



## LIFE IN A WHEELCHAIR: FROM ISOLATION TO PARTICIPATION

## SOCIOLOGICAL RESEARCH REPORT on wheelchairs and wheelchair services in Romania

## **OVERVIEW**

This research was conducted between January 2012 – February 2014 as part of *The Wheels of Change Move On* – towards appropriate wheelchair provision, sports and accessibility for mainstream participation of Romanians with disabilities' project financed by the United States Agency for International Development (USAID).

SPECIAL THANKS to all those beneficiaries of the Motivation Romania Foundation who participated in the research and to all our colleagues in the regional teams for their essential support in conducting this study.

This study is made possible by the generous support of the American people through the United States Agency for International Development (USAID). The contents are the responsibility of Motivation Romania Foundation and do not necessarily reflect the views of USAID or the United States Government.

In Romania, the chances for social inclusion of persons with mobility disabilities are decreased, due to reduced access to mobility equipment and services. This is the main finding of this research that addressed the impact of mobility equipment and services on the health, posture and social participation of wheelchair users, as perceived and expressed by themselves.

Since there are no statistics in the field, we can only estimate the number of persons with mobility disabilities in Romania, which leads us to a number that falls anywhere between several tens of thousands and 200,000 (potential) wheelchair users. This is a category of population deprived of a series of fundamental rights and of access to social and professional life unless it is provided with wheelchairs, which is the essential equipment for positioning and mobility.

The mobility of these persons is not a priority of the Romanian healthcare system. First of all, it is under-financed, as shown by the WHO statistics. In Europe, Romania ranks 46 out of 53, with 5.8% of its GDP assigned for expenses related to healthcare<sup>2</sup>. Secondly, only a small amount is directed towards equipment and medical devices (3.3% of the overall healthcare expenses), placing our country on the last position in a OECD study.<sup>3</sup>. In countries with an effective healthcare system, public funding is the main financing source for mobility equipment. Additionally, it is recommended to complete public funding with donations, contributions from wheelchair users, as well as payment for wheelchair services related to donated or imported equipment<sup>4</sup>.

In Romania, the healthcare system provides a standard subsidy that covers the cost for an average quality wheelchair, which, in most cases, does not accommodate the real needs of the wheelchair user. As far as wheelchair services are concerned, the healthcare system is still focused on financing hospital type services, instead of community-based services. Moreover, the social services system also fails to provide specific services dedicated to persons with mobility disabilities.

Public policies in the field of disability do not address particularly the issues related to this category. On the contrary, the debate becomes more targeted when it comes to health insurance and the wheelchair provider's market, as many of those who need a wheelchair aplly for a subsidy provided by the county health insurance agencies. A research conducted by the Romanian Academic Society within a project implemented by Motivation Romania Foundation (2009–2011)<sup>5</sup>, revealed information regarding subsidies for wheelchairs between (2003–2007), namely 12,600 subsidies. Nevertheless, the number of those who need such an equipment is much larger. Some of the users purchase the wheelchairs themselves, others receive it as a donation. In addition to them, there is a large number of persons completely deprived of mobility due to the lack of wheelchairs: in Romania, 20% of those who need a wheelchair do not have such an equipment<sup>6</sup>. Some of them are not aware of the fact that they are entitled to such an equipment, others do not wish to use one (because of associated stigma) or still wait to receive it. In terms of the extent to which the market can answer these

http://www.motivation.ro/uploads/studii%20SAR/Raport%20de%20cecetare%20-%20Imobilizat%20la%20domiciliu.pdf

<sup>&</sup>lt;sup>1</sup> Report of the Romanian Academic Society 'Immobilized at home – The crisis of wheelchair financing in Romania', 2009, in partnership with Motivation Foundation Romania:

World Health Organization, 'Total expenditure on health as a percentage of the gross domestic product': http://gamapserver.who.int/gho/interactive charts/health financing/atlas.html

<sup>&</sup>lt;sup>3</sup> Romanian Academic Society, 'Immobilized or integrated? Status, access to mobility equipment and to independent living services', 2010

<sup>&</sup>lt;sup>4</sup> World Health Organization, 'Guidelines on the provision of manual wheelchairs in less-resourced settings': http://www.who.int/disabilities/publications/technology/wheelchairguidelines/en/

<sup>&</sup>lt;sup>5</sup> Idem 1

<sup>&</sup>lt;sup>6</sup> Idem 2

needs, the public healthcare system (the main wheelchair purchaser) covers 30% at best (based on information provided by the National Health Insurance Agency).

This study includes a smaller number of persons who need a wheelchair but do not use one, as it was conducted with the participation of (potential) beneficiaries of Motivation Romania Foundation.

Over the past 19 years, through its activity in the field of disability, Motivation Romania has acquired a significant background in what represents the needs of wheelchair users in our country. This project meant a scientific approach to the subject, and the results will help us to diversify the range of equipment and services provided to our beneficiaries.

The reasearch set off from the biopsychosocial model on functionality, disability and health and supports the provision of customized mobility equipment and assistive devices, together with dedicated services (including training on independent living skills), so that persons with mobility disabilities achieve the highest degree of health and independence.

The subject of our research were persons who use or need a wheelchair, persons who are considered to have mobility disabilities. Although we did not approach the issue from the perspective of their health status (according to the ICF terminology), i.e. in terms of diagnosis, we cannot overlook the fact that a large section of this category is made up of persons with traumatic spinal cord injuries. This is the reason why we think it is relevant to include in this study some information that can be found in the 'International Perspectives on Spinal Cord Injury' report of the WHO<sup>7</sup>, which pleads for suitable medical and rehabilitation services, followed by support services and accessible life environments for persons with traumatic spinal cord injuries.

The research span from January 2012 to February 2014 and it took a close look at the impact of mobility equipment and services, as perceived and expressed by the wheelchair users. The target group included 1,191 wheelchair users or persons who need a wheelchair, whose opinions and perceptions were recorded through 1,034 questionnaires (face to face meetings), 100 phone interviews and 12 focus groups (with 130 persons in the same category, some of them having answered the questionnaire, too). The respondents are current or future beneficiaries of Motivation's services, and this renders the findings of the research not entirely relevant for the general population of wheelchair users in Romania. The most consistent quantitative information comes from the answers to the questionnaires, qualitative information was extracted from the discussions with the focus groups, while phone interviews provided more details and added to the conclusions that derived from the analysis of the questionnaires.

The main factor that influences social participation of persons with mobility disabilities is the degree to which their self-care abilities and wheelchair mobility skills are developed. In order to facilitate data interpretation, we have created clusters of abilities, based on their complexity: basic, average and advanced abilities. There is an additional category, that of persons who do not have (almost) any abilities.

The situation of our beneficiaries is shown below:

<sup>&</sup>lt;sup>7</sup> World Health Organization, 'International Perspectives on Spinal Cord Injury': http://apps.who.int/iris/bitstream/10665/94190/1/9789241564663 eng.pdf

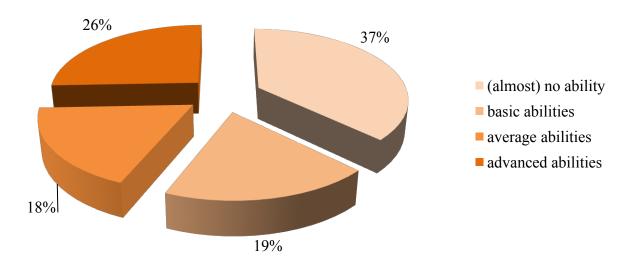


Chart 1. Level of abilities in wheelchair users.

According to the chart above, the abilities of more than half of our beneficiaries (56%) do not exceed the basic level, which causes setbacks in their access to independent living and social participation.

When structuring data according to age categories, we find that 59% of the adults of active age have average or advanced skills, while 85% of the children fully depend on their caretakers. In the case of the elderly, the low level of abilities increases their need for assistance and support, as compared to the adults in the active age category.

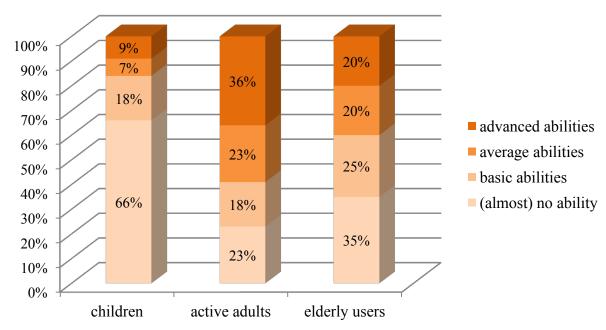


Chart 2. Wheelchair users abilities, according to abilities and age categories

It is rather obvious that the level of abilities in adults of active age is clearly superior to that of children. This is due to the fact that many children need to use mobility equipment as a consequence of complex diagnoses, which have a great impact on their mobility and intellectual functions, while many of the adult wheelchair users had been involved in accidents or were subjected to traumas that affected their mobility abilities only partially. The

profile of the active rehabilitation activities implemented by Motivation Romania is directly related to these features. Therefore, active rehabilitation camps and sessions for adults focus on developing autonomy and independent living skills, in the same way as the activities designed for children have an important component dedicated to training parents and providing the required information for the best possible quality of life, both for their children and for themselves.

On the other hand, the elderly have less developed self-care abilities and wheelchair mobility skills as compared to adults of active age. Most of them do not need a wheelchair because they did not have one since birth or due to some childhood condition (infantile paralysis, cerebral palsy) or perhaps because they were involved in an accident. In most cases, it is about progressive conditions associated with their age, that reduce some of the skills and abilities.

The use of a wheelchair contributes to the development of self-care abilities and wheelchair mobility skills. Out of the 1,034 subjects, 11% do not have a wheelchair, thus being completely unable to move around in an independent way, which negatively impacts on many areas of their personal and social life.

Those who participated in our focus groups mentioned being on the waiting list for a subsidy from the county healthcare insurance agency. They stressed the importance of an informed decision and of a genuine opportunity to chose when it comes to the purchase of a wheelchair, as well as the need for a customer management type of approach. This correlation, mentioned also in other research materials<sup>8</sup>, can be supported by comparing the values of some of the indicators recorded at the level of the entire group of subjects to those that refer to persons who do not use a wheelchair, although they need one.

Whenever the wheelchair user lacks a mobility equipment, he/she lacks the opportunity to move around freely, which does have an impact on their personal and social life.

	Meeting friends	Going out	Shopping	Traveling	Participating in household chores	Driving a car
All beneficiaries	29%	17%	11%	8%	37%	8%
Beneficiaries who do not have a wheelchair	9%	6%	3%	2%	20%	1%

A similar reasoning shows us that wheelchair users have better self care abilities and mobility skills as compared to persons who need a wheelchair but do not have one:

	Almost no ability	Basic abilities	Average abilities	Advanced abilities
All beneficiaries	37%	19%	18%	26%
Beneficiaries who				
do not have a				
wheelchair	55%	19%	14%	12%

<sup>8</sup> Idem 1

\_

918 of the respondents have at least one wheelchair, 20% have two or more wheelchairs. In terms of the most frequently used wheelchair, a general description of the equipment used by our beneficiaries shows the following:

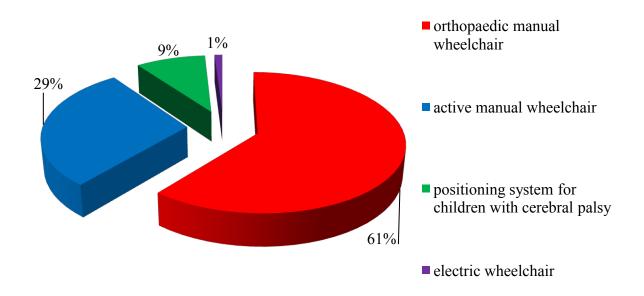


Chart 3. Types of wheelchairs used by beneficiaries

72% of the provided manual wheelchairs have a cushion (here not included positioning systems and electric wheelchairs that have an integrated cushion). Moreover, one of the findings shows us that **in Romania, generally speaking, wheelchairs do not have many adaptations.** In our opinion, the main reason is lack of information on behalf of the wheelchair users, the additional cost, as well as the lack of expertise and of equipment providers. Therefore, wheelchair users do not have access to adaptations and appropriate assistive devices.<sup>9</sup>.

According to the legal provisions, any person is entitled, once every 5 years, to receive the amount of 1,265.90 lei for the purchase of a wheelchair, as long as the equipment is prescribed by a specialized physician. This situation has two major outcomes: on one hand, the value of the subsidy provided by the state does not allow access to really good wheelchairs. Therefore, the equipment wears down rather quickly, does not meet all the user's needs and children outgrow it fast.

In terms of financing resources for wheelchairs, most of the wheelchair users (47%) received it as a donation from private sources (non profit organization or individuals) or purchased it through the subsidy from the county healthcare insurance agency (34%). A lot less wheelchair users (5%) borrowed the mobility equipment or used their own or their families' financial resources. Given that they depend on the limitations imposed by public financing or, more or less, on various opportunities that involve individuals or legal persons, we can say that wheelchair users in Romania do not have a real chance to choose the equipment that they use.

When asked about the providers, 38% of the respondents do not know or do not answer the question; and this is indicative of the scarce information on mobility equipment features and

<sup>&</sup>lt;sup>9</sup> Idem 7

market. This supports the idea that the choice of the wheelchair is not real, nor an informed process.

Most of those who answered the questionnaire are satisfied with their wheelchair. When it comes to wheelchairs provided by Motivation (where, predominantly, their needs had been assessed and their measurements taken), the feedback is even more positive.

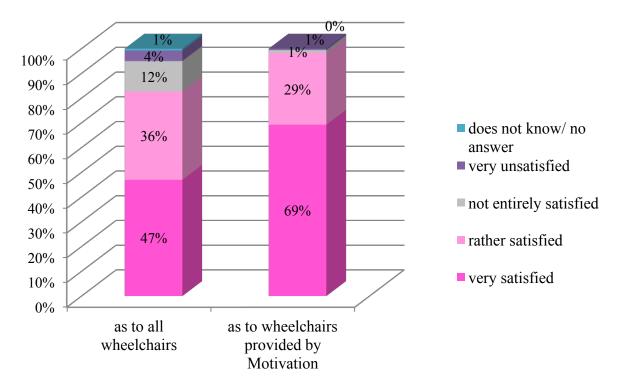


Chart 4. Level of satisfaction with the used wheelchair.

The opinions of the wheelchair users are less differentiated when the level of satisfaction is measured against a certain set of criteria. A wheelchair should solve the issues of mobility and postural support but, equally, should be available at an affordable cost. We have translated these aspects into 6 indicators that were presented to our respondents: comfort, durability, wheelchair handling, cost, degree of ease in folding and wheelchair weight.

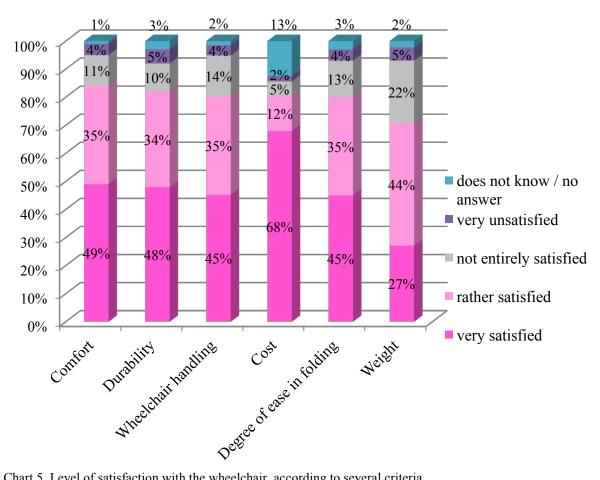


Chart 5. Level of satisfaction with the wheelchair, according to several criteria

It was concluded that the respondents were most satisfied with the level of comfort provided by the wheelchair (84%). What dissatisfied respondents in most cases was the weight of the wheelchair (27%). Motivation scores very well in all areas, with the same trend of satisfaction concerning comfort and with the same need for improvement of the equipment's weight.

Participants in focus groups told us that the main quality of a wheelchair is the way it fit its user. Literature in the field<sup>10</sup> and the expertise of our staff use this concept in relation to the needs of each individual user:

- physical needs (postural and functional) of the wheelchair user: height of the spinal cord injury, postural problems, decreased sensation, muscle tone issues, abilities, etc;
- life environment: where will be the wheelchair used;
- wheelchair user's lifestyle.

The degree to which the wheelchair fits influences the posture and health condition of the user and can prevent negative future conditions such as postural problems and pressure sores, but also lack of comfort and mobility difficulties. First and foremost, the wheelchair must meet the user's needs, but we are looking also at the practical aspects: weight, handling, efficient folding and various adaptations that enhance activity. However, the choice to own a good wheelchair is also a matter of cost, since good quality wheelchairs usually come at a price which is higher than the one covered by the healthcare system.

Thus, 83% of the respondents are satisfied with their wheelchair. We believe that this positive perception is influenced by their limited experience in using the wheelchair, especially when

<sup>10</sup> Idem 4

it comes to users who are less active. We define limited experience from two perspectives: beneficiaries who do not use their wheelchair to its full capacity and beneficiaries who cannot operate a real comparison, since they never had the chance to use a good quality mobility equipment that.

The 918 wheelchair users were asked whether they were using any other type of mobility equipment or assistive devices, and only16% gave affirmative answers. When contrasting the low level on interest for mobility equipment and assistive devices and the low level of self-care abilities and mobility skills (56% of the respondents acquire only the basic abilities), we see that, although truly needed, assistive technlogy is not considered by many beneficiaries as a solution to improve freedom of movement and social participation. Lack of information and the high cost of mobility equipment and assistive devices are the main reasons. Moreover, the provision of such equipment needed by persons with disabilities is not a priority as far as the policies in the field are concerned. The 'International Perspectives on Spinal Cord Injury' report shows that in countries with limited and average resources, only 5% to 15% of those who need assistive devices have them. Their cost had been identified as the most important cause of this shortcoming<sup>11</sup>.

Considering the beneficiaries' need for customized wheelchairs, Motivation is, according to our knowledge, among the very few providers who offer also the services adjacent to mobility equipment provision, such as: assessment of the user prior to wheelchair provision, training on the use of the wheelchair or counselling for acquiring independent living skills. 79% of the wheelchair users were trained by Motivation specialists so as to (re)gain their independence (the wheelchair users themselves or their caretakers, in the case of children or persons with reduced abilities). 613 persons were visited in their homes, 187 participated in seminars (1-3 days), 84 were in one week summer camps, while 106 participated in 2 week training sessions.

Beneficiaries appreciate the essential role of our organization regarding training for an independent and active life. 83% consider that their lives improved to a great extent after receiving such services.

When asked what was the major change after the training provided by the Motivation regional teams, the respondents mentioned the following:

- 52% realized that there existed other persons who faced the same type of issues;
- 46% stated that they had become more independent
- 21% considered that their health improved;
- 19% declared that they started meeting their friends more frequently or going out more often.

The gathered information shows that those respondents who received independent living training are more involved in the social life:

	Meeting friends	Going out	Shopping	Traveling	Participating in household chores	Driving a car
All	29%	17%	11%	8%	37%	8%
beneficiaries						
Beneficiaries						
trained by	34%	20%	13%	10%	41%	9%
Motivation						

<sup>&</sup>lt;sup>11</sup> Idem 7

Also, their self-care abilities and wheelchair mobility skills are somewhat more developped than those of the users who did not receive such services:

	Almost no ability	Basic abilities	Average abilities	Advanced abilities
All beneficiaries	37%	19%	18%	26%
Beneficiaries trained by Motivation	33%	19%	19%	29%

When asked whether they would be interested in receiving training for independent living skills provided by Motivation, 79% of the respondents answered affirmatively (whether they had or did not have a wheelchair at the moment the research was conducted). The main interest was prevention of medical issues (51%), as well as participation in activities dedicated to socializing (48%).

Wheelchair users are most interested in health condition, proved by how much they value prevention of medical issues (among the topics for independent living skills training) and benefits of medical rehabilitation (physical therapy and other similar therapies), in order to regain several abilities, to avoid the worsening of their condition and other medical problems. At the time when this study was ongoing, 74% of the respondents considered that such services were necessary. To a certain extent, rehabilitation services are included in the healthcare insurance system. Persons with mobility disabilities are entitled to 2-4 rehabilitation sessions per year (two weeks), in rehabilitation centers throughout the country or as outpatients. Most of the participants in the focus groups stated they would be interested in services provided to them as outpatients, especially if transportation was covered.

The services covered by the healthcare system agencies seem insufficient to meet the needs of the beneficiaries, which was revealed by the answer of 41% of the respondents who, at that moment, did not benefit from medical rehabilitation services, although they needed them, according to them.

60% of the respondents live in the urban area, while 40% in rural settlements. As the specialist in the field are well aware of, our sample also proves that males are better represented among those who suffer from a mobility disability.

Most of the beneficiaries who fall into the category of active adults (aged 18-59 years) are not married, do not have children and live with their parents (these are the identified trends). Wheelchair users have more reduced chances of finding a partner, as compared to persons who do not have this disability. This is translated into an additional need for support from social groups or networks to which they belong or from the entire community.

Education is one of the most salient indicators of social participation and the values for wheelchair users are really low. Thus, the 1,034 (potential) wheelchair users have the following features, in terms of education:

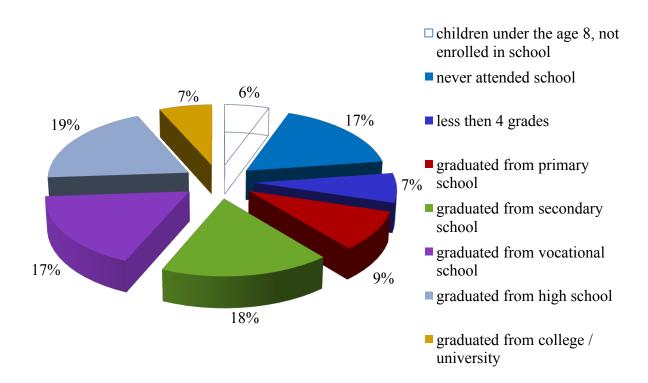


Chart 6. Level of education in wheelchair users

In the previous chart we notice the signficant number of respondents who had not attended school (17%). We have previously seen the way the educational path is influenced by the level of self-care abilities and wheelchair mobility skills: the level of abilities is directly proportional with the chances to attend school. The arguments come from statistics: for instance, in the case of active adults, the percentage of those who never attended school is 11% (general value), while 21% of adults have only basic abilities and 4% have average abilities. Therefore, it can be stated beyond any doubt that school attendance is conditioned by the level of self-care abilities and wheelchair mobility skills.

However, we must mention the lack of openness of the educational system in Romania regarding the needs of persons with mobility and associated disabilities. The main features of this system are low responsiveness to making architectural spaces more accessible and inflexibility of regulations (for example, regulations on access of parents - caretakers in school or on assessment procedures). Also, Romanian schools are less accessible to children with learning disabilities because it encourages competitivity over teamwork and focuses on a theoretical approach and accumulation of information. This is how the educational system (and to a certain extent parents themselves) neglect the role that socializing can have on the development of these children and even in terms of educating their peers to better understand diversity and tolerance. On a global level 12 we see the same trend: children and youth with traumatic spinal cord injury have lower chances to attend school and need to overcome various obstacles in the transition from school to the labor market.

If we were to compare school attendance in the case of wheelchair users (children who have the required age and adults), as well as in the case of the entire category of persons with

<sup>&</sup>lt;sup>12</sup> Idem 7

disabilities and that of the general population<sup>13</sup>, in terms of percentage, the percentage of persons with disabilities who did not attend school (14%) is 7 times higher than that of general population (2%), while for wheelchair users, it is 12 times higher (25%)<sup>14</sup>! Disability does decrease opportunities for school attendance and the duration of school attendance.

As for the integration on the labor market, when compared to the general population, the number of persons with disabilities who are employed is a lot more reduced<sup>15</sup>, and this is valid also for wheelchair users<sup>16</sup>:

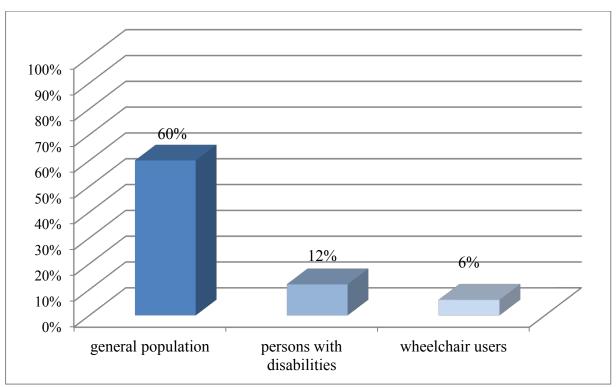


Chart 7. Employment rates in general population, persons with disabilities in general, as well as in wheelchair users.

It must be mentioned that in many European countries the number of persons with disabilities who are employed can reach even  $50\%^{17}$ .

Education is the most important predictor of employment, therefore it is only natural that the level of employment in the case of persons with disabilities, in general, and wheelchair users, in particular, is reduced as compared to that of the general population. In addition to education, another factor is the degree to which self-care abilities and wheelchair mobility skills are developed. 79% of those who are employed have average or advanced skills.

<sup>&</sup>lt;sup>13</sup> The last two aspects are taken from 'Diagnosis: EXCLUDED FROM THE LABOUR MARKET – Setbacks in the employment of persons with disabilities in Romania'. Data referring to general population mentioned in the report are taken from the 2002 National Census.

Unlike in the previous chart, here the percentage is calculated taking into account the number of children who have the required age for schooling and the number of adults, not the overall number of respondents.

<sup>&</sup>lt;sup>15</sup> Data on general population is taken from the 2002 National Census.

<sup>&</sup>lt;sup>16</sup> Employment rate of persons with disabilities (who have the required age and work capacity) is 12% (source: presentation made by the General Manager of the Department for the Protection of Persons with Disabilities, October 2012), the same percentage is mentioned in 'Diagnosis: EXCLUDED FROM THE LABOUR MARKET – Setbacks in the employment of persons with disabilities in Romania': idem 13

As shown in 'Diagnosis: EXCLUDED FROM THE LABOR MARKET – Setbacks in the employment of persons with disabilities in Romania' there are other factors that impact on the employment of wheelchair users. First of all, we must mention architectural barriers, which is an important reason why persons with disabilities are inactive. In this context, the study on accessibility conducted by Motivation Romania, as part of this project, shows an accurate image of the Romanian everyday reality, which is utterly different from the environment that we want to create for wheelchair users in Romania, so that they can have the same context for their social and professional activities as any other person.

As a rule, professional experience should also be a catalyst of employment. 36% of the wheelchair users of active age have some work experience, which entitles them to receive an invalidity pension. This is also a factor that hinders their reintegration on the labor market. The reluctance is not caused necessarily by the inability to work, but is due more to the insecurity of jobs and the unpredictable, bureaucratic feature of the entire process that enables persons with disabilities to receive again the above mentioned financial compensation (in case they lose their jobs).

Most of the wheelchair users do not have a consistent social participation. Among other elements, it is important whether the wheelchair user sees the mobility equipment as a barrier in his/her social life, and this depends to a great extent on each individual's personality and on the support provided by the environment. It is the person with disability that has the possibility to change the mindset of those around him/her, by asking for help when it is required, by acting in a natural way and by earning the respect of the others.

Physical activities can enhance good health and psychological and social wellbeing. Unfortunately, following the general trend in Romania, wheelchair users in general are not involved in sports activities. Only 3% of the respondents participate in wheelchair sports (basketball, tennis, table tennis, swimming, etc), while 15 % expressed their interest for such activities (same sports, mainly basketball). 84% of those who mentioned being interested in sports have average and advanced abilities. Therefore, it is rather safe to conclude that persons with mobility disabilities do not participate in sports activities because they lack the required abilities.

Generally speaking, wheelchair users choose to spend their spare time as shown below:

\_

<sup>&</sup>lt;sup>18</sup> Idem 13

<sup>&</sup>lt;sup>19</sup> Accessibility Map: <a href="http://www.accesibil.org/">http://www.accesibil.org/</a>

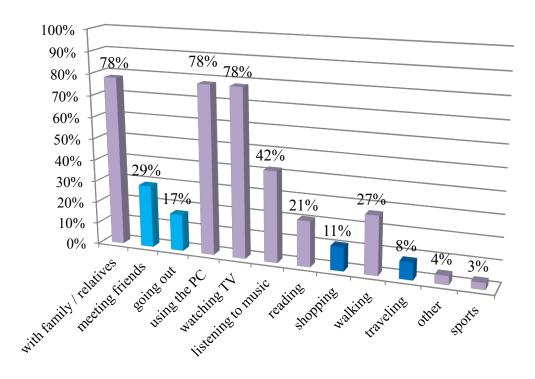


Chart 8. Spare time activities of wheelchair users

In terms of socializing, only 29% of the beneficiaries spend their spare time meeting friends, and 17% mentioned going out. On the other hand, only a small part of them access public services: 11% go shopping and 8% travel.

In terms of age groups, naturally, children are less involved in social life as compared to adults, due to their age and to (as we will see shortly) their level of abilities, which renders their potential for physical autonomy considerably lower than that of adults. In other words, 85% of the children depend on their caretakers for all aspects of their everyday life: activities at home, going to school, going out to play (in some cases, it is not a playing activity but walk ing or sensory stimulation), meeting other children, etc.

Adults of active age are inclined to watch TV, to use the computer, to meet their friends, and prefer reading, going out and shopping. These activities are common for this category, due to age, degree of autonomy and to their self-care abilitiers and wheelchair mobility skills.

As compared to this category, the elderly have less opportunities for spare time activities, and traveling and sports are not on the list. Using the computer, going out or shopping are not frequent. In this age category, the number of persons who listen to music, go for a walk and read is reduced as compared to their younger peers. The most common activities in this case are watching TV and spending time with family or relatives.

Participation in community activities, adapted means of transportation, healthcare, mobility equipment and assistive technology, treatment and a good quality of life, in general, require financial resources. This is why we asked our respondents to evaluate their own financial situation. 13% consider that their financial status is good or very good, 55% think that it is average, while 30% think that their income is hardly sufficient or even insufficient (poor or very poor financial situation).

A previous research<sup>20</sup> showed that persons with disabilities have significantly lower incomes as compared to the general population (in terms of households, they reach approximately 60% of the national average). **The living standard of wheelchair users is generally low**, as their income is represented by the disability allowance, in the absence of a job or another source of income. On the contrary, medical rehabilitation, mobility equipment and assistive devices, treatment and other medical supplies, as well as adaptaed transportation require additional expenses. The situation is even more dramatic when it comes to adults of active age who should be able to support their families.

Lack of accessibility in public spaces is one of the factors that prevent wheelchair users from going out in community. Specialists in the field believe that the following main infrastructure elements should be made accessible: buildings (for living and for public services), means of public transportation, roads, food, water and sanitation facilities, spaces for culture and recreational activities<sup>21</sup>. Data gathered by Motivation<sup>22</sup> on the accessibility of public buildings prior to February 2014 shows that only 23% of such buildings are fully accessible, and 51% are not accessible to wheelchair users. Evaluated buildings include: offices of public authorities, institution for education, healthcare and social services, as well as for financial services, non profit organizations offices, tourist facilities, means of public transportation, areas designed for sports activities, etc.

Only 24% of the homes of the respondents are fully accessible.

## The discrimination of persons with mobility disabilities can be identified in entire systems:

- poor implementation of legal provision regarding accessibility of public buildings and transportations;
- low number of persons who have access to medical rehabilitation services;
- lack of policies that support access to assistive technology and high quality mobility equipment;
- perpetuated prejudice that adults or children with mobility disabilities also have, as a rule, learning disabilities, the prejudice that persons with disabilities cannot work;
- lack of support services and services that provide care at the wheelchair user's home;
- lack of consistency in policies that support positive discrimination for employment, etc. Beneficiaries require equal opportunities for social integration.

One of the objectives of this research was to evaluate the respondents' interest for services provided by Motivation Romania, such as identifying the needs of wheelchair users, training on wheelchair mobility and independent living skills, physical therapy services, adapted vehicles, so as to be able to shape these services according to the requirements of wheelchair users. The questionnaires were also a good way to promote our phone line dedicated to them.

Most of the respondents appreciated positively the services provided by Motivation Romania. This is what they mentioned in relation to this topic:

- longer physical therapy sessions or physical therapy services for outpatients (transportation included);
- the efforts made to provide good quality wheelchairs for a cost that can be covered by the state subsidy;

<sup>21</sup> Idem 4

<sup>22</sup> Idem 19

<sup>&</sup>lt;sup>20</sup> Idem 13

- the fact that Motivation Romania is among the few providers of information and counselling services on wheelchair use and independent living for wheelchair users (even while in hospital);
- the involvement of wheelchair users in the provision of these services;
- home visits in the case of wheelchair users who cannot leave their homes;
- socializing and wheelchair sports;
- raising awareness campaigns regarding the issue of disability.

The meeting with Motivation Romania changed the lives of a great number of persons, according to their own declarations. They received services, information and support regarding several aspects: training on the use of the wheelchair, independent living counselling, counselling on procedures to access disability allowance and invalidity pension, an appropriate wheelchair, urinary devices, etc. For some beneficiaries, meeting the Motivation Romania teams had been a decisive moment, as they were exposed to **a model of social integration** that they did not believe was accessible to them. We were truly impressed with the testimony of one of the wheelchair users: 'Motivation managed to get us out of our homes (I had not been out of the house for years) and to integrate us!'.

During the focus groups, we have asked participants to list, in order of their priorities those measures that should be taken into consideration in order to improve the status of wheelchair users in Romania. They have named the following actions:

- 1) implementation of the legal provisions that refer to accessibility of public buildings and of public transportation;
- 2) making social benefits more flexible and developing the social services system, medical rehabilitation and employment services, as well as the assistance and the support to facilitate independent living;
- 3) increasing the amount of the disability allowance, according to the inflation, increasing the amount of the subsidy for wheelchair;
- 4) ensuring access to healthcare system and medical rehabilitation (more cost free services supported by public or private providers); increasing quality of healthcare services;
- 5) ensuring access to special education, improving its standards and shifting stress towards practical activities, which can be approached easier by children with learning disabilities; performing a reform of the educational system so that qualifications and the resulted professions are correlated with the labor market;
- 6) educating public opinion and raising awareness regarding persons with disabilities.

We have analyzed the opinions and testimonies of 1,191 (potential) beneficiaries of products and services offered by Motivation, which helped us formulate several **recommendations for the organization's future activity:** 

- certainly, the results will confirm the value of Motivation's activities dedicated to wheelchair provision and independent living skills that need to continue: customized wheelchair provision, along with training for independent living and other related services, peer group training and addressing the needs of the beneficiaries;
- developing assessment and physical rehabilitation services;
- empowering wheelchair users and their family members/caretakers for better self-representation;
- encouraging and supporting parents to enroll children in school;
- advocacy for public space accessibility and for an increased inclusion of persons with disabilities in mainstream schools and on the labor market;

- creating services to improve accessibility (adapted transportation, mobility devices, etc)
- generating a particular approach to address the issues of the elderly.

Taking into consideration all of the above mentioned facts, this study conveys the necessity of benefits and services that can meet the needs of persons with mobility disabilities, especially in terms of customized mobility equipment and assistive devices, along with related specialized services (including independent living training), so that they can achieve the highest degree of health and independence. In our opinion, policies in the fields of healthcare, education, as well as those targeting social and political inclusion should be based on the reality of this category's access to mobility equipment and appropriate services.