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DEVELOPING A HIGHER EDUCATION CURRICULUM IN SET TEACHING FOR THE HEALTH PROTECTION AND PROMOTION OF INTELLECTUALLY DISABLED INDIVIDUALS

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HEALTH REQUIREMENTS OF INDIVIDUALS WITH INTELLECTUAL DEVELOPMENT NEED ASSESSMENT REPORT

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EXECUTIVE SUMMARY

Individuals with intellectual disabilities also face some problems in accessing and using health services. The main reason for this problem is that they must determine where and how to get health services. This problem arises due to their poor literacy skills, communication and cognitive limitations, and difficulties in applying for, obtaining, and using information about health services.

Individuals with intellectual disabilities face accidents, fractures, musculoskeletal deformities, dental problems, depression, pain, and sensory loss as a high-risk group from the early stages of their lives. Such problems, which threaten their quality of life, may occur independently or in conjunction with another disorder. Therefore, their life expectancy is relatively shorter compared to normal individuals. The level of utilization of environmental resources by individuals with disabilities to improve their health is also lower than their peers. In other words, their health literacy is relatively low compared to healthy individuals. In addition to these risks, the false belief that people with disabilities cannot protect their health themselves or that their health does not need to be improved dramatically increases the effects of the problem.

The low health status of individuals with intellectual disabilities, their differentiated care and service needs, their disadvantages in accessing services, and their limitations in using health resources make them a special group in health service. Individuals need to understand, follow and apply health-related information to make decisions about their health. These skills can be developed through education. Teachers are the main actors here. Improving teachers' competencies in this field is a prerequisite for improving the quality of life of individuals with intellectual disabilities due to their health status.

In the project, based on the literature review, it was determined that they experienced several problems that can be listed under the headings of physical and sports activities, nutrition problems, sleep problems, sexual and reproductive health, protection from infectious diseases, emergency and first aid and personal hygiene. Based on this point,

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interview questions were developed, and the opinions of different stakeholders taking responsibility for educating individuals with intellectual disabilities were consulted. The data obtained from the participants were enriched with two general questions added to the interview questions.

In the needs analysis, data from 299 respondents from four countries - Turkey, Czech Republic, Portugal, and Slovenia - helped develop a more holistic view of the issue. The most crucial overall finding is that there is a need for more opportunities to improve the health of people with intellectual disabilities. In addition, service needs may differ depending on the level of disability. These results have been accurate in recognizing that the project's primary goal of developing a higher education curriculum for special education students was a sound decision.

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TABLES

FIGURES

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LIST OF ABBREVIATIONS

ID: Individiual with disabilities

WHO: World Health Organization

UNICEF: United Nations International Children's Emergency Fund

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1- THE NEED TO PROTECT AND PROMOTION THE HEALTH OF PEOPLE WITH INTELLECTUAL DISABILITIES

Among the main reasons why individuals with disabilities cannot benefit from health services sufficiently is that they do not know where and how to receive health services (WHO, 2011). Individuals with intellectual disabilities have low competencies in applying for health information, obtaining information and using the information obtained due to their literacy, communicative and cognitive limitations (Emerson & Hatton, 2014; Geukes, Bröder & Latteck, 2019; WHO, 2011). Their differentiated care and service needs, low health status, disadvantaged access to services and limitations in using health resources make them a special group in the field of health care (Şahin&Şahin, 2021).

Individuals with disabilities exhibit certain risky behaviours such as smoking and having a sedentary life more than their peers due to their disabilities. Disabled individuals have worse general health levels than normal individuals. When the health status of individuals with disabilities is compared with that of normal individuals in 43 countries, including Turkey, the data show that the picture is generally unfavourable for the disabled. While 80% of normal individuals describe their health status as good or very good, only 6% describe it as poor. For people with disabilities, these rates are 21% and 42%, respectively (United Nations International Children's Emergency Fund [UNICEF], 2019). People with disabilities start to experience oral motor health problems such as accidents (Ho et al., 2019), dental problems, fractures, depression, pain, musculoskeletal deformities, sensory losses or swallowing difficulties in early years (Geukes, Bruland & Latteck, 2018). These problems can occur alone or in combination with another disease (UNICEF, 2019). Therefore, the average life expectancy of people with intellectual disabilities is relatively lower and their quality of life becomes worse due to diseases (Chesney, Goodwin & Fazel, 2014; Haveman et al., 2011). On the other hand, as a reflection of the common misconception that people with disabilities do not need to improve their health and protect

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themselves from diseases, potential risks become health problems (WHO, 2011). Physical activities help individuals with disabilities maintain and improve their health (Allen, Dodd, Taylor, McBurney & Larkin, 2004; Diaz, 2019; Durstine et al., 2000; Fragala-Pinkham, Haley & Goodgold, 2006; Geukes, Bruland & Latteck, 2018; Rimmer, Heller, Wang & Valerio, 2004) and improve their social interactions with their peers (Thomson et al., 2020).

The immune system of people does not differ significantly according to their disability status unless there is a special condition specific to their disability. However, the results of different studies show that individuals with disabilities are included in screening and preventive services within the scope of preventive health services at a lower level. In a study conducted in the UK, when individuals with intellectual disabilities with diabetes were compared with individuals with diabetes alone, it was found that weight monitoring of individuals with intellectual disabilities was performed less frequently than their peers (Disability Rights Commission, 2006, cited in WHO, 2011).

Individuals with disabilities also have problems accessing health services and accordingly, their health needs cannot be adequately met (Akbulut, 2015; Burton & Phipss, 2009). According to the results of the research report titled "Disability and Development" by UNICEF, which includes data from 37 countries, individuals with disabilities in need of health services (13%) have 3 times more problems in accessing services than normal individuals (4%). As reported in the "World Report on Disability" published by WHO in 2011, according to the results of the 2002-2004 World Health Survey, it was determined that disabled individuals received significantly lower levels of service than their peers because they could not access the service despite needing inpatient and/or outpatient treatment. In addition, it was found that 64% of individuals with disabilities had problems in accessing services under rehabilitation services such as occupational therapy and speech therapy (WHO, 2011), and 41% of them did not

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adequately meet their treatment needs for simple oral health (Desai, Messer & Calache, 2001).

Understanding health-related information, following information channels and applying the information acquired is the only way for individuals to make decisions about their own health. It seems possible for individuals with disabilities to reach a level where they can make decisions to improve their own health through individual-oriented health education activities (Şahin&Şahin, 2021).

2-KEY AIMS AND OBJECTIVES

This project will improve the level of self-responsibility of individuals with intellectual disabilities in matters related to their own health. The overall aim of this project is to develop a higher education curriculum called "Health Education and Health Promotion of Individuals with Intellectual Disabilities". The main objectives of the project can be listed as follows:

a. Developing a higher education curriculum

The aim of curriculum development is to improve the competencies of special education teaching students to protect and improve the health of individuals with disabilities. Before the curriculum is developed, a needs analysis report on "Health Needs of Individuals with Intellectual Disabilities" will be prepared. Then training materials will be prepared.

b.Preparation of an online course module

The developed curriculum will be prepared as an asynchronous interactive e-learning module to be used online.

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3- METHODOLOGY

3.1 Target audience

The target audience of this project consists of special education department students, academicians, and special education teachers. The ultimate beneficiaries of the project are individuals with intellectual disabilities.

3.2 Research Model

The needs analysis report of the project was prepared using a qualitative "Phenomenology" design. Phenomenology focuses on phenomena that we are aware of but do not have a detailed and deep understanding of. We may encounter these phenomena in different ways in our daily lives, such as events, experiences, perceptions and situations. However, this does not mean that we fully understand these phenomena (Yıldırım & Şimşek, 2016). Therefore, phenomenology is used for studies aiming to investigate the phenomena that we frequently encounter on a daily basis, which are not foreign to us, but whose full meaning we cannot grasp, and constitutes a suitable research ground (Tekindal & Arsu, 2020). In this project study, this pattern is to ensure that the possible health risks that individuals with intellectual disabilities may experience are understood within the framework of the knowledge and experiences of different stakeholders. According to this model, in the first stage, the problem situation is determined, in the following stages, the literature is examined, questions are asked, data are generated, and then these are analyzed and a report is written (Creswell, 2020).

3.3 Study Groups

In the project study, data were collected from four countries (Turkey, Czech Republic, Portugal, and Slovenia) voluntarily. Data were collected from 64 families (21%), 18 individuals with intellectual disabilities (6%), 63 health professionals (21%), 40 special education teachers (13%), 42 academicians/experts (14%), 51 special education students (17%) and 21 members of non-governmental organizations (7%).

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3.4 Data collection Tools

During the preparation of the needs analysis report, semi-structured interview forms prepared by the research team and validated by expert opinion were used as data collection tools. Semi-structured interviews include an arrangement that includes logical and narrative integrity regarding the order of the questions and facilitate the narrative with beginning and transition statements while collecting data (Polat, 2022).

Form A (Appendix 1), one of the interview forms was created to collect data from the intellectually disabled student or his/her family about their child. Form A includes 10 socio-demographic questions and 9 open-ended questions to determine the facts.

Form B (Appendix 2) was prepared to collect data from special education teachers, specialists, academicians, non-governmental organization volunteers, special education department students and health professionals. Form B includes 3 socio-demographic questions and 12 open-ended questions in total. The questions directed to determine the facts in both forms are similar. There are partial differences in the instructions depending on the group from which data is collected.

3.5 Analysis

The analysis was based on the problem areas identified in the literature review. Each problem area highlighted in the literature was considered a theme. For this reason, a process from deduction to induction was followed in the analysis. The content analysis method was applied in the analysis. This method calculated frequencies and percentages of the participants' responses, and at least a few thematic expressions related to each thematic area were included. In the analyses, the responses collected from different stakeholders with forms A and B of the data collection tool were blended, and the resulting codes' frequency, percentage, and status expressions were given together.

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4.1 TURKEY RESULT

In this section, the health education and health promotion of individuals with intellectual disabilities in Turkey is examined according to the views of experts, academicians, health professionals, families, teachers, and representatives of non-governmental organizations who assume responsibility for children with intellectual disabilities or their education. The socio-demographic characteristics of the groups from Turkey were analyzed, followed by the analysis of the views of different stakeholders on health issues identified based on the literature.

4.1.1 Descriptive statistics

Table 1. Participants descriptive statistics.

Responder	N (82)	% (100)
Family	24	29.27
Students with ID	2	2.44
Health profession	14	17.07
Teachers	11	13.42
Expert/ academics	9	10.96
Student with SET	12	14.63
NGOs representative	9	10.96

The research was conducted with a total of 82 participants from Turkey. Of these participants, 24 (29.27%) were families, and 2 (2.44%) were students with ID. Participants were 14 (17.07%) health professionals, 11 (13.42%) teachers, and 9 (10.96%) experts/academics. Participants were 12 (14.63%) students with SET, and 9 (10.96%) were NGOs representative.

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Table 2. Families and students with ID descriptive statistics

Demografic characteristics			N	% (100)
Participants	Students with ID		2	7.70%
	Families		24	92.30%
Education level	K1-K8		23	95.83%
	K9-12		1	4.67%
	Undergraduate		-	-
FAMILIES Job	Education related job		-	-
	Health related job		-	-
	The other job		22	91.70%
ID age	12≤		10	38.50%
	13-14		3	11.54%
	15≥		7	26.92%
Body mass index	Underweight (18.5≤)		5	19.23%
	Healthy (18.5-25)		8	30.77%
	Overweight (25.0-30)		4	15.38%
	Obesity 30.0≥		4	15.38%
Diagnosis	Mild		-	-
	Moderate		5	19.23%
	Severe		18	69.23%
	Profound		1	3.85%
Chronic disease	Yes		6	23.08%
	No		15	57.69%
Hospital frequency	0-4		12	46.15%
	5-8		3	11.54%
	9≥		8	30.77%
Inpatient treatment	1.Hospitalization Diagnosis……	0-5 day	5	19.23%
		6-10 day	1	3.85%
		11≥	-	-

Table 2 shows the demographic characteristics of the participants. Data were collected from 24 (92.30%) families who have a child with ID and 2 (7.70%) students with ID. Regarding the educational level of the students with ID, 23 (95.83%) of these students were at K1- K8 level, 1 (4.67%) was K9-K12 were graduates. The research was conducted with 10 (38.50%) students aged 12 and younger, 3 (11.54%) students aged 13-14, and 7 (26.92%) students aged 15 and older. The level of diagnosis was moderate for 5 (19.23%) participants, severe for 18 (69.23%), and profound for 1 (3.85%). There was no student with a mild diagnosis among the participants. While 6 (23.08%) of the

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participants had chronic diseases, 15 (57.69%) did not have chronic diseases. According to body mass ratios, 5 (19.23%) students were underweighted, 8 (30.77%) were healthy, 4 (15.38%) were overweight, and 4 (15.38%) were obese. While 12 (46.15%) students state a frequency of 0-4 hospital visits per year, 3 (11.54%) students visit 5-8, and 8 (30.77%), students have more than 9 hospital visits yearly. Furthermore, 5 (19.23%) participants stated they received inpatient treatment for 0-5 days and 1 (3.85%) for 6-10 days per year. When asked about the professions of the families, 22 (91.70%) families with children with ID stated that their job is other. No family said that they have a profession in education and health.

4.1.2 Physically and sporting activities

According to the Ministry of Public Health (2023), physical activity is the movement of the body to spend energy. Physical activity can be defined as activities that occur with energy consumption by using our muscles and joints in daily life, increase heart and respiratory rates, and result in fatigue of different intensities. These activities can be listed as sports such as soccer, basketball, or dance, exercise, physical games, and activities during the day that involve all or some of the basic body movements such as walking, running, jumping, swimming, cycling, squatting, standing, arm and leg movements, head and trunk movements. The most crucial aspect that distinguishes exercise from these is regular physical activity. The exercise involves regular and repetitive body movements.

The Public Health Agency of Turkey (2014) published the "Turkey Physical Activity Guide" for students. In this guide (p.90), physical and sportive activities are recommended for children with intellectual disabilities for at least 60 minutes a day and adults for at least 150 minutes a week, primarily aerobic physical activity of moderate intensity (to be able to maintain a conversation without being out of breath during the activity). A broad list of physical activities has been published, ranging from yoga to sensory-motor activities.

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This report first sought to answer the question, "How active you are physically (e.g., walking, running, mobility), and do you engage in sporting activities (any sports)?". The responses to this question were collated from the stakeholders listed in Table 1. Some of the participants' comments were positive. They think that individuals with intellectual disabilities can actively participate in at least one sport (14 walking, 7 playing table tennis, 2 playing tennis, 12 running, 2 wrestling, 4 athletics, 3 basketballs, 3 soccer, 2 cycling, 8 swimming, 1 gymnastics, 1 handball, 2 using sports equipment, and 1 volleyball). A total of 64 responses were identified.

Two of the special education teachers pointed out that although students with intellectual disabilities do not participate in sports activities as a hobby, they participate at a basic level within the scope of the course. However, students' participation in sports activities may differ according to their level of disability. One teacher stated, "It is also seen that especially individuals with mild mental disabilities are more willing to participate in physical activities and sports branches. (Teacher 6)". Whether sporting activities are carried out as individual or group activities is another factor affecting the level of participation in the activity. One of the participants suggested that individuals with intellectual disabilities can be more successful in individual sports than group sports. It was stated that it would be difficult for individuals with intellectual disabilities to be successful in sports with complex rules. The opinion of a participant representing an association supports this prediction with the following statements.

> *"(The group) Sports are also difficult because they usually have rules. Since the rules cannot be bent most of the time, sports are often impossible. Individual sports seem possible... They have difficulties when they have to follow complex rules." (Association Representative 5)*

Transportation to the venue(s) to participate in sportive activities is one of the difficulties faced by individuals with intellectual disabilities (4). Individuals with intellectual disabilities have problems traveling to places where physical activities are

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performed independently. A health worker participant expressed this situation as follows:

> *"Individuals with intellectual disabilities can walk, but I think they may have difficulty in actions that require mental thinking skills, such as moving from one place to another" (Healthcare professional)*

A group of participants (10) of different stakeholders also stated that individuals with intellectual disabilities do not like to move, have a sedentary lifestyle, and have difficulty in physical and sportive activities. On the other hand, some disability groups, such as Down syndrome, show weakness in muscle movements. The level of intellectual disability and the age of the disabled individual are also determinants of participation in sportive activities. The opinions of another group of fourth-grade students in the special education department (5), which support the fact that individuals with intellectual disabilities show psycho-motor developmental weak muscle movements, can be reported as follows:

> *"Some individuals with intellectual disabilities can do activities such as walking and running, but unfortunately, these activities have no rhythm and order. It is random. Therefore, participation in sportive activities becomes difficult. Since some individuals do not develop motor skills, their physical movements are limited" (Student 9).*

The opinions of physiotherapists and nurses among health professionals are also parallel to the opinion of "Student 9". These participants pointed out that the muscle development of individuals with intellectual disabilities lags behind their peers, so they participate in activities at a limited level. It was even found that some individuals with intellectual disabilities needed the help of someone else to perform physical activities and did walking exercises with the help of physiotherapy. One of the special education specialists stated this situation with the following statements:

> *"Individuals with intellectual disabilities are often dependent on their parents or caregivers, and their dependency increases as their disability*

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increases. For this reason, I can say that the participation of moderately and severely disabled individuals in physical or sports activities is limited" (Expert 1).

4.1.3 Feeding problems

According to the Ministry of Public Health (2023), nutrition is taking the nutrients the body needs in adequate amounts and at appropriate times to maintain and improve health and quality of life. Adequate and balanced nutrition is possible by taking sufficient energy and nutrients necessary for the body to grow and function. Since adequate and balanced nutrition is a significant public health issue in Turkey, the "Department of Nutrition and Movement" was established within the Ministry of Health. In 2022, this Department published the "Turkey Nutrition Guide (Ministry of Health, 2022)". In addition to the importance of adequate and balanced nutrition, this guide has developed some recommendations to prevent obesity, diabetes, cancer, and cardiovascular system diseases caused by excessive and unidirectional food intake. In this report, an answer to the question "What kind of feeding problems does a child with ID have? (e.g., food selectivity, food refusal, not eating enough fresh fruits or vegetables, less consuming milk, meat or poultry, lack of a dietary regimen)" was sought.

When the responses of the participants were analyzed, contradictory answers were found. One group of participants reported that individuals with intellectual disabilities do not make food choices (30), while another group reported that they do make food choices (23). Uncontrolled eating has been reported as a nutritional problem in individuals with intellectual disabilities. This problem may lead to obesity or malnutrition depending on the type of food chosen. The response of one of the experts stated that the most significant nutritional problem of individuals with intellectual disabilities is food selectivity and that they want to eat only a few types of food. One of the special education department students stated the problem situation in this regard with the following statements:

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> *"...Individuals with intellectual disabilities often face situations such as overfeeding or refusing to eat. They are generally picky about food. They show behaviors such as refusing healthy nutrition and wanting to consume unhealthy foods." (Student 8)*

Another nutritional problem was reported as individuals with disabilities not realizing they were full and continuing to eat accordingly. In other words, uncontrolled eating (10) emerged as another nutritional problem. The opinions of two of the special education students regarding food selectivity are as follows:

> *"...I think they do not know whether they are hungry or full, and they can eat all the time. My observations show that they have problems with their willpower to eat. They eat all the time... (Student 3)*

4.1.4 Sleep problems

According to DSM V, a sleep-wake disorder is a medical diagnostic group. A sleep disorder may occur in conjunction with another physical or mental illness or on its own. Etiology may be medical, psychological, or both. There are different types, such as insomnia, hypersomnia, and narcolepsy (APA, 2013). The main symptoms of sleep problems can be an inability to sleep, excessive sleepiness, snoring, and difficulty breathing during sleep/pauses in breathing. Decreased sleep quality negatively affects the individual's life in a broad spectrum, such as forgetfulness, not enjoying activities during the day, loss of concentration, sexual reluctance and difficulty in regulating emotional reactions, and deterioration in mood in all individuals with normal or intellectual disabilities.

In the study, participants' view on sleep disorders of individuals with intellectual disabilities were examined. The participants were asked, "What kind of sleep problems does a child with ID have? (e.g., awakening at night, lack of quality sleep)". The answers given by the participants wereconflicted. While 16 of the responses indicated that individuals with intellectual disabilities do not have sleep problems, 26 indicated

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that they do have sleep problems. The contradictory results may be due to a wide range of responses, such as the participants' lack of knowledge on the subject, the presence of a secondary disease condition accompanying intellectual disability, the level of intellectual disability, and the personality characteristics of the individual with intellectual disability.

One of the health professionals and one of the field experts suggested that individuals with intellectual disabilities do not have sleep problems on the contrary, they sleep quite deeply (good quality). The most frequently reported sleep problem (19) is that individuals with intellectual disabilities wake up frequently at night and therefore have low sleep quality. Accordingly, it indicates that individuals with intellectual disabilities have difficulty waking up during the day (8) (sleepy state). One of the experts stated that the cause of sleep disturbance in individuals with intellectual disabilities might arise due to different factors.

> *"...Some individuals with ID may have problems sleeping late and waking up frequently at night. There are also problems of not waking up in the morning due to sleeping late at night. In addition, many individuals with ID have chronic insomnia problems. This also negatively affects their quality of life." (Expert 3)*

4.1.5 Sexual and reproductive health and right

According to the World Health Organization, sexual and reproductive health is complete physical, mental, and social well-being concerning the reproductive system. The Ministry of Health published "Sexual and Reproductive Health Service Standards" in 2007 (For detailed information, see https://ekutuphane.saglik.gov.tr/Home/GetDocument/326). According to this guide, the scope of sexual and reproductive health services and the individual's rights are defined in detail. The fourth issue, which is trying to obtain information about the current situation in the project, is sexual health and reproductive services. For this purpose, "What should a child with ID know about sexual and reproductive health

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and rights? (e.g., protecting from transmittal diseases, unwanted pregnancies, sexual identity)" was asked.

When the responses were analyzed, 7 participants stated they had the necessary knowledge about sexual and reproductive health. A significant number of participants (30) stated that individuals with intellectual disabilities do not have the necessary knowledge about sexual and reproductive health and that their awareness about sexuality is low. One of the special education teachers pointed out that individuals with intellectual disabilities know bad touching, but their competence in sexual health issues is low.

> *"...People with intellectual disabilities generally know about the circle of trust, about bad touching. However, they do not know about sexual health issues such as protection from sexually transmitted diseases. Most of the time, they do not feel the need to do so. Individuals continue their lives without any sexual life." (Teacher 1)*

> *"...In order to ensure the physical and psychological safety of the child, skills such as sexual education, safety education, protection from strangers.... should be frequently included in every developmental period." (Expert 5)*

Five participants claimed the opposite of the above view, suggesting that individuals with intellectual disabilities cannot distinguish bad touching. One of the factors affecting the level of sexual health knowledge of individuals with disabilities is the level of disability of the child. The association representative and a field expert pointed out that knowledge of sexual and reproductive health can be acquired through education.

> *"...I do not think that IZ individuals have any knowledge about their sexual health, sexual hygiene, and sexual activities. These students should be aware of these issues with the education they will get." (Association 2)*

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"...If they are not educated, they do not know. Unfortunately, the vast majority have not received sexual education." (Expert 5)

4.1.6 Protect yourself from contagious / infectious disease

Infectious diseases are diseases caused by microorganisms. One of the ways to protect against these diseases is personal precautions. Since they spread quickly, they can affect many people in a short time. In schools, one of the most important reasons for student absenteeism is infectious diseases due to communicable diseases. In Turkey, the fight against infectious diseases is carried out according to the "Guidelines for Combating Infectious Diseases" published by the Ministry of Health (For details; https://hsgm.saglik.gov.tr/dosya/mevzuat/genelge/Bulasici-Hastaliklar-ile-Mucadele-Rehberi-Genelgesi-2017-11.pdf).

The report also examined the level of protection of individuals with intellectual disabilities from infectious diseases and COVID-19. When the participants' responses were analyzed, contradictory results were found regarding the students' knowledge of protecting themselves from infectious diseases. A group of participants stated that students with intellectual disabilities do not have enough knowledge to protect themselves from infectious diseases (15), while a relatively small number of participants stated that individuals with intellectual disabilities know how to protect themselves from infectious diseases (4).

"...During the pandemic, special education schools stayed open longer than other educational institutions, and since the educators and staff in the schools were very careful about the use of mask distance disinfectants, students learned to act following these rules." (Teacher 4)

"...These individuals are less likely to protect themselves against epidemics. Because they do not receive recurrent training against the situations mentioned in the example, these individuals (especially those at moderate and

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severe levels) have many problems in the continuation and generalization of their skills in protection against epidemics." (Teacher 6)

The level of disability has been reported as an important factor for individuals with intellectual disabilities to have the knowledge and skills to protect against infectious diseases. During the Covid 19 pandemic, it was reported that individuals with intellectual disabilities took the necessary precautions regarding hygiene and disinfectant use to protect themselves from the disease (12), paid attention to social distancing (12), paid attention to the use of masks (9) and performed personal hygiene such as hand washing (5).

"...These individuals are very careful in protecting themselves against infectious diseases. They follow the rules and act cautiously in terms of wearing masks and social distancing." (Expert 4)

4.1.7 Emergency and first aid

In case of an accident or a life-threatening situation, first aid is defined as the non-pharmaceutical application made with the available means from the scene to save life or prevent the situation from worsening until the help of health personnel arrives. In this study, the knowledge levels of individuals with intellectual disabilities about emergency and first aid practices were examined. Data were collected by asking the participants, "How should a child with ID do in case of an emergency (e.g., call emergency number, asking help to an immediate person, going to a safer place) or what should he/she know about the need for first aid (e.g., bleeding control, cardiac massage, heimlich maneuver)?"

When the responses were analyzed, it was found that the participants gave contradictory answers. A group of participants reported that individuals with intellectual disabilities did not get first aid training (29), while a relatively small number of participants (9) reported that these individuals get first aid training.

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According to the participants, individuals with intellectual disabilities may seek help from their surroundings when they need first aid (11), even if they do not know first aid, they can call the ambulance to request help (11). The participants generally made statements indicating that first aid and help-seeking behaviors of individuals with intellectual disabilities are different behaviors. In addition, the level of the individual with intellectual disability has emerged as one of the determining factors in the performance of both behaviors.

> *"..I think they are sufficient to seek help from others or authorities in an emergency, but most of them will be incompetent when they have to apply for help themselves. Thanks to the courses they take in schools, they can intervene in situations such as bleeding, but they may be unable to help in other situations." (Association 4)*

> *"...individuals with intellectual disabilities can be taught simple things according to their level of intellectual disability. For example, an individual with a mild to moderate intellectual disability can learn the emergency number. However, only an individual with a mild intellectual disability can call this number in an emergency. In emergencies, they can ask for help from the immediate or non-closed environment or draw attention to their location. However, they know little or nothing about first aid. I think they do not know what to do in a situation requiring first aid." (Expert 3)*

> *"...Individuals with mild intellectual disabilities can grasp them more easily. But individuals with moderate and severe intellectual disabilities may have difficulty in grasping it." (Student 8)*

4.1.8 Personal hygiene

Personal hygiene is the self-care practice of individuals to protect and maintain their health. In this study, participants' views on the importance given to personal hygiene rules by individuals with intellectual disabilities were determined by asking the

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question, "How should a child with ID care about his/her personal hygiene (e.g., hand washing habits, brushing teeth, bathing)?".

The primary purpose of teaching personal hygiene to individuals with intellectual disabilities is to ensure they can perform these skills independently or with minimal dependence. In the study, the answers given by the participants were predominantly that individuals with intellectual disabilities perform personal hygiene with assistance (34). When the responses were examined in detail, it was revealed that the level of disability of the individual was determinative in the assisted behavior.

> *"...A mild student can do personal hygiene independently. They can acquire these skills, and some students can do it partially. Moderate and severe students cannot perform all their cleaning skills fully and independently. It can be said that they can perform these skills with more support." (Expert 1)*

> *"...an individual with ID can do personal hygiene to a great extent if they are mildly disabled. However, individuals with moderate and severe intellectual disabilities have difficulty washing hands, brushing teeth, bathing, and bathing independently." (Teacher 3)*

Personal hygiene skills can be categorized in different ways. According to the systematics used by Kurtoğlu and Caykaytar (2022), personal hygiene skills can be categorized as basic skills (toileting, nutrition....), skills that support basic skills (hand and face washing, tooth brushing, and dental care, bathing, hair combing.....), personal care (nail cutting, skin, and hair care, menstrual skills....) and advanced self-care skills (selection of clothes, taking medicines appropriately...). One of the experts emphasized the level of implementation of personal hygiene skills, especially those that support basic skills and health status.

> *" These individuals are more likely to get diseases because they are generally weak in personal hygiene skills. In general, they may have more skin diseases,*

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microbial diseases, and dental problems due to not bathing regularly, not having dental hygiene skills, and not shaving regularly...(Expert 3)"

A group of participants (9) pointed out that personal hygiene is among the basic skills that individuals with intellectual disabilities should acquire in order to protect and promote their health. Personal hygiene skills can be learned and taught. The family of the individual with an intellectual disability is primarily responsible for teaching these skills. Therefore, it is emphasized as one of the issues that should be prioritized in family education.

"...Even individuals affected by moderate and severe intellectual disabilities can meet their hygiene sufficiently if they receive qualified education. If there are problems, families do not think their children can do these skills and do not try to teach them." (Teacher 1)

"To protect and improve the health of these individuals, they should first be supported in personal hygiene and self-care skills. Skills such as bathing, hair and feather cleaning, and tooth brushing should be acquired by individuals with I/DD. For this purpose, parents and their children can be made aware of the items to consider regarding cleaning and self-care with booklets... (Expert 4)"

4.1.9 Protect and promotion

Individuals with intellectual disabilities have relatively lower health literacy than their peers (Şahin & Şahin, 2021). This situation leads to a relatively lower level of utilization of resources that will protect and improve their health compared to healthy individuals. In the project, data were also collected on the possible factors or issues affecting the health of a child with intellectual disabilities and what can be done to protect and promote the health of a child with intellectual disabilities.

When the literature is reviewed, there is a general emphasis on the need to improve the psycho-social and economic environment to protect and improve the health of

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individuals with intellectual disabilities. In particular, the family's education level on the subject is among the important determinants of the family's values, preferences, priorities, resource allocation, and interaction with the child. On the other hand, the level of acceptance of society for the disabled child and the family is also determinant in the acquisition, development, and implementation of appropriate health behaviors of the individual with intellectual disabilities by taking society as a role model.

> *"Being excluded by the people around them negatively affects the individual's psychological health. Therefore, it is essential that the environment shows an accepting attitude and be in a friendly relationship (Student 9)."*

One factor that negatively affects the general health status of individuals with intellectual disabilities is a secondary health problem, which occurs more frequently, especially as the level of disability increases. Cardiovascular system diseases, which occur more frequently in people with epilepsy or Down syndrome, are the most common. Epileptic seizures are a problem situation that negatively affects the child with intellectual disabilities' own health and peer interaction. Besides decreasing the child's health status, chronic diseases increase the number of days spent in hospitals/health institutions and increase education absenteeism. Therefore, educators, in particular, should be aware of the factors that negatively affect the health status of individuals with disabilities and give importance to disease prevention. When necessary, they should be able to provide first aid intervention.

> *"Many individuals with intellectual disabilities have epileptic seizures in addition to their disabilities. This is the most important and common health problem. Especially individuals with Down Syndrome often have heart diseases..." (Teacher 4).*

A group of researchers emphasized the importance of health education in improving the health status of people with intellectual disabilities. Health education activities can be embedded in the main curriculum or as extra-curricular activities. The effectiveness

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of the training is possible with planning for all stakeholders who take responsibility for the child's education.

> *"These issues can be included more in the education curriculum. However, since the education children receive only in schools will not be sufficient, it would be good to provide family training to the families of these children about what to pay attention to in this training. Afterward, social workshops can be applied wherever they come into contact with society to ensure the continuation of the education they have received and to make it more qualified" (Teacher 9)*

4.2 PORTUGAL RESULT

The results presented in the section are related to the two questionnaires (General - Annex A and Specific - Annex B) applied to different subgroups using the Google Forms tool. Therefore, they can potentially represent essential elements for analysing persons with ID on the health theme.

The formulary was open from the middle of February until the end of March, and the data were collected over six weeks from the several groups that were contacted: Families with ID children; Healthcare professionals; Teachers of SE; Experts in ID; Students with ID; local associations connected to SE. All of the answers were collected through open and semi-open questions. The contact was established mainly by email and in short meetings with local teachers and associations. From the semi-open questions, we could analyse the thoughts and ideas behind them, presenting quotes in some of the following subsections.

4.2.1 Descriptive statistics

There were, in total, 68 participants answering the Google Forms questionnaire. The sample has been collected from the following groups: Families with ID children; Healthcare professionals; Teachers in SE; Experts in ID; Local associations connected

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to SE; Others. The sample comprised 37 women (54,4%) and 31 men (45,5%). The following table presents the overall data.

Table 3. Participants' descriptive statistics.

Answers	**N**	**%**
Family (father and mother)	16	23,5
ID person/student with se	13	19,1
Health profession	9	13,2
Teachers	11	16,2
Expert/ academics	3	4,4
Ngos representative	11	16,2
Others	5	7,4

From the data, the group with more answers is the family (father and mother), followed by persons with ID/students with SE, and next, the teachers and NGO representatives. These numbers reflect the expectations regarding the parents' interest in this situation.

The following table briefly describes the families and persons with an ID that answered (most probably, the last number is due because of the help that these persons had to fill out the questionnaire).

Table 4. Family with ID children/adults

Demografic characteristics		**N**	**%**
Participants	Student/adult with ID	13	45
	Mother	10	34
	Father	6	21
Education level	K1-K8	2	24
	K9-12	21	72
	Graduate	1	3
Job	Education related job	-	-
	Health-related job	-	-
	The other job	12	35
Id age	12≤	-	-
	13-14	2	5,8
	15≥	32	94,2
Body mass index	Underweight (18.5≤)	0	-
	Healthy (18.5-25)	21	62

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	Overweight (25.0-30)	12	35
	Obesity 30.0≥	1	3
Diagnosis	Mild	21	62
	Moderate	10	29
	Severe	3	9
Chronic disease	Yes	0	-
	No	34	100
Hospital frequency	0-4	34	100
	5-8	0	-
	9≥	0	-

From the previous data, we state that 45% were students/persons with ID (most probably helped by someone), and 55% were parents (father and mother). Most of the participants are in the band of k9-k12 (72%), being healthy (62%) and with a mild ID (62%). None of the participants has a chronic disease; all are in the band of 0-4 times that went to the hospital last year, and from the data collected in Google Forms, more than 50% didn't go to the hospital.

4.2.2 Physically and sporting activities

The following table condensates the information regarding the physical and sports activities. From the data collected, persons with ID can face many challenges when participating in sports activities. Some of these are connected to the lack of access to appropriate facilities and equipment, and some are because of funding and resources for training. Also, we need to consider the social stigma and discrimination from other groups. Even so, in the middle of the difficulties, there still exist will to develop different activities related to sport. Many of them are connected to walking, in group or alone, also others refer the use of swimming pool.

Table 5. Physically and sporting activities

Type of Activity	**N**
None	4
Swimming	5
Practice some collective sports activity	33
Practice some sports activity alone	23
Practice walking	24
Practice running	1

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Most participants state that these persons practice some collective sport (football and swimming in clubs) are the top of the answers (33), followed by general walking in the middle of the city/countryside (24) and some activity alone (23). Since it is the highest city in Portugal (1056 meters) the nature surrounds the city, the air is fresh and healthy, which helps to promote activities like walking.

4.2.3 Feeding problems

Persons with ID can face many challenges concerning feeding, including sensory, physical or even behavioural issues. The following results present some of the difficulties. Among all the answers, some people state swallowing because of physical issues that can result in choking, which is very dangerous or even life-threatening; others refer to the sensory processing difficulties that make certain textures, flavours, or even food temperatures unappealing or intolerable. Some individuals with ID may also exhibit behavioural issues related to food, such as food refusal or overeating. These issues can be related to various underlying factors, such as anxiety, sensory issues, or a history of food insecurity. Some refer to medical conditions requiring special diets, such as gastroesophageal reflux disease (GERD) and celiac disease, which cause many problems. These issues can make providing a balanced and nutritious diet a tough challenge. The following table states the feeding problems, when they exist, with the answers again being given by parents in most cases or ID persons with the help of someone.

Table 6. Feeding problems

Type of Problem	N
None	17
Not allowed to eat some fruits or fresh vegetables	5
It needs a specific food regime	27
Cannot eat meat	2

The results say that 27, most of the persons, need a specific food regime, followed by 17 that didn't have any problem regarding feeding problems. A few participants state the problem with some fruits and fresh vegetables. Among these are some issues of

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diabetes and the connection of food with a high value of sugar, which means some problems in controlling the will to eat this kind of food. Usually the participants say that there is a need for close control of these persons.

4.2.4 Sleep problems

Individuals with ID are more likely to have sleep problems than the general population. Some of these problems were shared in the Google Forms questionnaire: difficulty falling asleep (some take longer than usual to fall asleep); sleep-disordered breathing (risk for sleep apnea that generates fatigue); insomnia (causing anxiety and depression); night terrors (distressing experiences for all family or for the caregivers). The following table presents the results of the 68 participants divided into different categories.

Table 7. Sleeping problems

Type of Situation	**N**
Wake up in the middle of the night.	17
Lack of quality sleep (meaning that the person wakes tired in the morning)	9
It depends on the specific situation	18
No problem	11

It is possible to see that two situations cover most cases, the wakening in the middle of the night, representing 17, and the other that most of the participants (not the parents) state that every case is a singular case with particular situations, 18. Then 11 say there is no problem with that, and 9 refers to cases when the person wakes or doesn't sleep properly at night.

4.2.5 Sexual and reproductive health and right

Sexual and reproductive health and rights (SRHR) are significant, not only for the general population but also for individuals with ID as well. However, in this last case, several complex challenges exist to achieving these rights. Most are connected to limited access to information and services, the continued social stigma and discrimination, and the lack of autonomy to make decisions. From the questionnaires,

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some information is concentrated on sexual health and contraception, the knowledge of sexual identity and a few persons said the access to services (the barriers to accessing reproductive health services or limited financial resources).

We produced the following table from the combined results of the semi-open questions presented in the questionnaire.

Table 8. Sexual and reproductive health

About sexual and reproductive health	**N**
Information about the knowledge of your sexual identity	37
Information on protection against sexual diseases	20
Information on unwanted pregnancy	16
Without knowledge or an opinion	28

In this type of questionnaire, we can notice a kind of protection and, at the same time, prejudice regarding sexual life and knowledge on this subject. The results show that more than half of the participants in this inquiry, 37, state the need to have information and learn about sexual identity. Still, at the same time, 28 say that they don't have knowledge or even don't have an opinion on the situation. So, it stays an issue in society that affects all persons, even those suffering from ID.

4.2.6 Protect yourself from contagious/infectious disease

The risk of contracting contagious or infectious is higher for persons with ID. This type of disease can be due to compromised immune systems or limited access to healthcare. Several issues were stated by the semi-open questions: good hygiene is one of the most important aspects (frequent hand washing, covering the mouth and nose when coughing or sneezing or avoiding touching their face); a few numbers of persons stated the vaccination process is an important point; the social distancing was mention by a large part of the enquiries (probably because of the last year's practice during the COVID pandemic situation); regular health check-ups with the family doctor; the use of personal protective equipment (the use of masks not only by the caregivers but also, when it's possible, the ID persons to protect against the spread of infectious diseases). There is a group of persons that said that education/formation and different resources

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for ID persons and their families and caregivers can be a way to help to promote awareness and prevent the spread of infectious diseases.

The following table presents the notion regarding contagious diseases from the semi-open answers.

Table 9. The notion of contagious/ infectious disease

Learning about contagious/infectious disease	**N**
Be aware of protection rules	40
Avoid social contact while maintaining distancing	17
Know how to protect by using, for example, masks	17
Information about the knowledge of your sexual identity	14
I don't have any knowledge	28

From the data, we can check that 40-person state that it's essential to be aware of the protection rules. But also, on the other hand, 28 people say there isn't any knowledge of this theme, which is somehow worrying. 17 know to avoid contact while maintaining distance and, for example, mention the use of masks during the COVID pandemic.

4.2.7 Emergency and first aid

This question results in another very challenging situation regarding the answers obtained. Emergencies can be particularly complicated for everybody, but regarding persons with ID, it's even much more challenging. One of the main aspects of the participants that answered the questionnaire is that most people with ID have difficulty communicating their needs and understanding what is happening around them. This is a huge problem, but even if they can contact and express it, there are others, like mobility or physical limitations.

Table 10. Emergency and first aid

Emergency And First Aid	**N**
Call the emergency number	28
Ask a person for help right away	59
Go to a safer location	31
Doesn't know or have knowledge	3

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From the table, we are able to see that the most important aspect of an emergency is to ask a person for help, 59, but this could be a problem in situations of physical limitations and knowing or having a clear understanding of what is happening at the moment. Also, nearly half of the participants answered that it should be good to go to a safer location (31), and 28 said that calling the emergency number is the thing to do now.

4.2.8 Personal hygiene

The case of personal hygiene in individuals with ID is, again, an arduous and challenging task. The participants state that most of the time, cognitive or physical limitations are obstacles to proper personal hygiene. The visual support that could be given in school (in the cases of students) is only partially followed at home. Also, using adaptive equipment in schools is not continued at home (the lack of financial support for families). So, these are some of the problems stated in the semi-open questionnaires.

Next, we presented the table with the results.

Table 11. Personal hygiene

Personal hygiene	**N**
Know hygiene habits	62
Knowing how to brush your teeth	62
Knowing how to bathe	67

There is a unanimous opinion regarding the need for personal hygiene habits; almost all participants focus on brushing tooth and bathing correctly as the most important.

4.2.9 Protect and promotion

Persons with ID need help to access and receive adequate health care. The participants, families, caregivers, teachers, NGO representatives, ID experts, and others refer to this questionnaire for several important issues regarding protection and promotion. The analysis reaches the following conclusions about the most important ones regarding protecting and promoting health in persons with ID.

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Next, we present the resume:

- Inequality in services – the general population's health suffers problems. Still, when it comes to persons with ID, the experience is even worst, producing massive inequalities, such as higher rates of chronic disease (diabetes is one refer example) and poor mental health because of the lack of care from the social welfare and health services;
- The need for promotion – there is a clear need to promote healthy behaviours and lifestyles in people with ID. The participants talk about physical activity and the eating process;
- Barriers (not only physical) – there is a deficiency in transportation networks and a difficulty in communication between the several intervenients, which sometimes produces difficulty to understand the healthcare information provided by the government or other types of institutions;
- Mental health – the increased risk of mental health problems like anxiety and depression, which worries the families and caregivers. This problem should be discussed and diminished;
- The lack of formation – the importance of access to a wide range of tools, going from ICT to other types, like cards, specific drawings, short films, and the designing of specific apps for simple purposes (explaining the basic hygiene rules or what to do in an emergency);
- Supporting the caregivers – something the government must be aware of. Most of the time, these people have high-stress levels and need support to help them manage the situations. There should be a network that can provide help to these persons.
- Parent's school – providing specific formation to help parents deal with this situation. *"No one is prepared for this!"*

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4.3 SLOVENIA RESULT

The following chapters present the results of an open-ended questionnaire that explored the different perspectives of various groups of people who come into contact with children with intellectual disabilities (ID) on selected health education/promotion topics. The methodology is based on a qualitative approach with emphasis on the descriptive-interpretive method. The first part presents the demographic characteristics of the participants and the second part presents the views of the different stakeholders on selected health topics.

4.3.1 Descriptive statistics

In total 75 participants completed the survey. The sample consisted of various target groups (Family with a child with ID; Healthcare professionals; Teachers; Expert/academics; Students with SET; NGOs representative). The sample consisted of 55 women (73%) and 20 men (27%). Detail data are presented in Table 1.

Table 12. Participants descriptive statistics.

Responder	**n**	**%**
Family	7	9
ID	-	-
Healthcare professionals	30	40
Teachers	8	11
Expert/academics	10	13
Student with SET	18	24
NGOs representative	2	3

Table 12 presents the detail data about the child with ID as reported by their family members – mothers. All participants in this target group were describing their perspective surrounding their children.

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Table 13. Family with ID or ID descriptive statistics

Demographic characteristics		**n**	**%***
Participants	ID with student	-	-
	Mother	6	
	Father	-	-
Education level - EQF	LEVEL 1	-	-
	LEVEL 2	6	
Job	Education related job	-	
	Health related job	-	
	The other job	6	
ID age	12≤	5	
	13-14	1	
Body mass index	Underweight (18.5≤)	-	
	Healthy (18.5-25)	4	
	Overweight (25.0-30)	2	
	Obesity 30.0≥	-	
Diagnosis	Mild	5	
	Moderate	1	
Chronic disease	Yes	1	
	No	5	
Hospital frequency	0-4	6	

Note: All children with ID were identified as females by their mothers.

*Percentages were not calculated as in this small sample this would lead to the most common error in reporting percentages.

4.3.2 Physically and sporting activities

In conversations with mothers of children with intellectual disabilities, it became clear that efforts are made to keep the children as physically active as possible. Most of these activities take place outside - in nature. However, four mothers reported that when the weather is bad, they use very simple equipment indoors or outdoors for physical activities and follow the instructions of physical therapists and kinesiologists. They are aware of the importance of physical activity for children's health. However, two mothers find it difficult to physically activate their children due to the severity of their intellectual disabilities.

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> *"Most of our sports activities take place outside in nature because there is a lot of space, and we mostly play ball games." (Mother with a child with ID)*

The health professionals interviewed all worked in primary health care. In their responses, they emphasised the importance of physical activity for the health (not only physical but also mental) of children with intellectual disabilities, especially in terms of improving resilience, increasing mobility, and ultimately bonding with the family because they do it together. They talk a lot with their parents, most of whom work, about how to manage their time so that they can engage in regular physical activity each day. Health education is thorough, according to most health professionals (n=20), and is directed at all family members. Health workers (n=12) see challenges in the low health literacy of some parents, in sometimes overprotective parents, and in the lack of time available for health workers to work with families and children with intellectual disabilities.

> *"From my experience in a children's clinic, I have noticed that many parents still need guidance on healthy lifestyles. In addition, many parents are faced with overcrowded schedules that prevent them from focusing on important aspects of their children's health." (Healthcare professional)*

Teachers were largely critical of the curriculum, noting that it contains little content or lessons related to physical activity for children with intellectual disabilities (n=6), although they are aware of the importance of this issue. They also note that as teachers, they have little knowledge about health-related topics in general and can hardly influence changes to the curriculum in elementary school. On the other hand, teachers face similar challenges as health professionals: on the one hand, parents who passively try to promote a healthy lifestyle for their children, and on the other hand, overprotective parents and their own lack of knowledge. The work of school nurses in providing health education in schools is described as very important by most teachers. Absolutely all participants would like to see more knowledge in this area. The experts/academics (n=7) share similar views as the teachers in emphasising the

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involvement of children in the school system and the involvement of health professionals in curriculum development, which would also contribute to more physical activity in schools.

> *"As a teacher, I find that I lack knowledge about children's health and physical activity. Therefore, I think it would be useful to involve health experts in the school system so that they can contribute with their expertise to raise awareness and improve children's health." (Teacher)*

Students with SET (n=12) are even more aware than teachers of the importance of physical activity for the health of children with intellectual disabilities and point to concrete solutions when describing their vision: interprofessional collaboration between teachers and health professionals and connections with parents; more forms of extracurricular activities - trips to the mountains, vacations, camps, etc. Some students (n=5) point out that they have collaborated with some non-governmental organisations during their studies to organise the activities mentioned above. The representatives of the non-governmental organisations particularly point out the risk of inequalities in access to the activities organised by the non-governmental organisations.

4.3.3 Feeding problems

In their responses, health professionals (n=14) refer to the high risk of obesity in children with intellectual disabilities, which is related to lack of exercise. They generally do not perceive eating habits or nutritional problems unless they are due to an underlying diagnosis. Parents' descriptions (n=4) suggest that the eating habits of children with intellectual disabilities are similar to those of others, such as cravings for sweets (candy and sugary drinks), pickiness (vegetables), irregular eating, and frequent reminders to drink enough. One parent of a child with diabetes (type 1) mentioned the problem not because of eating or eating disorder, but because of peers and binge eating at school. This problem was also mentioned by four elementary school teachers, suggesting that this problem (although easily solved) is very common.

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Otherwise, teachers did not specifically encounter children with intellectual disabilities who had feeding problems such that they needed feeding assistance or other forms of assistance with eating. The other participant groups did not comment specifically on this issue.

> *"I think peers have a big influence on my child's eating habits. If one of them eats unhealthy foods, there is a good chance that my child will also choose similar foods ..." (Mother with a child with ID)*

4.3.4 Sleep problems

Parents of children (n=3) with intellectual disabilities were most likely to talk about sleep problems, while the other participant groups did not specifically answer this question. Parents did mention occasional sleep problems, but these are not treated medically. They mainly emphasise regular performance of daily activities (called sleep hygiene), including physical activity before bedtime. They cite night-time awakenings as the most common sleep problem. One parent also reports extreme difficulty getting their child to sleep and relies on the use of homoeopathic remedies. Regarding sleep, one teacher points out that insomnia is recognised in a child when he or she has difficulty participating in daily activities at school and that the curriculum is designed to address this to some degree. However, he is concerned about how this will be possible later in elementary school when the child is in the higher grades where he has less freedom.

> *"If he did not get enough sleep, his behaviour was obviously ... um, very poor, and his learning was also impaired in school. It's worrisome how he will do in the higher grades." (Teacher)*

4.3.5 Sexual and reproductive health and right

Apart from health professionals, professionals/academics, and students with SET, it is noticeable that sexual and reproductive health is still a taboo topic that many people do not want to talk about. Health professionals (n=27) stress the importance of health

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education on this topic in schools and institutions where children spend most of their time. It is about health education for children with intellectual disabilities and at the same time for their teachers and parents. Most of the problems arise from the reactions of parents who, due to their protective role towards their children, do not recognise the challenges/difficulties related to sexuality. They do not see their children in this role and, of course, do not talk to them about it. Only one mother emphasised that she explained to her daughter the menstrual cycle and how to behave during menstruation (utensils, symptoms and signs). However, none of the parents involved talked to their children (and other professionals) about sexuality or reproduction. Students with SET (n=15) consider this topic very important, but say that they did not learn anything about this topic during their studies that would be useful for their future work with children with intellectual disabilities.

> *"I feel like I can not explain it to her. I look at her as soon as it comes to kids around her she expresses how much she would like to have one of her own, and the way she talks about other people's kids. I do not really know; I do not know how to address that ..." (Teacher)*

> *"I find that many parents are afraid to talk openly about sex with their children because they want to protect them. But that's exactly why a lot of problems can arise, because they do not recognise their kids' needs." (Healthcare professional)*

4.3.6 Protect yourself from contagious/infectious disease

Health professionals (n=15) and teachers (n=6) highlight the good interprofessional collaboration, for example, with the health promotion centres organised within the primary health care framework, where there is regular collaboration between the school and the school nurse. This results in various forms of health education activities and health education materials (workshops for children, workshops for teachers and parents, etc.). Five parents emphasised their high satisfaction with the health staff, especially during the Covid 19 epidemic, because it was difficult to convince children

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to comply with the measures and movement restrictions. Teachers (n=7) indicated that they had become well acquainted with this issue during the Covid 19 epidemic, but also acknowledged that it was difficult for children with intellectual disabilities to follow and adhere to certain measures all the time, which can probably be generalised to all children.

> *"During the Covid 19 pandemic, children mostly adhered to the precautions about wearing masks, but less so to the precautions about hand disinfection and spacing. However, frequent encouragement and monitoring was needed because some children had difficulty adhering to certain measures due to information overload, requiring additional adjustment and support." (Teacher)*

4.3.7 Emergency and first aid

Most parents (n=5) know the first aid number and basic CPR procedures. They do not think about it specifically. Some mention that they know the Heimlich grip, but also point out that this skill should be refreshed. In this context, students from SET also point out that there are very few lessons on first aid in their curriculum, and they consider this content very important for their future work. Some (n=7) also mention that this knowledge should be broader and linked to current diseases in society (e.g. allergies, diabetes, celiac disease, Crohn's disease, lactose intolerance, etc.). Teachers (n=6) also agree with students (although one of them does not see it as his job) and support changes in the curriculum. Health care professionals have not written much on this topic - probably because it is part of their daily tasks - but they have pointed out that parents and teachers (especially if the child has such a diagnosis) should know more about it.

> *"First aid topics and content are not adequately covered in higher education. I think it's important for kids to learn the basic rules of how to help others at an early age, such as calling for help, finding a person. It would also be useful*

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to include content about other illnesses, as I have found in my own practise that many children show an interest in their own health." (Expert/academics)

4.3.8 Personal hygiene

Health professionals (n=22) point out that teaching healthy personal hygiene habits is part of socialisation, which should be the primary responsibility of parents and schools, without diminishing their role, but still placing the burden on parents. This is also the most important content of health education in elementary school, but health experts note that some children with intellectual disabilities have difficulty maintaining the habits they have been taught. All teachers also place great emphasis on personal hygiene (especially during age 19) but acknowledge that much reminding and supervision is needed to ensure that personal hygiene is practised consistently. This difficulty or challenge is much greater when working with older children with intellectual disabilities. Students with SET (n=12) feel confident in this regard and consider the issue very important. Some parents (n=4) point to several difficulties that are not specifically related to long-term habituation - establishing a routine. This issue was much more serious for the mother of a daughter with a severe intellectual disability (e.g., brushing teeth, anogenital care, etc.), who also pointed out how important it becomes for parents and the school to work together to establish habits of.

"It's always a challenge for parents to teach their children healthy habits, but with children with intellectual disabilities, it's even more difficult. Success requires a lot of patience, perseverance, and most importantly, collaboration with teachers who work every day to reinforce the habits and integrate them into daily life ..." (Healthcare professional)

"The problem is that she cannot do anything for herself, she can only feed herself. She needs to be bathed, for her soiled napkin to be changed, and I can't pick her up into the bath alone." (Mother with a child with ID)

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4.3.9 Protect and promotion

Teachers (n=5) believe that the health of children with intellectual disabilities can be affected by a negative attitude towards health in school - by neglecting this aspect and also by their ignorance of the health situation. Parents (n=4) remain most concerned that children's health can be affected by exacerbation of the underlying condition, lack of collaboration between all stakeholders - school and health professionals - and family circumstances (finances, available time and other resources). Non-governmental organisation representatives point to social exclusion and unequal access to key systems that ensure appropriate care for children with intellectual disabilities as potential problems. Non-governmental organisation representatives also note that the health of children with disabilities can be affected by the lack of collaboration among all stakeholders-school and health professionals-and by family circumstances (finances, available time, and other resources). Students with SET (n=12) cite lack of knowledge as one of the most important risk factors for the health of children with intellectual disabilities, as well as possible parental disinterest in collaboration or, conversely, parents who are overprotective and do not allow for second opinions or perceptions in health care. However, students agree that all key stakeholders need to do more health promotion. Experts/academics, teachers, and health professionals also agree. Experts/academics (n=4) point out that because of the unique situation - education and health care - there is also a need to collaborate with health faculties in training future students of education and inclusive education.

> *"She is susceptible to the slightest cold and infection. When she gets sick, she needs to be cared for at home, so she needs a whole person ... Sometimes I also feel overwhelmed by financial obligations because I worry that I cannot provide everything he needs …" (Mother with a child with ID)*

> *"… Ignorance often leads to stigmatisation and social exclusion of children... Therefore, it is crucial that all those involved in the education of children continuously educate themselves and work more closely together. It is also*

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important to raise awareness of this issue, as this can help break down stigma and barriers and create a more inclusive society." (Expert/academics)

4.4 CZECH REPUBLIC RESULT

The following chapters present the results of an open-ended questionnaire that explored the different perspectives of various groups of people who meet children with intellectual disabilities (ID) on selected health education/promotion topics. The methodology is based on a qualitative approach with the descriptive-interpretive method. The first part presents the demographic characteristics of the participants, and the second part offers the views of the different stakeholders on selected health topics.

4.4.1 Descriptive statistics

In total, 75 participants completed the survey. The sample consisted of various target groups (Families with a child with ID; Healthcare professionals; Teachers; Experts/academics; Students with SET; NGOs representative)—the sample comprised 92 % of women and 8 % of men. Table 15 shows detailed data.

Table 14. Participants descriptive statistics

Responder	**n**	**%**
Family	17	22,6
ID	3	4
Healthcare professionals	10	13,3
Teachers	10	13,3
Expert/academics	20	26,6
Student of SET	10	13,3
NGOs representative	5	6,6

Table 14 presents detailed data about the child with ID as reported by their family members – mothers. All participants in this target group described their perspectives surrounding their children.

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Table 15. Family with ID or ID descriptive statistics

Demographic characteristics			**n**	**%**
Participants	ID student		3	15
	Mother		14	70
	Father		3	15
Education level - EQF	LEVEL 4		2	11,8
	LEVEL 5		4	23
	LEVEL 6		6	35,3
	LEVEL 7		4	23
	LEVEL 8		1	5,9
Job	Education related job		5	29,4
	Health-related job		2	11,8
	The other job		10	58,8
ID age	12≤		-	-
	13-14		-	-
	15≥		3	
Body mass index	Underweight (18.5≤)		-	-
	Healthy (18.5-25)		2	
	Overweight (25.0-30)		1	
	Obesity 30.0≥		-	-
Diagnosis	Mild		1	
	Moderate		2	
	Severe		-	-
	Profound		-	-
Chronic disease	Yes		3	
	No		-	-
Hospital frequency	0-4		3	
	5-8		-	-
	9≥		-	-
Treatment	1. Hospitalisation Diagnosis:……	0-5 day	3	
		6-10 day	-	-
		11≥	-	-
	2. Hospitalisation Diagnosis:……	0-5 day	3	
		6-10 day	-	-
		11≥	-	-

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4.4.2 Physical and sport activities

Physical health and participation in sports activities is an essential topic for people with intellectual disabilities aged 12-18, which is gaining importance. The national strategic document is the Concept of Sports Support 2016-2025 in the Czech Republic (available online by the Ministry of Education, Youth and Sports; https://www.msmt.cz/sport-1/koncepce-podpory-sportu-2016-2025). This Ministry of Education, Youth and Sports document contains the principles of support and education in the context of the inclusive tenets in the European Union. A crucial national organisation dealing with this issue from the position of families of children with ID is the Society for the Support of People with Mental Disabilities, z. s. existing for over 50 years. It has more than 7000 members in 57 organisations in 14 regions of the Czech Republic (https://www.spmpcr.cz/o-nas). Its activities, along with the actions of other non-profit organisations in social services, are very often directed at activating and maintaining positive habits in a healthy lifestyle.

Results of the research investigation show that parents of children with intellectual disabilities (95 %) perceive a lack of opportunities for physical and sports activities with children and families without disabilities. The availability of activities and participation decreases with the depth of children's intellectual disability and associated disability. The distance from large urban agglomerations and the network of day service centres and special education centres has a negative effect. Many parents (40 %) are busy with work and other activities, so they do not find enough time to focus on their children's health. All surveyed parents consider this area necessary for the quality of life of their children with mental disabilities and the whole family. Primary and secondary schools of ordinary type and special schools provide most activities for them and their children and siblings. Physical activities include outdoor activities within the school (outdoor and indoor) and leisure activities (swimming, sports club). NGOs play an essential role. Physical education is done precisely in schools and is considered very important (96 % of teachers).

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Physiotherapy is also essential, says health professionals (44 %). There is the possibility of staying in sanatoriums or spas. It is also necessary to ensure the child is not overburdened and receives enough rest to regenerate and restore his strength. They consider physical activity vital for a child not only in terms of health but also for his overall development. It is an essential activity for a good mood and should entertain the child. Children with Down Syndrome prefer peace and less activity, so they need increased motivation and create a specific group. Thanks to movement, the child develops motor skills, coordination, and strength, improves his endurance and gains experience with teamwork and competition.

> *"Contact and time with peers and friends are formative. The child can develop not only physically but also mentally. They learn to cooperate in team games and thus strengthen their communication skills." (Two academics)*

The most common activities are swimming, ball games, athletics and horseback riding, skiing, hiking, yoga, and dancing (80 %). NGOs offer dance classes that serve socialisation. The variability of activities depends on the age and physical capabilities of the child (e.g., physical disability or reduced muscle tone). Of paramount importance are the support and guidance of the adults with whom they spend time (at home/school) and the level of stimulation and opportunities to try new things and gain confidence and practice in those previously learned. It is necessary to encourage and motivate children more often. There is reduced motivation for new physical activities. The activity must entertain the child, says the teachers (32 %).

All participants (100 %) would appreciate more knowledge in this area. University students volunteer on trips to the mountains, vacations, camps, etc., in cooperation with non-governmental organisations.

Experts from practice and academics state (60 %) that *"A physically active child means that they devote themselves to activities that develop him in intellect, planning, thinking, learning, motor skills and coordination. A physically active child is usually energetic and tends to be constantly on the move. The child does not have excess weight or fat. Physical activity is*

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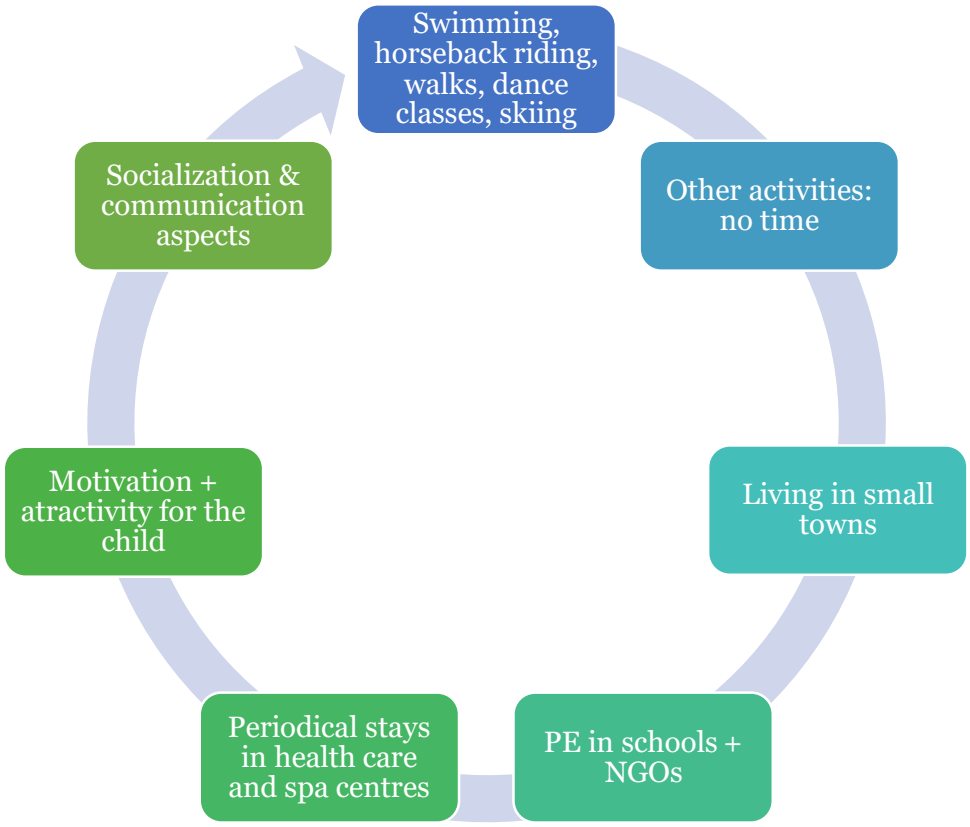
vital due to the increased risk of being overweight. Such a child likes running, jumping, dancing, playing with a ball and trying various sports." Another explains, *"It is a child with a zest for life and spends part of the day actively moving – playing, walking. He does not shy away from this activity."*

One of the experts had an interesting idea: *"They may also be able to handle prolonged physical activity without fatigue. It has adequate physical strength and endurance, healthy bones, and firm muscles."*

Statements of parents of children with ID:

> *"The swimming and dancing my daughter would like are not unoffered in our city."*
>
> *"We are happy for the school clubs and weekend trips with a non-profit organisation."*

Figure 1. Analytical categories



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4.4.3 Feeding problems

This issue is intensively addressed in the family environment, special primary and secondary schools, and social services. Training in food preparation, self-service activities and hygiene habits are essential to the school curriculum and activation activities. Schools and similar operations in the Czech Republic are governed by strict rules and standards, especially Decree No. 107/2005 Coll., on School Catering (https://www.msmt.cz/vzdelavani/skolni-stravovani).

Results of the research investigation show that the socio-economic factors significantly impact the way of life and healthy lifestyle of the family and the child, including good eating habits. In this case, the approach of the home environment to the child's diet is crucial – the formation of eating habits based on home habits and the currently frequently discussed financial options. The research confirmed that eating habits result from coexistence with the family in which the individual moves, with culture, perception of the environment and life attitude. Attitudes to food are influenced by genetic influences, the personality of parents, their education and interests, the impact of siblings, the economic situation of the family, and its cultural and social background. Some children learn the differences between healthy and unhealthy diets and how to name them. Children and adolescents with mild and moderate intellectual disabilities often know how to live a healthy life, but when choosing foods or drinks, the survey shows that most children choose unhealthy foods and beverages. They cannot realise that it is not enough to name everything, but it is also necessary to follow it.

Most of the questionnaires from experts (46 %) showed that children with intellectual disabilities suffer from other diseases and defects (epilepsy and allergies) related to nutrition. We cannot forget any food intolerance, which will also affect the composition of the diet.

Regarding food refusal, the research has shown difficulties with the independent choice of food preference or multiple types of food. Schools or other catering facilities

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have a limited assortment and planned menu with the possibility of choosing more types of food during the day. Flexible and individualised dieting is problematic unless it concerns diet recommendations from a paediatrician or other physician-specialist for larger catering establishments. According to the parents, this does not apply to meals in the family. Parents must report known intolerances to their child's substances and foods at school and social services. Strict standards govern schools and similar operations in the Czech Republic.

Respondents (66 %) did not experience a lack of fresh fruit or vegetables during the year. Price or limited availability is not the issue. There was no lower consumption of milk, meat, or poultry. Sometimes it is necessary to promote health and growth, or to support the maturation of the nervous system, to administer vitamin preparations (e.g. based on omega-3).

Respondents pointed out some exciting factors due to intellectual disability: more severe degrees: mushy, soft food is necessary, and absence of solid food. With a mild intellectual disability, an ill-considered diet, and investment in a low-quality diet, an inadequate independent way of preparing a diet appears. For all of them, it is problematic to design a diet separately – the need to eat according to the preparation of another person's diet. Many often have impaired or restricted digestion, the need for feeding through a tube or other alternative means. Diets for people with intellectual disabilities are necessary, but there is often a problem with their observance. It draws attention to factors such as: pickiness in food, bad eating habits, disturbed normal eating rhythm (e.g. eating at night), incomplete representation of certain foods or food groups in the diet, low sensory attractiveness of food, risk of excess salt, sugar, saturated fats, dyes and preservatives in food and beverages, low variety of diet, risk of deficiency or loss of essential nutrients, irregular and unbalanced eating, refusal of food or overeating, insufficient and inappropriate drinking regime, drinking energy and alcoholic beverages.

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According to teachers and parents (86 %), children's behaviour depends on the popularity of food and the type of food. In children with intellectual disabilities, it is associated with lived experience. Furthermore, stereotypes of children's eating habits and ignorance of various food preparations and their terminology play a role. Opinions of experts from practice and academics (98 %) show that children with ID may be reluctant to try new foods, selectivity of colours, and structures, insufficient drinking regime, hypersensitivity to odours, and food consistency. Children often do not touch the food, let alone taste and possibly eat it. A preference for very sweet or salty foods may be related to the need for higher levels of stimulation."

> *"Necessary for the child is often the own "service", how the food on the plate looks and is arranged. The structure and hardness of food (e.g., nuts, vegetables) related to the link between biting/chewing and calming down (otherwise, it is solved by special grabber aids) is also up for discussion." (Mother of a child with ID)*
>
> *"We often encounter these difficulties in preschool age, gradually improving slightly. An interesting factor is also the soundtrack of food, such as crunch (chips, biscuits, carrots), which helped to limit other, especially sound, stimuli from the environment." (Teacher of a child with ID)*

The boy (11 years old, MID) justified this: "*When I eat, I don't hear anything else, and I have peace*.". Two health professionals pointed out that in early development, there may be difficulties in the sensitivity of the orofacial area. Other challenges are related to the coordination or maturation of primary functions. Food intake includes sucking, good work of the tongue, biting, chewing, and swallowing. In many cases, it is necessary to adapt food (consistency, texture) and its administration – according to the development and needs of the child. In connection with eating, motor problems in the processing of food in the mouth (jaw movements, tongue movements, swallowing) may appear as primary difficulties in the target group. Impaired motor skills are manifested in the handling of cutlery and in the ability to deliver food to the mouth.

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Food intake (catering) in the target group of pupils requires, similarly to other activities, a structure in which the child fixes the required habits (eating in a quiet/calm environment, regularity of food, development of the child's sensitivity to tastes and smells, etc.).

Experts (74 %) believe that *"the regular provision and composition of food in the facility dramatically benefit children with intellectual disabilities, as eating in the facility positively affects their nutrition. They have a proper energy intake, animal, and vegetable protein, calcium, vitamins, and iron."* Statements of parents of children with ID:

> *"… He loves food, especially fries, Coke, anything with ketchup, sweets, ice cream. Because of a sick heart, we have to watch the portions and limit what he likes best*." (Mother of a child with ID)

4.4.4 Sleep problems

Sleep research is a current topic in the Czech Republic. The BRAIN team research group from the Faculty of Biomedical Engineering of the Czech Technical University is researching sleep disorders in cooperation with the National Institute of Mental Health (NIMH). Scientists state that a person sleeps a third of his life, and a sufficiently long and quality sleep plays a significant role in his mental and physical condition. The first day of spring, 21 March, is International Healthy Sleep Day, which highlights the impact of sleep on our health. Research points out that more than 30 % of the population in the Czech Republic, both adults and children, are at risk of sleep disorders (https://aktualne.cvut.cz/stalo-se/20220322-fbmi-cvut-spolupracuje-s-narodnim-ustavem-dusevniho-zdravi-na-vyzkumu-spanku).

Research by the Department of Special and Inclusive Education (Masaryk University, Faculty of Education) pointed out specific difficulties in children with intellectual disabilities and associated autism spectrum disorders. Parents of children with such disabilities consider significant sleep difficulties that affect their children's health. Problems with quality sleep, both in the course and in time, are affected by negative

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emotions, long-term stress and anxiety states, and a sudden change of environment. Insufficient sleep affects children's vitality, fatigue and long-term attention during the day. The experts interviewed also agreed that if a person does not get enough sleep, there is a decrease in mental performance. In the long term, it is also at risk of developing severe health problems, such as obesity, diabetes mellitus or various cardiovascular issues.

Results of the research investigation: Based on the analysis of the answers from the questionnaire survey, it is possible to determine the highest frequency of responses stating that insomnia and the inverted sleep rhythm are the most frequent cases (92 %). Four experts mention the medical point of view, which includes disregard of the physiological curve of performance and rest, disturbed daily regime, disruption of biorhythms, excessive sleepiness or insomnia, fatigue disproportionate to the previous exercise, lack of rest after the workout, sleep ventilation disorders (20 % of respondents). However, experts also reported that sleep difficulties are not frequent with ID (50 % of the experts surveyed said they had not experienced sleep disorders in the target group of children). From their point of view, it often depends on the course of the day, setting the daily regime so that it includes a regular and suitable ratio of activity and rest for the child – and the appropriate form of its choice. There may also be problems of hyperactivity, which affect the dynamics of behaviour and the need for rest / its effectiveness. Taking regular medications can affect sleep. Staying and living in an institutional facility can negatively affect sleep quality.

Opinions of experts from practice and academics and parents of children with ID:

> *"Difficulties with calming down before falling asleep, restless and superficial sleep, insomnia, night terrors, inverted sleep rhythm, more sensitive perception of the phases of the moon or, conversely, with fatigue increasing need for sleep – even "afternoon" rest, or relaxation during the morning (related to this is also possible medication – it is long-term tuning, adaptation*

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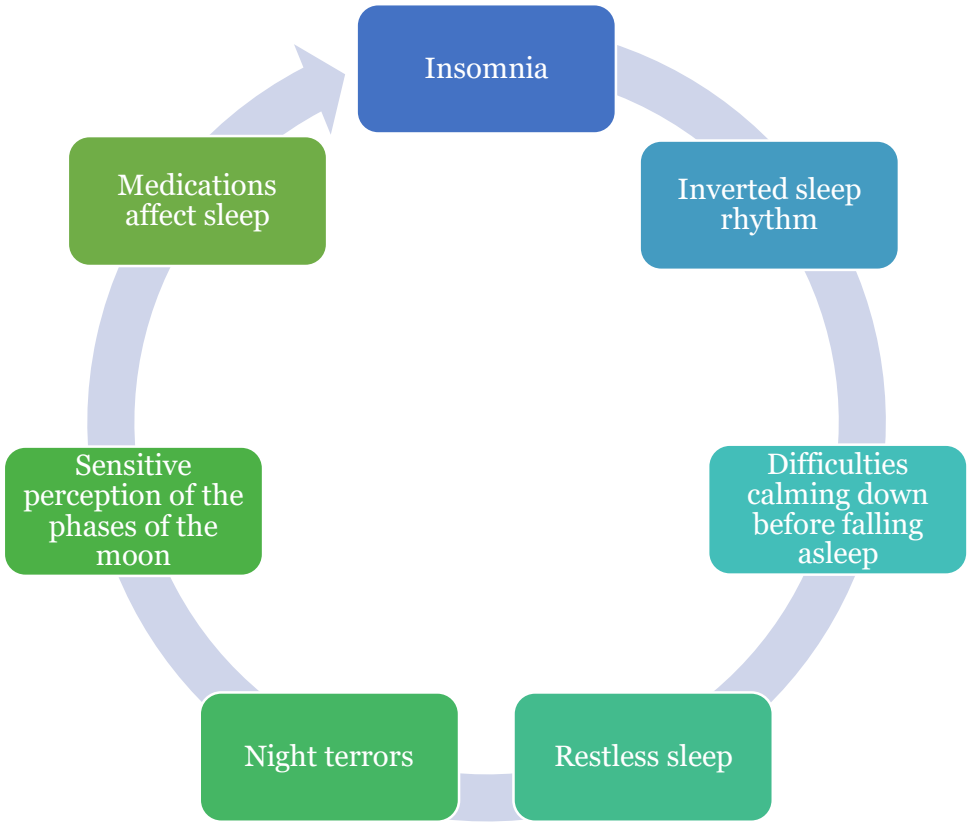
to the recommended regime measures by the physician)". (Speech therapist, Psychologist)

"Our child has a disturbed sleep rhythm mainly after stressful events, which he often experiences at school. He is not one of the favourites there." (Mother of a child with ID).

Figure 2. Primary outcomes concerning sleep problems



4.4.5 Sexual and reproductive health and rights

Results of the research investigation: Awareness of a child with ID and confidence in the possibilities of behaviour and reactions are perceived by experts as important indicators (38 %). Educators (86 %) consider it essential to distinguish between un/safe behaviour and a good knowledge of what sexual harassment or abuse is. At the same time, the child's approach to others, perception and respect for their boundaries are also critical. 70% of the surveyed experts emphasised awareness of appropriate behaviour towards others and oneself and identifying challenging situations.

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Information about rights is also essential, often neglected. Some do not know about sexual and reproductive law and behave according to the boundaries set by their surroundings (family, social environment). Information about adolescence and related factors is another essential part of a healthy approach to sexuality (menstruation, ejaculation). The child should have mastered the basics of anatomy to understand how the body works. The child must also be reassured that bodily changes are natural. Sexual health includes awareness of preventive examinations and prevention of sexual harassment and abuse. Information on the risks related to sexual behaviour (infectious diseases, pregnancy) is necessary. It is good to establish rules eliminating undressing in public (for children with ASD) or rules for masturbation (place, hygiene). Statements of parents of children with ID suggest having **a key worker.** Information about one's and others' appropriate and inappropriate behaviour is important. The child must know who can/cannot touch him and who can/cannot touch him, which is an essential issue for all parents (100 %).

NGO experts emphasised the ability to ask for assistance or possibly have someone to assist (20% of experts surveyed mentioned this possibility). Students of SET consider this topic very important in their studies. The information must be provided in a personalised manner to be understandable for youngsters with intellectual impairment. Parents, guardians, and health professionals should cooperate and maintain a uniform approach. Popularisation-educational videos (e.g. Tea and Consent) or dramatisation of various situations can serve very well for this. The level of intellect of the target group will fundamentally condition the method of mediating topics. Opinions of experts from practice and academics follow. They think we must strengthen the prevention of abuse of children with intellectual disabilities. It is crucial not to taboo the topic in the family or school. They also said the child should be able to discuss coping strategies sensitively and openly for various situations. Direct statements follow:

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"Furthermore, they must be informed about sexual myths (shame, guilt, false beliefs) that are widespread in sexuality and to which they must not succumb. They must know they have the right to enjoy sexual behaviour and control it following social/legal ethics."

"Similarly to intact individuals, emphasis should be placed on basic awareness regarding sexual and reproductive health for children with intellectual disabilities. Education should be linked to defining the fundamental differences between the sexes, the act itself, and the individual's rights."

"We consider it necessary to explain matters related to sexual health, create ideal situations and teach clients to react appropriately. Including these topics in education and during everyday activities is appropriate. Using appropriately elaborated methodologies available in the Czech Republic is also possible."

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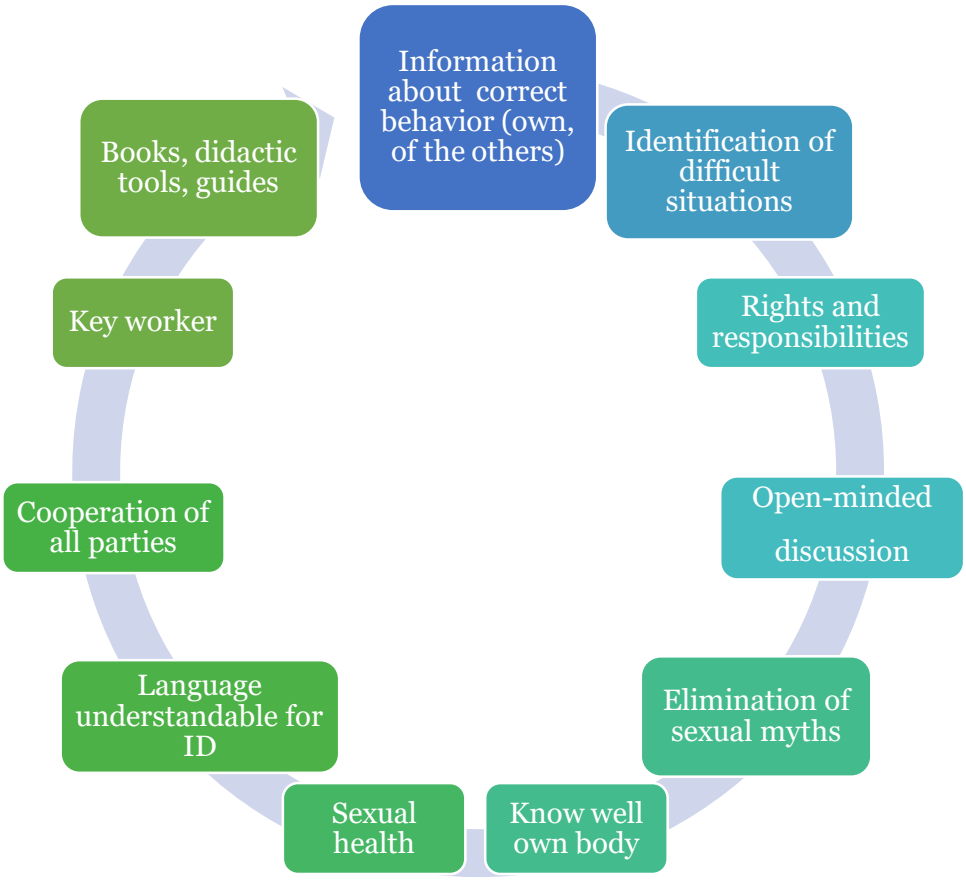
Figure 3. Main outcomes



4.4.6 Protect yourself from contagious/infectious disease

Through its institutions, the Czech Republic reflects the European Parliament resolution of 8 July 2020 on the rights of persons with intellectual disabilities and their families during the COVID-19 crisis (2020/2680(RSP)). The agenda reflects coordinated EU action on the rights of persons with intellectual disabilities and their families during the COVID-19 crisis (available online EU: https://www.europarl.europa.eu/cmsdata/209923/P9_TA-PROV(2020)0183_CS.pdf). COVID-19 and other infectious diseases have long been explained to citizens through various tools. The Ministry's state agenda offers online education and counselling (https://www.mvcr.cz/clanek/koronavirus-covid-19-lide-s-postizenim-disabilitou-a-specialnimi-komunikacnimi-potrebami.aspx). The information is targeted for people with disabilities and special communication needs.

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Health statistics related to the issue of infectious diseases are on the agenda of the Institute of Health Information and Statistics of the Czech Republic. Reporting and registering contagious diseases is specified in the Public Health Protection Act No. 258/2000 Coll., as amended, and the Decree of the Ministry of Health of the Czech Republic No. 195/2005 Coll. Both documents regulate the conditions for preventing the emergence and spread of infectious diseases and hygienic requirements for operating healthcare facilities and social care institutions. Decree No. 473/2008 Coll. is on the system of epidemiological vigilance for selected infections. Reporting is carried out by the prescribed mandatory reporting "Notification of infectious disease".

The answers of practitioners to this question were identical. We can summarise them as follows (90 %): Based on experience from the covid period, protective equipment such as a mask/respirator can be very unpleasant to wear/manage to breathe and talk for some children and difficult to tolerate.

> *"It's hard to keep the distance. She's very friendly, kind-hearted, guileless. She hates the mask. She suffocates in it. It's essential to inform often and to repeat instructions." (Mother of a child with ID)*

Social distancing is undoubtedly possible, but it is essential to fill this time appropriately so the child does not feel the absence/restriction of social contact significantly. Communication with at least the closest people can stay maintained. An adequate level of information will help cope with the situation. The child then understands the case and the related need to protect himself according to his possibilities and takes the measures. Protection against disease has the same principles as in the entire population (80 % of the respondents). In addition to the above statement, 20 % of respondents described a specific procedure (training of situations, explanation, education, and prevention). Opinions of experts and academics follow:

> *"As for sex, it appears to be a central education and building awareness of infectious diseases, how they are transmitted and the possibilities of actively defending against them. Active protection procedures must be explained*

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appropriately to the child's capacities. Actions in the context of the prevention of infectious diseases must always be feasible for the child. "

"..... Just like everyone else – increased hygiene – washing and disinfecting hands, environment – ventilation, not meeting people who are sick, to use a mask or neck warmer that is pleasant to the client ...." (Special needs teacher)

"..... Compliance with preventive measures, social distancing, taking vitamins and food supplements to support immunity, to educate prevention according to intellectual possibilities..., the possibility of educating, explaining, training, modelling situations ...." (NGO representative)

4.4.7 Emergency and first aid

Valid laws and curricular documents govern education at Czech schools. The issue of first aid is part of them. First aid is mentioned in the objectives of primary and secondary education (primary, secondary, and special schools), where it is stated that one of the objectives is to teach pupils to develop and protect physical, mental, and social health activities and to be responsible for them. A critical organisation providing nationwide and conceptual first aid education for professionals and the public is most often the Czech Red Cross. It operates in the humanitarian, social, health and health education fields and is the oldest organisation that educates the public on first aid (online: https://www.cervenykriz.eu/prvni-pomoc). It is common practice that in each rescue vehicle (integrated rescue system), there are unique communication cards for disabled patients. On the cards are printed pictures showing the most critical aspects of the treatment. The rescuer offers the children the views and explains what will happen. On the cards are images of the rescuer, doctor or family members and various activities that are part of the treatment, such as pressure measurement, palpation, injections, etc. In addition, children are told by cards with a bed, ambulance, or helicopter how they will be transported or whether they will stay at home. These cards can be used by people with intellectual disabilities of all ages and deaf and hard of hearing, or foreigners who do not understand Czech. It is an efficient means of

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communication that can significantly facilitate and improve health care for people with special needs and should, in my opinion, be used in all regions of the Czech Republic (online: https://www.prosestru.cz/novinky/komunikacni-karty-vprednemocnicni-neodkladne-peci-113026).

For pupils with intellectual disabilities, it is crucial to be aware of their limitations and health risks (e.g., allergies, symptoms of diseases, and risk of stressful situations). It is necessary to pay increased attention to problems in crisis communication and the application of acquired knowledge and experience in an adequate first aid situation, both in the role of the treated and the caregiver. Experts (46 %) perceive as problematic the evaluation of possible risks and complications during the provision of first aid to children with mental disabilities. Measures to eliminate these risks as much as possible are crucial. Courses of communication with children and adolescents with cognitive disabilities seem to be a possible systematic solution. There are many such courses in the Czech Republic, but the vast majority are aimed at special educators who meet with disabled children daily, as well as social workers and assistants. For paramedics and other non-medical healthcare workers, special courses focused directly on this topic are less common.

Parents and experts believe that communication with ID people on the issue of first aid and emergency treatment would be very beneficial not only for rescuers but for all people who work in healthcare. Practitioners mentioned the need to explain specific situations when we need to look for emergency solutions and behavioural/response instruction that can help manage the problem as much as possible. Essential is the support of a person who can help the child orient himself in the case and work to solve it. Then, it will undoubtedly be mastering the procedure of calling for help. The starting point is also information – orientation in activities and environments that may pose a risk – to prevent complications (and strengthening attention to changes and situations we can evaluate as risky). The possibility to call the emergency line should be associated with sufficient communication competence – orientation in the given

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case – its comprehensible description – as well as adequate speech comprehension so that the child can understand the coordinator's recommendations and, if possible, apply them. A safer place is based on orientation and the support/help of others, for example, when moving to this place. Dramatherapy can be used to practice appropriate procedures. Information cards with contacts to close people or organisations will help in training. It is necessary to use clarity. Regularly practising asking for help from others - friends, family members or neighbours- is essential. Another part is the training in preventive measures.

The experts' answers were rather complementary. In addition to the general description, 95 % of respondents stated that having a safe place in critical situations and teaching steps such as calling the right person is a crucial part of the training for these emergencies. It must be done in a way that is understandable for the child. The special needs teacher stated that teaching a child to recognise someone unwell is necessary. It is required to teach the child to identify the primary symptoms – e.g. what loss of consciousness looks like, bleeding, etc. Also, the need to call somewhere or ask for help. Three teachers explained that children with intellectual disabilities usually like ambulances and police and suggested starting from the natural interest and information, the purpose of use, and when to call emergency lines. Another suggestion pointed out that children with ID must be systematically prepared to handle crises.

> *" ...the need to proceed according to a pre-rehearsed model situation (95%), to ask for help from others. Noteworthy is the ability to recognise danger, practice various conditions, and ask for help – verbally, gestures, pictograms, SOS button on the phone, phone, card in the wallet, agreement on asking for help from an adult." (Doctor)*

> *"To learn the basics - to seal minor injuries with a plaster. The basis could be the knowledge that it is better to do something than nothing."*

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4.4.8 Personal hygiene

The training environment is the family, special schools and social services. Training in self-service activities and hygiene habits is essential to the school curriculum and activation activities, especially for children with severe symptoms. Opinions of experts from practice and academics:

> *"Personal hygiene and its mastery are directly related to developing self-care from childhood. An important role is played by the leadership and support of the surroundings in the home/school environment and the dissemination of awareness and practical management of hygiene within the daily routine. A solid regime and consistency are essential."*
>
> *"Structuring (visual support and simplification) is often more effective than verbal instructions. It helps to clarify why these habits are fundamental and what should be done when (a necessary procedure for children with ID and ASD)."*

Some informants explained that these children may be more prone to accidents or accidents due to personal hygiene tools (electric toothbrushes, razors, hair dryers, etc.). Habits influence this sphere in the family and social environment. We use imitation. During the training, we determine which practices the person can handle independently and which help is needed. It is necessary to have a habit in the daily care of your hygiene: brushing your teeth – preventing rotten teeth, and cleanliness of teeth. Regular hand washing – prevention of diseases, viruses and bacteria. Regular daily hygiene of the body – cleanliness, prevention of skin diseases. Good habits when using a handkerchief – blowing your nose to prevent infections, using a paper handkerchief. Regular washing or cleaning of hands with a wet cloth (antibacterial gel) – prevention of own illness – touching the face or preventing infection from public transport or social spaces. It is necessary to repeat these activities regularly in school and at home. Some suggested (two academics) using **occupational therapy.**

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"As with all other activities, these should be subject to a repetitive sequence of steps that the child mechanically adopts and automates by daily repetition. It is optimal to use procedural schemes reminiscent of individual steps. It is also advisable to present the activities in sequence according to how the normal day is organised. The child can gradually get used to the actions and ritualise them. Marie Montessori emphasised that it is not necessary to help the child with a task that the child can (even if only partially) manage on its own. Therefore, sufficient time and patience are required to master personal hygiene and appropriate procedures so that the child performs the tasks himself."

4.4.9 Protect and promotion

The questionnaire survey shows that parents have difficulty finding a suitable paediatrician or specialist (e.g., dentist) who treats children with ID near their home. The issue is increasing in the localities of small municipalities compared to large urban agglomerations. Some families with children with intellectual disabilities may also face various financial problems, affecting their ability to provide needed care and support for their children. It can also affect access to education and healthcare. The perception of one's body/health as an entity to be cared for. The adoption and observance of rules related to health and one's safety. The level of awareness is appropriate to age and difficulties. Sufficient guidance and support in the home environment – and all others in which the child moves – is also worth considering—risks associated with using medications, e.g., psychiatric medications. Experts suggested having an appropriate level of adequately presented information for children and their surroundings so that the child has support in a safe and informed environment with a discreet approach to their development and related changes (growth/adolescence) in their needs. One special needs teacher said that "Lack of information, inability to evaluate suitable and unsuitable foods, increased risk of obesity – pickiness in food (just unhealthy) or, conversely, malnutrition, eating disorders, overeating." (NGO). Many informants (55

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%) perceive the need to educate an entire society, to lead it to consideration, empathy, and help. Taboos and the absence of interviews are irresponsible and do not bring about a shift in knowledge and skills. They lead to risky situations and improper solutions with severe consequences. The protection and promotion of the health of children with intellectual disabilities are connected with health education for the target group and especially with the readiness and knowledge of those who work with the target group, i.e. teachers and parents, who should follow similar (identical) procedures. Direct statements follow:

> *"Lack of exercise – e.g., when staying at home (e.g., if the child does not want to leave the apartment), in isolation. I also observe these problems – diet, healthy diet, drinking regime, amount and form of physical and sports activities, smoking, alcohol use, quality and duration of sleep, mental health, stress, sexuality." (Physiotherapist)*
>
> *"Inability to communicate that the child is in pain (if the child does not speak, sign) – e.g. he starts to show aggression, and eventually, we find out that his tooth hurts. Sometimes they can't adequately describe what's bothering them – worse diagnosis. They don't perceive as much what is or isn't healthy for them – dependence on their surroundings. As a speech therapist, I also see a great challenge in communicating with these children and establishing social interactions." (NGO, Special Needs Teacher, Occupational therapist, Speech therapist)*
>
> *"Expensive rehabilitation, which health insurance companies do not support, is difficult to finance. And to prevent discrimination against them." (Mother of a child with ID).*
>
> *"To train doctors and medical staff in hospitals and emergency departments about the specifics of people with intellectual disabilities. Physicians should be informed about appropriate procedures for people with ID. Regular visits*

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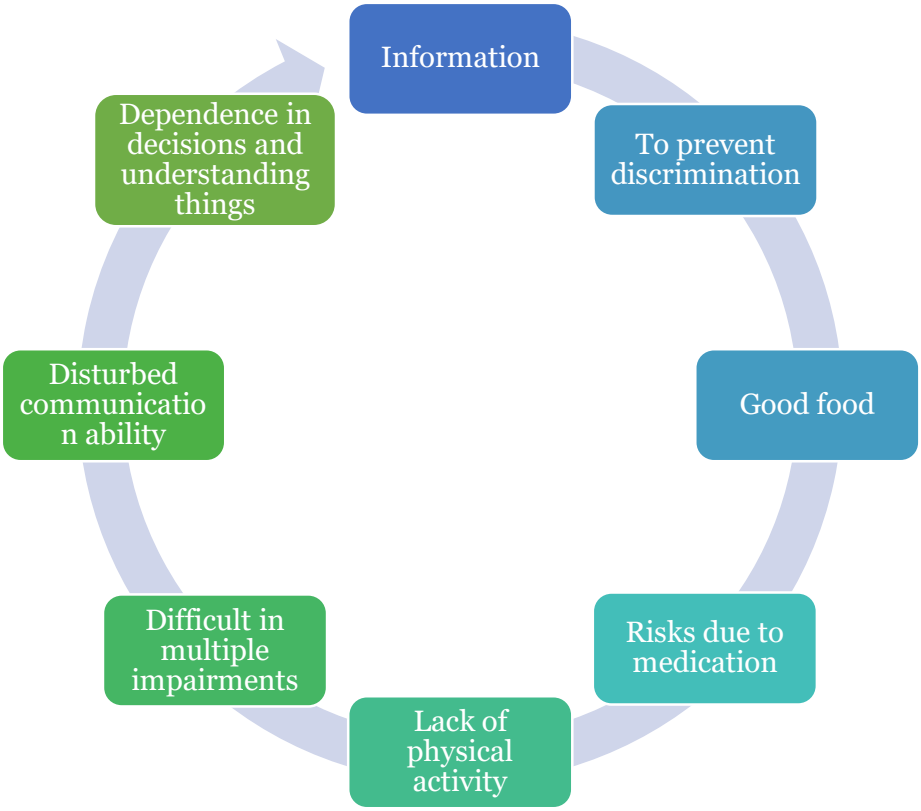
to the doctor and medical facility are the prevention of undesirable phenomena." (Father of a child with ID)

Figure 4. Aspects associated with people with ID in health protection and promotion issues



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5.CONCLUSION AND RECOMMENDATIONS

Following the data collection and analysis carried out for needs analysis and identification of the current situation, some conclusions were reached. In preparing this sub-section, common findings from four different countries are included. In addition, country-specific prioritized or prominent issues are also indicated.

The general opinion of the participants regarding the level of participation of individuals with intellectual disabilities in physical and sportive activities is that individuals with disabilities can actively participate in at least one sports branch. However, it is thought that those with simple rules in sportive activities and mild intellectual disabilities will be relatively more successful than those with moderate and severe intellectual disabilities. Unlike other countries, participants in Slovenia drew attention to activities outside the home - in nature. In Czechia, it was found that university students and NGOs volunteer in activities such as camps and nature trips with people with intellectual disabilities in cooperation. On the other hand, there are some difficulties in transporting persons with disabilities to the places where physical and sportive activities will be carried out. Participants in Turkey stated that disabled children with Down Syndrome or other musculoskeletal problems, especially those with psychomotor disabilities, do not like physical and sportive activities and have a more sedentary lifestyle.

Slovenia teachers criticize that although the importance of physical activities in children with intellectual disabilities is known, the subject is included in the physical education course or other course contents to a limited extent. Concerning these findings, it can be suggested that physical and sportive activities in schools should be planned and implemented by considering the disability level of students, physical facilities for sportive activities should be increased, physical activities that can be performed in the home should be taught, and children with problems in musculoskeletal development should be directed to early and accelerated intervention programs. It is crucial to ensure the participation of special education teachers, other

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teachers and specialists, and families in such activities. Planning and implementing the necessary support for the additional needs that may arise in self-care, communication, and social skills that individuals with intellectual disabilities are expected to use during such activities is an essential factor in the success of such activities. It is also a significant achievement that individuals can perform such activities independently. For this reason, it should be aimed to achieve this outcome through self-management and technology at different levels for individuals with appropriate disability levels.

Another issue analyzed was nutritional problems. Food choice and uncontrolled food consumption were the most frequently mentioned nutrition problems. Apart from this, participants in Portugal and the Czech Republic emphasized the need for dietary nutrition due to celiac disease and some allergies. Uncontrolled eating is a significant risk factor that can trigger overweight or obesity, leading to deterioration in an individual's health. In order to reduce the nutritional problems of individuals with unidirectional nutrition, a reward schedule can be applied to encourage feeding with different types of foods, or the organization of meal times during the day and portion control can be taught to limit uncontrolled food consumption. The dietary routines and habits of individuals with intellectual disabilities have an essential relationship with families and their practices. Therefore, it is necessary to ensure family participation to protect and improve nutrition-related health. Therefore, special educators who will work on this subject should have basic skills in subjects such as assessing the habits of families, informing them about necessary practices, training, monitoring, and providing feedback.

The third issue examined was sleep problems. The most frequently reported sleep problem is poor sleep quality due to frequent awakenings at night. Poor sleep quality harms an individual's vitality and long-term attention, resulting in poor mental performance. Respondents in the Czech Republic reported insomnia and sleep rhythm disturbance as the most common problems. Sleep problems can also increase

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behavioral problems in individuals. Accurately identifying the causes of behavioral problems, especially in individuals with moderate to severe disabilities with limited communication skills, is the first step toward effective intervention. Therefore, teachers working with individuals with behavioral problems should consider this factor and make appropriate assessments. Special education teachers should be able to collaborate with the family and other specialists (e.g., neurologists) in planning the necessary intervention, including various physical arrangements at school and home.

Sexual and reproductive health is the fourth topic examined. Since it is considered taboo by the participants in Turkey and Slovenia, there may have been limitations in obtaining broad and detailed responses to the questions. The responses of participants in four different countries indicated that the rights and knowledge level of individuals with intellectual disabilities on this issue is low. Participants in Portugal and Czechia pointed out that the knowledge of protection from sexual diseases and unwanted pregnancies is low and that health education activities are needed. Health professionals in Slovenia thought that health education could be provided in schools and institutions. Students of special education departments stated that this topic is essential but needed the opportunity to learn more in their undergraduate education. As with nutrition and sleep, the family has an essential role in this issue. Starting from an early age, teachers must include family training in addition to school training to achieve successful results and prevent undesirable situations. Since there is not enough content on sexual and reproductive health in the school curricula attended by individuals with intellectual disabilities, there is no obstacle for teachers to include this issue in students' IEPs. Therefore, studies should be planned to raise teachers' awareness, knowledge, and skill levels on this issue.

Protection against infection and infectious diseases is another issue examined. The responses seem contradictory. One group of participants stated that individuals with intellectual disabilities could independently fulfill skills such as social distancing, personal hygiene measures, mask use, and hand washing related to protection from

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infections and infectious diseases. Another group stated that their competence in these issues could be higher. Especially with the Covid 19 pandemic, taking and implementing personal precautions in schools was strictly followed. At this stage, some individuals with intellectual disabilities may have learned personal protection. Students with intellectual disabilities thought to have low competencies can be examined by factors such as the level of disability, the period when the child started education, and the level of family participation. In addition, studies can be conducted to ensure that teachers have basic knowledge about emergency action plans and preparation for possible new outbreaks that are transmitted through other means and require different measures.

The topic of emergency and first aid also emerged as a topic with different responses. Emergency and first aid are cognitive and affective subjects. Intervention for individuals needing emergency first aid, such as injuries due to traffic accidents, can be a complex subject to implement for practical reasons, even for those with first aid knowledge. Continuing with the same example, calling the police or emergency services to report the emergency to the authorities and providing precise information is another challenge for individuals with intellectual disabilities because of cognitive and communicative limitations. Participants in Turkey generally think that individuals with intellectual disabilities cannot perform even basic first aid practices such as bleeding control because they have not received first aid training. On the other hand, participants in Turkey and Portugal stated that individuals with intellectual disabilities could perform behaviors such as asking for help from someone else in an emergency and heading to a safe area. Moreover, participants in Turkey emphasized that the level of disability is an essential determinant in learning and practicing such competencies. In Slovenia, students of special education departments stated that there is very little course content on first aid in the curriculum. In the Czech Republic, it was also found that the competence of health professionals to work with individuals with intellectual disabilities was low. The lack of such content in pre-professional education

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and professional development programs can be seen as the primary reason for this situation. Although they get theoretical training, considering the prevalence rates of intellectual disability, it can be said that the opportunity for health professionals to gain experience in such issues is low. For this reason, it may be a facilitating situation for health personnel to cooperate with families and special education teachers when necessary.

When the topic of personal hygiene is examined, there is no significant problem in fulfilling basic skills or the skills that support them (toileting, feeding, brushing teeth, bathing...). However, the fact that all participants from different countries focused only on basic skills can be considered a significant problem. Participants' views on personal care skills, such as skin and hair care, menstrual skills, or advanced self-care skills, such as choosing clothes, and taking drugs regularly, are not included. Paradoxically, while it is aimed for individuals to become more independent as they age, it is more challenging to depend on an adult for advanced personal hygiene skills. This situation indicates that the participants had limited knowledge about personal hygiene. Therefore, personal hygiene skills should be included in the health protection and promotion curriculum, including what personal hygiene skills are, by whom, and how to teach these skills.

When the recommendations on health education and health promotion are analyzed, improving the psycho-social and socio-economic environment in which individuals with intellectual disabilities live, and family education are common issues in all four countries. It is crucial to increase the social acceptance of individuals with intellectual disabilities and to provide other members of society with the ability to live with differences. Increasing the health knowledge of teachers and increasing the competence of disabled students to use health-related resources will contribute to the improvement of his/her quality of life. As the number of days spent in good health increases, the number of days away from educational environments will decrease. Health education or health promotion is a right for all individuals. Protecting and

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ensuring this right is not only the responsibility of schools or families but also requires teamwork involving other relevant experts. For this, it is essential to ensure cooperation between experts in disciplines such as education and health. Awareness and basic knowledge of the issue is a prerequisite for cooperation. In order to achieve this, it is necessary to utilize various technologies that include distance learning and interaction opportunities in addition to or instead of traditional means. Designing and presenting these technologies to the target audience's characteristics will contribute to increased efficiency. Similarly, it is essential to develop and provide access to assistive technologies for individuals with intellectual disabilities to protect and improve their health.

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7.APPENDIX

7.1-Form A - Proxy & ID Questionnaire (English)

Your Health (Or Your Child's Health)

Dear Participant,

There are a couple of open-ended questions about the health of a child with intellectual disability. Answering these questions totally is confidential and voluntary. Your answers are valuable for the curriculum that would be developed to promote the health of children with intellectual disabilities. If your child has some challenges to answer the questions, you or your spouse/partner can answer the questions on behalf of your child.

Please answer the following demographic questions.

1. Responder (Participant): Who _____
2. What is your education level (the last education level you graduated from)? _____
3. What is your profession/job? _____
4. What is your age (or your child with intellectual disability: ID)? _____ years old
5. What is your gender (or your child with ID)? Boy ___ Girl ___
6. What is your child's height and weight (or your child with ID)? (Please measure and then answer!) Height _____ Weight _____
7. What is your disability level (or your child with ID)?
   Mild _____ Moderate _____ Severe _____ Profound _____
8. Do you have a diagnosed chronic illness/disease, which named in the last 12 months (or your child with ID)?
   Yes (Write name of illness or diseases: ……) No (___)
9. How many times did you go to hospital/health institution in the last 12 months (or your child with ID)?

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Yes (how many times: …….) No (___)

10. Have you ever received inpatient treatment at a hospital/health institution in the last 12 months (or your child with ID)?

    Yes (how many days did you (or he/she) stay in totally: ……. - What was the diagnosis/es?.....) No (____)

Questions About Child's Health

1. How active you are physically (e.g., walking, running, mobility) and do you engage in sporting activities (any sports)?
2. Do you have any feeding problems? (e.g., food selectivity, food refusal, not eating enough fresh fruits or vegetables, less consume milk, meat or poultry, lack of a dietary regimen)
3. Do you have sleep problems? (e.g., awakening at night, lack of quality sleep)
4. How well do you know about sexual and reproductive health and rights? (e.g., protecting from transmittal diseases, unwanted pregnancies, sexual identity)
5. How well do you protect yourself from contagious/infectious diseases or COVID-19? (e.g., social distancing, wearing mask, using sanitizer)
6. Do you know what to do in case of an emergency (e.g., call emergency number, asking help to an immediate person, going to a safer place) or need for first aid (e.g., bleeding control, cardiac massage, heimlich maneuver)?
7. How much do you care about your personal hygiene (e.g., hand washing habits, brushing teeth, bathing)?
8. What are the possible factors or issues affecting the health of a child with ID?
9. What should be done to protect or promote the health of a child with ID?

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7.2-Form B - General Questionnaire (English)

A Child's Health

Dear Participant,

There are a couple of open-ended questions about the health of a child with intellectual disability (ID). Answering these questions totally is confidential and voluntary. Your answers are valuable for the curriculum that would be developed to promote the health of children with intellectual disabilities.

Please answer the following demographic questions.

11. Responder (Participant): Who _____
12. What is your education level (the last education level you graduated from)? _____
13. What is your profession/job? _____

Questions About the Health of a Child with Intellectual Disabilities (ID)

10. How do you describe a physically active child (e.g., walking, running, mobility) and how does a child engage in sporting activities (any sports)?
11. What kind of feeding problems does a child with ID have? (e.g., food selectivity, food refusal, not eating enough fresh fruits or vegetables, less consume milk, meat or poultry, lack of a dietary regimen)
12. What kind of sleep problems does a child with ID have? (e.g., awakening at night, lack of quality sleep)
13. What should a child with ID know about sexual and reproductive health and rights? (e.g., protecting from transmittal diseases, unwanted pregnancies, sexual identity)
14. How should a child with ID protect himself/herself from contagious/infectious diseases or COVID-19? (e.g., social distancing, wearing mask, using sanitizer)
15. How should a child with ID do in case of an emergency (e.g., call emergency number, asking help to an immediate person, going to a safer place) or what

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should he/she know about the need for first aid (e.g., bleeding control, cardiac massage, heimlich maneuver)?

16. How should a child with ID care about his/her personal hygiene (e.g., hand washing habits, brushing teeth, bathing)?
17. What are the possible factors or issues affecting the health of a child with ID?
18. What should be done to protect or promote the health of a child with ID?

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