around the most appropriate service models to rectify this were also identified as important factors. The quality of the services as gaps in clinical knowledge and diagnostic overshadowing contributed to poor recognition of need and subsequent inadequate treatment. Capacity building and improving the knowledge of service providers was identified as a way of improving access, particularly in relation to improving the quality of services (Whittle et al., 2018).

WHO recognizes disability as a global public health issue, a human rights issue and a development priority. Disability is a global public health issue because people with disability, throughout the life course, face widespread barriers in accessing health and rehabilitation services. Some health conditions may also be a risk factor for other health problems, which are often poorly managed, such as a higher incidence of obesity in people with intellectual disability and higher prevalence of diabetes or bowel cancer. Disability is a development priority because of its higher prevalence in lower-income countries (WHO, 2015).

To say that people with mental disabilities do not understand anything is wrong. people with intellectual disability understands as much as his level of perception allows, he will react to a mocking smile or an insulting phrase depending on his thinking, perception, concentration abilities. Even if a person does not understand the insult himself, an unpleasant action or word can hurt his loved ones. Not mocking and respecting everyone around is a rule to which no exceptions should be applied, regardless of the diagnosis, the person's actions, the way of speaking or other personality characteristics (Kerseviciute, 2018). A study has shown that people with intellectual disability often experience superiority shown by others, fear of being ridiculed, being insulted, facing irony or silent rejection from those around them. Mentally disabled people place of residence, i.e. y living space, choose or are forced to choose according to their material condition, nature of the disorder, family situation. Adults with mental disabilities feel best in the home environment, where they are used to close material surroundings and family members (Vosyliute, Baranauskiene, 2014).

Study on equal access to healthcare for people with intellectual disabilities (2017) report found out that people with intellectual disability are not respected and treated as other patients by health professionals. It highlights a couple of issues common in all Europe. The first one is that healthcare staff often has difficulty communicating with PWID and is not trained in communicating in an accessible way. 80% of the respondents rated the information about medical procedure given by professionals as hard to understand. 100% of the responding countries reported that medical professionals often prefer to communicate with the support person instead of the patient. Very few hospitals seem to have social service staff trained to facilitate communication with people with intellectual disability.

There is a need to prepare and publish guidelines for health care specialists, on proper diagnosing, treatment and nursing of persons with intellectual disability, with the focus of their special needs (Krysta et al., 2019).

Many professionals reported stress in dealing with people with intellectual disability and anxiety about misdiagnosis (Pelleboer, 2017). The table below presents the most important principles of potential attribution of PWID behaviors (by Sappok T, Diefenbacher A, Winterholler M. (2019).

Potential attribution of people with intellectual disability behaviors

Sappok T, Diefenbacher A, Winterholler M. (2019)

Behavior	Possible causes	Diagnostic test or empirical treatment
Rolling and throwing self on the ground, “like a seizure”	Colic	Upper abdominal ultrasound
Striking self in the face, spitting	Toothache, sinusitis, herpes zoster	Internal medical diagnostic work-up
Agitation, self-inflicted injury	Pruritic skin disease	Medical and dental examination
Rubbing the ear	Otitis, tubal ventilation disturbance	Inspection of the unclothed patient, physical examination of the entire body
Refusal of food	Neck pain, toothache pharyngitis, ulcer	Otoscopy, nose drops against swelling
Manipulation in the genital area	Urinary tract infection or other infection	Oral inspection

Regurgitation, rumination	Reflux, achalasia, gastrointestinal disease	Gastroscopy as indicated
Moor agitation, aggression against others or self, shouting	Urinary retention, fractures, other acute and severe pain (e.g., testicular torsion!)	Urinalysis; inspection and examination of the genital region
Shouting, antalgic posture	Fracture, other injury	Physical examination

As Statkuviene (2019) states, when communicating with a person with an intellectual disability, it is important to avoid communication interruptions and not to touch his/her belongings. You should talk to the person naturally, maintain eye contact at the same level, and respect personal space. A simple style of speech, short sentences should be presented to people with intellectual disability. The absence of preconceived attitude, not following stereotypes, patience, taking your time, talking to the excursionist, smiling, pleasant tone of voice, communication according to age are important. It is not easy for people with intellectual disability to remember the information they receive, so it is necessary to repeat it constantly. Stimulants, large gatherings of people or noisy places should also be avoided. Persons with mental disabilities are characterized by a disturbed interest in objects and the environment; peculiar games (e.g. finger game, string game); repetitive movements (swaying, facial expressions). To interest and provide security to a person with an intellectual disability, it is advised to give him or her an item, e.g. booklet, postcard (Statkuviene, 2019).

Good communication takes the main place in the treatment and caring people with intellectual disability. Recommendations for effective health care staff–patient communication (Sappok et.al 2019; Boardman, 2014):

- Use short sentences without subordinate clauses.
- Use words and formulations that are used by the patient.
- Make use of persons in the patient’s near social environment as “translators.”
- Avoid foreign words, metaphors, irony, and negatives (say, e.g., “Speak softly” rather than “Don’t shout “).
- Check whether you have been understood by asking the patient to repeat what you said in his or her own words.
- Work with pictures or objects to illustrate what you mean.

- Demonstrate how you will be examining the patient.
- Involve the patient (e.g., the patient can be "doctor" to a stuffed animal or listen to his/her own heart via stethoscope).
- Avoid jargon and to allow time for the individual to process information.
- Use pragmatics covers such areas as: initiation; topic selection, maintenance and closure; turn-taking; repairing conversational breakdown; and use of appropriate conversational style.
- To allow a longer appointment time and to check who will be accompanying the patient to the appointment.
- Let diagnostic tests be prepared and practiced in advance with persons whom the patient trusts, e.g., blood drawing, blood pressure measurement, electrocardiography, or encephalography, letting the patient become acquainted with the necessary materials and procedures ahead of time.

People with intellectual disability usually have very limited health literacy. There are three aspects to health literacy: I) the patient's ability to read and understand health information; II) the patient's ability to engage with the healthcare process; III) the removal by healthcare systems of unnecessary complexity and barriers to patients' understanding and involvement (Boardman et al., 2014).

The communication skills of people with intellectual disability can be divided into three categories: pre-symbolic, symbolic and verbal.

Pre-symbolic communication. According to Boardman et al (2014), people with very severe or profound intellectual disabilities who only use pre-symbolic communication will be unable to understand or use symbolic forms of communication such as speech, pictures, photographs or signs. They will largely rely on the people around them to anticipate their needs and to interpret their vocalizations, facial expressions and body language.

About 60% of people with intellectual disability are able to use symbolic methods such as pictures, symbols, signs or speech to communicate (cit. Emerson, 2001). People with intellectual disability recognize a few familiar photographs, whereas others may have a much greater understanding of language and be able to recognize a variety of different pictures and/or symbols. They may be able to respond to a pictorial narrative even when they do not use words (Boardman et al, 2014).

Graphic symbols, such as photographs, Makaton and Pics for PECS, are often used in the field of augmentative and alternative communication (AAC) to support people with intellectual disability. Most of the participants preferred coloured symbols. Of all the six types of symbols, they preferred to use photographs and considered these as being the most appropriate symbols for adults, whereas, for them, Talking Mats is better for children (Pampoulou, Diamanti, 2020).

Little implemented in practice, but with deep historical roots, innovative for effective communication, instruction, suitable for spending free time, can be applied in home conditions and at the institutional level - narrative (storytelling) methods.

Narratives allow humans in different cultures to relate to others. Through narratives, people understand each other's experiences and make them meaningful. Narratives develop from birth and throughout everyday interactions between people, and they are crucial for building and sustaining relationships with others. All people start their narrative development before they are verbal. Narrative also plays a central role in how people understand those with profound intellectual disability, and help construct the meaning of what is communicated by them (Gjermestad, 2017,.cit. Bruner, 1987).

People with autism present with a typical triad of impairments that relate to social interaction, communication and imagination. They tend to take language literally and find it difficult to comprehend metaphors, irony and humor (Boardman et al., 2014, cit. Shields, 2001). Lack of knowledge about ID among nurses, with most of them viewing people with intellectual disability as more difficult to care for because they would comply with requests less easily, be possibly more aggressive and less cooperative (Pelleboer, 2017). The results showed that people with intellectual disability lag behind in syntax and morphology and present difficulties in specific aspects of morphology and syntax inherent in the Greek language, especially in subject-verb agreement and in converting nouns from singular to plural (Katsarou, Andreou, 2022).

World Health Organization, Regional Office for Europe (2021) policy brief identifies the key barriers to inclusive health systems in the fields of governance, leadership (need to improve national laws and policies with leadership capacities), data (need for routine health information surveys and disability-specific surveys to compile and analyze data on people with disabilities and interventions and share them with relevant stakeholders) and healthcare workers (need for knowledge about specific vulnerabilities and additional needs of people with intellectual disability, skills to communicate, explain health issues in simple language to people with intellectual disability and obtain informed consent).

Health care professionals need to develop their skills and knowledge in order to better support the health literacy and communication needs of patients with intellectual *disabilities. Developing the competencies of health care workers is a necessary condition for the provision of quality health care services to disabled patients and the performance of effective professional functions. Capacity building and improving the knowledge of service providers was identified as a way of improving access, particularly in relation to improving the quality of services.*

3. Legal framework describing the equal treatment of people with intellectual disability

People with intellectual disabilities have the same rights as other members of society. They have the right to live in the least restrictive social environment, to meet their daily needs, and to receive personal health care services in the same way as other members of society (Methodological recommendations for mental health care, 2015).

A person's ability fully express himself in society is not limited by illness (disability), but by the stigma created by an immature society. Stigma creates a negative image of a person with a disability: people with disabilities are dangerous to society, incompetent, they must be isolated from others, and with such statements, they encourage the appropriate behavior of society: discrimination of persons with disabilities, i.e. restricts the rights to receive adequate personal health care services, to participate in the process of public policy development, to employment, etc. (Corrigan P.W at all, 2002). International organizations and the documents prepared by them protect the rights of persons with disabilities.

The United Nations Convention on the Rights of Persons with Disabilities is the first binding international human rights instrument specifically related to disability. Its purpose is to "promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, as well as promote respect for the inherent dignity of these persons."

The EU is a party to the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) and as such, it must implement the Convention fully in its territory. To assess the quality of services and compliance with Human Rights principles of institutions providing inpatient health care services using the World Health Organization (WHO) methodology.

The UN Convention on the Rights of Persons with Disabilities Article 12 "Equality before the law" states that all persons with disabilities have the right to capacity on an equal basis with other persons in all areas of life, and states undertake to apply appropriate measures to enable persons with disabilities to use the assistance they may need in realizing their legal capacity. The provisions of equality before the law clearly state that a person's disability and/or his decision-making abilities cannot be the basis for denying a person's legal capacity and thus reducing his legal status as a legal subject. The convention enshrines a new model of supported decision-making, and obliges the introduction of new forms and methods of assistance that would not limit the rights of individuals, but primarily offer them assistance in making independent decisions. It aims to ensure legal capacity for people with disabilities on an equal footing with other persons, and for its realization, a system of assistance measures will be used (UN General Assembly, 2007). The UN CRPD states on art. 5 that “Equality and non-discrimination” call on State Parties to “prohibit all discrimination based on disability”; on its art. 9 that “Accessibility” states that State Parties shall take appropriate measures to “ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, and other facilities and services open or provided to the public, both in urban and in rural areas”, including medical facilities and on its art. 25 that “Health” states “persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination based on disability.” It calls on State Parties to:

- “provide persons with disabilities with the same range, quality, and standard of free or affordable health care and programs as provided to other persons”,
- “require health professionals to provide care of the same quality to persons with disabilities as to others, including based on free and informed consent”
- “prevent discriminatory denial of health care or health services or food and fluids based on disability” (UN General Assembly, 2007).

Formal confirmation, accession, and ratification of the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) in project countries:

- Spain – 2 Dec 2007;
- Belgium 30 Mar 2007;
- Lithuania – 18 May 2012;
- Greece – 31 May 2012;
- Finland – 11 May 2016.

People with intellectual disability has very limited visibility in Greek law and regulations. It is important to mention that Greece has ratified, inter alia, the Convention on the Rights of Persons with Disabilities and the Optional Protocol. Between 2020 and 2021, in accordance with the European and international directives, strategies, and conventions, Greece created the National Action Plan for the Rights of People with Disabilities. The goals mentioning health and health care for people with disabilities (in general), aim at: a) improving the accessibility of people with disabilities in primary care, rehabilitative and restorative care, and sexual and reproductive care, mostly through the recruitment and training of new and existing professionals, b) the modification and monitoring of “involuntary hospitalization”, c) the de-institutionalization and the transition to community-based mental healthcare facilities, d) creating a map of accessible healthcare facilities (mostly in case of an emergency and in need of evacuation), e) making hospitals and other healthcare facilities more accessible for people with disabilities (including physical, digital and communicational accessibility issues).

On 2010 May 27 The Seimas of the Republic of Lithuania adopted Law no. XI-854 regarding the Convention on the Rights of Persons with Disabilities and its Optional Protocol, which ratified the 2006 December 13 United Nations Convention on the Rights of Persons with Disabilities and its Optional Protocol (hereinafter referred to as the Convention) adopted in New York. The purpose of the ratified Convention is to promote and ensure the full and equal use of all human rights and fundamental freedoms by all persons with disabilities, as well as to promote respect for the inherent dignity of these persons. The convention enshrines the equality of disabled persons before the law, the requirements for freedom and security, personal inviolability, the rights of free movement, citizenship, and independent life, the right to health, work, employment, and education, the opportunity to participate in political and cultural life.

The Council of Europe promotes, protects, and monitors the realization of the human rights of all persons, including persons with disabilities. Disabled people have the right to use and exercise all human rights on equal terms with others, which are guaranteed in the European Convention on Human Rights, the European Social Charter, the United Nations Convention on the Rights of Persons with Disabilities, and other international treaties. The strategy of the Council of Europe on the rights of disabled people "Human rights: a reality for all" sets out the organization's priorities for the 2017-2023 period.

General Council of Europe 2017-2023 the purpose of the disability strategy (Strategy) is to implement equality, dignity, and equal opportunities for disabled people. This requires ensuring autonomy, freedom of choice, and full and effective participation in all areas of life and society, including community life.

The EU system is complemented by the national monitoring systems of the EU member states, which are responsible for promoting, protecting, and monitoring of the Convention on the Rights of Persons with Disabilities and its implementation at the national level. These systems can take many forms and consist of multiple organizations, such as:

- national equality bodies,
- ombudsmen,
- national human rights institutions,
- monitoring committees include representatives of organizations active in the disabled people's rights field.

Members of the EU system work to promote interoperability with national monitoring systems.

Access to health care Access to health care means that sick people have access to hospital treatment, doctor visits, and the ability to buy the drugs they need. People with disabilities have the same right to quality health care as everyone else. However, they are often unable to exercise this right because healthcare services are too expensive or unavailable. In addition, disabled people may not be able to access hospitals and other essentials, so they usually cannot visit them when they are sick. In the coming years, the European Commission, together with the countries of the European Union, will strive to ensure that healthcare services become more accessible to the disabled.

It underlines that in the area of health, the main competence is within the Member States, while the EU has a supportive role. Chapter 5 on “Equal access and non-discrimination” states that people with disabilities have the right to equal access to all health services and high-quality healthcare. It points out that in the EU people with disabilities report unmet healthcare needs 4 times more than people without disabilities.

It recognizes that there is a gap in EU law to ensure equal treatment of persons with disabilities outside the field of employment, such as healthcare and access to goods and services, and that persistent inequalities and discrimination underline the need for further progress in EU legislation.

It calls on the Member States to improve access to the “entire healthcare portfolio” and make healthcare inclusive, accessible, and person-centered (Union of Equality, 2021).

The document of the World Health Organization - WHA74.8 Resolution on the highest attainable standard of health for persons with disabilities, recognizes that people with disabilities are still more likely to be unable to get access to essential health services, public health functions, medicines, and treatment, due to environmental, financial, legal and attitudinal barriers in society, including discrimination and stigmatization, as well as lack of reliable and comparable data. It expands the concept of medical care for persons with disabilities from a narrow medical perspective to a holistic social model. It stresses that “disability-sensitive, quality, basic and continued education and training of health professionals, including effective communication skills, are crucial to ensure that they have the adequate professional skills and competencies in their respective roles and functions, to provide safe, quality, accessible and inclusive health services".

It reaffirms that "health services should be provided to persons with a disability based on free and informed consent, emphasizing that the necessary information to exercise such consent must be transmitted in a reasonable, accessible, and understandable manner" (World Health Organization, 2021).

This side event aimed to engage Member States, health sector partners, and civil society in dialogue on the entry points to prioritizing and strengthening disability inclusion in national health agendas to address health inequities for persons with disabilities. The main challenges identified by participants are the lack of adaptation of health systems during the Covid-19 pandemic, the lack of accessible information, also about medical treatment, the negative attitudes of healthcare professionals, which can lead to inappropriate behaviors, and the lack of participation of people with disabilities in decision making, as most of the time family members mediate between the medical world and a person with a disability.

The legal experience of the countries participating in the project regarding personal health care services for persons with intellectual disabilities is very different. In Greece, the law adopted in 1992 (correction in 2020) states: The law legislates the ordinance of "involuntary hospitalization" for people with intellectual disability, with a high prevalence in Greece. According to this law, involuntary hospitalization must be the last choice for the patient and must not exceed 6 months. Moreover, the people with intellectual disability has to be treated with respect during his/her hospitalization. Nonetheless, through this law, people with intellectual disability is deprived of its basic rights, either because of the law itself or because of its defective implementation. For instance, people with intellectual disability is unaware of their rights during their stay in a mental health facility, or of their right to exert judicial means. Moreover, their hospitalization usually exceeds the limit of 6 months (Terms of prerequisites of involuntary hospitalization in private psychiatric clinics, 2020). In Lithuania, according to Article 12 of the Law on Mental Health Care of the Republic of Lithuania, "Conditions of Compulsory Hospitalization and Compulsory Treatment", it states: A patient with mental and behavioral disorders who refuses to be hospitalized may be compulsorily hospitalized, but not longer than 3 working days, only if it can be reasonably concluded from the patient's behavior and/or other objective data that there is a real threat that he/she may cause substantial damage to his/her health, life and/or property by his/her actions or inaction (Law of the Republic of Lithuania on Mental Health Care, 2019).

In Finland, the "Act on the Status and Rights of Patients" document emphasizes:

- Section 3 Every person is without discrimination and entitled to health and medical care by their state of health. The patient has a right to good quality health and medical care. Individual needs must be considered.
- Section 4a: A plan concerning examinations, treatment, and medical rehabilitation plan must be drawn with mutual understanding with the patient.
- Section 5: the patient has a right to be informed and the health care staff should give the information in a way the patient can understand. If the patient due to sensory handicap or speech defect cannot be understood, interpretation should be provided if possible.
- Section 6: Patient’s right to self-determination: The patient must be cared for in mutual understanding with them. If the patient refuses a treatment an alternative medically acceptable way must be chosen in mutual understanding. If an adult patient with an intellectual disability cannot decide on the treatment given, the legal representative or a family member, or a close person of the patient must be heard before making an important treatment decision. Patients must be cared for according to their best interests (Act on the Status and Rights of Patients, 1992).

The availability of health care services is one of the factors affecting the lifestyle, health status, and end of life of the population. Therefore, deeper knowledge and skills of health care professionals about intellectual disability would help to provide better services to persons with intellectual disabilities.

Conclusions

- Not all European countries can boast of comprehensive research on the accessibility of health services for people with intellectual disabilities. In the presented review of the literature, we rely not only on the experience of the participants in the project, presented in scientific sources, but also on the experience of other countries of the world. In particular, there is a lack of research on health care professional preparation and professional performance challenges when working with people with intellectual disability. Representatives of social sciences study this phenomenon more widely from the point of view of social services and provision. There is little research focusing on the preferences of adults with intellectual disability.
- There is still no single definition that directly describes people with intellectual disabilities. Deficits in intellectual functioning and difficulties in social skills and socialization are the main features that characterize individuals with intellectual disabilities. The rate of intellectual disability reaches 2 percent in the EU countries and in the world. The causes of these disabilities are varied and often unclear, but genetic, social and psychological factors are believed to play a role. IQ test score 70 or bellow indicates intellectual limitations. There types of intellectual disability: mild, moderate, severe and profound intellectual disability.
- Historically people with an intellectual disability have been excluded from society and many continue to live separately in institutions, group homes and segregated campuses There are several models of disability that describe the nature of disability and the place of a person with a disability in that society. Aspiration is a social model that is particularly opposed to the medical model. Based on the social model, the difficulties of the person with disabilities are solved by focusing on the powers and abilities of the disabled person, and the resources of not only the individual, but also the surrounding environment are used. Studies identified the following barriers for accessing COVID-19 services for people with intellectual disability and people with ASD.
- People with intellectual disability may have more physical and mental health conditions in midlife and old age compared to the general population. Many physical and mental health conditions, including epilepsy, immune conditions, cardiovascular disease, sleep disorders, gastrointestinal disorders, neurologic conditions, psychiatric disorders, deafness and visual impairment, obesity, trauma were highly

prevalent in the group of people with ID. Adults with ID had substantially higher risk of death from pneumonitis, influenza/pneumonia and choking, heart disease. Adults with mild/moderate ID also had higher risk of death from diabetes mellitus.

- Persons with disabilities constitute a vulnerable population group in Europe, systematically exposed to high levels of poverty and social exclusion, with adverse effects on their health and well-being. Developing the competencies of health care professionals is a necessary condition for the provision of quality health care services to disabled patients and the performance of effective professional functions. Capacity building and improving the knowledge of service providers was identified as a way of improving access, particularly in relation to improving the quality of services. The analysis of the scientific literature showed that all over the world, including European countries, medical and nursing personnel lack the knowledge to competently work with people with intellectual disabilities. The biggest challenges faced by people with intellectual disabilities and their families are related to organizational and access barriers to health care services and lack of effective communication.
- Legal documents often emphasize persons with mental illnesses or physical disabilities. Greater focus on meeting the needs of people with intellectual disabilities is missing. Insufficient legal regulation of the provision of health care services to persons with intellectual disabilities in the countries participating in the project.

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