

REPORT

on

FIRST TRAINING SEMINAR OF THE EMPOWERARE PROJECT

Он-лайн обучение
„Права на хората с увреждания
в България“

26 април /неделя/ 10:00- 16:00 ч./ ZOOM



- Наталия Григорова: модератор
- Илиана Тонова: учител
- Иван Дечев: учител



The first training seminar "**Rights of People with Disabilities in Bulgaria**" on the project funded by the Active Citizens Fund of the EEA Financial Mechanism, EmpowerARE was held online in the context of the pandemic of COVID-19 on April 26, 2020 in the ZOOM platform.

Familiar with its previous projects with the interests and needs of people with rare diseases, the leading organization Bulgarian Huntington Association (BHA) focuses this first training on providing information on key topics and legal regulation and inviting people with proven expertise and practice in the field. at the training seminar - **Ivan Dechev**, Chief Expert at the Ombudsman Institution of the Republic of Bulgaria, Department of Rights of Persons with Disabilities and Discrimination and **Iliana Tonova**, a patient with a rare disease and an expert from experience. The training was moderated by Natalia Grigorova, project manager.

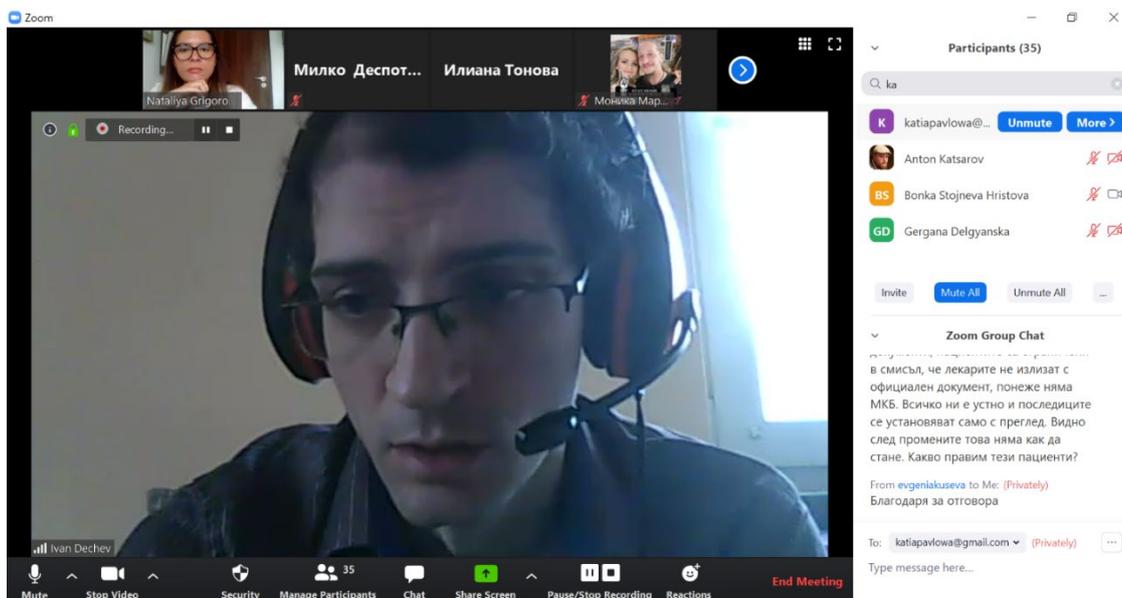
During the training, information was presented on the basic guaranteed rights of people with disabilities in Bulgaria and cases related to them. A preliminary set of training materials was sent to the participants, and during the training an opportunity was created for discussions, questions and work on individual specific cases.

The participants in the training were 35 people, including 5 showers from the project team and 30 participants representing civil society organizations and people with disabilities. Invited to fill in a questionnaire evaluating the training, with which to check the level of their knowledge, old and newly acquired, on relevant topics, as well as to give their opinions and recommendations for the next two trainings, 21 (70%) participants responded to the survey.

----- www.activecitizensfund.bg -----

The "Empowering People with Rare Diseases" Project is implemented with financial support provided by Iceland, Liechtenstein and Norway under the EEA Financial Mechanism.

THANK YOU TO ALL WHO DEVOTED SOME OF THEIR PRECIOUS TIME TO GIVE THE FEEDBACK WE NEED TO PLAN THE MOST USEFUL TRAININGS FOR YOU!



ANALYSIS OF THE FEEDBACK SURVEY FROM THE PARTICIPANTS IN THE FIRST TRAINING UNDER THE EMPOWERARE PROJECT

The participants in the training seminar who responded to the survey were from 8 districts of Bulgaria - Sofia city, Sofia region, Varna, Burgas, Shumen, Lovech, Haskovo and Stara Zagora.



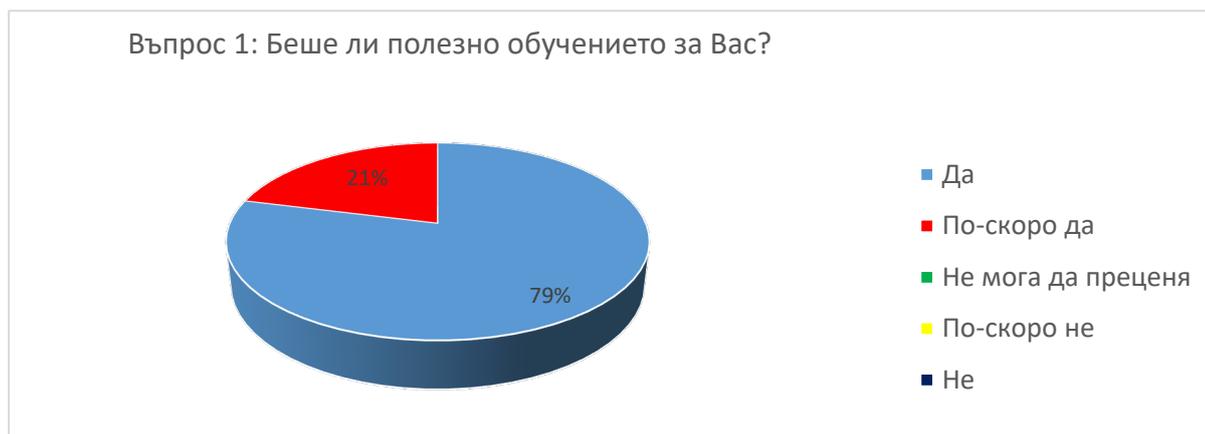
19% of the respondents are men, the remaining 81% are women.

The age of the respondents by age groups is as follows:



Answers to Part I. of the Questionnaire

Question 1.

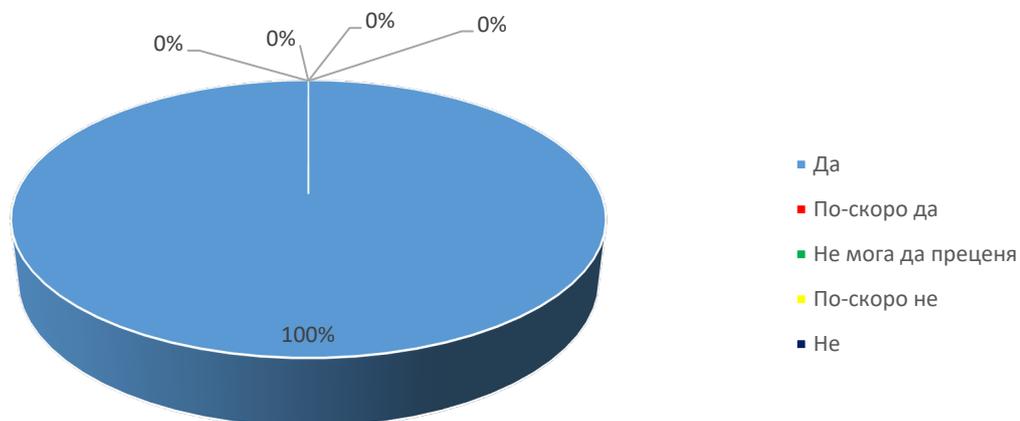


Question 2.



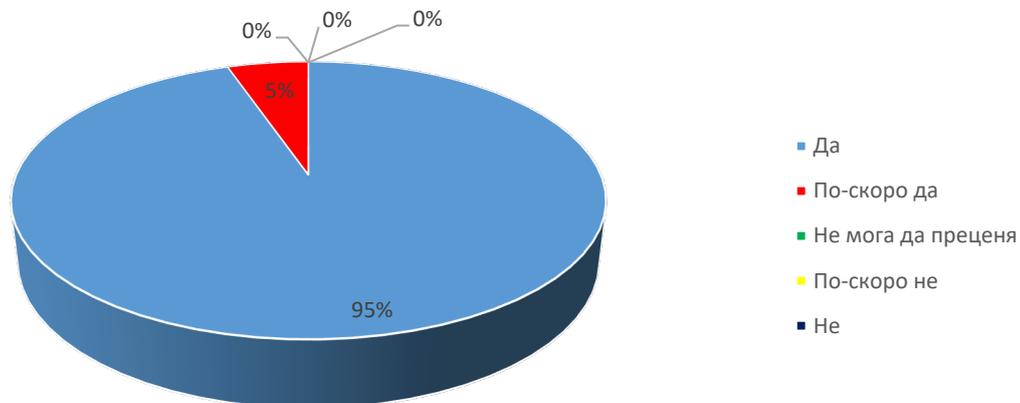
Question 3.

Въпрос 3: Организацията на обучението беше ли подходяща за Вас?

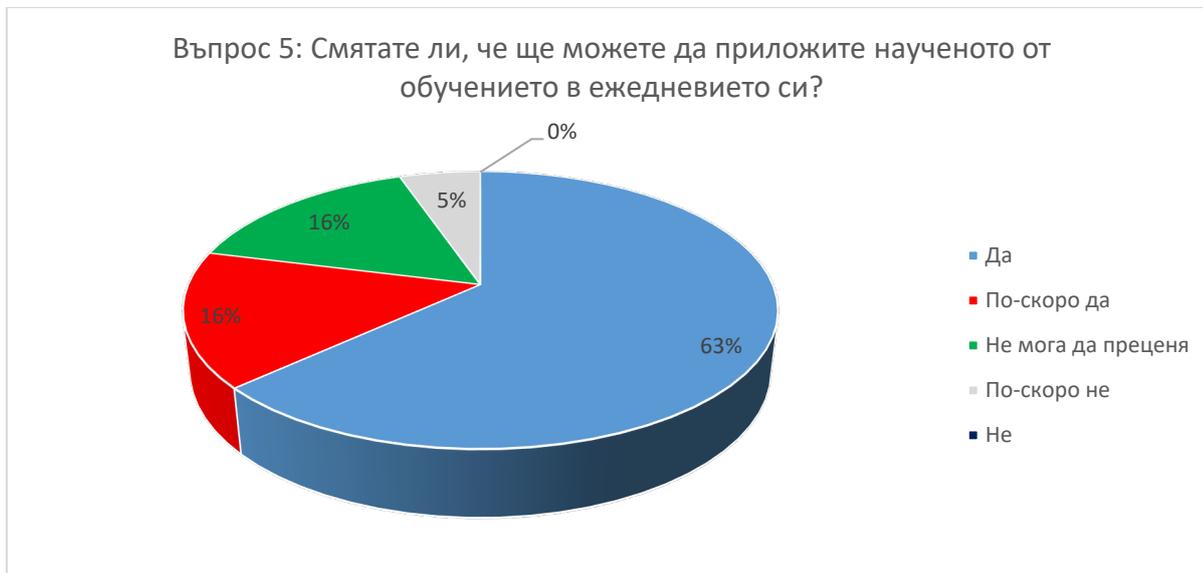


Question 4.

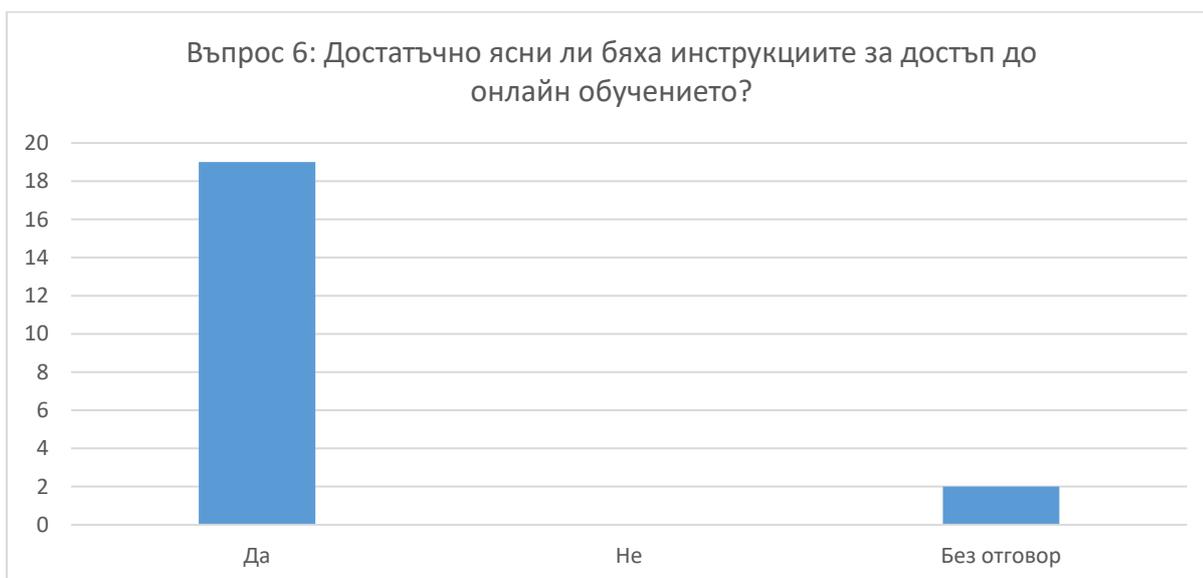
Въпрос 4: Смятате ли, че обучителите Ви предоставиха адекватна информация?



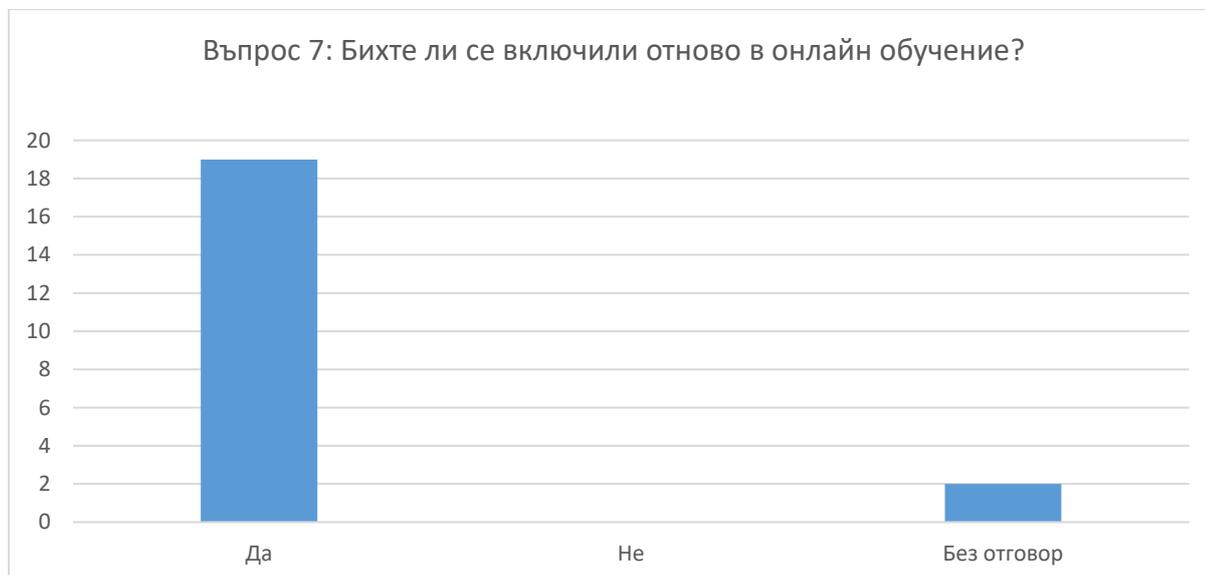
Question 5.



Question 6.



Question 7.



For the planning of the topics of the future trainings, the feedback from the participants gave us the desired information, to which topics they are most interested and consider them the most useful. To this end, open-ended questions have been asked, the answers to which we share with you.

Answers to sub-question 4 : [Proposals for changes in the Ordinance on Medical Expertise / please suggest changes that you consider necessary, as you understand them /](#)

As expected, proposals were given here, only by some of the respondents - 10 people (47.61%).

50% of them propose as a necessary change the persons who have permanent disabilities, without the possibility to improve their condition, to be certified for life. This high percentage is a clear reason that this proposal should be included in the report to the institutions to be drawn up at the end of the project, emphasizing its strong support.

20% of the respondents believe that when diagnosing TEMP, all diagnoses accompanying the underlying disease should be taken into account.

20% emphasize another desired change - It is necessary to revise the percentages for some high-risk diseases, which are currently low and determine a low% THP / can not be in people with genetic diseases over 3 years of age the disability rate is only 30%. The proposed disability rate is 50%, which would allow for state support.

Seen as a necessary change for 20% of respondents is the financial support provided by the state for people with rare diseases to provide the minimum for a dignified life.

20% also suggest that, as a necessary change, there should be more full-time employment opportunities for people with rare diseases, as well as 4 or 6 hours of employment with appropriate additional support from the state, so that these people have the resources to live normally and to take enough care of their health.

The same 20% of respondents wished as a necessary change to have better quality medical care and specialists who are familiar with rare diseases, a proposal that is submitted in response to other questions and many other respondents.

The percentages are over 100, because some of the respondents suggest several necessary changes.

Answers to Question 8, part I: What part of the training was most interesting and why?

19 people gave an answer here (90.48% of the respondents).

The most common answer given by 10 people (47.61%), which gives us a happy indication of well-planned training, is the Rights of People with Disabilities - Laws and Institutions, where 3 people (14.28%) explicitly emphasize that the two presentations of the expert to the Ombudsman Ivan Dechev were very interesting and useful for them.

Everything was interesting and useful to me is an answer given by 8 people, 38.09% of respondents.

2 people (9.52%) emphasize that the information about TEMC was very interesting and useful for them and define it as the most applicable.

2 people (9.52%) identified as the most interesting for them the third part of the training in which the participants had the opportunity to work on a case study and ask questions to the panelists.

The answer (1) that the most interesting to the respondent was the information about the driver's license gives us an indication that some details of the legally regulated assistance to people with disabilities are not well known to everyone and such information should not be omitted during the trainings.

2 people (9.52%) found the Presentation to be very interesting for the financial and social benefits to which people with disabilities are entitled / the Law on Integration of People with Disabilities.

The feedback on the perception of the discussion parts as "very important in order to clarify the matter" specifically written "in the regulations and laws" was very useful for the planning of future trainings. Giving concrete examples helps to clarify insufficiently clear texts. "

Answers to Question 9: Would you change or add to any of the parts and if yes – in what way?

As expected, a smaller number of answers were given to this question, which is explained by some of those who did not make specific proposals for changes or additions with "I do not consider myself competent enough".

Specific proposals for changes and / or additions or assessments were given by 8 people (38.09%)

There are proposals for changes only in the direction of the inclusion of cases after each part and in respect of one of the considered cases a proposal for inclusion of more information. Considering and resolving cases is considered very useful.

A proposed topic for inclusion in future education is for children with rare diseases.

Commented, but not as a weakness of the organization, but as a new type of unfamiliar online training, are "the few technical / internet problems we encountered."

An overall shared assessment of 5 of the specific answers given (62.50%) is that the training was very well structured and competently conducted, comprehensive and comprehensive and without the need for changes.

Answers to Question 10, part I: Do you think that other similar trainings are needed for people with rare diseases and if so - on what issues?

18 people (85.71%) of the respondents gave a positive answer that other similar trainings are necessary.

Surprisingly, the only answer is "NO", given that this respondent's answers to other questions show a positive attitude towards training (proposing a change "Inclusion and inventory of lifelong TEMP solutions, especially for incurable diseases and / or lack of limbs Additional attendance to be requested and allowed only in case of aggravation and at the patient's request "; identifies as the most interesting part of the training" Rights of people with disabilities - Laws and institutions ", states that he would not change or supplement any of the parts). But, of course, everyone has the right to an opinion and perhaps this respondent thinks that he / she has received all the necessary information.

The most common answers are: "Yes, they are definitely very necessary", with very valuable additional explanations "because people with rare diseases often feel confused and do not know who to turn to. The institutions in Bulgaria do not work uniformly enough and it happens that in order to solve a specific case you have to go around several social services and health specialists and get the answer "you are not for us"., In variants and "Yes, I think people do not know to what specialists to refer and are very late with diagnoses. They spin in a vicious circle. This is our healthcare system. Most doctors treat the consequences, not look for the causes of the disease "and" such training is rare and very necessary (and concerns not only people with rare diseases, but all people with disabilities). "

In response to this question, more suggestions are given for the inclusion of these in future similar trainings:

Trainings related to employment opportunities, where it is emphasized that one of the big topics that should be addressed is employment and motivation of employers to hire such people. Appropriate working conditions and remuneration - 3 people (16.67%)

To include information on the situation of people with rare diseases in other countries, formulated as "acquaintance with all patient organizations and initiatives supporting people with rare diseases not only in Bulgaria but also in the EU."

This is a proposal that the project planned to respond to with the involvement of the Norwegian partner FRAMBU Resource Center for Rare Disorders, which is already working to identify their good practices, innovative for Bulgaria and is waiting for this feedback to respond in the most appropriate way. of the needs and expectations of people with rare diseases in Bulgaria.

Training or a short guide with guidelines on what a person with a recently diagnosed rare disease should do step by step - what examinations to perform and where, what documents to collect, which specialists are the most proven in the field, which NGO could help, etc.

Training on discrimination in the workplace.

Trainings on the Social Services Act. The Child Protection Act and the Social Assistance Act, also formulated as "on the same issues (as the current training), including innovations and amendments."

www.activecitizensfund.bg

And the interesting proposal in future training "to emphasize psychological support, with specific examples of how to deal with a person with a rare disease, when due to the limitations to which his body has to put much more effort than healthy people, and at the same time it must be fought on an equal footing with them in order to have its place in the labor market or in other endeavors. '

And one of the answers to topics of future training is: "Medicines. Responsibilities. Providers. Deadlines. Pharmacy tourism. Problems. "

It is clear that there are many topics on which people with rare diseases need much more information, and within the EmpowerRARE project we will try to meet at least some of their needs.

Answers to Question 11, part I: What actions do you think should be taken to empower people with rare diseases?

There are 14 specific answers to this question in the survey, while the non-respondents most often give the answer "I have no suggestion" or "I do not think I am competent to answer."

Some of the answers given also indicate that the meaning of "empowerment" is not understood and therefore here we will give the interpretation of the European Patients' Forum about what is empowerment of patients:

EMPOWERMENT IS: A PROCESS THAT HELPS PEOPLE GAIN CONTROL OVER THEIR OWN LIVES AND INCREASE THEIR CAPACITY BY ACTING ON ISSUES THAT THEY THEMSELVES CONSIDER IMPORTANT.

THE DIFFERENT ASPECTS OF EMPOWERMENT ARE:

- self-efficacy,
- self-awareness,
- confidence,
- coping skills,
- health literacy

The main goal of empowerment is to strengthen the capacity and resources of the vulnerable group.

In order to achieve empowerment, it is necessary to inform, train, advocate, achieve equal cooperation / partnership with the current authorities to participate in the decision-making concerning the empowered decisions.

The specific actions proposed by the respondents are:

To prepare a program to support people with rare diseases and to monitor its implementation - proposed by 3 people (21.23%).

Wider participation in the meetings of the Committee on Rare Diseases with an advisory vote - submitted a proposal by 2 people (14.29%).

Instead of Ordinance 16, to accept all RARE DISEASES FROM WHO TO BE ON THE LIST (add the official name of the "list") - offered by 2 people (14.29%).

----- www.activecitizensfund.bg -----

The "Empowering People with Rare Diseases" Project is implemented with financial support provided by Iceland, Liechtenstein and Norway under the EEA Financial Mechanism.

Raising awareness about these diseases.

Non-profit associations, such as organizations of people with rare diseases, have the opportunity to contribute to the establishment of a disease registry, as well as to receive information related to the disease they represent

Informing the general public about the difficulties that such people are experiencing and what anyone could do, if they wish, to support them. By activating the victims and the society to put additional pressure on the relevant structures of the state to introduce favorable changes

Continuing training, including advocacy and civic activism

Proposals to be lobbied for are:

Expanding the possibilities for free genetic research, for their early detection and possible treatment

Opportunities for state-paid treatment abroad, if there are none.

Establishment of an institution familiar with all the rights of people with rare diseases and disabilities, to which the person or his relatives can turn and it can give specific guidelines and recommendations according to the individual case of the person, to be explained step by step the sequence and institutions to which the sequence and specificity of the documents can be addressed.

Creating a document that summarizes the information from all legal provisions and indicates the specific institutions and the order to which people with rare diseases or their relatives should turn.

Study of the needs of people with rare diseases and assistance in introducing legislative changes.

Specific commitment of doctors to people with rare diseases.

Social services and support, specialized according to the needs of people with rare diseases

Answers to Question 12, part I: Do you have other suggestions, comments or recommendations?

7 of the respondents gave specific answers to this question.

Proposed in future trainings are considered Practical issues of legislation - Ordinance 16, R&D, PLC, etc.

The survey should be created in a format for mobile phones or via Google form

Here again, the proposal to monitor more people with really special needs and to stop paying for fake heifers, which shows the importance for people who really have disabilities, to eliminate the possibility of abuse of their assistance rights is repeated.

To facilitate the procedure for issuing TEMCs.

Establish a mechanism for people without income through which they can benefit from the assistance.

Again, it is urged to abolish re-certification in the case of obvious incurable diagnoses. /Etc. Down syndrome, amputated limbs /

Creating a mechanism to ensure specific commitment of doctors to people with rare diseases, in the main areas and the possibility of their financial remuneration in order to be personally committed to the specifics of the

www.activecitizensfund.bg

The "Empowering People with Rare Diseases" Project is implemented with financial support provided by Iceland, Liechtenstein and Norway under the EEA Financial Mechanism.

disease and to monitor all current treatment options and follow-up care, which according to the submitter of the proposal would greatly contribute to a better future for people with rare diseases.

Make a register of rare diseases, if there is none.

To prepare a list of contacts of civil society organizations working in areas related to people with disabilities / rare diseases - in the country and abroad.

To the answers to this question the respondents in 2 cases have added an explicit expression of gratitude to the project team - for the sent visual information on the individual modules and our special gratitude for "the opportunity to participate in training that is of real benefit to people and work. as a social worker. "

In Part II, questions were asked about what they learned from the training, and below are the graphical results of the participants. Average success of IL of the multiple choice questions - 78%, which shows a very good success of the training and a contribution to better informing and empowering the participants.



THE EMPOWERARE PROJECT TEAM AGAIN EXPRESSES THANKS FOR THE VALUABLE INFORMATION FROM THE FEEDBACK!

WE WILL DO EVERYTHING IN OUR POWER TO MEET YOUR EXPECTATIONS AND TO CONTRIBUTE TO THE EMPOWERMENT OF PEOPLE WITH RARE DISEASES IN BULGARIA!

"This document was created with the financial support of the Active Citizens Fund of Bulgaria under the Financial Mechanism of the European Economic Area. The entire responsibility for the content of the document lies with the Bulgarian Huntington Association and under no circumstances can it be assumed that this document reflects the official opinion of the Financial Mechanism of the European Economic Area and the Operator of the Active Citizens Fund Bulgaria. "