YOUNGCARE

RELIEF FOR YOUNGER PEOPLE IN NEED OF CARE AND THEIR INFORMAL CARERS

National report:

An Overview of the Situation of Informal Caregivers and Younger Adults in Need of Care in Lithuania

Co-funded by the European Union

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ABOUT THIS PUBLICATION

This report summarizes the national overview of informal care services and caregivers of individuals aged 18 to 65, outlines the needs and challenges encountered by the YoungCare target group, and provides practical support along with examples of good practices. Erasmus+ project **YoungCare: Relief for Younger People in Need of Care and their Informal Carers** (Grant agreement: 2022-1-DE02-KA220-ADU-000086558). **PROJECT WEBSITE:** https://youngcare.eu/

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1. Aims of the national report

The project "YoungCare - Relief for younger people in need of care and their informal carers" aims at improving the situation of younger people in need of care. This is a group of younger adults up to the age of 65 who have become dependent on care as a result of a drastic event such as an accident or serious illness and can no longer manage their everyday lives without help. In most cases, these people are neglected in care services and have problems receiving care tailored to their needs. In most cases, therefore, they are cared for at home. The partner organisations from Germany, Italy, Lithuania, the Netherlands and Portugal want to draw attention to the sometimes precarious situation of young adults in need of care and the people who care for them.

The national report is supposed to be an important part in assembling an European compendium. The compendium is meant to provide a scientifically based but practice-oriented and easily accessible overview of the situation of younger people in need of care and their informal carers. It is aimed primarily at these informal carers and people in need of care who are confronted with disease and care for the first time or who feel the need to improve their situation. It is part of Work Package 2 of the YoungCare project, which is intending to collect evidence on the perspectives of the target group, creating an extended knowledge base and developing solution strategies. The results of this work package are also meant to contribute to the development of the digital learning opportunities and for the development of the publicity strategy in the following work packages. In order to accomplish the task of the European compendium being the main output of this Work Package the national reports from all the partner-countries (Germany, Portugal, Italy, Lithuania and the Netherlands) are an important piece of input and information.

Although the main aim is to be a fundamental piece towards completing the European compendium the publication of the national reports also gives an overview of the situation of YoungCare in each of the countries represented by a partner organisation. It is important because it sheds light on the daily struggles and hurdles young people in need of care and their informal carers have to face locally. Also, the political, public and scientific discussion will be elaborated. Particularly because of the scarcity of data and information, it is important to use the national reports to provide insight into the everyday lives of young people in need of care and their informal caregivers.

2. Methodology

Before describing the methods applied to achieve the above-mentioned aims, it is important to specify the target groups summarized as “younger adults in need of care”. The main criterion for the differentiation is the question if the need for care has already existed since birth or was acquired in the course of life (between 18 and 65 years of age). We intentionally use the term "younger adults" for the project to describe the age group that can neither be described as children and young people, nor as senior citizens. This is done with the knowledge that this age group encompasses a large age variation.

The distinction between the need for care since birth and a later acquisition seems to make sense in the context of the YoungCare project's objective to develop a practical educational tool. The thesis is that the first group (from birth) is already introduced into the social and care system through the offers in the child and youth sector. Even if problems arise with the transition to adulthood and care services (presumably) deteriorate, this group has experience with the issues of care and the social system. In the second group, there is a need to acquire this knowledge in an extreme situation.

People in need of care are defined as those persons who are dependent on help in managing their daily lives. All people who informally help other people to cope with their everyday life are defined as carers.

The following methods were applied during the finalization of this National Report:

2.1 Desk Research

The partners conducted the desk research in their countries with a special focus on the national situation and focused on the following topics:

- Facts and figures on care services, care needs, types of illnesses, and types of care provided
- Scientific work on the topic
- Political and practical debates on the topic
- Obstacles and difficulties for the YoungCare target group in the provision of care and services
- Suitable offers and good practice offers for the YoungCare target group
- Suitable practical support for those affected and their carers (first aid)

2.2 Interviews

In each country, narrative interviews with an open structure were conducted. They were conducted primarily with informal carers but if possible, depending on the individual situation of the persons concerned, persons in need of care were also interviewed. A short amount of interviews were conducted with experts to improve the understanding of the overall situation.

In Lithuania, 12 interviews were conducted: three interviews with experts, one with a person with a need for care, and eight with informal caregivers. One expert had a dual role in our study, as she was both an expert and a brother who needed care. Among the interviewed family caregivers six were mothers and two sisters. All research participants, including the experts, were female. Only one interviewee with a disability was a male. Two of the caregivers and care-dependent persons were under the age of 50, two were 60 years or older, five were 70 years and older, and one was 89 years old. Based on one

of these interviews, there is also a short portrait of one person in need of care, which can be found in Chapter 3.5. More details regarding the participants are presented in Table 1.

Table 1. Description of research participants

Category of survey participant	Code	Age	Short description
Expert	E1 Lina		Coordinator of formal care in the daycare center. More than 20 years' experience as a social worker.
Expert	E2 Vidas		The head of the Lithuanian Association for the care of people with mental disabilities.
Expert	E3 Rima		Member of the Commission for Monitoring the Rights of People with Disabilities for four years, as a human rights activist, has 14 years of experience. She gives support to her brother (age 34), who has had autism since childhood. The primary informal caregiver was the father.
Category of survey participant	**Interview No. and changed name**	**Age of the person in need of care**	**Type of disability and short description**
Informal carer, mother	RP1 Ona	56	The daughter has multiple disabilities from childhood (Down syndrome and others) at a teenager's time her CP (cerebral palsy) increased her disability. The main informal caregiver is the mother (age 89), son Titas (age 68) helps a lot.
Informal carer, mother	RP2 Eva	52	The daughter acquired a disability after big head trauma. Mother (age 75) caregiver for 16 years as the main informal caregiver.
Person in need of care	RP3 Tomas	33	Tomas acquired a disability after big spine trauma (he fell from the 9th floor). For 13-14 years the informal caregiver is the mother. Although Tomas is in a wheelchair, he lives independently.
Informal carer, mother	RP4 Ana	29	Her daughter at age 8 months acquired a disability due to a complex complication of the flu. Mother (age about 60) gives care for 29 years as the main informal caregiver.
Informal carer, mother	RP5 Egle	47	Her daughter at age 30 acquired a severe disability, and she did not communicate and was connected to a variety of machines that pumped saliva and helped her breathe, and she was fed through tubes. For 17 years, the main informal caregiver was the mother (age, 77 years). The husband helped a lot, but he died two years ago.
Informal carer, sister	RP6 Gita	57	Sister (age 60) has been an informal carer for her sister for 13 years. Her sister had a stroke 13 years ago.
Informal carer, mother	RP7 Lina	42	Mother (age 73) takes care of a son (age 42) who has schizophrenia, first noticed at age 24.

Informal carer, mother	RP8 Rita	50	Mother (age 72) for 30 years takes care of her ill son. Her son was diagnosed with schizophrenia when he was 20 years old.
Informal carer, mother	RP9 Daiva	45	The mother (age 62) for three years takes care of the daughter who, at age 42, acquired a disability after a myocardial infarction, after which she went into a coma for 3 weeks.

3. Results

3.1 Overview of the national situation

3.1.1. Statistics of the target group

In 2021, in Lithuania, people of working age with disabilities accounted for almost a tenth of the working-age population and over 5 percent of the total population of the country (Table 2), while 21,217 people were living in Lithuania with extremely complex disabilities, which not only causes a person to lose the opportunity to work but also needs both informal and formal assistance.

Table 2: Dynamics of the total population in Lithuania, number of working-age population (in thousands), number of working-age persons with disabilities, and percentage of the total population of the country in 2016–2021 (Lietuvos Gyventojai, 2022).

	2016	2017	2018	2019	2020	2021
The total population of the country	2888600	2847,9	2808,9	2794,2	2794,1	2806,0
Working age population in the country (15-64 years)	1790300	1761,5	1731,5	1721,7	1724,6	1749,1
Working-age people with disability	163885	162632	160340	157957	157957	147456
Percentage of the total population of the country	5,6%	5,7%	5,7%	5,6%	5,6%	5,2%
Percentage of the working-age population of the country	9,1%	9,2%	9,2%	9,17%	9,15%	8,4%

By the end of 2022, it was projected that there will be approximately 223,000 individuals living with disabilities in Lithuania, representing a slight increase compared to the previous year (Socmin, 2023a). However, the number of working-age individuals with disabilities, which is one of the target groups of YoungCare, has experienced a slight decline. The following graph illustrates the trends in the number of people with disabilities in Lithuania from 2016 to 2021. Specifically, the figure showcases a gradual decrease in the number of working-age individuals (18-65 years) with disabilities over the same period (Figure 1).

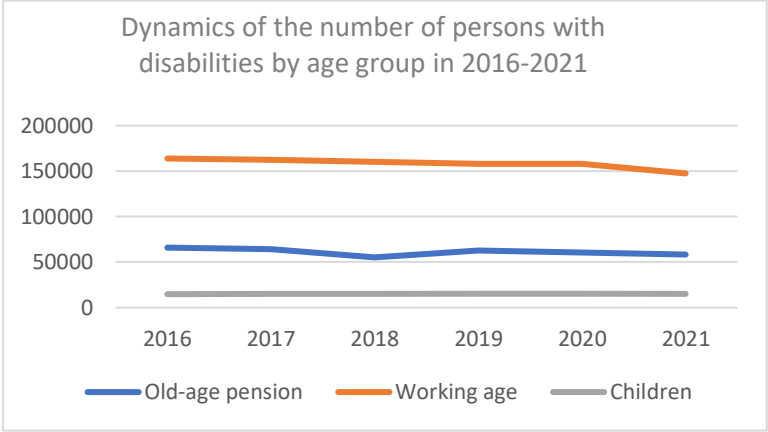


Figure 1: Dynamics of the number of persons with disabilities by age group in 2016-2021

According to the Ministry of Social Security and Labour, the most severe disability is most often caused by tumors, diseases of the circulatory system, and mental and behavioral disorders. However, there are no statistics on persons with disabilities of working age in Lithuania, by type of disability. The data provided by the Mental Health Center of the Institute of Hygiene reveals that the incidence of schizophrenia, schizotypal and delusional disorders remain relatively stable, with an average of 8 cases per 1000 inhabitants (0.8% of the population) in the country (Figure 2). These mental illnesses manifest themselves in a particularly complex way, involving areas such as thinking, perception, volition, and emotions, making it difficult for the person with a mental disability to learn and work, and in many cases leading to severe disability. The disease affects not only the person affected but also his or her immediate environment, especially the family.

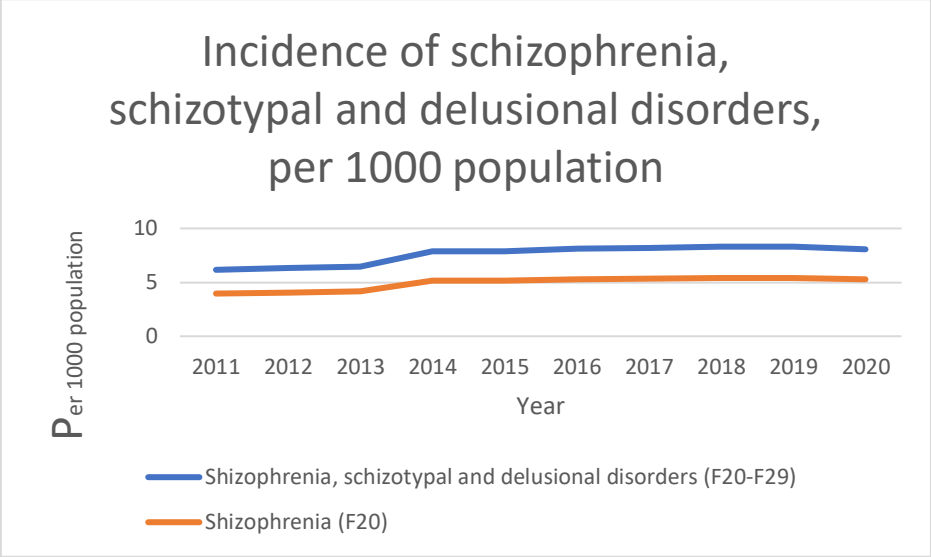


Figure 2: Incidence of schizophrenia, schizotypal and delusional disorders, per 1000 population.

In Lithuania, the available general statistics on individuals with disabilities do not accurately represent the number of working-age people with disabilities relying on the support of their relatives. Additionally, there is a notable lack of data on informal caregivers who take care of their family members or relatives. Consequently, assessing the precise coverage of the project's target group in Lithuania can only be inferred based on general statistical information about disabled people.

3.1.2. Social support system in Lithuania

In Lithuania, historically, social services for people with disabilities have primarily concentrated on financial assistance and special social services, with institutional care (day, short-term, or long-term) being the most prominent of these. However, since 2012, there has been a growing emphasis on community-based services to complement these special social services. Recognizing the limited availability of social services for adults with

intellectual and psychosocial disabilities, significant attention has been given to the pilot testing and implementation of four community-based services between 2020 and 2023. These services include sheltered housing, social workshops, assisted employment, and support with decision-making (Genienė, 2021; Pučkienė, 2021). Figure 3 provides an overview of the range of services available to people with disabilities.

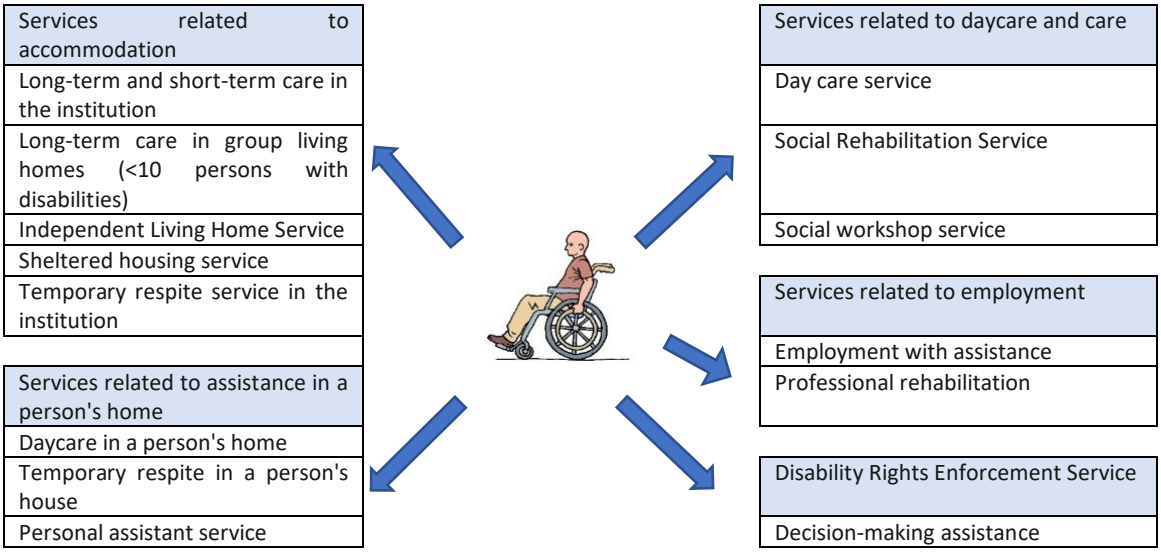


Figure 3. Types of services for a person with a disability and his relatives

SOCIAL SERVICES. In Lithuania, a range of services is available to individuals with disabilities, including general, special social, and preventive services. *General social services* are designed to support individuals and their family members who find themselves in challenging social situations. These services encompass various forms of assistance, such as information provision, counseling, mediation, representation, meal provision, clothing and footwear assistance, transportation organisation, sociocultural services, personal hygiene, and care services (Socmin, 2023b). While individuals with disabilities can also access these services, they are more commonly utilized by individuals facing a social crisis or living below the poverty line.

Special social services. These services consist of *social care* and *social care services* that are more in line with the needs of persons with disabilities and their families. *Social care* services consist of home help, development, and support of social skills, family social care (when family members do not perform their guardian functions), accommodation in a care home, an independent living home or group home, psychosocial assistance, accommodation in protected housing, social rehabilitation in the community and temporary respite services (Socmin, 2023b).

Special social care services. Currently, social care services are divided into daytime, short-term, long-term, and temporary respite services (Socmin, 2023b). Like most post-Soviet countries, social care institutions were influenced by the medical paradigm (Ruškus,

2002), so until now it is possible to find social care institutions with a population of 200 or more people each. In 2022, 18 thousand working-age persons with disability got services at daycare centers, 5 353 working-age people got services in state care homes for people with disability, 124 in municipal care homes, and 132 in private or NGO care homes (Official Statistics Portal, 2023a). Altogether there are 74 care homes for adults with disabilities, including state and municipal institutions, NGO and private care homes as well as group living homes (Official Statistics Portal, 2023b). In 2022, 725 residents were living in independent living homes for older people and adults with disabilities (Official Statistics Portal, 2023c), however, it is not known how many of these are persons with disabilities of working age.

Home help is more of an emergency for older adults with special needs to deal with situations they are no longer able to take care of themselves and their home environment. *Respite services* are supposed to help families combine work and caring for a family member with a disability, but they are poorly recognized and difficult to organize due to bureaucratic reasons. According to the Ministry's data, in 2021, temporary respite was provided to almost 140 people in 35 municipalities in the country, and in 14 municipalities, temporary respite can be provided, but no one has yet applied to receive this service (Socmin, 2023c). Other services are geared towards people with mild and moderate disabilities and do not meet the care needs of people with disabilities and their families, so they are mostly offered social care services. Family members caring for people with disabilities can use the *temporary respite service*. The respite service is available to relatives who are caring for a disabled person who has an activity level of 55% or less. The respite service can be provided either in the person's home, in a day center, or a social care institution. A family with a person with a disability may receive up to 30 days (720 hours) of respite services per year, but in the event of a crisis in the family, respite services may be provided for up to 90 days continuously (Socmin, 2023c).

In addition to the development of community-based services, since 2018, the pilot of *integrated home care* has been more responsive to the needs of people with disabilities, especially in the case of medical care needs, by providing integrated nursing and social support. The intensity of the service consisted of 2 to 8 hours of assistance in the person's home: 1 to 4 hours of nursing care and 1 to 4 hours of social care; up to 5 times a week. The integral support team consisted of a social worker, a nurse, a physiotherapist, and an individual care specialist. There are no precise statistics on how many persons with disabilities and their relatives received this service, but it is considered to be more in line with the needs of the family members, i.e., to get away from the person with a disability being cared for and to return to the labour market. With EU support, from 2020 onwards, integrated home care was provided in all municipalities. After the end of the EU funding, this service was reformed into home daycare and competed with outpatient home care services.

To activate the involvement of persons with disabilities in social services and to free informal carers from permanent care, NGOs (Independent Living, Lithuanian Disability

Organisations Forum, etc.) have paid particular attention to the introduction of *personal assistant* support. So, in 2021 in Lithuania, personal assistant services have been launched for persons who have a disability and for whom the need for this assistance has been identified. A personal assistant provides personalized assistance to a person, both in his/her home and in the community. The activities of a personal assistant cover a very large number of areas of activity – from domestic assistance, leisure, organisation of mobility to help express oneself, communicate, etc. No studies have been carried out on changes in the family, but the Ministry of Social Security and Labour of the Republic of Lithuania projects that the provision of personal assistance will enable 50-70% of disabled family members who have been caring for a disabled household member to return to work, which should increase the number of disabled people in employment (Asmeninis asistentas, 2021).

Professional rehabilitation services, provided in methodological centers, are designed to restore and develop a disabled person's ability to work so that he or she can get a job (Socmin, 2023g). As this service was centralized and only available in major cities, the employment statistics for people with disabilities did not change, so from 2020 onwards, efforts were made to activate the *assisted employment* service (Pertvarka, 2023).

Preventive services only were introduced in 2022. They are services for identifying potential recipients of social services, targeting people who are experiencing various difficulties, and finding, contacting, supporting, and/or involving them in the assistance process (Catalogue, 2022). This service creates preconditions for more people with disabilities to be included in the social protection system in the future. However, other pre-preventive services, such as family support, community work, and open youth work, are poorly linked to services for working-age persons with disabilities.

FINANCIAL SUPPORT. Persons with disabilities are entitled to two types of financial support: care benefits (compensations for care expenses) and nursing benefits (compensation for nursing expenses). The dynamics of the number of recipients indicate an unchanging situation in the period from 2015 to 2021 (Socmin, 2023a) (Table 3).

Table 3. Number of persons receiving compensations for care expenses and nursing expenses, (in thousands) (Socmin, 2023a).

	2015	2016	2017	2018	2019	2020	2021
Number of persons receiving care benefits	56,4	56,3	57,4	59,1	56,2	55,7	56,2
Number of persons receiving nursing benefits	41,5	41,3	39	37,3	37,9	36,2	34,5

By orders of the Ministers of Social Security and Labour of the Republic of Lithuania and the Ministers of Health, the criteria for determining the level of working capacity and the descriptions of the procedure for determining the level of working capacity were approved. By these documents, a complex assessment of medical (i.e., a person's basic working capacity) and aspects of a person's activity and ability to participate determines

the level of the working capacity of a person. 'Level of working capacity' means the capacity of a person to exercise a previously acquired professional competence or acquire a new professional competence or perform work requiring less professional competence. Working capacity is estimated as a percentage and its level is determined by intervals:

- If the person is assessed as having 0-25% of working capacity, he or she is deemed to be unable to work or can only work in a workplace or adapted working conditions adapted to the nature of the disability.
- If the person is assessed as having between 30% and 55% work capacity, he or she is considered to be partially able to work, able to work in a job adapted to the nature of his or her disability, or in a job that does not require adaptation.
- If a person is found to be 60-100% able to work, he or she is considered able to work.
- A more detailed analysis of the situation of persons of working age with disabilities shows that the majority of persons of working age have a working capacity of 30-40%.

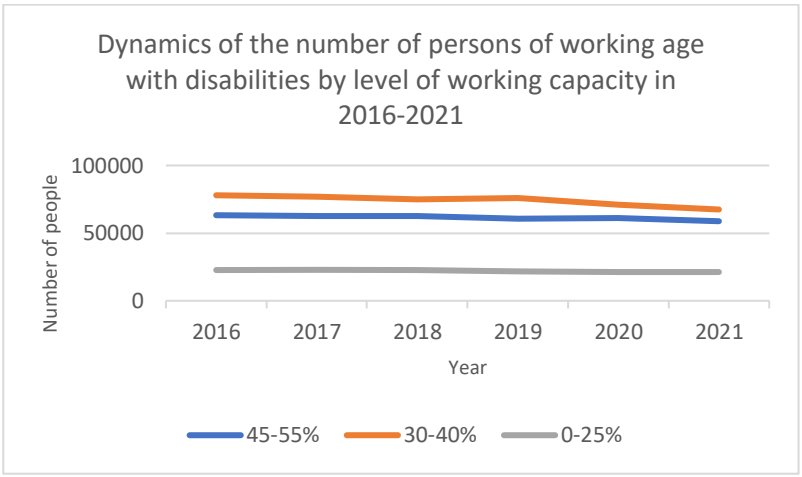


Figure 4: Dynamics of the number of persons of working age with disabilities by level of working capacity in 2016-2021.

The dynamics of the number of persons of working age with disabilities by the level of working capacity in 2016-2021 is stable (Figure 4). According to the legislation currently in force in Lithuania, means that a person can work, but with certain reservations, he or she is also guaranteed state benefits. If the Ministry of Social Security and Labour (the Ministry) determines the level of disability and the level of working capacity (not work skills, but rather independence), a disability pension is paid, and if the person with a disability needs social care or nursing at home, their relatives are reimbursed for the cost of the care or assistance (care). A person with a disability can receive only one pension. If he/she is receiving a pension for sickness (or loss of working capacity), he/she cannot receive a disability pension unless his/her pension for sickness is lower than the disability

pension. In that case, the difference between the amount of the sickness pension and the sum of the disability pension and the other pensions received shall be paid (Socmin, 2023b).

In Lithuania, in 2023, financial support (called the disability pension) for adults who have acquired a disability since childhood is €184-414 (depending on the level of incapacity for work), but only €184 if you have acquired a disability after the age of 24 and have lost 60 percent of your working capacity (Sodra, 2023). For severe disabilities requiring nursing care, the targeted nursing allowance ranges from €279.3 to €382.2, and for milder disabilities requiring care, the targeted allowance ranges from €88.2 to €161.7 (Socmin, 2023d). Their relatives who have been caring for a family member with a disability for at least 15 years and have themselves lost the ability to work receive €184-276 (Socmin, 2023e). A family can apply for financial support for the adaptation of housing (except for the purchase and installation of relocation equipment and a lift) from the state budget - EUR 8 330, from the municipal budget - at least EUR 5 553 (Socmin, 2023b). This is one of the lowest levels of financial support in the EU for people with disabilities and their families. This can be explained by the level of expenditure on social protection per inhabitant, which in 2020 was almost double less in Lithuania (5217,06 Euro per inhabitant), compared with the average in the EU (9536,71 Euro per inhabitant) (EUROSTAT, 2023).

From 1 July 2023, a new procedure for the provision of mobility equipment will come into force, adding new, more innovative accessories to the list of equipment, and extending the list of equipment for which people with mobility disabilities can receive compensation. Some devices will be reimbursed more frequently. The administrative burden has been reduced, and almost all the devices will be available for people with disabilities to purchase on their own or at the Technical Assistance Centre for Disabled Persons or at the municipality. Increased reimbursement of the cost of some equipment (Alkas, 2023).

SITUATION OF INFORMAL CAREGIVERS IN THE LABOUR MARKET. Lithuania is one of the countries with a developed labour market policy approach: flexibility of working time, including teleworking, emergency leave, and a high level of employment protection for carers (Jungblut, 2015). On request of an employee taking care of a sick family member, part-time work may be granted by the opinion of a healthcare institution (Labour Code, Article 146). Part-time work, in other words reducing the number of working days per week or shortening the typical working day (shift), may also be agreed between the employer and employee. Unpaid leave for up to 30 days a year can be granted to an employee taking care of a sick family member (Article 184). The period of care is taken into account when the working duration entitling the worker to annual leave is calculated (Article 170). Employees who are taking care of sick or disabled family members have more flexibility in choosing the time for their annual leave (Article 169). Employees shall be granted their annual leave at the time of their choice subject to the recommendation of a health institution (Jungblut, 2015, p. 59).

3.2. Overview of the political, public and scientific discussion

3.2.1. Overview of the political discussion

During the past few years, several substantial developments within the national legislation have been carried out in Lithuania by reforming existing laws and adopting new laws. In 2020 the Parliament of Lithuania have been adopted substantial changes to the Law of Education concerning *inclusive education*. The law comes into force in 2024. Inclusive education has been defined as an engaging system of education to ensure reasonable accommodation for every person to develop individual capacities and capabilities, receive the required support, experience success within the process of learning, in social, cultural, and/or other activities, also to not be discriminated based on diversity of educational needs and/or the required educational support. The new law also explicitly legitimates educational support, though named as special support and guarantees accessibility of a child with special needs access to all types of support, including educational, psychological, social, health, and other support. One of, if not the main, amendment within the law is the elimination of the provision, allowing a school to deny access to school for a child with a disability/special need for the presumed lack of accommodations at school. Instead, from 2024 every child living in the area, assigned to a school, has the right to that school. The school has no right to deny access to a child, instead, the school has the obligation to ensure all support that the child requires. It must be said that there are a lot of fears and anxieties, especially among teachers and parents, about the unpreparedness for that reform, the lack of support for a teacher, and the lack of capacity of a school to accommodate educational environments. It is important to mention that the Law of Education explicitly extends the scope of education to lifelong learning, thus for adult people as well as for children, implicitly including those with disabilities. Article 3 of the law highlights lifelong learning among the main aims of education in Lithuania. Article 5 of the law highlights the principle of continuity of education, including by providing reasonable accommodation, thus implicitly including for persons with disabilities, concerning lifelong learning. Similarly, lifelong learning is a provision within Article 16 of the Law on Informal education of adult people. Article 28 of the Law on the Network of Providers of Education provides the guarantees of providers of education to ensure accessibility of education, its diversity, and lifelong learning opportunities.

On 2021, July 1, the new arrangements for personal assistance have been adopted as part of the Law on Social Integration of People with Disabilities, namely, the ministerial order on the Determination of the Requirements for Personal Assistance and the Provision of Personal Assistance (No. A1-478) to provide individual in-home support and support in public spaces (by accompanying and communicating) to a person, thereby responding to individual requirements of a person and promoting his/her independent living and activities in all areas of life. The municipalities are responsible for the implementation of the provisions on personal assistance. The determination of the need for personal assistance is performed by a social worker. The role of a personal assistant is to promote the independent living of a person with a disability, provide the required hygiene and

feeding support that a person may require, accompany a person to the health, public administration, work, and leisure settings, provide mobility support, also support to maintain social relations and social activities. Personal assistance doesn't include household cleaning, childcare, teaching assistance, or supporting decision-makers. These regulations on personal assistance have been welcomed by organisations of persons with disabilities but also criticized by them because it doesn't fully cover the individual budget of the assistance when a person with a disability has to pay 20 percent of the cost of personal assistance.

The Law on Social Enterprises was repealed in 2022 and went into effect on January 1, 2023, after receiving harsh criticism from organisations of people with disabilities for encouraging segregated and sheltered employment. Meanwhile, the Law on Employment was updated by the Lithuanian Parliament to encourage the employment of people with disabilities in an open labour market. Several measures have been introduced within the law in this regard. Subsidies for the salaries of persons with disabilities are provided when a part of the salary of a person with a disability is compensated by the State. For persons with severe disability (25 percent of workability level) subsidies are unterminated, for persons with moderate disability (30-40 percent of workability level) subsidies are provided until 36 months, for persons with mild disability (45-55 percent of workability level) subsidies are provided until 6 months. It is critically noted that the disability classification by degrees on workability level is maintained, also that subsidies are terminated despite the requirements of a person with a disability and the employer. Another positive measure is the provision of reasonable accommodation at the workplace, which is aimed at the accommodation of work conditions, including settings designed for the rest of workers with disabilities. Subsidies for work assistance are provided for the employer of a person with a disability are also provided. The mechanism of the active labour market policy is also carried out through the means of professional and vocational training, apprenticeships, internships, professional rehabilitation, recognition of informally acquired competencies, support for mobility at work, and support for initiation of an individual business. There are indeed many factors that still have negative impacts on the employment of persons with disabilities in an open labour market, including but not limited to the negative public stereotypes and employers' attitudes, lack of accessibility to mainstream professional and vocational education, and specific support to women with disabilities.

Innovations in the employment of people with disabilities in the open labour market will start on 1 January 2023. The target is to have 39% of people with disabilities in the open labour market by 2025 and 47% by 2030 (Socmin, 2023f). Introducing *job carving* services is already on the policy agenda (Job Carving, 2023). The idea is to separate the functions performed by skilled workers that do not require a high level of qualification and give them to someone with fewer skills, such as a person with a disability. The introduction of these services is likely to enable people with disabilities to enter the open labour market.

In 2022, December 20 (enters into force from 2024, January 1), the Law on the Protection of the Rights of Persons with Disabilities has been adopted at Lithuanian Parliament, the new law has replaced the outdated Law on Social Integration of the Disabled. The new law, it has been officially proclaimed that persons with disabilities are recognized as subjects of human rights and have a full range of all human rights. The Convention on the Rights of Persons with Disabilities (CRPD) is explicitly incorporated in Article 1 of the Law by saying that the Law is guided by the spirit and provisions of the CRPD. The duty of nondiscrimination based on disability is explicitly claimed within the law. To facilitate effective coordination of service provision for persons with disabilities, a single point of contact for all types of services is being established, along with the case management service. The new position of disability coordinator at municipalities will be established. Access to information, including alternative modes of communication, is being developed throughout all sectors, ensuring free access to communication for a person using the modes of communication as required by a person. However, the reform of the disability assessment mechanism constitutes the most important change by introducing the new concept of participation. The existing system of determination of special needs and workability is based on a medical model of disability and applied by making a capacity assessment of a person. If the existing disability determination system is grounded on 90 percent of medical criteria, the new system is grounded on 60/50/40 percent of medical criteria. The new system focuses on the determination of individual requirements for social participation. The new system is operationalized by four components: a) coordination of support by determination of individual requirements of a person and the plan of implementation of individual support, including responsible institutions and monitoring of implementation; b) accessible means of communication by ensuring the required support for information and communication; c) development and application of Easy Read; d) accessible physical and communicational environment, including public environment, built environment, transportation for ensuring independence and mobility of a person and service providers in the community. The new system of disability determination and disability coordination makes substantial changes within disability policy and legislation in Lithuania and appears to be around complying with the CRPD. However, some reservations and concerns remain about the scope and capacity of the reform, particularly, as regards persons with disabilities in institutions, including in group homes, and other adult persons with disabilities who live with their parents, while both populations are dependent on institutions or parents, and have very little independent living opportunities for them.

3.2.2. Overview of the public discussion

The main actor in public debate on disability issues is the "Lithuanian Disability Organisations Forum (Lithuanian Disability Forum, 2023), which brings together 16 organisations that collectively represent the interests of around 300,000 people with disabilities, their families, and people with disabilities. The Forum was established in 2001 to bring together organisations representing different disabilities to work together to change disability policy in Lithuania. One of the Forum's key objectives is monitoring the

implementation of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in Lithuania. This international instrument, adopted in 2006, was ratified in Lithuania in 2010.

The Forum's 2022 report reflects the public debate about people with disabilities. The report provides an analysis of various issues related to the lives of people with disabilities: the application of the Convention on the Rights of Persons with Disabilities in Lithuanian case law, the situation of women and girls with disabilities in Lithuania, issues of accessibility by Article 9 of the UN Convention on the Rights of Persons with Disabilities, preparedness in case of dangerous situations and humanitarian crises (Art. 11 of the Convention Art.), independent living and inclusion in the community (Art. 19 of the Convention), education (Art. 25 of the Convention), work and employment (Art. 27 of the Convention), and participation in cultural life, active recreation, leisure and sport (Art. 30 of the Convention). The report identifies problem areas and makes recommendations to improve the case law on incapacitation, accessibility of infrastructure in medical treatment, social services, cultural institutions, and public transport for people with disabilities.

The report states there is a serious lack of community services in municipalities, and people of working age with particularly low levels of workability are not able to participate in the open labour market and access public community services. They do not have access to personal assistants according to their individual needs, and temporary respite services for relatives, family members, or other legal guardians and carers are not guaranteed. Although the legislation of the Republic of Lithuania provides for such possibilities, in practice community-based services are hardly available in municipalities, especially for persons with more severe or complex disabilities. All special social services and the development of community-based services in the regions are an independent function of municipalities, and there are currently no legal or political instruments to influence local authorities to provide such services and to allocate sufficient funding (Žmonių turinčių negalią, 2022).

According to 2018 data, social poverty and exclusion among people with disabilities in Lithuania is over 35%. It is reasonable to conclude that relatives or caregivers of people with severe disabilities are most often exposed to the risk of poverty as one of the family members is forced to take care of the person with a disability and to withdraw from the active labour market due to the lack of social services available in municipalities (Žmonių turinčių negalią, 2022, p.77).

The report states that discrimination based on disability is more acute for women and girls than based on gender, but notes that women and girls with disabilities are subject to double discrimination and are more vulnerable to discrimination based on both their disability and their female gender. Women experience discrimination not only in violence but also in education and training, employment, social policy, civic participation and decision-making, sexuality, prejudice and social representation, motherhood, family, and other areas of daily life (Žmonių turinčių negalią, 2022).

The issue of nondiscrimination of people with disability and discrimination by association with disability of informal caregivers take place in public discussions as well. In 2021 Supreme Administrative Court of Lithuania adopted the final and uncomplaining decision on the case, in which the applicants – an autistic young woman and her mother - sued the Ministry of Social Security and Labour and the Ministry of Education, as well as the vocational school for the discrimination on the grounds of disability and age, as well as for the discrimination by association with a person with a disability about the restriction of the right of a young person with a disability to vocational education. The case has begun in 2018, when the applicant, 21 years old autistic person was denied access to vocational education school due to the lack of reasonable accommodation and the lack of all kinds of support, necessary for the realization of the right to vocational education of a young adult with disability at that school. The school argued that such kind of support is provided only to children and young people before they are 21 years old. However, the court recognized that the Ministry of Education has not guaranteed the right of disabled young women to vocational education and lifelong learning, she was directly discriminated against on the grounds of her disability. Also, the court has recognized that the mother of the young autistic woman has been subjected to discrimination by association with disability (Office of the Equal Opportunities Ombudsperson, 2021).

In addition to public discussion in Lithuania, some international discussions have to be mentioned. The UN Committee on the Rights of Persons with Disabilities has handed down an important decision concerning the rights of unpaid carers in the case of Maria Simona Bellini from Italy. The applicant cared for her profoundly disabled daughter as well as caring for her disabled partner. Her daughter's needs required, in effect, 24 x 7 care either at their home or at a day center – which the applicant also had to attend to provide essential assistance. To support her family, the applicant was permitted by her office to work from home (to 'telecommute') but in 2017 this permission was revoked and in consequence, she lost her job.

The Italian social system provides no legal recognition or support for family caregivers and the only state assistance the family received was 'a very low disability allowance' for their daughter and the applicant's partner (i.e., for persons with disabilities). The applicant took domestic legal proceedings to challenge this state of affairs – but without success. She then made an individual complaint to the UN Committee on the Rights of Persons with Disabilities claiming that the facts amounted to a violation of the UN Convention on the Rights of Persons with Disabilities (CRPD).

Although the CRPD provides no rights for family carers, the Committee accepted that in many instances '*the rights of persons with disabilities cannot be realized without the protection of family caregivers*' (para 6.8) and accordingly that Article 28(2)(c) of the CRPD '*recognizes the right of family caregivers to State protection provided that this recognition is indivisibly linked to the protection of the rights of family members with disabilities'*.

Article 28 concerns the right of persons with disabilities to an adequate standard of living for themselves and their families and Article 28(2)(c) requires the State to secure this right

without discrimination based on disability, to: 'ensure access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability-related expenses, including adequate training, counseling, financial assistance, and respite care'.

In its decision, the Committee noted that (para 7.4): disability support services must be available, accessible, affordable, acceptable, and adaptable to all persons with disabilities and be sensitive to different living conditions, such as individual or family income, and individual circumstances. … [and reiterated that states had a duty to] provide adequate support services to family carers so that they can in turn support their relatives to live independently in the community. This support should include respite care services and other supportive services. [and that] financial support is also crucial for family carers, who often live in situations of extreme poverty without the possibility of accessing the labour market and that states parties, therefore, have the obligation to provide social support to families of persons with disabilities and foster the development of counseling services, circles of support and other adequate support options.

That Committee concluded that (para 7.6): the lack of individualized support services provided [for] … the daughter and partner; the failure by the State party to promote, facilitate and provide appropriate legislative, administrative, budgetary, judicial, programmatic, promotional, and other measures to ensure the full realization of the right to live independently and be included in the community as enshrined in the Convention; and the failure to provide adequate support services to family carers so they can, in turn, support their relatives to live independently in the community, including by providing respite care services, other supportive services, financial support, social support, counseling services, and other adequate support options amounts to a violation of the … daughter's and partner's rights under article 19 of the Convention.

3.2.3. Scientific discussion

The foundation of care for community members who need care due to frailty, and reduced functional capacity brought on by aging, disability, or chronic illness is provided by family caregivers. In the EU, unpaid family caregivers provide almost 80% of all care (Lafferty et al., 2022).

Lithuania is one of the countries with the highest proportion of informal carers among people of working age (14%). The Nordic nations and continental Europe have the lowest percentages of informal carers, with the lowest percentages being in Denmark (3%) and Sweden (4%) as well as Germany and Austria (both about 6%). The latter can be somewhat attributed to tradition and partially to the presence of an effective formal care infrastructure. Lithuania is also one of the countries with the highest proportion of full-time informal carers (5.8%) (Jungblut, 2015).

According to Lafferty et al. (2022), family caregivers commonly alter or reduce their work schedules, decline promotions, assume less-demanding jobs, retire early or quit their jobs entirely to fulfill caregiving commitments. As a result, employers may encounter low job

productivity, increased absenteeism, decreased employee engagement and morale, increased presenteeism, and high staff turnover rates in the absence of appropriate workplace rules and support.

Caring for a person in need of care is not only physically demanding but also psychologically and materially demanding. It is expensive to support a person in need of care, so carers often do not give up their normal jobs. It is quite easy to become overworked when doing double jobs (Kaip slaugant artimąjį, 2019). Span et al. (2019) also state that numerous mental and emotional pressures were frequently confronted by caregivers. Being a caregiver may be extremely unpleasant, especially when dealing with a loved one's discomfort or challenging behavior.

Additionally, allowing family caregivers to maintain a professional identity can raise contentment, improve life quality and elevate levels of self-esteem (Jungblut, 2015). Allowing caregivers to continue working may be advantageous for both employees and employers, who will be able to keep skilled workers on staff and save money on hiring, training, and education expenses for new hires. Additionally, allowing caregivers to continue working benefits both the economy and the wider community (Lafferty et al., 2019).

Crettenden, Wright, and Skinner (2014) did a study “The Juggling Work & Care” aimed to describe the employment participation of mothers caring for a child (0-25 years) with developmental disabilities and how this varies across the lifespan of the child. The findings show that raising children with developmental disabilities has a considerable influence on parents' ability to enter and stay in the workforce. Compared to mothers of children the same age in the general population, fewer mothers of children with disabilities were employed, and it was found that this difference was substantially correlated with the degree of the severity of a disability of the child. Since many women reported that their children's disabilities had stopped them from returning to work as anticipated, this outcome was not the consequence of a lack of willingness to work. Additionally, they felt that caring for a child with special needs added stress to their workload. For some people, this stress was made worse by the financial implications of working fewer hours and having uncertain job prospects.

In Europe, more than a third of people care for a person from proximity. Although the situation of each family carer is very individual, care has a profound influence on the well-being of the carer. On the one hand, caring for a loved one can bring satisfaction and fullness: the ability to help and take care of a person with a disability in the family can cause pleasant emotions. On the other hand, those who care for their loved ones are often characterized by decreased well-being, higher levels of stress, symptoms characteristic of depression, and other psychological difficulties (VU mokslininkai).

Spann et al. (2020) discuss the need for help for informal carers. Their capacity to provide care may occasionally be constrained, for instance, if care requirements were so complex that they required specialized training or if they persisted for a long time, resulting in the

loss of informal support if members of the care network relocated, grew too old to provide care, or passed away (p. 705). As the authors state, several measures have been identified to help informal carers, such as emotional support that is frequently given informally by friends, family, and coworkers, which were deemed to be particularly useful in building the resilience of carers. The well-being of carers was significantly impacted by a supportive workplace culture. However, this kind of support was frequently ineffective because caregivers found it difficult to express their needs and worries, and some caregiving situations were stigmatized. Peer groups at work and in the community, both virtually and physically, enabled carers to share their experiences and seek support from others going through similar things. Counseling, whether privately arranged or offered at the place of employment, assisted people in gaining emotional support and boosting their resilience. In addition to allowing them to receive the necessary support, the fact that their family and society valued their contributions helped carers feel better about their circumstances (p. 707).

Larkin, Henwood, and Milne (2019) note, 'there is an extensive body of evidence about the ways caring impacts negatively on carers' lives and well-being, the picture is often more complex. It suggests that links between caring and carer outcomes are neither linear nor inevitable, they vary significantly in depth and nature and may be mediated by several context-specific factors' (p. 64).

A study conducted in Lithuania (Sučylaitė, 2015) aimed to reveal subjectively significant changes in health and quality of life among informal carers. The study revealed that informal carers feel that they have lost their own life (self), that they have lost the ability to understand and meet their own psychological and social needs and to care for their own health. They perceived the lack of sleep as a health impairing factor, three caregivers complained of heart tachycardia, and attacks of high blood pressure, and all caregivers complained of a lack of energy and altered social relationships. The study showed that even if they have other close relatives, they rarely get help from them, and there is a lack of social support and specialists who know how to communicate sensitively with the patient. Even after the death of their relative, informal carers feel like strangers in their own lives, plagued by depression and anxiety disorders (p. 56).

Some recent research carried out in Lithuania (Naujanienė et al., 2021; Merkys, Bubelienė, Blažaitė, 2021) has demonstrated that the adequate support and social inclusion of persons with disabilities, children including, and their parents and caregivers remain a big challenge for the social security system as whole. Negative disability stereotypes, lack of know-how on support measures, and lack of accessibility to social services, particularly, to regular services in the community remain the main obstacles and challenges regarding support systems for persons with disabilities and their caregivers. Research has demonstrated that the disability issue is highly problematized by professional social workers, and such problematization is strongly related to the lack of accessibility to and availability of services, tailored to the requirements of persons with disabilities, their support and social inclusion (Naujaniene Ruškus). Autism, intellectual disability, and

psychosocial disability of persons with disabilities and/or their caregivers are particularly problematized by social service professionals. Usually professionals, especially in small towns and rural areas, feel powerless and disoriented when facing disability issues and requirements for support and social inclusion. The unmet needs and requirements of families with a person with disabilities have grave critical consequences for them, including but not limited to violation of their rights, promotion of family dysfunctionality, and the stereotypical problematization of disability, which became professional a main reason for powerless and stress instead of addressing inaccessibility and unavailability of services. As the research demonstrates, professionals tend to problematize persons with disabilities and their caregivers instead of looking for constructive and effective solutions, including service accessibility, or strengthening their professional capacities for providing support.

In summary, academic literature is full of debate on the experiences and challenges of informal carers. Informal carers face many challenges, including psychological stress, health problems, stigma, financial difficulties, balancing work and care, social networks, etc. However, most of the academic literature is based on informal caregiving in the field of older age people care. In contrast, there is still little scientific debate about informal carers of working-age people or young adults with disabilities.

3.3. Needs, challenges, and solutions

In Lithuania, the first stages of the transition from institutional care to community-based services for people with disabilities took place in the period 2014-2020, coordinated by the Ministry of Social Security and Labour. However, despite the measures taken by the Lithuanian State to implement the recommendations of the UN Committee on the Rights of Persons with Disabilities on the implementation of Article 19 of the Convention (the right to live independently and to be included in the community), the main challenges have remained the same throughout the period: a) failing to ensure that all people with disabilities have real choices about where and with whom to live and that they are not forced to live in social care homes; b) the absence of a program for the provision and delivery of personalized personal and financial assistance to enable persons with disabilities to live independently in the community with all the assistance they need, and c) a general lack of a wide range of accessible and appropriately adapted services in the community (Žmonių turinčių negalią, 2022).

The results of our research have highlighted the following problems faced by informal carers: *accessibility to community-based services*, *balancing between paid work and caring duties*, *financial strain, impact on emotional and physical health, stigma, the lack of information about possible support, and adaptation of housing.* Detailed descriptions of these problem areas are provided through the narratives of the study participants.

3.3.1. Issues of accessibility to community-based services.

According to the Ministry of Social Security and Labour, in 2023 there were 33 state institutions in Lithuania, where 5 830 persons with disabilities were living as of May, with

292 more waiting in line. These institutions cover a wide range of ages, so it is not possible to say how many working-age people with disabilities are living there. The list includes group homes but is dominated by institutions with 100 or more residents. Ten have more than 200 residents and one has more than 300 residents.

In an alternative report (2015), this type of social care institution was criticized for violating the principles of dignity, rights, and inclusion of persons with disabilities. As a result, most of the informal carers, even in the absence of sufficient financial assistance and services at the community level, cared for their relatives with disabilities in their own homes. Research participant of our study (RP3 Rima) told:

> *What do you [the municipality's Social Department] do when relatives die? A person has the right to live in their community and their home. Then, of course, the main answer is a care home, unless the disabled adult has a carer. We used to say right away that, well, that's ok, but if the person has lived in the community, then they still have the right to live in their own home, not to be exiled somewhere there. Then the discussion with the municipality would end rather angrily.* (TD3 Rima)

The situation started to change in 2010, when Lithuania ratified the Convention on the Rights of Persons with Disabilities, recognizing that a person with a disability should not be humiliated because of his or her disability, and when the state committed itself to taking appropriate measures to ensure that people with disabilities and their caring family members have access to the range of social support they may need to exercise their rights and to lead a good life. In 2012, the Deinstitutionalization of Institutional Care (hereafter "the Deinstitutionalization") began, focusing on the transformation of the social care system and giving rise to the differentiation and development of social services (Genienė et al., 2021). However, the reform of the care system in Lithuania is more focused on people living in institutions, while "in the community, people with disabilities and the family members caring for them still do not receive enough social services in the home, and in many cases can only choose between the care institution and their isolation, poverty, fatigue“(Pučkienė, 2021, p.77). This is also borne out by statistics that show a low level of accessibility for people with disabilities to the new type of services.

As mentioned in this report, in 2021 21,217 people were living in Lithuania with extremely complex disabilities, which means an intensive need for care. However, data from the Ministry of Social Security and Labour of the Republic of Lithuania (Socmin, 2023h) show that the number of beneficiaries is significantly lower. That is, "in the first six months of 2021, 568 people with disabilities were assisted by a personal assistant, […] and 297 personal assistants provided personal assistance". Meanwhile, in the first quarter of 2022, 815 people with disabilities were assisted by a personal assistant. 67% of these people are of working age. 282 of them have a physical disability, 112 have a complex disability and 82 have a mental disability. Interviews with experts revealed challenges that informal carer face seeking the services provided by personal assistants. Sister (E3, Rima) of the brother who is an autistic person told:

> *We are very happy about that because so far there has been no suitable person or service... or I prefer to say help. [...] But we had to fight a little for that assistant. Because I had to apply to the social assistance department, which found that my brother didn't need that personal assistance. [...] I had to write this individual letter, with all kinds of questions about that personal assistance, [referring to] the Convention and everything. Because how can you tell [without seeing that he is not entitled] because he is? The [social welfare department] very quickly changed its decision that the personal assistance already belongs to the brother. And now my brother has an assistant. We are increasing the number of hours, because it is possible, of course, you have to pay for it.* (E3 Rima)

In-home support services and daycare in a person's home are the most widespread and popular services for people with disabilities. Offering in-home support services, the assessment of social services is done in the period of ten or twenty days, when an application for such services is provided. However, our research shows that the system works in such a way that if a person with a disability has a relative, the person with a disability is considered to have minimal need for help from service providers. This is the same as saying that he or she already has someone to help them. Thus, the relative who cares for the person with a disability remains the main provider of care for the person with a disability. An expert who took part in the study said:

> *It's not about what these people need, because [...] if there are relatives, help for a person with a disability is seen in a different light, as if it were minimal.* (E1, Lina)

In 2021, only 140 people were provided with temporary respite services. Families share their need for respite services. The story of research participant Egle (age 77) revealed that caring for a daughter with complex needs requires full-time care while she needs time for caring about her own health. She told me: "I need eye surgery but don't know how to leave my daughter's care to others". Although the legislation provides for the provision of this service in a person's home, it is usually only offered in an institution. The story of our research participant (RP3 Rima) revealed that offering this service in an institution is not acceptable and that there is no other alternative:

> *Dad doesn't work - he stays with his brother. So, then we decided to get that temporary respite somehow. But they [the support department] offered us only a care home.* (E3 Rima)

The lack of accessibility to services is exacerbated by the lack of cooperation between social care and health care providers. Outpatient home care services are licensed personal health care services to combine social services and palliative care services (SAM, 2023). As this research shows, one of the problems in the provision of in-home services is the (dis)integration of health and social care. Expert Judita, who coordinates home social care services, said:

> *There are all kinds of experiences. Sometimes I have had good communication and joint work with medical institutions and medical teams. And there are sad, really sad experiences where nobody is interested, completely.* (E1 Lina)

In response to the needs of persons with disabilities, various integrated social services are being developed and tested, focusing on the independent living and inclusion of persons with disabilities in the community. Genienė, Šumskienė, Gevorgianienė ir Mataitytė-Diržienė (2021) new social services are not fully recognized or accurately identified. The service of help in decision-making is hardly understood by informal carers. Our research shows that the introduction of new services is a challenge for relatives of people with disabilities. The relatives of a person with a disability can influence the person with a disability to refuse services. An expert in the field of people with mental disabilities told:

> *The parents see this [the young person's placement in sheltered accommodation] as a certain loss of resources, pensions, and so on, and that is what prevents the person from going out and trying to live independently. [...] We wanted to take some young people into a sheltered housing program so that they could live on their own in some isolation. That's where the mothers rebelled. [...] Unfortunately, you can't take those people and oppose the family.* (E1 Vidas)

3.3.2. Balancing between paid work and caring duties.

Taking care of a family member needs time and effort, which can be difficult when paid employment is involved. Balancing multiple roles can lead to role strain, defined by Goode as 'the felt difficulty in fulfilling role obligations', and those who may not be able to meet all of the demands expected of them may begin to engage in bargaining and role decisions (Lafferty at al., 2022). Family caregivers may thus think about changing their work schedules to fulfill their caring obligations in response to the constraints of juggling work and care.

Paid work can help family caregivers in a variety of ways and can function as a buffer against the possible negative consequences of caring if it is provided with the right support. For instance, spending time at work can give caregivers a break from their caregiving duties and can promote crucial positive interactions with coworkers, both of which may prevent some family caregivers from becoming socially isolated (Lafferty et al., 2022). The story of Anna (RP4), a research participant who has been caring for her disabled daughter for 29 years, reveals the dual role of paid work: it is not only a way of earning money but also a source of emotional support. Research participant told:

> *Then I wrote to Kaunas City Council and asked them to create conditions for me to be able to work. Because work is not only money for me, but also a psychological support in my life.* (RP4 Ana)

3.3.3. Financial strain

Financial strain directly relates to the possibility to get earnings from paid work. However, there is another important aspect of our study. Almost all the carers in our study are older women. Some have been raising a child with a disability since childhood, some became carers during their working years. They are currently recipients of a retirement pension, which means that they are likely to have a low income, the amount of which is also dependent on the fact that they have had to reduce the amount of paid work they have had to do over the course of their career. One participant (RP9 Daiva) has taken early

retirement to look after her daughter, which results in a lower retirement pension. Scarce financial resources also make access to social services more difficult, as people with disabilities are partly paid. Expert Rima (E3) stated that "it is not fair that personal assistance (and some other services) is charged when the family is already living close to the poverty line". Other participants in the study also spoke about financial difficulties. Research participant Ana told:

> *Family finances have always been a challenge for us. While my husband and I were both working, we were still doing well enough, but when he retired and his health deteriorated significantly, life got much worse. If I didn't work, the family would not have enough money from our pensions to take my daughter to the daycare center and pay for services.* (RP4 Ana)

Charges for services and financial deprivation may encourage families not to seek help to save family finances. Rima, an expert who helps her father care for her autistic brother, said:

> *((The social department)) starts explaining that some parents don't want to go there ((to the organisation)), especially in rural areas. It is difficult because the parents themselves do not have the right education. So somehow, they probably imagine that the money an adult child with disabilities gets is like theirs. There are all sorts of cases.* (E3, Rima)

The story of Egle (RP5, age 77) who takes care of her daughter (age 47) for more than 17 years revealed that the family bought all the life support equipment with their own money and received no compensation. The subject of compensation is still a sore subject, as not all care is reimbursed.

3.3.4. Impact on emotional and physical health.

Research shows (Sučylaitė, 2015) that informal caregivers show signs of emotional exhaustion, depersonalization, and burnout, which can be interpreted as a precursor to depression and anxiety disorders, and at the same time as an indication of poor quality of life (Sučylaitė, 2015, p. 56). A sudden deterioration in health, such as a stroke, can come as a shock to the family. But there are also difficulties as the person gradually weakens. Caring relatives can feel lonely and abandoned, and they also have to bear the emotional stress of the sick person (Kaip slaugant artimąjj, 2019). Research participants of our study told:

> *The woman is one hundred percent conscious. But unfortunately, there she is absolutely nothing can do physically. Because of multiple sclerosis. The reconciliation of her relatives has come and is only almost, I would say, now, little by little.* (E1 Lina)

> *I don't know, I don't want to remember [sobs]. Must be some kind of loss? You always hope. We were always hoping [that it would get better]. But then when they did the various scans [head shots]. In the beginning, they said that the brain could grow back. Somehow there is... But it doesn't grow back with her.* (RP5 Egle)

> *I've got over it, very, very much. I still believed that maybe it would get better. Of course, it was very difficult. It was very difficult.* (RP2 Eva)

Caring takes time and effort, as various difficulties can arise depending on the person in need of care well-being, health, or other problems. Depending on the level and availability of support, people's freedom, and ability to make a range of decisions about their care varies (VU mokslininkai, n.d.). The psychological and physical strain she may be experiencing is evidenced by the research participant's (RP5 Eglė) account of how she and her husband used to share the care of their daughter and only started looking for help when her husband died two years ago. In addition, when her daughter became disabled, the grandparents took over the care of their granddaughter. A participant in the study said:

> *My husband and I were on duty one time, half the night, and the other half the night because we were also running at night. We don't leave her because she's sick... you can never [leave] her. The light is always on, and the grandchildren fall asleep. At night they fall asleep, and when they fall asleep there's already a cough, and they start coughing. Whether it's too cold, it's already starting or it's too hot. You have to put the covers on already. That's how you play.* (RP5 Eglė)

The disability of a family member, especially in the case of mental disability, affects the whole family. As the participants in the study said, in the case of mental disability, the whole family or an informal carer is often affected. Participants in the study said:

> *The availability of services tailored specifically to these people is very good. Help for families in particular. Sometimes there is not even a person. There are all kinds of psychological blackmail in the family because of the illness, the parents are tired, and if they don't get help, they stay in their traumatic relationship. Then the family gets sick.* (E2 Vidas)

In addition, after some time in some families, the formal services are not seen as supplement help, but as psychological competition – some mothers compete with formal services team as 'don't they want to take over the role of me -> mother' (E1 Lina). Despite the difficulties, expert Lina evaluates, that developed formal service has a huge impact on informal carers' life – they can have rest moments, take a short break, or even live their lives. Another expert (E3 Rima) said: "Often relatives are implicitly burnt out from caring, yet they find it difficult to detach and allow the person with disabilities to start living independently". She also suggested that psychosocial support for parents should be provided when their adult children with disabilities start to live independently. Furthermore, there is a need for parents' education groups to teach the principles of the Convention on the Rights of Persons with Disabilities.

Informal carers are worried about the future of their relatives in need of care - who will take care of them when they are unable to do so? In our study, most of the informal caregivers were older age mothers caring for their adult children, so their stories explicitly or implicitly expressed concern about what would happen when they were gone. This concern is another source of emotional tension. The story of Ona (age 89) revealed that the question of the future is quite cruel to her and her son as informal caregiver. One tries not to think about it and hopes that maybe his oldest son Titas will continue and will be the informal carer of his sister (age 56) who has needs in care.

3.3.5. Stigma.

Greater understanding for caregivers and the eradication of stigma could result from increasing awareness on a social level (Spann et al., 2020). According to Goffman (1963, cited by Stewart, Stutz & Lile, 2018), the stigmatizing feelings experienced by family members of people with disabilities are due to 'courtesy stigma'. The behaviors that family caregivers encounter from larger society as a result of their relationship with a person with a disability are better understood using this approach. As our research shows, people with mental disabilities are the most stigmatized in the labour market. Expert Vidas said:

> *If we ask the question of whom you wouldn't want to work within the same workplace, it's people with mental disability, they're ranked in the first place. [...] Foreign authors have pointed out that among disabled people, people with mental disabilities are the least likely to be employed or to participate in the labour market. They are the least involved in social activities and the most difficult for society to relate to. This gives rise to stigmatisation. The illness imposes its own cross, its own stress for life. This is the attitude of society.* (E2 Vidas)

3.3.6. The lack of information about possible support.

Scholars state (VU mokslininkai, n.d.) that in Lithuania one of the main difficulties experienced by family carers is access to the necessary information. Since health care and social support are not finally integrated in Lithuania, this can cause difficulties in finding answers to family carers' questions. As our research demonstrates, not only do families struggle with the lack of services, but they also stressed that parents lack knowledge about what services they are entitled to, especially when it comes to home-based services. Expert Rima (E1) was critical of both the social care system and the municipalities. One of the problems she saw was that there are no official statistics by the municipality on how many people there are by type of disability. The result is that if relatives turn up and look for the social services they are entitled to, they are more likely to receive those services. And if you "don't apply, you are left to fend for yourself and be on your own" (E1). Rima often advises parents on what services they are entitled to under the Convention on the Rights of Persons with Disabilities and teaches them how to write formal letters.

The difficulties experienced by carers are complex and mutually influencing. Hiding the disability and avoiding help can be an expression of stress. Our study shows that in the case of mental disability, relatives tend to hide the disability and avoid using available services. Expert Vidas (E2) told about the importance of working with informal carers and educating them:

> *The lack of understanding, the lack of knowledge, and the fear of going out to get that knowledge. And somehow to look for new ideas, innovations, or how. [...] It all starts with those relatives and how many fears they have, how much they want to be involved, how much they want to be interested, and the more interested they are, the less afraid they are. Relatives don't know enough about what help is available and avoid it.* (E2 Vidas)

The story of research participant Ona (age 89), who looks after her daughter with the help of her son (age 70), reveals that the family was so used to being alone, that mother didn't see any need neither for psychological support, no for new compensated accommodation for making easier daily care.

Our research shows informal caregivers lack information from the service system, so parents create informal sharing networks. Mother (RP4 Ana) who cares about her daughter told:

> *There is a lack of information about the facilities, benefits, and allowances to which the disabled person is entitled. Social workers should personally inform individuals or carers about opportunities. Currently, parents and other carers who know each other only share information and experiences.* (RP4 Ana)

Other participants in the study also talked about getting the information they need from informal support networks. Research participant Gita (RP6), who is the informal carer of her sister said: "We did everything automatically. It was like you knew what to do and we got everything [...] a special bed." She looked for information and help from people she knew, as she did not get any information from the medical or social services at that time, and "the internet was not so [...] good that you could look it up". When the stroke happened, Gita's sister's daughter was still in the last year of school and as Gita recalls, "it was difficult [...] you mobilize yourself to do it and we managed enough". Gita's daughter also helped to look after Gita's sister at that time.

The solution to the dissemination problem was sought using a Case Manager. This service was criticized by disabled people's organisations because the person with a disability was receiving services in one organisation, so it was considered that the Case Manager should work at the organisational level, in the institution responsible for the distribution and referral to social services. The participants of the study shared advice for the service system:

> *For example, a professional would come in and ask: what? If you need help, they would help you find it or refer you to it. [...] Sometimes it might be good to have a specialist. (RP1 Ona)*

3.3.7. Transport

Inadequate transport is another reason why the lives of people with disabilities and their carers are difficult. The Public Transport Assessment Study on the Accessibility of Public Transport Environments for Persons with Disabilities (Public Transport, 2017), shows that the number of accessible transport facilities is far too low. Even if enough accessible vehicles for people with disabilities are acquired, the problem will persist unless all accessibility issues are addressed. People with disabilities do not always have access to public transport services due to: difficulty in getting to the station, lack of or insufficient parking spaces, lack of access to public transport, inaccessible toilets, inadequate ticket offices, etc. The results of our study highlight the difficulties faced by informal carers. Research participant Ana told:

> *A few years ago, we had problems with the shuttle service. As long as my husband and I both transported our daughter and the two of us moved her from the wheelchair to the car and vice versa, there were no problems. When my husband had a heart attack, the doctors forbade him to do any heavy lifting. [...] The day center had transport to take the children to school, but nobody wanted to pick us up from the house and take us to the X center at around 7 am. Besides, I had to somehow get from Centre X to work in ((district)). In the evening, I would take them home. My work started from 8 am to 5 pm, and so did the drivers, and nobody wanted to drive before and after working hours. In the beginning, I took my son, and we also used BOLT services (food delivery), and ordinary cars, but I had to ask the drivers to help me to take my daughter out of the wheelchair and put her in the back seats in the car, and then to put her in the wheelchair when we got to the center. (RP4 Ana)*

Lithuanian legislation provides for transport services, compensation for purchased transport, and adaptation of public transport or infrastructure for people with disabilities. However, the story of research participant Ana (RP4) shows that the implementation of laws in real life is rather challenging. She said:

> *Every 6 years, a vehicle allowance is due, but it is very small. We have heard that in foreign countries, disabled people get new vehicles adapted to their needs. A few years ago, we bought a car with a special platform to carry our daughter in a wheelchair from a disabled person in Germany. He sold his old one because it was time for a new car. In Lithuania, the compensation does not even cover a third of the cost of the old car. (RP Ana)*

3.3.8. Adaptation of housing

In the 11 years since the launch of the Disabled Persons Housing Adaptation Program 2007-2018, 3 266 dwellings have been adapted. Housing adaptation is implemented by the description of the procedure for adapting housing for people with disability, approved by the Minister of Social Security and Labour of the Republic of Lithuania on 19 February 2019 by Order No A1-103 "On the Approval of the Description of the Procedure for Adapting Housing for the Disabled". The action involved the implementation of housing adaptation works for persons with disabilities, the collection, compilation, and dissemination of information on housing adaptation, and the involvement of people with disability associations in the monitoring and supervision of the implementation of housing adaptation. Statistics show that 2020, 49.5% and 62.82% of the housing adaptation needs were met in 2020 and 2021 respectively (Žmonių turinčių negalią, 2022). The stories we heard in our research revealed the difficulties experienced by informal carers in adapting their accommodation. Research participant Ana (age 60) told that she has had a lot of difficulties" adapting accommodations for her daughter, but finally, they were satisfied with the results:

> *We asked for a shower room with a special bathing wheelchair. [...] When the Commission came to inspect the situation and assess the need, they also recommended the installation of a lift in the stairwell. In 2014, a lift and a shower room were installed in the house under a tripartite contract with us, a construction company that we had to find ourselves and the municipality.* (RP4 Ana)

Research participant Ona (age 89) that the Compensatory Measures Service has not found a way to adapt the bathroom, so the girl is usually washed in bed. The mother also appreciates the support work with her daughter, especially physiotherapy. The mother said that "now even she can sit up in bed by herself".

All community-based services are considered suitable practical support for persons in need of care and their informal carers. However, the coverage of services still falls short of actual demand. Stories of research participants resound with the need for more individualized services regarding age, gender, financial possibilities, and living location.

3.4. Good practice examples

We present two examples of good practice in Lithuania. The first is a project 'Caring for a relative' that focused specifically on caregiving relatives initiated by researchers. The second is the NGO "Destiny's Friends", founded on the initiative of people with mental disabilities and their relatives, which provides services not only for people with disabilities but also for their relatives.

"Caring for a relative": Observing the growing number of people caring for loved ones at the European level and the need for these people to receive psychological support, Scientists of the Vilnius University Center for Psychotraumatology, in cooperation with the University of Linkoping (Sweden), have developed and presented an online program "Caring for a relative", designed for people who care for their relative and, as a result, experience psychological difficulties. The program was attended by more than fifty people caring for their relatives. Participants enrolled in the program used an eight-week online psychological program. The program was rated as useful: the symptoms of depression, stress, and anxiety among carers decreased, and the quality of life of participants improved (VU mokslininkai). The implementation of this program was financed by project funds and the program is no longer running at the end of the project, however, we see this as a very relevant and timely example of good practice, which is why we wanted to present it.

"Destiny's Friends" (*"Likimo draugai")*: Kaunas Club "Destiny's Friends" is a non-governmental organisation providing general and special services to people with mental disabilities. The club was formed in 1995 and acquired legal status on 30 January 2001. Here, people with mental illnesses address their problems related to the stigma of the illness, lack of employment, the need for self-help, and many others.

As the club's website points out, "The club is an ideal place to develop self-help skills because the members of the club are not patients or clients, they are equal members of the organisation. They have to take care of the design and development of the services, the finances, the administration, and the order of the organisation. To participate in the activities, they have to develop the skills of autonomy, to follow the rules, discipline, to carry out various tasks, to interact with others, and so on".

The aims of the Club are: to promote the integration of people with disabilities into society; to meet the psychological, social, spiritual, cultural, and other needs of people with disabilities and their family members; to protect the interests, rights, and human dignity of people with disabilities and their families; to improve, to learn, to pursue knowledge in different areas of life and to share experience; to maintain contacts with other organisations; to change and form a favorable attitude of the society to people with disabilities and their families.

The club provides a range of **services**: social skills training, daily living skills training, music classes, individual support, crafts classes, support for relatives, vocational guidance and counseling, and self-expression training.

Social skills training: There is not a single member or guest who comes to the club just for a specific activity. When there are more visitors, they interact with each other on a wide range of topics (domestic, physical and mental health, political issues), share impressions of the previous weekend or the emotions of yesterday's basketball game, read and discuss press articles, play board games, surf the internet or just drink coffee or tea. In this way, the visitors develop their ability to communicate, to open up to people in need, and to help each other and themselves. Self-help groups are organized, based on the principles of cooperation and sharing experiences. In the groups, visitors share their experiences and sympathize with each other, thus reducing negative emotions. Here they can meet new people, make friends, find answers to their questions and discuss various topics.

Daily living skills training: During the daily skills training sessions, visitors are taught personal hygiene, self-management, healthy lifestyle skills, household chores, table manners, food production, budgeting, how to know and manage their illness, encouraging physical activity in nature, etc. The club provides opportunities to do small household chores, pay taxes on the computer, and communicate online.

Music classes: The music classes include listening to music, recognising the therapeutic effects of music, as well as weekly singing classes and participation in various ensemble festivals for people with disability. Two times, members of the club have been recognised as winners of the "Let's Sing Together" disability ensemble festivals and competitions.

Individual problem-solving support includes help from a psychologist or social worker. This help enables the person to discover the causes of their behaviour, thoughts, and feelings and the resources to make personal changes and feel good. By interacting with the person, the psychologist and social worker can quickly identify how the person is most likely to help themselves. The specialist's task is to transform painful experiences into positive energy - emotions that the person can use in his or her own life to achieve more and to feel better not only about himself or herself but also about society. The club also provides a transport service to activities or medical (and other) institutions for visitors with severe and moderate disabilities.

Crafts classes include painting, moulding, plaiting, weaving, decoupage, felting, painting on fabric or glass, knitting, embroidery, woollen felting, handicrafts made of paper,

recycled materials, natural materials, woodwork, beads, leather, and other techniques to create practical objects that enhance the domestic life. The work is not valued as artwork, but rather as an effort to develop the talents of each person with a disability to increase satisfaction with their work and to experience the joy of creativity. A specialist is present to teach, advise and provide emotional support.

Support for relatives: The club organizes self-help groups for relatives and individual support for relatives of people with a disability.

Vocational guidance and counselling: This service includes helping people with disabilities to acquire carer competencies and learn about the labour market. The aim is for people with disabilities to learn about their personal qualities, interests, talents, skills, and links to carers, to learn about the diversity and change of occupations, and to develop positive attitudes towards learning and carers.

Self-expression training: During the self-expression classes, people with disabilities develop their artistic singing skills, learn to relax during relaxation, and express emotions through drawing.

The Club cooperates with UAB Cosmoway, which provides several types of packaging services. This allows the club visitors not only to develop their work skills but also to be reimbursed for the costs incurred in these activities. The Club organises and celebrates various festivities such as Valentine's Day, Christmas, etc. The Club's visitors take part in Food Bank campaigns and use the products collected during the campaigns to learn how to cook.

The club's project activities are funded by the Department of Disability Affairs of the Republic of Lithuania and Kaunas City Municipality, as well as donations. From 2023, due to changes in the funding procedure, all those who wish to attend the club's activities must apply to the municipality of their declared place of residence and sign an application for social rehabilitation and/or the development, restoration, or maintenance of social skills before attending. It is hoped that these changes will not make it more difficult for those wishing to attend the club to get access to the activities organised by the club.

3.5. PORTRAIT

The person chosen for this portrait (RP2 Eva) reflected the challenges faced by relatives caring for a close relative with a disability. The participant, Eva, is an older adult, has been caring for her daughter alone for a long time, and had to take care of her granddaughter, who was not yet an adult when her daughter's accident occurred. Her story is presented in a narrative analysis manner.

Acquired disability and the start of informal care. Daughter Luka experienced psychosocial behaviour problems at the age of 36. She was found outside with a serious head injury (nobody knows what happened that night – either she felt down, or it was abuse – inside the brain damage). The daughter, Luka, was in a coma for six months and later recovered, but her abilities changed dramatically. Luka’s brain was seriously damaged, leaving her

unable to walk, with impaired perception of her surroundings and impaired intellectual, spatial, and linguistic abilities, has no memory of everyday life (short-term memory impairment) and was partially paralyzed.

The plot: Seeing that daughter Luka impaired disability, the mother, Eva, which recently retired dedicated her life to being an informal caregiver not only for the daughter Luka but also for her granddaughter who was a teenager at that time. The mother was a non-formal carer for almost 12 years (until age 72) until she occurred in need of being cared for, and it was time to search for formal help from outside. Provided by the ‘’Korys’’ organisation, formal care at home changed Eva’s life and her understanding of Luka’s care.

First story: No transfer of care between the hospital and home. Six months after her daughter Luka's hospitalization, she recovered from a coma and her mother was offered only one option: “Do you take her home or do we put her in a nursing home?”. Although it was very difficult for the mother to accept her daughter's sudden disability (she had previously buried her husband and another daughter), she could not give her daughter institutional care, so she took Luka home. As the mother was quite strong (just retired) and capable of caring at that time, it was understood from the formal medical system (hospital, primary care clinic) that the mother would know and be able to take care of her disabled daughter, who was partially paralyzed, could not walk, and had difficulty orienting herself. In Eva's words:

> When I brought her home from the hospital. *[...]* Moreover, there was no help from anywhere. The Social Department? No nobody, nobody came ((for 12 years)) until I broke my leg here about five years ago. (RP2 Eva)

Second story: Non-formal care is a constant challenge, but the caregiver will give the best to take care of the person with an acquired disability. It was very difficult for Eva, the mother, to accept the unexpected severe disability of her daughter, but when mentioned, she implicitly translates the dominant narrative of "I will not give up and I will not give my children away.” Although Eva found it difficult to accept her daughter's disability, she sought support in a variety of ways, both spiritual and from her social network.

> I have been through it, very, very much. I still believe that she would get better. I used to go to church, pray, and ask to get out of that hospital. I prayed *[...]* but whatever - that's God's will. I have come to terms with everything. I still do. *[...]* As long as I am still able, as long as I still have the strength, I will take care of it. I won't give up. *[...]* It used to be like this here: friends. They used to let me go. Those friends used to help me. (RP2 Eva)

Third story: The relief came, and then formal care started. Five years ago, when mother Eva broke her leg by lucky coincidence, a social worker from the local municipality was referred to mother Eva. Local social workers introduced the organisation "Korys" to mother Eva. ‘’Korys”” is an organisation that provide home-based social day care for people with disabilities. When Eva's daughter started to receive formal care, it was difficult for her to verbalize the change "I am so grateful. Very good [helped],” but in non-verbal language, she expressed that the change was big:

> It's very much for the better ((life changed)). I am very used to [the help], and these women are good. They are all nice. They come and feed Luka and do exercise, sweep, and tidy the house. It's very good *[...]*, I have very good feedback. (RP2 Eva)

Fourth story: In the case of severe disability, there is a lack of environmental adaptations and specialized respite services for non-formal carers. During the interview, Eva stressed the lack of environmental adaptations for her daughter, Luka, in the case of severe disability. She lives on the 4th floor of a block of flats; there is no hoist in the staircase, no lift for people with disabilities, and the flat does not have an accessible bathroom. Thanks to a social worker from the organisation ''Korys'' daughter Luka got a specialized bed where she was bathed and exercised by a physiotherapist:

> *There is no lift ((at home)). There is no lift, and [the Social Department] says there would be nowhere to put it. Several new lifts have been developed. Luka wanted to go outside. However, what can you do - there is no possibility that they have not adapted it. The entire staircase is not accessible. [...] The bathroom was not adapted and the bed? Yes, the bed - that's where ''Korys'' ((the formal care provider)) has helped. (RP2 Eva)*

Having been an informal carer for 16 years, Eva, the mother, only leaves her disabled daughter for short periods, and after talking to her daughter, she repeats several times that she would like to get a respite service in her home to get away from informal care and to have a break.

> *Well, of course, I would, yes, I would. I would. I have grandchildren and great-grandchildren. They say: - Grandma. In summer, let us go to the seaside for a day. But I say: 'How will we leave Luka'? I must have not been away for thirty years now. (RP2 Eva)*

Fifth story: Tensions over new outpatient home care services. In this interview, there was a growing choice of formal services for informal caregivers in Lithuania, and they were often left alone when trying to understand the changes in these services. Eva, the mother, shared that when she chooses outpatient care for her disabled daughter, she has to refuse day social care from a ''Korys" organisation. This situation is stressful because no one has explained to Eva why formal specialized social care in the home is being changed to more medicalized care in the home. The new formal service providers only communicate with Eva by phone, both when proposing new services and when deciding on the number of services. It can be assumed that more formalized support will be provided to non-formal carers at home.

> *No, there was nobody who came [from the outpatient nursing service]. Just a phone call. Said, she would come to exercise. I do not know how it is going to be there. I understood that there would be only one exercise per month. I then asked the doctor [family doctor]. The doctor said, every week [...] So, I do not know how it will be. (RP2 Eva)*

Sixth story: The needs of non-formal carers – the Self-Help Group and the Respite Service at home. During the interviews, it was obvious that Eva had dedicated her life to informal care, so it was difficult for her to understand receiving help for herself. Several times, Eva responded that she prays, goes to church, and receives help from the granddaughter she has raised, and from her other children. After repeating the question about helping herself

and giving examples, Eva admitted that it would be good to talk to other informal carers and came up with an atypical transport service that was relevant to her, taking her daughter Luka outdoors:

> *I would like to talk to others ((parents)). I would like to. [...] It would be good to take her out in the summer, just once. To be outside, breathe the air, and see everything around her. How would things change for her? It would be very good to take her outside even once during the summer [...] I would pay whatever it would take. (RP2 Eva)*

To summarize the interview, the mother has become an informal caregiver, devoting the rest of her life to the care of her daughter, who acquired a disability in adulthood. Without comprehensive help at the beginning of the daughter's acquired disability, Eva realized that she alone was responsible for her daughter's care at home. It was only after 12 years, due to a personal health crisis, that Eva turned to formal help at home. Even though formal help is only for her daughter, the mother indirectly feels great relief in caring for her disabled daughter. From the mother's story, it seems that the system of social services in the home has not yet developed, as the mother lacks a respite service in the home as well as an atypical transport service - taking her daughter outside.

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