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Coping of Disabled Adults and Care Load Arising from Disability

Tiina Linno

In the last decade, coping of the disabled persons and their inclusion in the society has come under increasing attention in the world and also in Estonia. One of the major reasons has doubtlessly been the increase in the activeness of the disabled in fighting for their rights. On the other hand, the society with its opportunities and conceptions has also changed. Improved treatment methods and technical aids, as well as well better skills for overcoming barriers arising from the environment and attitudes provide more prerequisites for creating equal opportunities for the disabled in all spheres of life.

Collection of the data on coping, inclusion and quality of life of the disabled is one of the relevant tasks of social policy. The aim is to monitor the changes in the opportunities and needs of the disabled and to improve policy measures based thereon. In 2009, the Ministry of Social Affairs conducted a survey on the disabled persons and the care load of their family members as a project of the European Social Fund. To a great extent, this was a repeated survey of the 2005 survey, but in addition to the disabled, their major assistance providers in the family were also engaged in order to collect information on their care load and quality of life.

This publication presents a summary of the main results of the survey and documents recommendations based on the results for the future shaping of the policies for disabled persons. It is relevant to understand that persons with disabilities and their households should be considered also in other spheres besides the social sphere. Compared to the present, attention to the disabled should be considerably increased in architecture, construction, transport arrangements, as well as development of e-services, education and elsewhere. Only then we can achieve actual results in our attempts towards a society with equal opportunities. Hopefully, this publication contributes to the decision-making in various spheres, taking into account the disabled.

Introduction

Today the so-called social model is utilised for determining a disability, taking account of the environmental and societal restrictions.

In Estonia, determining the degree of disability is based on the Social Benefits for Disabled Persons Act which provides that disability is the loss of or an abnormality in an anatomical, physiological or mental structure or function of a person, which in conjunction with different relational and environmental restrictions prevents participation in social life on equal basis with the others. In the past, disabilities were mainly treated as disease conditions of the body and the restrictions arising from that. Today, the so-called social model that takes into account environmental and societal restrictions is utilised for determining a disability.

In 2006, the UN Convention on the Rights of Persons with Disabilities was completed, Estonia signed it in 2007.

In 1997, the European Disability Forum was established in order to draw more attention to the problems of the disabled in Europe. As a result of the activities of the Forum the persons with disabilities have been given more consideration in the policies and laws of the European Union. In 2006, the UN Convention on the Rights of Persons with Disabilities was completed with the major purpose to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. Pursuant to the Convention, all persons with disabilities shall be ensured access to the physical, social, economic and cultural environment as well as to health care and education and information and means of communications. The Convention does not create new rights or laws for the persons with disabilities, instead it emphasises the existing rights with the objective to use them better for the consideration of the needs and situation of the persons with disabilities. Estonia signed the Convention in 2007.[1]

From that time, several action plans have been prepared in the European Union in order to facilitate confirmation of the principles of the Convention in the Member States and development of appropriate policies and measures. In this connection, the principle to engage persons with disabilities in the development of policies and process of decision-making is an important issue.

One of the relevant aspects of the policy for the persons with disabilities is collection of data regarding these persons. Surveys, development and awareness-raising are also stressed in the plan of action of the Council of Europe "Improving the quality of life of people with disabilities in Europe 2006–2015”, serving as the basis for the development of policies for the persons with disabilities and improved inclusion in the society also in Estonia.

Since 2005, the Ministry of Social Affairs has conducted four researches[2] focused on persons with disabilities, engaging also children with disabilities and their parents, as well as adults with disabilities, and their family members. The overview below builds on the principal findings of one of them, "Survey of the Disabled Persons and the Care Load of their Family Members", conducted in 2009[3] with summary observations and policy recommendations for the coming years.

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[1] President of the Republic Toomas Hendrik Ilves signed the text of the UN Convention on the Rights of Persons with Disabilities on 25 September 2007. All 27 Member States of the European Union signed the Convention and 16 Member States among a total of 87 countries all over the world have ratified it.

[2] In 2005 „Coping and Needs of Disabled Persons”. Survey report (in Estonian) on the homepage of the Ministry of Social Affairs:
www.sm.ee/fileadmin/meedia/Dokumendid/Sotsiaalvaldkond/kogumik/Puuetega_inimeste_uuringu_raport_1_.pdf.
In 2008 „Measures Supporting the Employment of the Disabled in Estonia”. Qualitative research report (in English) on the homepage of the Ministry of Social Affairs:
http://www.sm.ee/fileadmin/meedia/Dokumendid/Sotsiaalvaldkond/kogumik/PITTM_final_EN__2_.pdf.
In 2009 „Coping of the Families Having Children with Disabilities” (target group: disabled children under 18 years of age and their family members). Survey report (in Estonian) on the homepage of the Ministry of Social Affairs:
www.sm.ee/fileadmin/meedia/Dokumendid/Sotsiaalvaldkond/kogumik/PLU2009_loppraport.pdf.
In 2009 „Survey of the Disabled Persons and the Care Load of their Family Members ” (target group: 16-year-old and older adults with disabilities, and their family members as their main assistance and care providers in the family). Report (in Estonian) on the homepage of the Ministry of Social Affairs:
www.sm.ee/fileadmin/meedia/Dokumendid/Sotsiaalvaldkond/kogumik/PIU2009_loppraport.pdf.

[3] The survey was conducted in cooperation between the Ministry of Social Affairs, OÜ Saar Poll and University of Tartu (Kadri Soo, CASS). Approximately 1200 adult persons with disabilities and 500 family members as assistance and care providers were interviewed all over Estonia.

The author thanks Jüri Kõre, Assistant Professor of Social Politics in University of Tartu, for reviewing the report, and my colleagues at the Ministry of Social Affairs for useful counsel and recommendations.

Persons with disabilities in Estonia

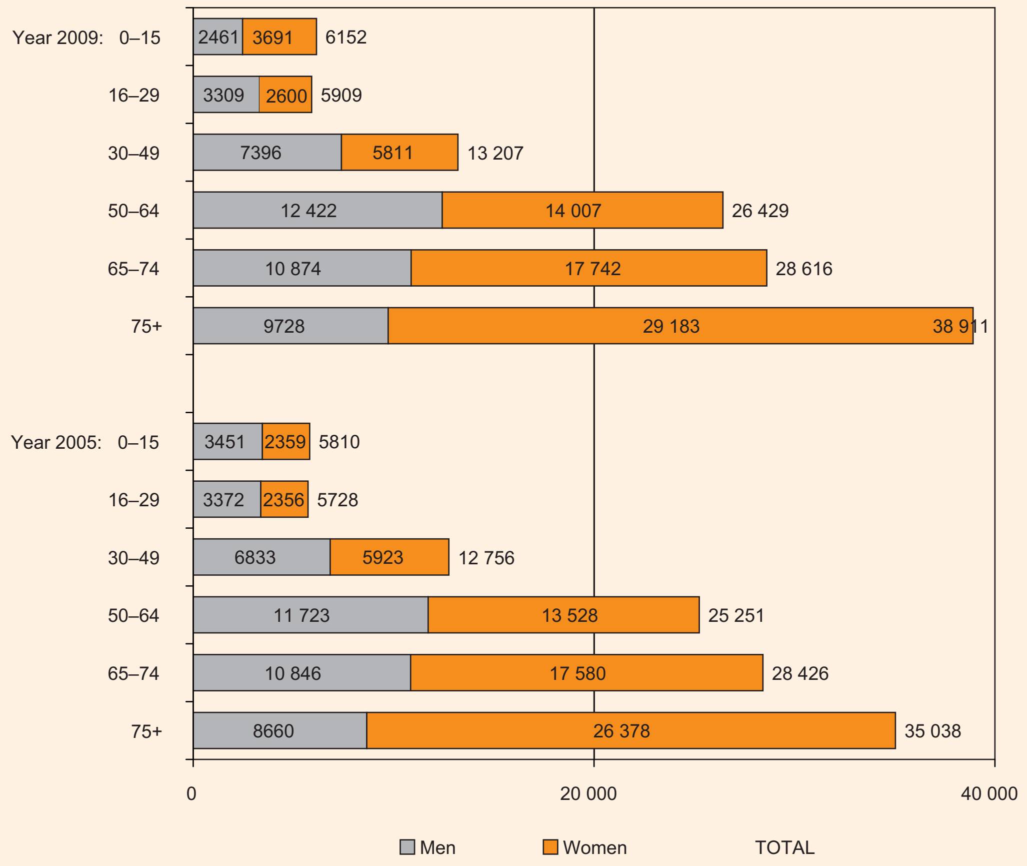
Disability and age

In 2009, persons with an officially determined degree of disability or, in other words, persons with disabilities, comprised 8.9% of the population[4] in Estonia. Compared to 2005 when the previous survey of persons with disabilities took place, the number of persons with disabilities has continuously increased. While in 2005 there were approximately 113,000 persons with disabilities in Estonia (comprising 8.4% of the total population), the number reached approximately 119,200 in 2009, i.e. an increase of 5.5%. The proportion of persons with disabilities in the total population has thus increased by 0.5 percentage points during the last four years.

Figure 1 shows the comparison of men and women with disabilities in different age groups in 2005 and in 2009.[5] The majority of them are 50 years old or older and constitute about 80% of all persons with disabilities. Due to the age structure, the proportion of women among the disabled persons exceeds that of men (60% and 40% respectively)[6].

The number of persons with disabilities in Estonia has continuously increased in the last years, in 2009 persons with disabilities comprised 8.9% of the population in Estonia.

Figure 1. **Number of persons with disabilities by age and gender, 2005 and 2009**



Source: Social Insurance Board

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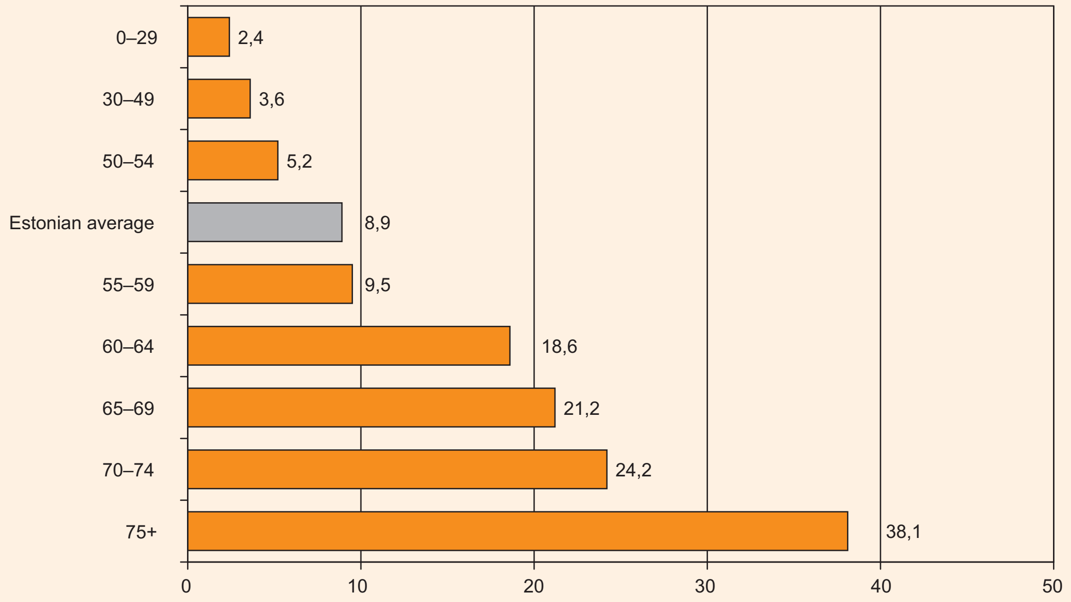
[4] In 2009, the average population size in Estonia was 1,340,271 according to the population data base of the Statistics Estonia.

[5] All data related to the gender, age, type and degree of disability of the persons with disabilities provided in this chapter are derived from the data of the Social Insurance Board: data for 2005 are as of 01/01/06, and for 2009, as of 26/08/09.

[6] Data of Statistics Estonia of 2009 as of 01/01/10.

Figure 2. **Persons with disabilities in the total population, 2009 (%)**



Sources: Statistics Estonia, Social Insurance Board

Figure 2 shows the proportion of persons with disabilities in the age groups of the total population. In order to obtain a better overview of the elderly, the proportion of persons with disabilities has been provided by five-year age ranges. The proportion of persons with disabilities in the total population starts to increase considerably from the age of 55, comprising nearly 10% of all persons in the age group of 55–59, nearly 20% of all persons in the age group of 60–64 and nearly 40% of all 75-year-olds and older persons in Estonia.

Type and degree of disability

In Estonia, Social Insurance Board coordinates granting of disability, differentiating between eight classes of disability: physical disability, visual impairment, speech or language impairment, hearing impairment, mental disability, mental disorder, other disability (health problems, chronic diseases) and multiple disabilities. The latter is granted to persons who have several disabilities, making it impossible to establish a dominant disability class among them.

In Estonia, Social Insurance Board coordinates granting of disability, differentiating between eight classes of disability.

The incidence of some classes of disabilities is much higher compared to others. As the age of a person and problems with mobility are interdependent and the persons over the age of 50 prevail among the persons with disabilities, it is understandable that physical disability is the most frequent as a dominant disability class (39%), followed by other disability and mental disability.

In case of each disability class, the degree of the disability is also determined depending on the extent a person's everyday independent activities and participation in public life are obstructed by the disability and what personal assistance he or she needs due to that. Three degrees of difficulty of the disability are distinguished – moderate, severe and profound disability;[7] the proportion of the persons with severe disability is the highest (55%), followed by moderate and profound disability.

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[7] Moderate disability is the loss of or an abnormality in an anatomical, physiological or mental structure or function of a person, as a result of which the person needs regular personal assistance or guidance outside his or her residence at least once a week. Severe disability is the loss of or an abnormality in an anatomical, physiological or mental structure or function of a person, as a result of which the person needs personal assistance, guidance or supervision in every twenty-four hour period. Profound disability is the loss of or an abnormality in an anatomical, physiological or mental structure or function of a person, as a result of which the person needs constant personal assistance, guidance or supervision twenty-four hours a day.

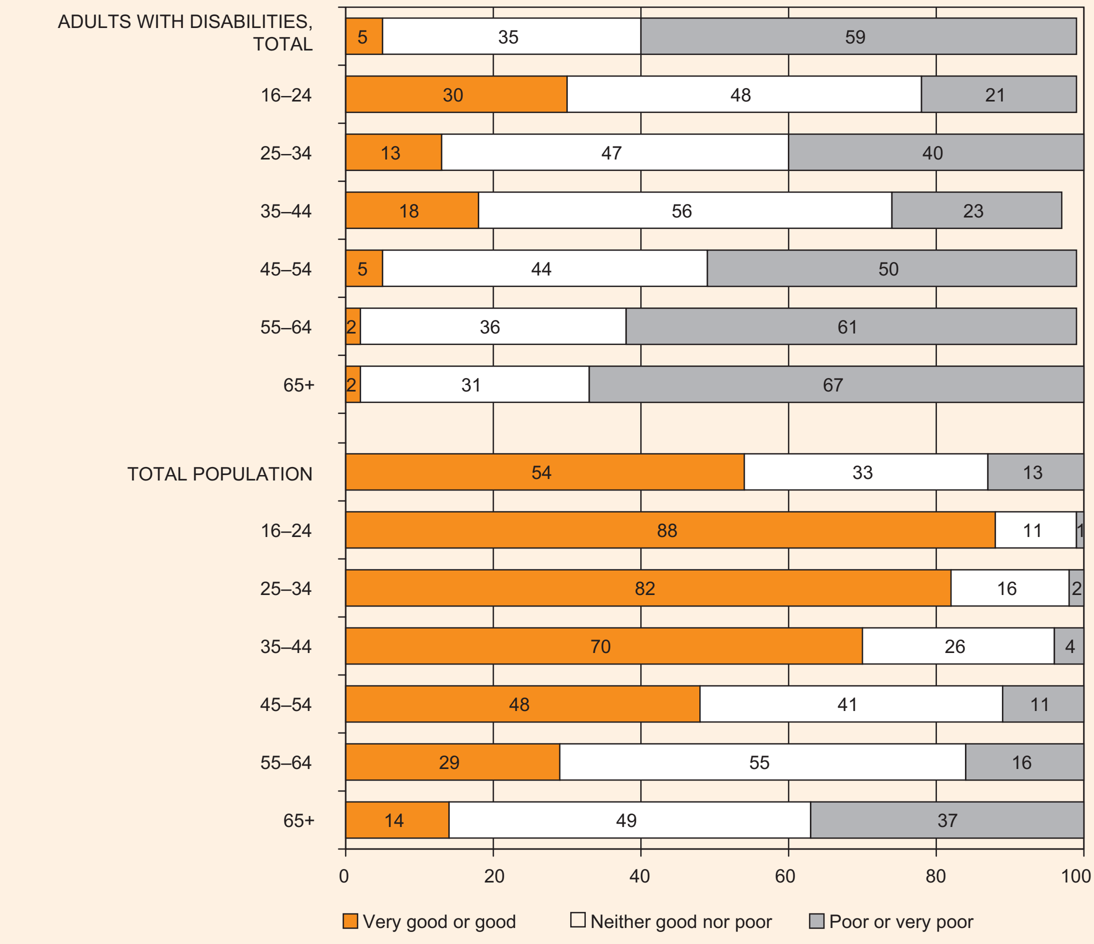
In the following analysis, the results are mainly provided by age, gender, degree and class of disability. As the survey included only a limited number of persons with hearing impairment, visual impairment, speech impairment and mental disability, no separate generalisations can be made for these classes of disability (indicated with * in figures). The results for other classes of disability are generalisable and comparable.

Problems associated with disability

Health and activity limitations

Activity limitations can arise from diseases as well as from the loss of some physical function or deviation, limiting a person's independent coping in daily life. Thus, although a disability is not a synonym for poor health, the survey results show that generally the 16-year-olds and older disabled persons regard their health as poor. In 2009, one-third of the persons with disabilities assessed their health as average, and more than half reported poor or very poor health (Figure 3). Only 5% regarded their health as good or very good. The more serious the disability, the more frequently health is assessed as poor or very poor. As expected, younger persons with disabilities regard their health as better and older persons as poorer. Still, a comparison with the self-perceived health of the total Estonian population[8] shows that the proportion of the persons with disabilities in the youngest age group (16–24) regarding their health as good is approximately three times lower (30%) compared to the total population (88%), while among the age group of 65

Figure 3. **Self-perceived health of adults with disabilities and total population, (%)**



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[8] Data of Statistics Estonia for 2009 as of 02/06/10.

The more serious the disability, the more frequently health is assessed as poor or very poor, and the more limited in daily activities one perceives.

and older, the difference is almost sixfold (2% and 14%, respectively).

Estimating the extent of one's activity limitations as well as the need for personal assistance, self-perceived assessments in both serve as important measures. Statistical surveys in Estonia have measured the occurrence of health based activity limitations among the total populations within the last 6 months. In 2009, 28% of all 16-year-old and older inhabitants in Estonia regarded themselves to be limited in their daily activities, either to some extent or considerably[9]. At the same time, the majority of adults with disabilities (92%) experienced activity limitations, 40% to some extent and 52% to a considerable extent. The more serious the disabilities, the stronger the perceived limitations. This relationship is quite expected, as the application for determining disability is mainly striven by the perceived increase in the activity limitations and the need for personal assistance.

The need for the personal assistance is indicated by the majority of the adults with disabilities, while nearly one third needs personal assistance on a continuous basis and nearly a half from time to time.

Need for personal assistance

The Social Benefits for Disabled Persons Act defines personal assistance or guidance as the provision of assistance to persons who do not cope independently with eating, hygiene, getting dressed, moving about or communicating. The majority of disabled adults indicate the need for personal assistance, while nearly one-third (36%) needs personal assistance on a continuous basis and nearly half (48%) from time to time (Figure 4). Survey results show that personal assistance is mainly required for managing daily domestic chores (79%). Nearly half (48%) of the adults with disabilities also require assistance in taking care of daily routine matters and self-care (45%), one-fifth in spending their leisure time. Although one would think that people in advanced years require much more personal assistance compared to younger individuals, the survey revealed that actually the need for personal assistance is similar for the non-active individuals regardless of their age[10]. 17% of the non-active working-age persons with disabilities and 13% of the non-active persons with disabilities of retirement age (who comprise the majority of their age group) do not need personal assistance, while of the active persons of working age, 40% do not need personal assistance. The need for personal assistance is also related to the degree of disability and differences are extreme in the need for continuous personal assistance – e.g. the number of people with profound disability needing constant personal assistance exceeds the respective number of persons with moderate disability four times (76%[11] and 19%, respectively).

The family members and other persons close to the disabled are often perceived as the so-called inner circle of the assistance providers. The load associated with the provision of assistance or care for family members is discussed in detail in the final part of the analysis.

Occurrence of disability and incapacity for work

Disability and incapacity for work are not overlapping notions, although their causes of occurrence may be similar. Loss of capacity for work, estimated only for the working age population, can be partial (10–90%) or full (100%). Although for the majority of the working age persons with disabilities, the disability is associated with a limited or more extensive loss of capacity for work, not all the persons with loss of capacity for work expe-

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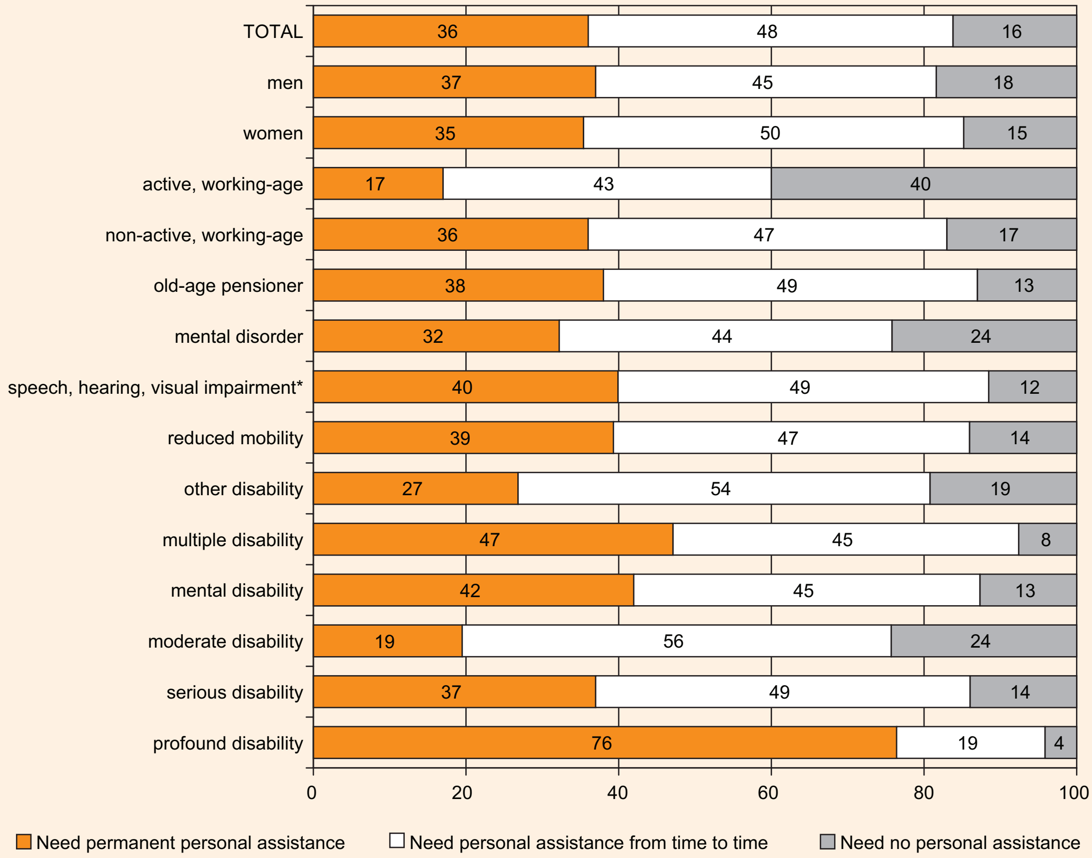
[9] Data of Statistics Estonia for 2009 as of 02/06/10.

[10] Persons who do not study, work or seek actively for work are considered inactive.

[11] In total, 96% of the adults with a profound disability need personal assistance. Pursuant to the definition of the RA of the profound disability all, i.e. 100% of the persons with profound disabilities should need permanent personal assistance. The difference may arise from the fact that here the persons self-assessment for personal assistance needs is measured, while for the granting of the RA of the disability the decision regarding the need for personal assistance is made by the expert, relying on several aspects of the independent coping of the person. While asking the self-assessment of a person for his or her need of personal assistance, there is also a possibility that the question is misinterpreted (e.g. it is interpreted as a need for additional personal assistance besides the existing assistance).

Figure 4. **Adults with disabilities, need for personal assistance, 2009 (%)**



rience a disability. The simultaneous occurrence of both is mainly related to the extent of loss of capacity for work. The majority of the persons whose loss of capacity for work is smaller, i.e. remains below 40%, do not have a disability. The co-existence of the incapacity for work and disability starts to increase considerably in case of loss of capacity for work by 70% and higher, where loss of capacity for work is associated with disability in more than a half of the incidents (Kreitzberg 2008).[12] This is indicative that loss of capacity for work refers to the risk of a disability, provided the disability is not acquired at birth or in childhood.

Pursuant to the data of the 2009 survey, nearly one third of the persons of the age 16+ with disabilities indicate that their disability is congenital or genetic (29%). The older the person, the more likely that his or her disability or loss of capacity for work is caused by health problems suffered in the past. Most of the adult persons with disabilities state that they have acquired their disability or incapacity for work as a result of either an occupational disease and overworking (33%) or any other health problem (52%), one fifth due to an accident at work, traffic or any other accident.

According to the survey, the average age at the initial granting of a disability was 54 years (48 and 57 for men and women, respectively) which is another reference to the fact that the majority of the persons with disabilities acquired the disabilities in the later working or pension age. Men specify an occupational disease or any accident as the cause of their disabilities or incapacity for work more frequently compared to women (22% and 14% respectively). E.g. men have specified occupational accident ten times frequently compared to women. Among women, the propor-

Non-active persons with disabilities, rather than seniors with disabilities are similar in their need for personal assistance.

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[12] Analysis of the Ministry of Social Affairs “Persons with Disabilities and Persons Receiving Pension for Incapacity for Work”, Mari Kreitzberg. Unpublished analysis (in Estonian), 01/01/08.

tion of those whose disabilities were caused by other disease not related to work or health problem was higher (57% of women and 43% of men).

Although the majority of the working age persons with disabilities experience a limited or more extensive loss of capacity for work, not all the persons with loss of capacity for work experience a disability.

In conclusion, adults with disabilities are people who need personal assistance to a larger or smaller extent and are unable to perform work suitable for them at all or in the amount corresponding to the general national standard for working time. A large proportion of health problems and professional accidents among the causes for occurrence of disabilities and incapacity for work refer to the fact that by timely application of preventive measures, the occurrence of disabilities and incapacity for work can be decreased or prevented. For this purpose, additional possibilities should be reviewed for the shaping of everyday working environment and observance of work safety, as well as in the appropriate legislation[13] and the National Health Plan 2009–2020[14], as well as in the strategies for other areas. The population approaching retirement age constitute the risk group, but preventive work must be naturally commenced much earlier in order to ensure that health problems would not amount in the 50s and 60s to the extent that prevents independent coping and working.[15]

The large proportion of health problems and professional accidents among the causes for occurrence of disabilities and incapacity for work refers to the fact that by timely application of preventive measures, the occurrence of disabilities and incapacity for work can be decreased or prevented.

Participation in education

Participation in education provides a person with knowledge and self-esteem and helps him or her recognise, which work could motivate him or her the most and become his or her vocation. Today, educational choices also have a remarkable impact on the success at work later in life. Higher educational level is associated with better salary and higher probability of finding work after studies (Rõõm 2007).

In Estonia, students are subject to the obligation to attend school until they acquire basic education or attain 17 years of age under the Basic Schools and Upper Secondary Schools Act. Those willing must be secured the opportunity to acquire secondary education by the state and local governments. All these rights and obligations are equally applicable to the persons with disabilities.

The survey shows that 3% of the persons with disabilities of the age 16 or older attend formal education or in-service training. The proportion of persons studying is considerably higher in the age group of 16–29, or one third (29%), 80% of them attend formal education, i.e. go to the basic school, upper secondary school or university, 19% attend in-service or re-training courses. In the next age group, 30–49, the situation is opposite, the proportion of those participating in studies is 7%; 20% in formal education, 80% in in-service or re-training courses. Students of 50 years of age or older with disabilities participate only in in-service or re-training courses.

40% of the adults with disabilities have acquired primary or pre-primary, 44% secondary and 17% tertiary level of education.[16] There is no remarkable difference between the highest attained educational level of men and women. The more serious the disability, the lower the educational level. Comparing the educational level of the Estonian persons with disabilities in the age group of 16–34 (age groups of 16–24[17] and 25–34, to be more exact) with the same age groups of the total population reveals that the proportion of persons with tertiary level of education, i.e. essentially persons with higher education, is two times smaller in both age groups (Figure 5). Also, the proportion of persons with sec-

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[13] See also the column „Working environment“ on the web site of the Ministry of Social Affairs: http://www.sm.ee/eng/for-you/employees/working-environment.html.

[14] See also “The Estonian National Health Plan 2009–2020“ on the web site of the Ministry of Social Affairs: http://www.sm.ee/fileadmin/meedia/Dokumendid/Tervisevaldkond/Rahvatervis/RTA/ERTA_english.pdf.

[15] See also policy analysis “Burden of Disease of Estonian Population” (Series of the Ministry of Social Affairs 1/2009), Taavi Lai and Kristina Köhler. Report on the web page of the Ministry of Social Affairs: www.sm.ee/fileadmin/meedia/Dokumendid/V2ljaanded/Toimetised/2009/toimetised_20091.pdf.

[16] Educational levels are based on international standard classification of education (ISCED 1997). UNESCO: http://www.uis.unesco.org/TEMPLATE/pdf/isced/ISCED_A.pdf.

[17] Data of Statistics Estonia for 2009 as of 04/06/10; the youngest age group starts with 15 years of age.

ondary level of education is about two times lower among persons with disabilities in the age group of 25–34.

The interest of the adults with disabilities in studies is related to age. The proportion of those willing to study but not participating in education is 8%. Still, among the age group of 16–29, the proportion of those willing to study, but not participating in education is nearly one-third (29%) and approximately a quarter in the age group of 30–49 (26%). The persons interested in studies or individual development report poor health condition as the major limitation, but also economic causes are mentioned (Figure 6). One-fifth lacks necessary information regarding educational opportunities, the amount of those failing to find a suitable course or just time due to the demands arising from work or family obligations is almost the same.

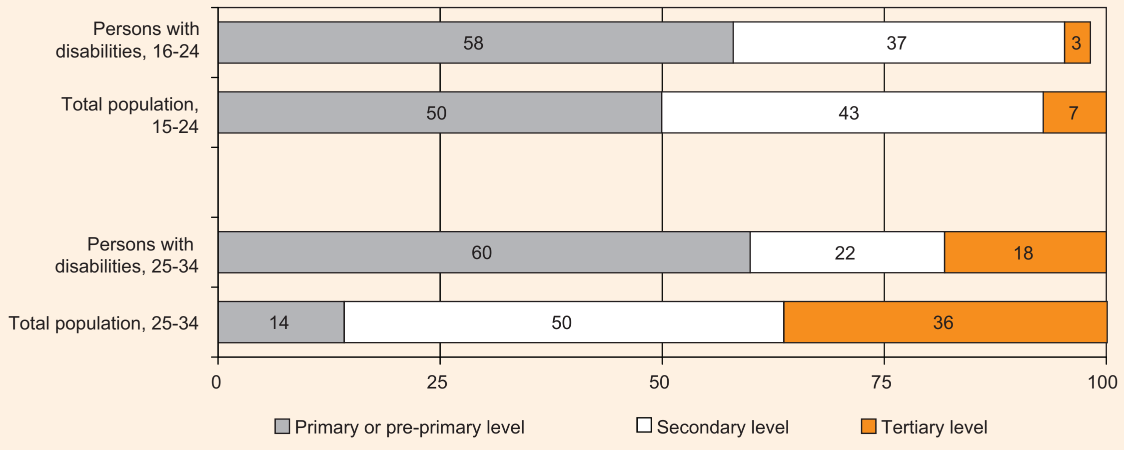
To sum it up, the educational level of the adults with disabilities is lower compared to the total population, while exclusion from education may constitute a considerable hindrance in self-actualisation and participation in professional life and independent coping. The survey findings indicate that the interest of younger persons with disabilities in education is still high, but health problems, insufficient financial opportunities and information regarding educational opportunities may become hindrances.

Thus, information regarding educational opportunities, including specialities as well as educational institutions, should be disseminated as much as possible. Educational institutions should also introduce themselves to persons with disabilities more actively than is the present practice. Introduction of education allowance and in-service training allowance, as well as supportive services for education (personal assistant service, support person service etc) designed for persons with disabilities should also be conducted more actively[18] in order to allow higher education, in-service training in the acquired profession, as well as acquisition of a new profession for persons with disabilities. On the other hand, social workers and the relatives and friends of persons with disabilities should make the adult persons with disabilities interested in education more aware that the active attitude of the persons with disabilities in seeking information and courage in contacting an educational institution is crucial as well.

Very often these are just serious and profound disabilities that constitute a major obstacle to participation in education although a person is interested. In this case every effort should be made to find competent advisers for the persons with disabilities so that they could assess his or her individual needs in coopera-

The educational level of the adults with disabilities is lower compared to the total population, while exclusion from education may constitute a considerable hindrance in self-actualisation and participation in professional life and independent coping.

Figure 5. **Educational levels of persons with disabilities and total population, age group of 16–34 2009 (%)**



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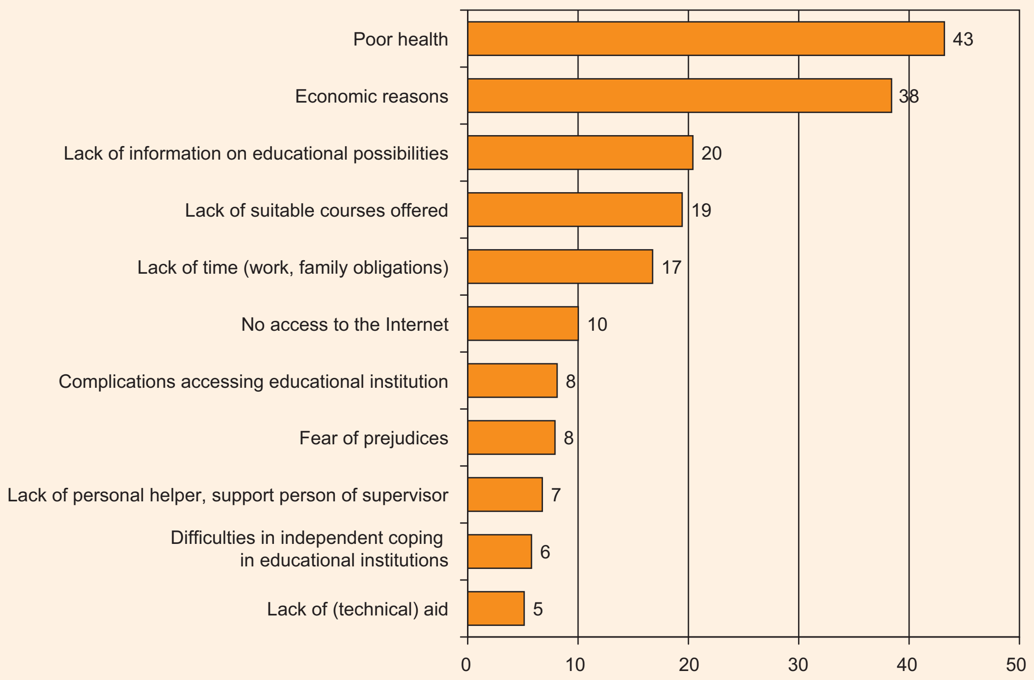
[18] Social Benefits for Disabled Persons Act

Figure 6. **Limitations to study or personal development, 2009 (%, adults with disabilities interested in education)**



tion. Thus, progressing gradually, solutions could be found for options of personal development by participating in formal education or by other means in case of poorer health and significant limitations to activities. This still assumes that agencies of national social, health care and educational systems are able to exercise efficient case management approach.

The interest of younger persons with disabilities in education is high, but health problems, insufficient financial opportunities and information regarding educational opportunities may become hindrances.

Participation in working life

Increasing the employment of persons with disabilities is established as one of the priorities of the policy for persons with disabilities in the European Union, as well as in Estonia. Active involvement of the persons with disabilities in the labour market is also a part of the Europe 2020 Growth Strategy, in the framework of which the aim is to increase employment in the age group of 20–64 to 75% by 2020 in the European Union (to 69% by 2009).[19] In order to achieve this aim, the increased participation of persons with disabilities in employment compared to the present is also crucial.

In Estonia, the services aimed at supporting the employment and working of persons with disabilities are provided by the Estonian Unemployment Insurance Fund (incl. career counselling, practical training, coaching for working life, labour market training, wage subsidy, individual support to working, adaption of premises and equipment and others).[20] Besides, since 1 January 2008, work allowance paid to a working disabled person at least 16 years of age who has additional expenses in relation to his or her work as a result of the disability, is applicable.[21]

Still, employment of persons with disabilities in Estonia remains modest. In 2009, 8% of all disabled persons of 16 years of age and older were working. Among the working age (16-64) persons with disabilities as the main

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[19] The European Commission. Europe in 2020: A Strategy For Smart, Sustainable and Inclusive Growth. http://ec.europa.eu/economy_finance/structural_reforms/europe_2020/index_en.htm

[20] The Ministry of Social Affairs -> People with disabilities -> Working: http://www.sm.ee/eng/for-you/people-with-disabilities.html.

[21] Social Benefits for Disabled Persons Act

target group of the labour market the proportion of the employed was still a bit higher – 17% (the proportion of the employed was the highest in the age group of 30–49, 24%), and 1% of retirement-age group.[22] By way of comparison, in 2009, 63% of all the 15-64-year-old people of Estonia worked.[23] In this regard both self-assessment of health and the degree of disability play an important role – among the working age persons with poor health, 59% are not willing to work while this indicator reaches 79% among the working age people with profound disability. As anticipated, and also as in case of limitations to education, the working age people with disabilities report problems related to disability, illness or injury as the main causes for not working[24], and to a lesser extent also the fact that they have not found a suitable job.

Almost three-quarters (71%) of all persons with disabilities who were working, did not experience any problems or concerns at work associated with disabilities during the last 12 months. Those experiencing problems mainly indicated difficulties in accessing workplace and insufficient or too costly transport to workplace. Almost half (49%) of the working people with disabilities would require assistance for improving working conditions. As expected, here also the largest share reports the need for transport to workplace and back home (41%). Also, almost one-fifth of them want to be able to choose the beginning and end of working time, distribute workload between working days as necessary, or the possibility to have breaks for rest during the working day as required (23%, 20% and 19%, respectively). 15% and 9% of the working people with disabilities mentioned the need for adjusting the workplace in accordance with their disabilities, and the need for a person providing assistance for reaching workplace and returning home. If possible, numerous working people with disabilities would also choose lower workload: while today, 18% of the working people with disabilities work up to 20 hours per week, 43% would like such working hours if possible, 7% would work up to 10 hours, but the majority of the working people with disabilities, 36% would work 11–20 hours per week.

Problems and needs related to job-seeking

The persons who are not working but claim that they would like to, constitute 29% of the disabled working age and 4% of the disabled retirement age persons. Taking into account the working-aged persons working now (15%), as well as those willing to work, the proportion of working-aged persons with disabilities in employment could be much higher compared to the current situation, i.e. almost half of the persons with disabilities (44%). In addition, 5% of retirement-aged persons already working (1%) or not working but interested in working (4%) should be taken into account. Despite the willingness to work, the majority (79%) of the working age unemployed persons with disabilities interested in employment had not actively looked for work during the last four weeks and half (51%) had not looked for work during the last 12 months.

The largest share (43%) of the working age persons indicated obtaining information on jobs offered as the assistance required for commencing work, almost a third (31%) would need adjustment of workplace and the same proportion (29%) need counselling on the suitability of jobs (Figure 7).

Employment of persons with disabilities in Estonia remains modest: among the working age (16-64) persons with disabilities as the main target group of the labour market, 17% were working while the respective figure for all adults with disabilities was 8%.

The persons who are not working but claim that they would like to, constitute 29% of the disabled working age and 4% of the disabled retirement age persons.

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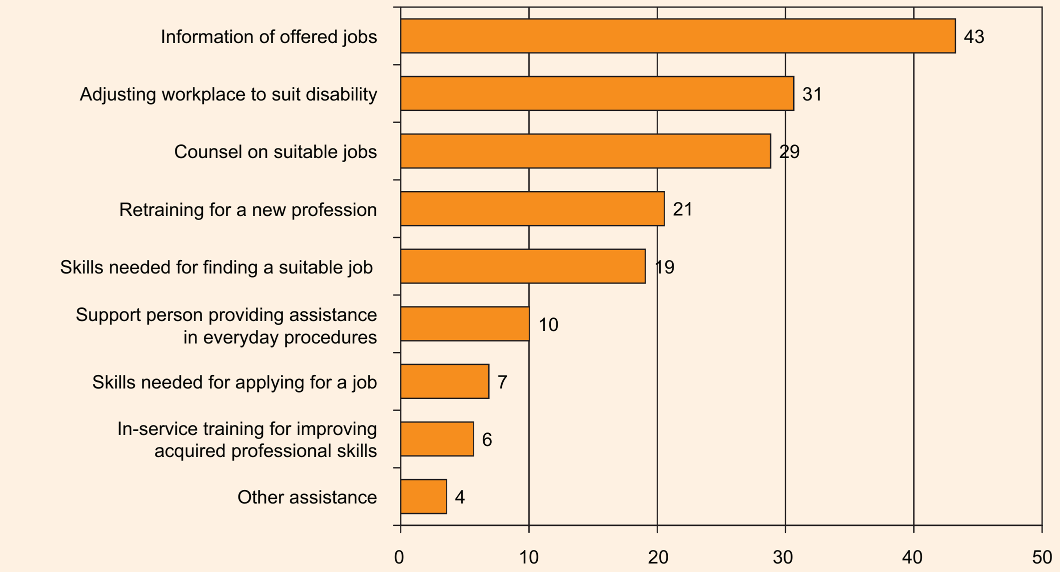
[22] In this survey, persons in the age range of 16–64 are considered working age and persons 65 and older retirement age people.

[23] Data of Statistics Estonia for 2009 as of 8/06/10.

[24] The participants of the 2008 qualitative survey on the measures supporting the employment of persons with disabilities also admitted that health comes first, followed by employment or education!

Working disabled persons are mainly concerned with access to the workplace and insufficient or overly costly transport for shuttling between the workplace and their home.

Figure 7. **The assistance required for commencing work (%, non-working working age persons with disabilities, interested in working)**



To find a job, persons with disabilities need more information on jobs offered, as well as counselling regarding jobs suited to the disabilities, re-training for acquiring new profession and adjustment of the future workplace.

We may conclude that both working and interest in working is related to age, health and degree of disability. The persons with disabilities already working are mainly concerned with access to workplace and insufficient or too costly transport for shuttling between workplace and home. They also wish to be able to choose the beginning and end of working time, distribute workload between working days as necessary, or to have breaks for rest during the working day as required (23%, 20% and 19%, respectively). The need for adjusting workplace and the person providing assistance for reaching workplace and returning home is mentioned to a lesser extent.

It can be pointed out regarding non-working persons with disabilities that mainly younger persons with less serious disabilities are interested in working, but they are often unable to find a job suiting their disabilities or an appealing job offer. Thus, to find a job, persons with disabilities need more information on jobs offered as well as counselling regarding jobs suited to their disabilities, re-training for acquiring a new profession and adjustment of the future workplace.[25] Retirement-age persons who are not working but interested in work, who also exist, cannot be analysed separately due to the small survey sample. On the other hand, national labour market policy provides support to persons interested in working despite their age. Pursuant to the State Pension Insurance Act, the pensionable age of men and women will become equal by 2116, reaching 63 years for both men and women. In addition, in 2009, Riigikogu (the Parliament) adopted a decision to increase pensionable age from the year 2017, so that it would reach 65 years by 2024. Thus, the contribution of the elderly persons into the employment in Estonia is going to increase in the coming years, and also those retirement-age persons with disabilities who are able and willing to work, should not be excluded from employment.

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[25] The same problems were also pointed out by the participants of the above-referred survey "Measures Supporting the Employment of the Disabled in Estonia 2008".

Economic situation

Personal income and additional expenditure arising from disability

Almost all adults with disabilities receive personal income in the form of pension for incapacity for work, or old-age pension (incl. superannuated pension), social benefits for disabled persons, salary or income from other sources. The average personal monthly net income for adults with disabilities in 2009 was approximately 4,665 kroons (1 EEK = 0.064 EUR). The average personal monthly net income for working persons with disabilities (including working persons of retirement age) was still somewhat higher, i.e. 6,910 kroons.

As a comparison, the average net monthly salary in Estonia in 2009 was 9,575 kroons as at Q3 2009 according to data of Statistics Estonia. Old-age pension and pension for incapacity for work constituted the major share in the income structure of adults with disabilities. Next came benefits and grants, salary (incl. income from business and household work) and other income sources.

The majority of the adults with disabilities (90%) indicate additional expenditure arising from disability. The comparison of working-aged and retirement-aged groups demonstrates that most of them spent money on pharmaceuticals due to their disability (85%, 88% of the persons of retirement age and 78% of the persons of working age). Another important cause for additional costs is transport, reported as causing additional expenses by almost each second person. The average monthly amount of additional costs associated with disability is approximately 1,600 kroons, while the average actual need according to the estimations of the adults with disabilities would be 2,700 kroons.[26]

Self-assessment of personal economic situation

One-fifth of the persons with disabilities have sufficient funds for coping, while only 1% is able to save money. About half (48%) of the persons with disabilities think that their personal income is barely sufficient for making ends meet. About one-quarter (26%) of the adults with disabilities do not find their income sufficient even for covering unavoidable costs (Figure 8). One-third of working-aged persons with disabilities and one-fifth of persons of retirement age do not have enough money to cover unavoidable costs. Irrespective of the degree of disability, the percentage of the persons not having enough money for unavoidable costs reaches one-quarter. The share of persons who can save some money or who have sufficient funds for coping is a bit larger among the persons with a profound disability. At the same time, persons with profound disability, but also persons with disabilities in the age group of 16–29, are dependent either on some household member of some other close person more than average. Although nearly half of all adults with disabilities are financially dependent on some other person (15% fully and 31% partially), more than half of the adults with profound disability (56%) and nearly three-quarters (73%) in the age group of 16–29 are financially dependent on another person.

Economic situation in different household types

Financial coping in a household depends on the number of household members working or having another regular income. Both salary as well as old-age pension and pension for incapacity for work play an important role here.

Due to a disability, the majority of adults with disabilities (85%) spend money on pharmaceuticals, while transport causes additional expenses for almost every second person.

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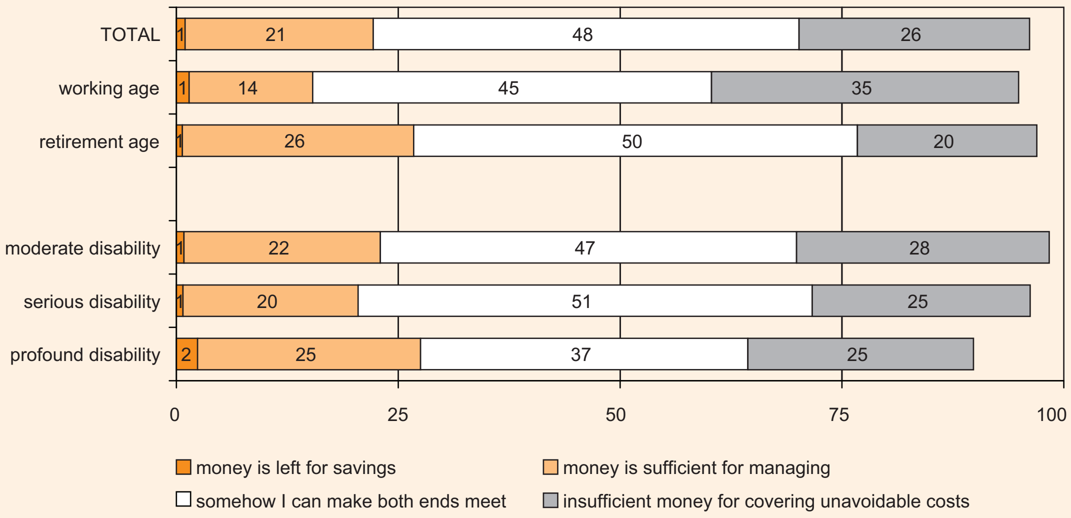
[26] While 90% of the survey respondents indicated additional costs, the actual needs for covering the additional costs in full were pointed out by 66% and the assessment provided here builds on their responses.

Nearly half of all adults with disabilities are financially dependent on some other person, 15% fully and 31% partially.

Figure 8. **Self-assessment of adults with disabilities of personal financial income, 2009 (%)**



Financially, working adults with disabilities and their households cope better compared to others, and older persons with disabilities regularly receiving old age pension also report managing better than others.

According to the survey data, more than half (58%) of the adults with disabilities live in a one-member or multimember household with an old-age pensioner[27] which is expected, taking into account the age structure of persons with disabilities (Table 1). Working active households constitute one-quarter and non-active households nearly one-fifth of the total.[28] The average monthly net income of the households of adults with disabilities is 7,360 kroons. Net income is higher when there is at least one member who is working: the average net income is 9,930 kroons in a one-member and 11,000 kroons in a multimember working household. Single non-active persons with disabilities have the lowest monthly net income, 3,830 kroons.

In conclusion, working adults with disabilities and their households are the best at managing financially. In these cases, the fact that these people may receive pension for incapacity for work or old-age pension besides salary can play an important role here. Older persons with disabilities receiving old-age pension on a regular basis also report better managing than others. For working-age people with disabilities, only salary or only incapacity for work may not ensure an equal level of coping.

Disabilities are most often associated with additional costs on medications and transport. According the self-assessment of adults with disabilities, in 2009, the actual need exceeded all additional costs incurred by them approximately 1.7 times. These results refer to the need to examine thoroughly the main income and costs of persons with disabilities in order to develop measures better supporting their financial coping, including direct financial support that would not still rob a person of motivation to make his or her own contribution to improving his or her standard of living.

Social services

Persons with disabilities have access to several social services targeted to all persons, but also to some that are designed specially for persons with disabilities.[29] Most impor-

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[27] Multimember household with an old-age pensioner — a non-working and non-unemployed household with at least one non-working old-age pensioner.

[28] Working household — a household with at least one working member aged 16 or more.
Unemployed household — a non-working household with at least one unemployed member aged 16 or more (i.e., who is not working, is looking for a job and is prepared to start working within two weeks).
Other non-active household — a household that does not fall under any of the abovementioned groups.

[29] Social services for persons with disabilities. Available on the web page of the Ministry of Social Affairs: http://www.sm.ee/eng/for-you/people-with-disabilities.html.

Table 1. **Economic situation of the households of adults with disabilities (%) and average monthly income in different household types (EEK), 2009**

	Proportion of all households,%	Average monthly net income of a household EEK*
TOTAL	**100**	**7360**
Single employed	2	9930
Single old-age pensioner	25	4720
Single non-active	10	3830
Multi-member working household	23	11000
Multi-member unemployed household	5	6540
Multi-member retired household	33	9075
Multi-member non-active household	3	6245

* 1 EEK = 0.064 EUR

Survey data show that technical aids are used by 59% of all adults with disabilities, 4% do not use technical aids but would need to.

tant among them are: allowance for buying technical aids on favourable conditions as a service, as well as adjustment of dwelling, rehabilitation and other above mentioned services required either for study purposes, work or just everyday coping.

Various aids

Part of activity limitations can be compensated for by various aids including both technical aids as well as various care and protection means (including products for personal hygiene).

Survey data show that 59% of all adults with disabilities use aids. 4% of the persons with disabilities do not use aids admitting still, that they would need them. Such persons constitute 63% of the adults with disabilities and among them 41% would need additional aids. The need for mobility support devices is the highest (53% of all requiring additional aids) needed more frequently by older persons with disabilities, followed by visual and hearing aids (44%) required mostly by the 75+ age group.

Care and protection means are mainly required by younger persons with disabilities in the age group of 16–29, prosthesis and orthosis by persons aged 30–49.

Adapting a dwelling

The aim of adapting a dwelling is to support independent coping of persons with disabilities in their home, eliminating hindrances and limitations that otherwise make coping impossible. Survey data show that the majority of the adults with disabilities live in apartment blocks (61%), 17% live in farms and 14% in one-family dwellings. The majority, i.e. almost three-quarters (70%) of the adults with disabilities live in two- or three-room dwellings.

About two-thirds (68%) of the adults with disabilities are of the opinion that their dwelling does not need any adaption. About one-tenth (11%) of the persons with disabilities have had their dwelling adapted according to the needs arising from their disability. On the other hand, 7% of persons with disabilities have their dwelling adapted but would need additional adapting. 13% observe that their dwelling needs adapting but it has not been implemented. It appears that the more serious the disability, the greater the need for adapting one’s dwelling. Among persons with a profound disability, every fourth (25%) observes that his or her dwelling would need adapting but it has not been implemented. The persons needing adapting their dwelling mostly face restrictions related to mobility

The persons who need their dwelling adapted mostly face restrictions related to mobility, but apart from that, unsuitable furniture and workspaces, excessive cold or warmth or humidity in the dwelling cause problems.

(Figure 9), besides that, unsuitable furniture and workspaces, excessive cold or warmth or humidity in the dwelling are pointed out.

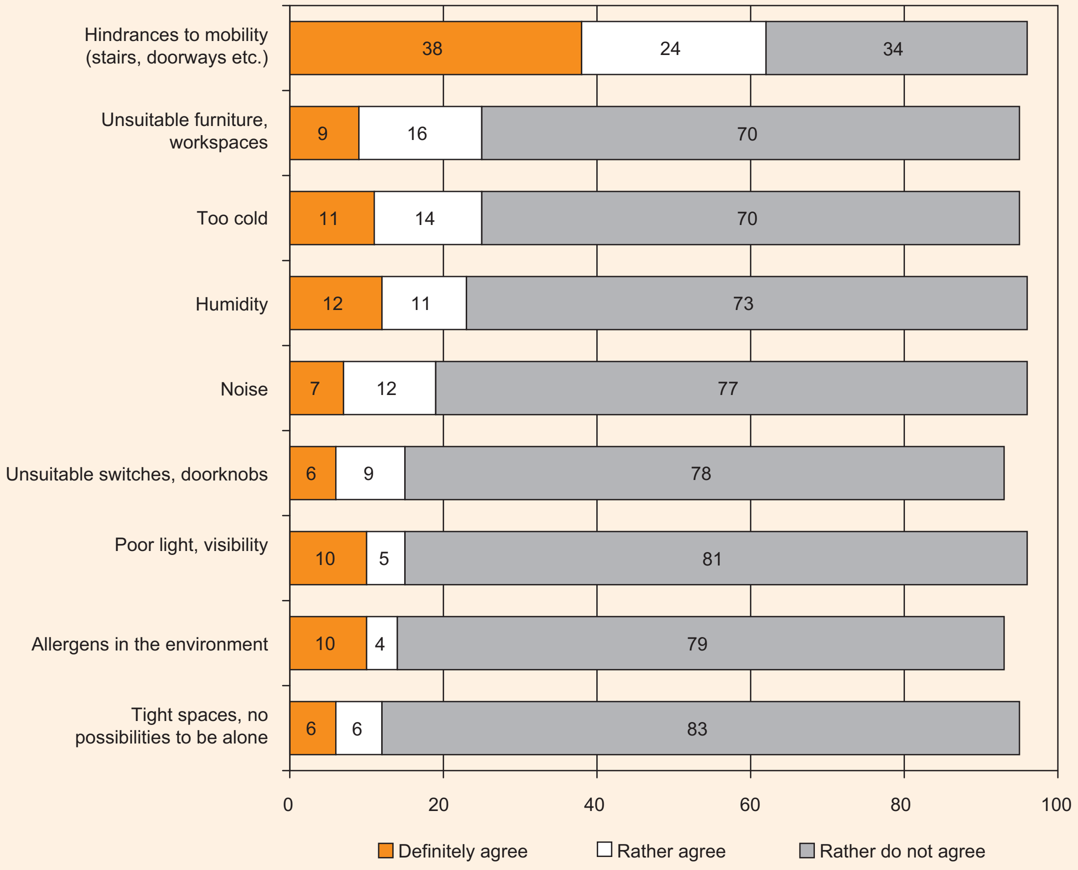
State-provided rehabilitation service

State-provided rehabilitation service (hereinafter R-service) is targeted to the persons with disabilities in order to support their ability to cope independently, to encourage their working or commencement of working and enhance their ability to participate in public life. Within the framework of the R-service, first a personal rehabilitation plan (hereinafter R-plan) is prepared for a person, serving as a roadmap for specialists (e.g. physiotherapist, psychologist, social worker etc.) providing individual services. The R-service also includes supervising the implementation of R-plan as well as interim assessment and improvement of R-plan.

During the past five years, R-plan was prepared for a bit more than a quarter (27%) of the adults with disabilities and based on that, the majority of them (87%) also received individual services. In 2009, 18% of the adults with disabilities had a valid R-plan. Almost three-quarters (72%) of the users of the R-service observed that they had benefited from its different services. 54% of the service users mentioned problems related to individual services, mainly pointing out long waiting lists (39%) and complicated procedures (33%). Almost every fifth person noted having received services less frequently or in a lesser extent than needed. 17% of the adults with disabilities claimed that the services received did not meet their expectations and the same proportion observed lack of information as a problem.

The service of the physiotherapist is the most needed, claimed by 81% of those needing

Figure 9. **Main problems related to independent coping in a dwelling (%, adults with disabilities having required or requiring adapting their dwelling)**



services. It is followed by psychologist (13%) and social worker service (11%), the rest of the services were listed less frequently (Figure 10).

Other social services[30]

According to the survey data, 22% of the adults with disabilities used other social services besides R-service within the last 12 months. Services used most frequently were: home care service (34%), followed by allowances for prosthetic, orthopaedic and other appliances (27%), social transport and a support person or personal assistant service (20% and 18% of the adults with disabilities having used other social services). Persons of retirement age used home care and social transport services more frequently compared to the working-age survey population.

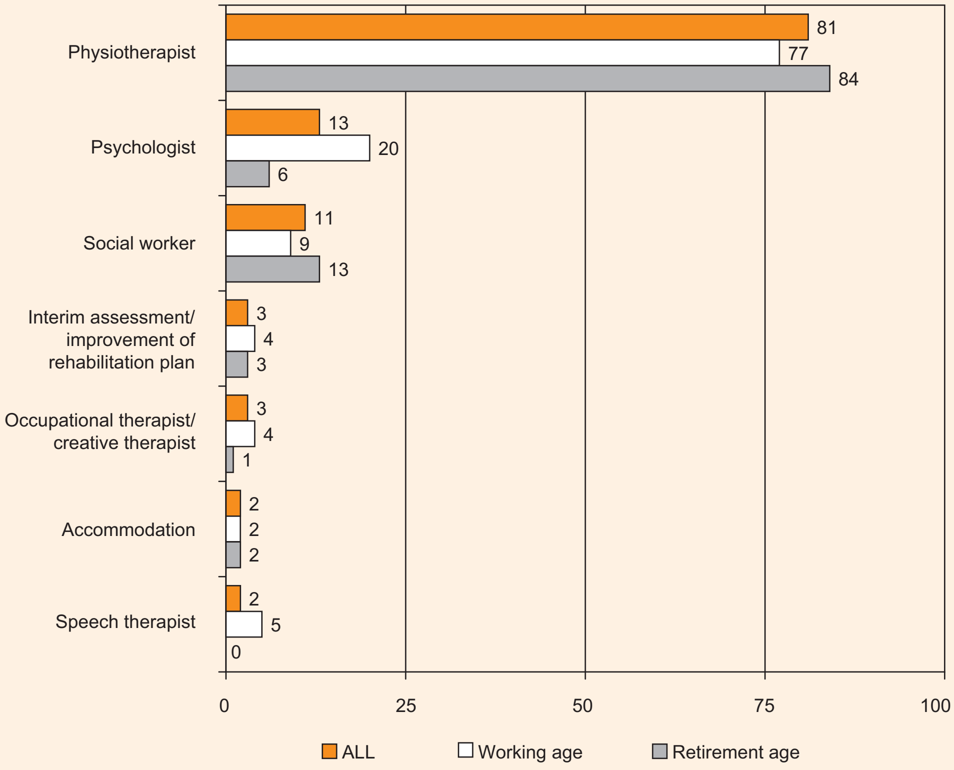
In the opinion of the majority of the users of social services, the services received met their needs; satisfaction of the users was the highest with day care centres and social transport (meeting the needs of 95% and 85% of service users, respectively). Dissatisfaction was the highest among the persons having used care service in a social welfare institution, 22% among them considered that the service failed to meet their needs and expectations. But it was exactly the welfare service for which the largest proportion (79%) of service-users had to make out-of pocket payments. As a comparison, 38% of the users had to pay for the day care centre and 28% for social transport.

One third (33%) of the adults with disabilities (11%) referred to the need for (social) services, i.e. somewhat (11%) more than the number of actual service users in 2009. The perceived need is highest for rehabilitation and home care service (Figure 11). Every tenth would like to use social transport service, almost the same proportion of the per-

During the past five years, the rehabilitation plan was prepared for 27% of the adults with disabilities and based on that, the majority of them (87%) also received individual services.

In 2009, 18% of the adults with disabilities had a valid rehabilitation plan.

Figure 10. **Need for individual services within R-service (%, adults with disabilities needing R-service)**



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[30] The question related to other social services (i.e. care service in a care institution) was asked only from those disabled persons of 16 years of age and older who lived in private households, as persons living permanently in care institutions constitute a separate research target group owing to the services received there and their use of and need for services should be addressed separately.

sons indicate the need for financial support for purchasing firewood or pharmaceuticals or for paying for care and other support services. Compared to working-aged persons, persons of retirement age need both home care services and rehabilitation services more often.

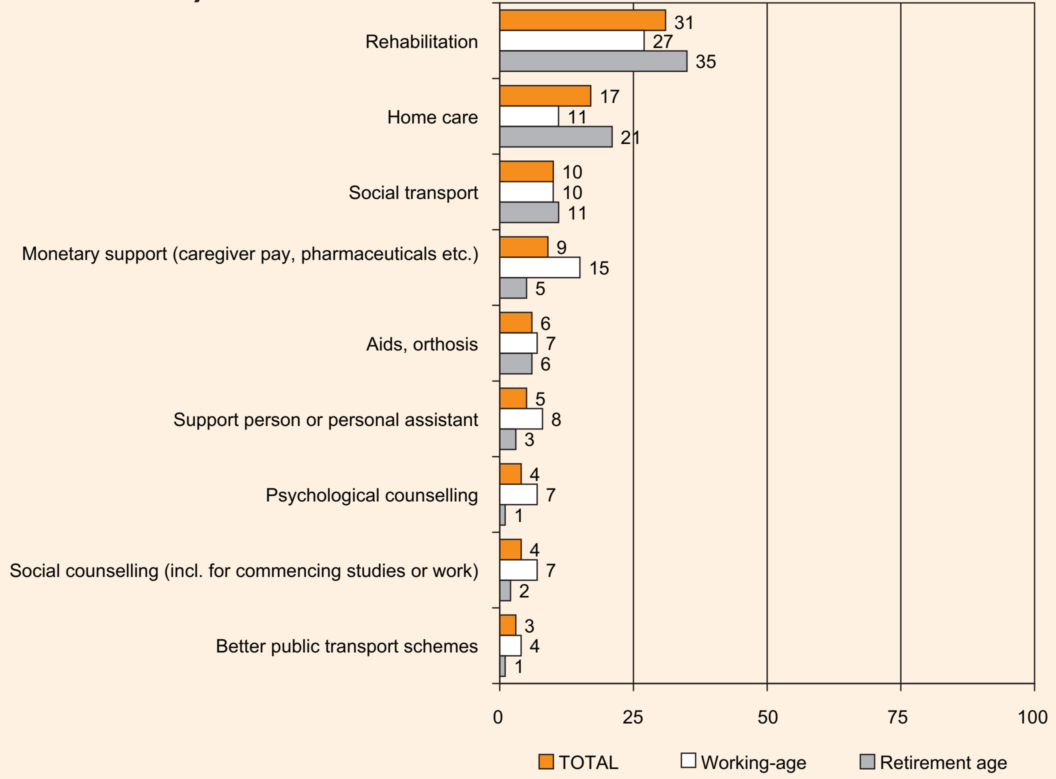
Of other social services, home care service, allowances for prosthetic, orthopaedic and other appliances, social transport and support person or personal assistant services were most often used.

Most often, i.e. for one-third of adults with disabilities, failure to receive services arises from lack of information, or they just have not thought of applying for some service (30%). Almost every fifth of the persons with disabilities needing services report that they lack money for the expenditures associated with services (19%). For 13% of persons with disabilities, local government has not made the services available. Some people also lack access to the institution rendering the service or they find it impossible to contact the institution (2%). 16% of persons with disabilities needing services have managed as much as necessary and therefore have not applied for the services.

In a nutshell, in 2009, almost two-thirds of the adults with disabilities used various aids. Almost one-fifth of adults with disabilities had a valid R-plan and also one-fifth used other social services (including an allowance for acquiring the (technical) aids on favourable conditions) during the last 12 months. The services needed by working and retirement age population are somewhat different. Working age persons need more often prosthetic, orthopaedic and other appliances and rehabilitation and financial support for paying for the services. Persons of the retirement age, on the other hand, need more visual and hearing aids and mobility support devices, rehabilitation and home care services.

All listed means and services are available today. The survey results rather indicate that the need for the referred services is bigger compared to other services and they are not always available in the required extent. As also indicated above, the amount of information and counselling needed regarding services should be considerably increased. The highest level of dissatisfaction among the beneficiaries of care service in social welfare institutions is an indication of the need to have a detailed examination of the causes.

Figure 11. **Need for social services (%, adults with disabilities needing social services)**



Clients temporarily and permanently living in the institutions should be included in the respective research.

Activity and social inclusion

Mobility and transport

About half of the 16 year-old and older persons with disabilities leave home either daily or almost daily, a bit more than one-third (37%) do it less frequently. 12%, including almost one-quarter (23%) of the age group 75 + and almost half of the (48%) persons with a profound disability have given up going out.

Use of means of transport and services provides persons with disabilities with an opportunity independently to go to work or school, engage in hobbies and establish and maintain social relationships. 9% of outgoing adults with disabilities do not need or use means of transport. Almost two-thirds (63%) of the rest use either personal car or the car of a family member or a person close to him or her, and half use ordinary or adjusted public transport (52%). Two out of three users can use personal and public vehicles as often as necessary.

10% of the adults with disabilities use ordinary taxi service, while 3% use taxi or transport service adjusted for the needs of persons with disabilities. Among the users of ordinary taxi and taxi or transport service adjusted for the needs of persons with disabilities, almost two-thirds use it less frequently than they would like to.

Apart from the problems arising from the person's disabilities or illnesses, it is reported that public transport is expensive or not available at the suitable times or routes, and in some cases, accessing the stops is also complicated. In addition, persons using an ordinary taxi or a taxi or a transport service adjusted for the needs of persons with disabilities report the lack of money as the main problem, while illness or poor health and insufficient information related to the special taxi or transport services are also indicated.

Leisure time and activity

Apart from participating in education and employment, the options of choosing how to spend one's leisure time are one of the more important indicators of a person's participation in public life. Among the 16-year-old and older disabled persons, the majority, i.e. 78%, are able to do it, while 34% are able to a large and 44% to some extent.

Among leisure time activities, the following have a high rating: communication with family members, relatives and friends, enjoyed by 85% of the adults with disabilities, followed by indoor hobbies, taken up by 76% of the adults with disabilities (Figure 12). Also two-thirds pay visits to family members, relatives or friends (65%) and 58% of the adults with disabilities are able to take up outdoor activities. But the proportion visiting social events with friends (32%) or meeting with people enjoying similar interests (35%) is smaller. At the same time, the interest in the last two activities is actually the lowest. The same can be said for visiting cultural events: nearly a quarter of the willing adults with disabilities cannot go to cinema, theatre or concerts, while half are not interested or cannot do it owing to the disability.

Cultural events and travelling are two leisure time activities that the persons with disabilities interested miss most – about one-fifth of the adults with disabilities cannot afford it, although they would like to (23% and 19%, respectively). Some of the people who participate in these activities would like to do it more than now (14% and 11%, respectively). It is interesting that communication with and visits to the close ones are frequent, but the number of those reporting their wish to do it more is also the highest for this activity (26% and 29%, respectively).

One-third of adults with disabilities feel that they definitely need various (social) services, whereat the services needed by working age and retirement age people are somewhat different.

Although communication with and visits to the close ones are frequent, the number of those adults with disabilities reporting their wish to increase the rate is the highest for this activity.

Every tenth adult with disabilities (11%) is a member of some organisation of persons with disabilities, while 7% actively participate in the activities of the organisation; 15% do not belong to any organisation but would be interested to.

Every tenth adult with disability (11%) is a member of some organisation of persons with disabilities, 7% actively participate in the activities of the organisation. 15% do not belong to any organisation but would be interested to, 72% do not belong to any organisation and are not interested in it. The proportion of those not belonging to any organisation for persons with disabilities, but are interested, is higher among the group of working-age persons compared to the retirement age persons (22% and 10%, respectively). There are more persons in the youngest age group (16–29) belonging to some organisation for persons with disabilities (24%), while 16% are active participants.

Social network and inclusion

Figure 13 reveals the assessment of adults with disabilities regarding the existence of the supportive network of the close ones as well as society as a whole. They agree most with the statement that friends and close ones accept the disabled person as he or she is and the friends and close ones help her or him in achieving his or her aims. The perception of the number of surrounding people the disabled can fully confide in is quite similar.

About half of persons with disabilities agree with the statement that all opportunities to participate actively in political and public life have been ensured to them. Less than half of adults with disabilities consider their life as interesting and eventful. The smallest proportion, i.e. one-third agrees with the statement that persons with disabilities can lead a full life in the Estonian society. Here the difference is the biggest among the persons with a moderate, severe and profound disability – the more severe is the disability, the less interesting and eventful the person's life is considered, and also opportunities for political and public activities are perceived as more limited.

This order of statements suggests that the support from close ones is perceived considerably stronger by persons with disabilities compared to the perceived inclusion as well as opportunities for active involvement in the society.

A separate section in this survey was dedicated to the extent of perception of restrictions arising from disability of the adults with disabilities, while fulfilling such social roles as a parent, a partner, a family member and a friend. 68% of the adults with disabilities do not perceive any limitations to parenting arising from disabilities and 65% do not perceive any limitations to being a partner. Almost three-quarters (72%) think that disability does not restrict them in being a fam-

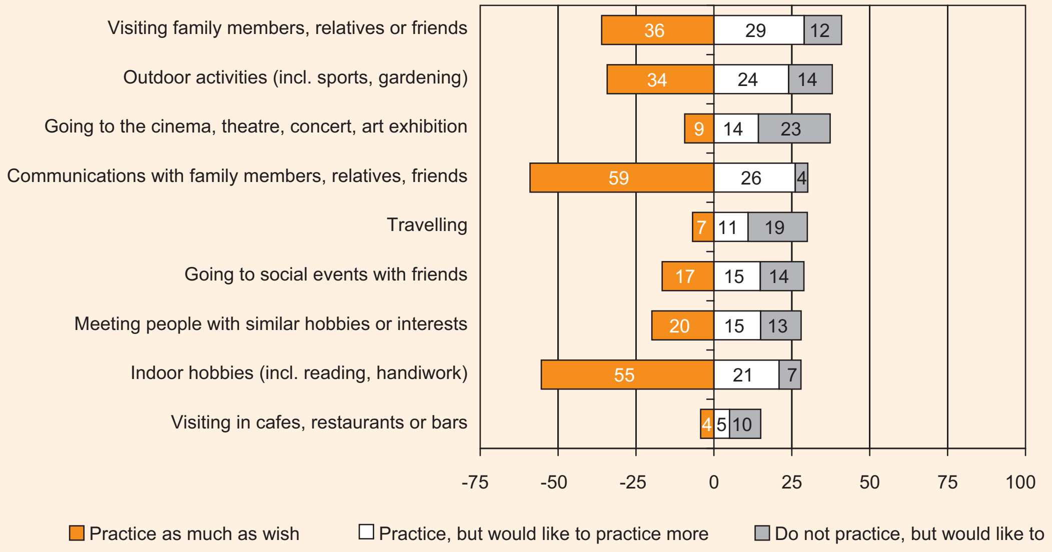
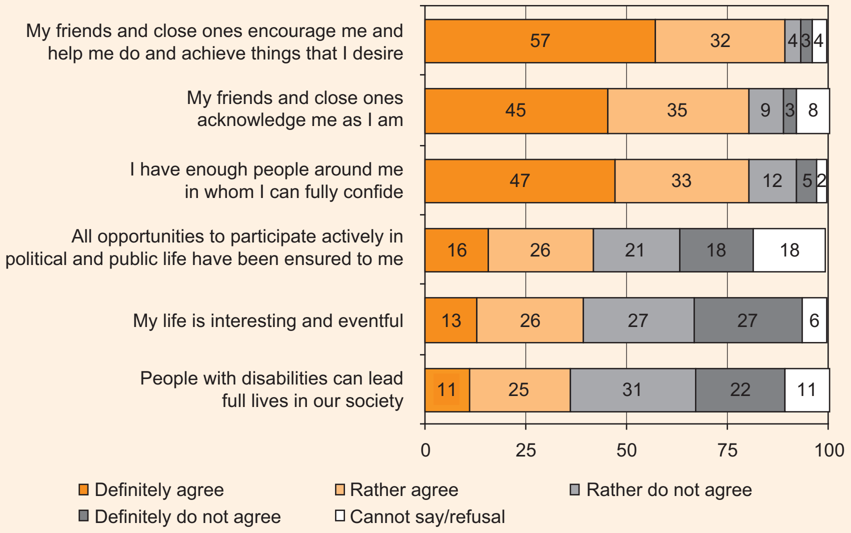


Figure 12. **Leisure time activities the adults with disabilities engage in and would like to engage in (more) (%)**

Figure 13. **Assessments of adults with disabilities regarding their supportive network and inclusion in the Estonian society (%)**



The support from close ones is perceived considerably stronger by persons with disabilities compared to the perceived inclusion as well as opportunities for active involvement in the society.

ily member and the same proportion (75%) think that a disability does not form an obstacle for being an equal friend.

In conclusion, one must take into account that two important aspects play a role also regarding leisure time: the age of the person and degree of disability. Persons with a profound disability specify most often that they are unable to take up various activities due to their disability or they are not interested. These are mainly activities assuming leaving home and having some degree of mobility (travel, visiting social events, outdoor activities). Younger people have a higher than average interest in communication and travel, while compared to the young, there are more people among the older who do not go to cultural events or take part in outdoor activities, but would like to (22% and 23%, respectively). Compared to younger people, there are also more elderly and disabled people who do not visit their family members and acquaintances (16%), although they would like to.

A relatively small proportion of adults with disabilities belong to the organisations of persons with disabilities. Therefore, such organisations offer support for coping and social support networks for a smaller number of disabled persons than could be expected, taking activity levels of such organisations into account. While taking into account the interest demonstrated by the adults with disabilities, another fifth of them could be included in the activities of the organisations. Persons who are not members of any organisation of persons with disabilities, but are interested, constitute 15% of all adults with disabilities.

Care load arising from disability

Above, we analysed some results confirming that the vast majority (84%) of adults with disabilities need personal assistance. On the other hand, about one-third (36%) of all adults with disabilities live in one-member households, i.e. there is no other household member to help or take care of them, if necessary. Of the single persons with disabilities, about three-quarters (76%) report that they are in need of personal assistance, while one-quarter needs it permanently. Thus it is important that people could receive personal assistance from outside.

Persons with profound disability specify most often that they are unable to take up various activities due to their disability or they are not interested.

About one-third of all adults with disabilities live in one-member households, i.e. there is no other household member to help or take care of them if necessary.

The majority, i.e. 64% of adults with disabilities, live in households with two or more members. Who of the household members is the main assistance provider for the persons with disabilities depends to a large extent on the age of the persons with disabilities – in case of adults with disabilities under 50, assistance or care is provided mainly by his or her parent or grandparent (56% and 40%, respectively), but in case of the 50–74 age group, a spouse or partner (75%). The older the persons with disabilities, the more likely that he or she is single.

As people living temporarily elsewhere may also belong to a household, the survey addressed assistance provided to persons with disabilities by the household members who are living together with the persons with disabilities and whose contribution to his or her assistance and care is the biggest both timewise or moneywise (hereinafter these persons are referred to as main caregiver in the family). Besides relatives, friends and acquaintances, family members are usually the ones who are first approached for assistance by the persons with disabilities. Helping and supporting each other is generally the factor that ties people together in a family and what is provided voluntarily with pleasure. It is still important that the load associated with it would not rise to the extent that would hinder studies, work or leisure time of some family member or have a deteriorating effect on his or her health and quality of life.

Main caregivers in the family

The survey results reveal that 62% of the caregivers of adults with disabilities in families are women and 38% men. This may somewhat contradict any possible prejudices that such a burden would mainly be left on female shoulders. A half of the caregivers (51%) are old-age pensioners. 29% are working, and three-quarters of them (74%) work full-time, or forty hours per week. 2% of the caregivers are studying, 7% are persons receiving pension for incapacity for work. The proportion of working and retirement-age persons among the caregivers is nearly equal, 57% and 43%, respectively.

Although the majority of caregivers are in the age range of 50–75, the survey also reveals that both minors and people in extremely advanced years can be found among the caregivers: the youngest person completing the questionnaire was 13 and the oldest 86 years old. Two thirds of the households with a caregiver are two-member households, i.e. the household comprises only the caregiver and the person needing care. This also explains the extremely young and old persons as well as relatively large amount of male caregivers as there is simply no other person in the household. One-fifth (21%) of the caregivers have been also appointed as official caregivers of the family member with disability.

Care load of family members

The survey gives ground to state, regarding the care load associated with the disability, that 59% of the main caregivers are also the only caregivers of their adult family member with disability. 41% share their care load with someone, nearly three-quarters (71%) with another family member. Next come some household member living outside the household or other person (35%). The proportion of caregivers whose care load is shared by an official caregiver of the person with disabilities or support person outside the household amounts to just 7%. 17% of the caregivers are also engaged in caring for or helping another person in the household; mostly these are minor children, but to a lesser extent also parents without a disability or other relatives or acquaintances.

59% of the caregivers provide assistance to a person with disabilities at least three hours a day, i.e. more than 20 hours a week; this can be considered a high care load. Caregivers of persons with a profound disability and also persons over 50 years of age often have higher care loads.

The majority, i.e. 77% of working or studying caregivers aged 16–64 have not been forced to decrease their work or study load or give up work or studies due to assisting or taking care of a disabled family member within the previous 12 months. 18% have been forced to do so, men more than women (22% and 14% respectively) and, quite expectedly, family members bearing a higher care load almost three times more than family members with a lower care load (29% and 9% respectively). Caregivers of persons with a profound disability (35%), multiple disabilities (25%) and younger persons with disabilities, i.e. persons in age groups 16–29 and 30–49, have been forced to make the greatest changes (27% and 24%, respectively). Three-quarters of caregivers having been forced to make changes have decreased their workload, nearly one-tenth have changed jobs. 6% have given up work, 7% have decreased their study load and 8% have given up studies.

Two-thirds (69%) of caregivers were able to spend less time on their own leisure time activities during the previous 12 months than they would have wanted to; this mainly concerned women and family members with a higher care load. Owing to the class of disability and degree of disability, the proportion of persons who have sufficient time for leisure is the lowest among the caregivers of persons with mental disabilities and profound disability.

Services aimed at reducing care load

61% of the caregivers of adults with disabilities think that they can cope with the present care load and they do not require assistance with care. 37%, however, find that additional assistance would be necessary, while 11% would need it to a considerable extent.

The need for additional assistance is indicated most often by the providers of assistance and care to disabled persons who are over 65 years of age (42–44%), and also caregivers living in urban areas (45%) and having a high care load (44%). In addition, the proportion of persons requiring additional assistance was the highest among caregivers of persons with a profound disability (54%) and a mental disability (56%). The need for additional assistance is smaller among caregivers of persons in the age group of 50–64 and persons with a moderate disability (28%).

46% of caregivers have experienced problems while obtaining services or allowances necessary for them, a large share of them (67%) indicate that they lack sufficient information on which assistance or services are available for taking care of a disabled member of the household. More than one-third (39%) think that necessary services are too expensive and 16% think that the venues where services they need are offered are too far. 14% complain of long waiting lists. In addition, caregivers mention that the procedure for obtaining services is too complicated and time-consuming, the services they need are not offered, or poor health does not allow them to apply for services.

One-third of caregivers listed specific services required to relieve their care load. Although separately, the largest share of them needs transport service (18%) and financial support (13%, Figure 14), several of the listed services together comprise assistance that would allow the caregivers to share their care load with somebody. Therefore, 38% of the listed services are related to institutional or open care, to be more precise, services of day or 24-hour care, support person, personal assistant, domestic help, nurse or day care centre are needed most. In addition, caregivers mention rehabilitation, health care and counselling services. Some caregivers are also willing to receive assistance for finding a job or obtaining information related to educational possibilities, as well as obtaining additional information for the class of disability of the person requiring care, care options or suitable technical aids.

To sum up the section addressing the care load and need of services of the caregivers

62% of main caregivers of disabled adults in families are women and 38% men, thus somewhat contradicting the possible prejudices that such a burden would mainly be left for female shoulders.

59% of the main caregivers are also the only caregivers of their adult family member with disability, 41% share their care load with someone.

Those forced to make the greatest changes in their studies or work are the caregivers of persons with a profound disability, persons with multiple disabilities and younger, i.e. 16-49-year-old persons with disabilities.

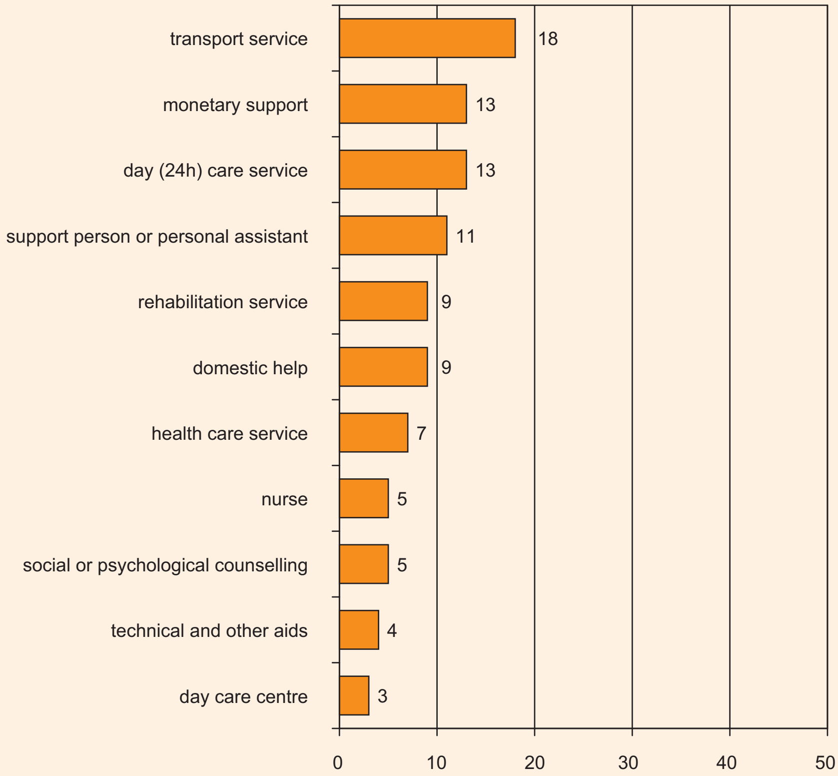
who are family members, it can be said that a large amount, i.e. two-thirds report that they do not need assistance from outside. Two-thirds of the caregivers also are the only caregivers of their family members with disabilities, and the care load of two-thirds is remarkably high – over 20 hours per week, i.e. at least three hours per day. Three-quarters of the caregivers in the age group of 16–64 who were working or studying, were not forced to make changes in their work or studies due to care during the last 12 months. Two-thirds of all caregivers still referred to the fact that due to care they had less leisure time for themselves, other family members or friends and acquaintances than they wanted.

More than one-third of the caregivers of adults with disabilities, however, find that additional assistance would be necessary while 11% would need it to a considerable extent. Additional assistance is more required by the caregivers living in urban areas, having a care load exceeding 20 hours and taking care of older persons and persons with profound disabilities.[31] A large part of necessary services is related to the services that allow sharing care load, but also transport and financial support for covering the costs associated with care are important.

A large share of the caregivers could not mention any necessary services, while not specifying that they do not need any – indicating the need for raising the awareness of family members of persons with disabilities of the services available for reducing care load. Caregivers who had already used the services identified lack of information on the suitable services as one major drawback. Thus, local governments and agencies, whose tasks include ensuring that persons with disabilities are coping, should pay more attention to the family members of persons with disabilities. Seeking for solutions enabling actual provision of services decreasing their care load should be more efficient.

A large share of the caregivers could not mention any necessary services, while not specifying that they do not need any – indicating the need for raising the awareness of family members of persons with disabilities of the services available for reducing care load.

Figure 14. **Services most required by the caregivers (%, caregivers that listed specific services)**



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[31] See also the analysis "Development of Funding Scheme of the Sustainable Care System for the Elderly for Decreasing Care Load" (AS PricewaterhouseCoopers Advisors, 2009). Available (in Estonian) on the web site of the Ministry of Social Affairs: www.sm.ee/fileadmin/meedia/Dokumendid/Sotsiaalvaldkond/kogumik/Etapp_III_Finantssusteem.pdf.

Conclusions

The survey *Disabled People and the Care Load of their Family Members* conducted in 2009 is partly a repeated survey of the abovementioned *Survey of Coping and Needs of Disabled People*, 2005. This analysis is a summary of the most relevant results of the 2009 survey. As the age groups of the surveys differed a bit, only the results related to the disabled persons aged 16–74 could be compared. Making generalisations on the changes of the last four years limited to this age range would still fail to give a true picture of the changes in the conditions of all adults with disabilities.

In general, comparing the persons aged 16–74 we can still claim that in several important areas, like participation in education and work, household and income structure and also health and limitations to activities, we have not experienced any major changes towards worse or better. This is an indication that although the situation of the disabled minors and adults in terms of financial coping and volume of services received could be better a certain state of stability is maintained. Taking into account the global economic downturn that hit also Estonia, increase in unemployment and spread of feeling of insecurity, retaining stability is not a bad result.

As we could see in the overview above, persons with disabilities are very diverse and their needs for personal assistance and measures for the best ways to overcome and cope with the limitations to activities are different depending on their age, class of disability and degree of disability.

The group of adults with disabilities comprises several target subgroups that require special attention. These are single and older disabled persons (often, these two characteristics coincide) and adults with a profound disability, whose inclusion into the public life lags behind, compared to others. Also the caregivers of the elderly and people with profound disability are those bearing heavier care load and thus having less time to spare for themselves. Survey results show that the caregivers themselves also belong to the older age group, aged 50–75. On the other hand, people aged 55–65 in Estonia constitute the risk group where the proportion of persons with disabilities begins to increase abruptly, mainly owing to deterioration of health. The plan of action of the Council of Europe "Improving the quality of life of people with disabilities in Europe 2006–2015" referred in the beginning of this paper specifies girls and women and children and adolescents with disabilities, as well as persons with disabilities among minorities and immigrant workers as the potential risk groups. The action plan prepared by the Council of Europe underlines mainstream approach to the development of the disabled policies and provision of services to them, meaning that besides the area responsibility, all ministries are equally responsible for ensuring that their initiatives should also take into account the rights of the disabled persons. But this requires efficient cooperation characterised by a common base in all issues addressing disabled persons.

Local governments that have been assigned a relevant role in supporting the coping of the disabled in Estonia must ensure the means and personal assistance that both the elderly and the disabled persons need for everyday coping. The activity of persons with disabilities in carrying out continuous explanatory work on how the society as a whole could better consider their rights and needs is still very important.

Based on the main results of the survey, some recommendations are provided on how the government and local governments could improve policies addressing adults with disabilities and their family members in the coming years.

Policy recommendations

- To pay more attention to the persons with disabilities living alone, especially older ones, and development of measures that they need in order to improve their daily coping.

- To improve cooperation of local governments in arranging social transport for improving the mobility of interested persons with disabilities.

- To improve case management in order to increase the independence of persons with disabilities and improve their inclusion in the society.

- To increase the awareness of persons with disabilities of study options in various educational institutions, including also the educational institutions in the provision of information.

- To raise the awareness of educational institutions about the needs of persons with various disabilities in order to enable their participation in the studies on equal basis with others.

- To continue providing information to the employers of disabled persons, promoting persons with disabilities as motivated, capable and loyal employees.

- To find more options for persons with disabilities for flexible and part-time employment.

- To facilitate the establishment of the networks of experience counselling for people with different classes and degrees of disability, similar to the existing network of experience counselling for persons with mental disorders.

- To raise the awareness of the role and load of the family members of persons with disabilities as providers of assistance or care.

- To pay more attention to the availability of services needed for decreasing the care load of the caregivers of persons with disabilities.

- To find more opportunities for the more consistent reflection of the information regarding persons with disabilities and their family members in the newspapers of the counties and local governments so that the know-how on the existing options would reach all that need it.

- To commit strongly to the introduction of universal design in all constructed and renovated buildings, aiming at the creation of maximum opportunities for persons with disabilities for active participation in public life.

- To consider additional analyses for the better arrangement of measures and funding thereof in order to provide more effective support for financial coping.

- To consider conducting an additional survey on the needs of the elderly and disabled persons temporarily or permanently living in social welfare institutions in order to improve the availability and quality of the services needed.

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Selected facts

- In 2009, the proportion of persons with an officially determined degree of disability comprised 8.9% of the total population of Estonia.
- In Estonia, the proportion of the disabled in the total population starts to increase from the age group of 50 years of age mainly due to illness and accidents.
- 40% of the adults with disabilities have acquired primary, 44% secondary and 17% tertiary education.
- Nearly a third (29%) of the disabled aged 16–29 and 7% of the disabled aged 30–49 attend formal education and in-service training, while almost a third of both age groups do not study (29% and 26% respectively), although they would like to.
- 8% of adults with disabilities are working: 15% of the working-aged and 1% of the retirement-aged population.
- Every tenth adult with disabilities (11%) is a member of some organisation for persons with disabilities, while 7% actively participate in the activities of such an organisation; 15% do not belong to any organisation, but would be interested to.
- Nearly half (46%) of all adults with disabilities claim that they are financially dependent on some other person, among the adults with profound disability, the proportion depending financially on some other person exceeds half (56%) and among the age group of 16–29, the proportion is nearly three-quarters (73%).
- Two in three adults with disabilities using means of transport can use personal and public vehicles as often as necessary.
- 36% of the adults with disabilities live alone, i.e. they do not have any household members who could give them personal assistance in case of need.
- 62% of the adults with disabilities of limitations to activities in families are women and 38% men.
- 59% of the main caregivers are also the only caregivers of their adult family members with disability, 41% of the caregivers share their care load with someone.
- 37% of the caregivers of adults with disabilities would need additional assistance for care, while 11% of them would need it to a considerable extent.

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Additional information:
Social Policy Information
and Analysis Department
Ministry of Social Affairs of Estonia
Gonsiori 29, Tallinn 15027
info@sm.ee

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