



Brochure "LESSONS LEARNED"

INTRODUCTION

The importance of documenting, storing and using "lessons learned" from project implementation.

In the implementation of each project there are challenges that require adjustments in the course of the activity to achieve the planned results. Some of the planned activities sometimes exceed the expected result, while others fail to achieve it or do not achieve it in the planned volume and the desired quality. These are situations that require an analysis of the reasons for success or failure and the lessons learned, provide valuable information on what to plan and what to avoid in future projects. In recent decades, more and more attention has been paid to lessons learned based on an understanding of how important they are to avoid repeating mistakes and identifying successful actions that deserve to be applied in the future.

The lessons learned are based on the monitoring of the project implementation and the analysis of the main reasons for successes and failures or shortcomings in the implementation process. Lessons learned draw the importance of team members and partners collecting lessons, to discuss project successes, unintended results, and formulate recommendations for similar projects in the future. The approach and organizational culture of collecting lessons stimulates the team to discuss things that can be done in different ways, the root causes of problems and ways to avoid them in the later stages of the project.

The main purpose of collecting lessons learned is to generate information that is of practical benefit to the organization, professionals and other key stakeholders, identifying aspects that can be changed and generate action-oriented information and knowledge. The purpose of the lesson booklet is to incorporate the lessons learned from the project into a formal document for use by other leaders of similar initiatives. This document can be used as part of the new planning of such projects, determining what problems have arisen, how they have dealt with these problems and how they can be avoided in the future. In addition, this document describes in detail what went well with the project and why, so that other project managers can benefit from these actions.

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LESSON LEARNED 1 –
THE "WORKING UP" OF THE COORDINATING TEAMS OF THE PARTNERS IS
NECESSARY TO HAPPEN AS EARLY AS POSSIBLE IN THE PROJECT IN ORDER TO
HAVE ANYTHING

Name of the project (Project No ACF-231, Call Topic: SEC-12-FCT-2017)
Empowerment of people with rare diseases (EMPOWERare), financially supported by the ACTIVE CITIZENS FUND BULGARIA UNDER EEA FM 2014-2021
Duration of the project / activity (dates from - to)
October 2019 - May 2021
The activity in which the "lesson learned" is identified is carried out throughout the implementation of the project.
Number and title of the activity in which the "lesson learned" was identified
Activity 1 - Management and coordination of the project implementation
Country and organization that identified and documented the "Lesson learned"
Bulgaria, Bulgarian Huntington Association (BHA)

Brief description of the context

The problem.

For the implementation of a partnership project, especially when partnering for the first time, it is extremely important that the partners "work together" to overcome cultural and organizational differences and build mutual trust and good understanding. This is one of the main reasons for planning periodic working meetings of the partners' coordination teams in international partnership projects. The project has planned activities such as working visits and a bilateral seminar, which provide an opportunity for face-to-face working meetings and live discussion of the project implementation, which with the outbreak of the pandemic could not be implemented in compliance with the work schedule and was below question whether they will be able to be implemented at all. The problem that arose in the implementation of this activity was caused by the travel restrictions that followed the COVID-19 crisis, which prevented a "live" meeting to thoroughly consider and discuss the implementation of the project and in the process to clarify and overcome any differences. in the methods of work and in the organizational culture of the partners. The challenge here was the changed reality of the project with the need to continue its management and coordination only in a virtual team, in which it is much more challenging to build trust, respect and team spirit.

Solution found.

Although it requires more resources such as time, the logical solution was to move to online meetings and communication and to discuss the possibilities for maximizing the provision of information that would be collected and exchanged under normal conditions in "live" meetings and to a "virtual working visit" is planned, taking into account that the experts involved have in parallel with the current project, in which they have low hourly employment and other work commitments.

What worked well?

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The partners mobilized their human resources for mutual presentation of their organizational culture and methods of work in similar projects and in a series of different communications managed to clarify their capabilities, discuss decisions on the changed project implementation and reschedule it to a new change.

What didn't work well?

As expected, what did not work well enough or at least easily was to schedule workshops in a time convenient for both partners in the context of the pandemic, which disrupted the usual employment schedule and adherence to the initial planned project implementation schedule.

Recommendation:

In future projects to provide the possibility for cooperation in project management and coordination and only in a virtual team. To this end, to build and / or increase the skills of experts to work in online platforms. The recommendation that can be made to change the planning of future projects is to include in the budget a planned cost for using an online platform for conducting virtual meetings and trainings.

LESSON LEARNED 2

THE CHANGE OF THE CONTEXT REQUIRES CONSENSUS BETWEEN THE PARTNERS FOR PLANNING A REQUEST FOR AMENDMENTS TO LEAD TO ITS EXPECTED RESULTS

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Activity 1 - Management and coordination of the project implementation

Brief description of the context

The problem

The emergence of COVID-19, only a few months after the start of the project, the onset of the pandemic and the imposed restrictions on social events and travel until the end of the project made it impossible to implement "live" planned activities such as working visits and bilateral seminars. As these activities had a clearly planned contribution to the expected results, the partner project management and coordination team faced the difficult task of finding the best compensatory activities to minimize the

the adverse effects of the change in context and make it possible to achieve the expected results. The risk associated with cost planning and adherence to a schedule based on external dependencies has been identified in the meantime by reference to lessons learned from past projects.

One of the main challenges was the inability to conduct the planned working partner visits, the purpose of which was for the partners to get acquainted with the context in the other partner country, with details of work, achievements, plans for future development, identified needs and desires of service groups. of good practices and their transferability to the partnership context. This important activity obviously had to be done in order to achieve the main goal of the project - empowering the vulnerable target group of people with rare diseases in Bulgaria by raising their awareness of transferable Norwegian good practices and opportunities for future partnerships between organizations in Bulgaria. both sides. However, without the possibility to carry out the planned trips, it was necessary to change the activity with a change in the work tasks of the partners with internal rather than external identification and presentation of good practices, agreeing on a mechanism for assessing the portability of foreign practices.

Solution found

What is needed to make the right decision to change the implementation of the project requires: Evaluation of goals and objectives. Identify activities or areas that need further effort. Identify effective activities or strategies. Comparison of costs and results of different activities. Assessment of the roles of the organizations in the project and the interaction between the organizations. The need is to look for opportunities for positive changes in the design of the project, which would lead to a change in the situation that threatens the implementation of the project. In a partnership project, any change must be a collective decision agreed in the partnership. Logically, in a situation where the changed context required reformatting the project tasks of the partner experts, especially with a large out-of-project workload of Norwegian experts, both the scope of the new tasks and their distribution among the partners and over time required serious discussion and consensus on the change to be requested from the funding organization. In the first short online discussion of the need to request a change with an extension of the implementation period, the way to prepare the discussion of the amendment was agreed. Subsequently, it was agreed to implement a "virtual working visit" in order to acquaint the Bulgarian team in detail with the natural activities of the resource center. It was agreed between the organizations that the Bulgarian partner should propose the change as before, get acquainted with detailed written information about the activities of the Norwegian partner, at a working online meeting, to discuss opportunities for contribution of the Norwegian organization and in which areas of good Norwegian practice specific interest from Bulgarian party for further detailed presentation of the bilateral seminar, which would also have to be held online. The detailed presentation of good transferable practices during the bilateral seminar was considered most appropriate due to the participation of the target group of people with rare diseases and the possibility, through direct questions and feedback from the evaluation questionnaires to assess the level of interest of the target. group to certain practices and to some extent to the prioritization of various practices as a direction for the development of the Bulgarian organization. At an online partnership working meeting, the alternative possibilities for achieving the expected results of the project were discussed and a consensus was reached to request changes in the duration of the project and in its planned activities. It was agreed that the requested extension of the project implementation period will provide an opportunity in case of possible travel to Norway and improvement in the situation there, which will allow a real business trip, only the Bulgarian partners to realize their working visit, and the Norwegian partner if possible. to attend a bilateral seminar "live" in Bulgaria.

Approved these activities are postponed in time with the extension of the project and are conducted online in case of obvious impossibility to attend and after the extension of the project implementation time. In the meantime, all the necessary information on Norwegian good practice should be prepared with a view to possible online presentation.

What worked well?

The proposed approach for discussing the necessary and possible changes in the implementation of EMPOWERare proved to be very successful and ensuring the active participation of the Bulgarian and Norwegian partners in planning and approving changes to be requested by the donor. The partners reviewed the possibilities of their human resources for acceptance and implementation of the amended project tasks and agreed on a possible new work schedule for implementation.

What didn't work well?

There was no failure in planning the request for amendments.

Recommendation:

The prudent project manager understands that in order for their implementation to be effective, they need to stimulate additional contributions from other team members. Project managers need to gain experience in different implementation scenarios. However, when you do not have the necessary experience on a given issue, it is better to consult an expert with experience in the field. Successful project implementation requires managers to identify project threats and risks and take corrective action. One of the main responsibilities of the project manager is to take care of a number of critical tasks to ensure the success of a project, offering pragmatic solutions to meet their requirements within the specified time and budget. Project managers must be well-informed and work for a project that has a culture of continuous improvement from day one. There are many things to consider - not only to avoid mistakes and reduced risks, but also to extract opportunities and always improve the quality of the project. To ensure equal active participation of the management and coordination teams of the partners in the decision-making for requested changes in the project in case of significant change in the context of its implementation in accordance with the capabilities of each partner.

The recommendation that can be made is for several stages consideration of the necessary changes to ensure maximum use of the expertise of the partners, taking into account the possibilities of their work schedules.

LESSON LERANED 3 - PROVIDING MEDIA COVERAGE OF A STARTING PROJECT IN THE CONDITIONS OF MANY EVENTS REQUIRES A LONGER, DETAILED AND INDIFIED IND.

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Activity 2 - Implementation of the Communication Plan

Brief description of the context

The problem

The delayed start of the EMPOWERare project posed a challenge to its contractors from the very beginning - to hold the Opening Meeting with a press conference of the project in one of the busiest months - December and succeed to draw attention to its socially significant topics, goals, planned activities and expected results of the project and receive good media coverage. Unfortunately, press conferences to present start-up projects to civil society organizations usually do not enjoy much interest from the media, and this requires careful planning for communication with them.

After coordinating with the Norwegian partner the content of the presentation and the main opening messages, coordinating the opportunities for direct users to participate and finding a "window" for the event, the Opening Meeting with a press conference was held on December 23, 2019, on Christmas Eve.

Solution found

Our decision, as it turned out to be successful, to address this challenge, was not only to send personal invitations to interested media and journalists, but also to send them more detailed information, providing them with contact information with a expressed willingness to provide of interviews at a convenient time for them to take new steps to improve services for people with rare diseases.

It was emphasized that people with a rare disease may be small, but the number of rare diseases is large and with their approximate number of over 400,000 affected by rare diseases in Bulgaria is recognized by the National Strategy for Rare Diseases 2009-2013 that " patients with rare diseases represent a group with many unresolved problems of a medical and social nature that remain unknown and hidden from society. These people are vulnerable and discriminated against because some of their basic human rights have been violated, which makes their situation very socially significant.

In order to overcome the frequent neglect by the journalists taking note of the coverage of the financial support of the project, in the additional materials it was emphasized once again that the implementation of this project was made possible by funding from the Active Citizens Fund of Bulgaria with financial support from Iceland, Liechtenstein and Norway under the EEA Financial Mechanism. Our connection with media representatives was not only on the day of the press conference, but also after that, with activity on our part and readiness to accept the convenient time for interested journalists to meet with them.

What worked well?

As we considered that some of the journalists who would cover our project could be employed elsewhere during our press conference and it is important that the information provided by us arouses enough interest in them to wish to meet with us, we decided to We "individualize" the submitted additional information in addition to the general address to the press, expanding the scope of the information with specifically interesting information for health journalists. The good

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coverage of the project in general and specialized print and electronic media proved that this approach to obtaining media coverage works well.

What didn't work well?

As expected, what did not work well enough was the number of journalists participating in the press conference and the media they represented.

Recommendation:

And in future projects not to rely mainly on the announcement of the invitation for a press conference by news agencies, but to apply and send individual invitations to the media and journalists along with detailed information material on interesting and socially important areas of the project.

The recommendation that can be made for a change in planning future projects is to maintain and continuously expand the list of contacts with the media and individual journalists who have shown interest in the topic, even if they have not covered it, to monitor the media for identification of new publications and journalists covering similar topics. To establish relations of cooperation with employees in similar organizations and institutions for exchange of contacts with media and for the possibility to use their media for dissemination of information about projects. To carry out media monitoring of the coverage of the projects with analysis of their coverage in the own and external print and electronic media.

LESSON LEARNED 4 - MAXIMIZING THE USE OF OWN MEDIA

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Activity 2 - Implementation of the Communication Plan

Brief description of the context

The success of the use of own media to disseminate information about the goals, tasks, planned activities, expected results and progress in the implementation of a project depends not only on the promotion of these media, but also on tracking the interest in them and strengthening the use of own media in which there is interest.

The problem

The activity envisages periodic announcement of the progress and results in compliance with the requirements for publicity and visualization. At the beginning of the project implementation at two working meetings the management and coordination team and the expert team for

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project implementation reviewed the events on the schedule and identified the appropriate content of the specified number of project bulletins.

With the emergence of the phenomenon of the COVID-19 pandemic, the implementation of a number of planned activities related to travel and gathering of groups of people is hindered by the imposed restrictions in territorial relocation and social communication, which affects the planned content of project bulletins. more importantly, the dissemination of information and the use of communication channels with a proven interest in them. The feedback from the direct users proved their interest in the project newsletter, but also raised the issue of the need for new and more frequently distributed content, for which it was considered that the planned 5 project newsletters were not enough.

Solution found

The solution found to the problem was to increase the number of project bulletins above the planned ones and to determine their content according to the new time implementation of the activities, reflecting their change and enriching the content according to the interest of direct users to a certain topic.

What worked well?

It has been proven that in case of interest shown by the direct users to a certain element of the Communication Plan, the strengthening of the activity above the planned one contributes to the activation of the users and to the increase of the information received from the feedback. Specifically, the interest in the project newsletter can be noted through its promotion of the active involvement of representatives of the direct users in the role of experts in practice as trainers in the project training for authorization.

Their brief presentation on the pages of the newsletter motivates other users to state their opportunity to contribute and provide their knowledge and skills in support of group capacity building.

What didn't work well?

It is logical that the observance of the pre-planned content of the project bulletins did not work due to the strongly changed context of the implementation and the necessary change in the manner and time of implementation of the project activities in order to preserve the possibility to achieve the planned results.

Recommendations:

If there are enough different events in the project to plan more issues of the project newsletter with a frequency of, for example, 3 months, not 6 months.

LESSON LEARNED 5 - JOINT FORMULATION OF MAIN MESSAGES WITH PROJECT BENEFICIARIES

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Activity 2/3 Implementation of the Communication Plan / Empowerment through training

Brief description of the context

The importance of the main messages of the project disseminated is great, as they give a public face to the project and ensure the increase of public awareness of the socially significant problems to the solution of which the specific project plans to contribute.

The problem

The conversations with representatives of the media and interested institutions and individuals once again highlighted the need to formulate an impact not only among the target groups, but also among the general public key messages of the project. And while the stakeholders and institutions in the field of the project had, if not always in-depth, then at least the most basic knowledge on the subject of the situation of people with rare diseases in Bulgaria, our conversations with journalists outside those in specialized health publications and with people from the general population,

which we specifically conducted to assess public awareness of the subject showed us that what they most often "hear" is the word "rare" with the interpretation that these are diseases that affect a small number of people in general and so on, although they assessed the importance of the discrimination of this vulnerable group recognized in political documents, they perceived it as a violation of the human rights of a small number of people.

Of course, one of the main messages of the project was the motto of the UN Sustainable Development Goals: "Nobody should be left behind".

But this public reading of "rare diseases" mainly as "rare", ie rarely affecting people, pointed us to one of the focuses of a message that should be formulated and sent to institutions and the general public - the large number of vulnerable and discriminated people , whose basic human rights have been violated, as they are not integrated into social policy and services, and their specific and urgent needs are not met.

Solution found

Communication is vital to the success of the project. If there is a lack of good communication in the team, it will be difficult for you to identify the root cause of the problem when things go wrong. Without proper communication, it is impossible to deal effectively with the problems of the project. The task of contributing to the formulation of project messages was assigned to the direct users as a group task and as a search for individual contribution with a planned follow-up discussion for approval before use.

It was important to explain that each proposal is valuable and will serve to achieve the planned results of the project as a feedback on what direct users believe should become part of public awareness and / or raise awareness of stakeholders and decision makers. in the field of important problems in the lives of people with rare diseases.

The most promising for raising the level of public awareness and understanding of the problem was considered to be the dissemination of proven global messages, combined with messages formulated in the project, in accordance with the national context.

What worked well?

What worked well in the project was the mobilization of all participants - both experts and direct users - to select messages for distribution (such as the message of the International Day of Rare Diseases "We are 300 million", the global message "Together we are strong", the motto of the movement of people with disabilities "Nothing for us, without us" as a request for the need for empowerment, the current message of the European Reference Network for Neurological Diseases "Huntington's disease and COVID-19 - a difficult combination" and joint formulation of impact messages. To formulate the main messages, discussions were held in an online project meeting of the partners, individual and group meetings with the direct users, with other organizations of people with disabilities, consultants and experts at the BHA.

What didn't work well?

Unlike the active feedback from the direct users, regardless of the sent information materials with messages about the condition of the people with rare diseases in Bulgaria to institutions, there is still no feedback from them. And although this can be partly explained by the state of emergency caused by the COVID-19 pandemic, this lack of feedback and reaction from the institutions concerned shows that there is a great need for advocacy and civic activation of people with rare diseases in defense of the law. their equality in social policies and health care.

Recommendations:

To be involved in the formulation of the main messages of the project, as consultants a wide range of stakeholders in support of direct users and experts in the project.

To be used in the future not only specific messages formulated in the project, but also globally disseminated messages of the global vulnerable group, part of which are the direct users and the target group of the project. To use all communication channels and to periodically disseminate the messages agreed upon in the direct users during each project event.

LESSON LEARNED 6 - A SUCCESSFUL TRANSFER OF GOOD PRACTICES CAN ALSO BE CARRIED OUT IF IT IS IMPOSSIBLE TO MAKE THE PLANNED TRAVELS BY NEGOTIATION OF CONTRACTING

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The activity in which the "lesson learned" is identified is implemented in the second part of the project implementation

Number and title of the activity in which the "lesson learned" was identified

Activity 3 - Sharing experience and good practices for building partnerships

Brief description of the context

The problem

The COVID-19 pandemic had a strong impact on the implementation of the planned activities of our EMPOWERare project, preventing the implementation of the planned activities "live" Working visit of Bulgarian experts and users in Norway and conducting a bilateral information seminar for presentation / introduction to the good practices and experiences in support of people with rare diseases in both partner countries. This posed an unexpected challenge to the project team since

as the acquaintance with the Norwegian experience and good practice in providing support to this vulnerable group and especially the Norwegian experience in its empowerment was planned to serve in organizing and conducting empowering trainings.

Solution found

The impossibility of holding these events necessitated the search for a compensatory solution for obtaining at least partial, if not directly acquired initial information about the Norwegian experience and good practice, which would serve us in empowering consumers. This opportunity naturally burdened the project contractors with additional unplanned work - a problem that is subject to discussion with the funding institution in the direction of a possible adjustment in the budget.

The presentation of developed information material on good Norwegian practices and experience in the field of support for and empowerment of people with rare diseases by the Norwegian partner and its translation into Bulgarian as an initial presentation enabled the Bulgarian partner to make a first assessment of their portability in the local context. and discuss with beneficiaries priorities in the transfer of practices.

The second step in the corrective solution found was a detailed presentation of Norwegian good practices at a bilateral webinar, replacing the planned bilateral attendance seminar with the possibility of clarifying questions and answers and arranging between partners to provide additional information after the webinar where needed.

What worked well?

The consensus reached between the partners for online presentation of good Norwegian practices and focus on transfer on good practices, prioritized by the beneficiaries in consultation with them, worked well according to the feedback from the direct users of our project. We were given a presentation of the main experience of our Norwegian partner FRAMBU, which was translated into Bulgarian, uploaded on the project website and reflected in the next issue of the project bulletin to ensure the possibility of widespread acquaintance of users with possible transmission practices and to increase their awareness of the areas in which the partnership between the Bulgarian and Norwegian organizations could continue. Providing sufficient time to provide feedback between the disclosure of good Norwegian practices and the holding of a bilateral seminar with a detailed presentation of the practices by Norwegian experts worked well. The activity of the users during the bilateral seminar by asking clarifying questions proved that the previous acquaintance with the Norwegian practices worked well, allowing the practices to be meaningful and evaluated.

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What didn't work well?

There is no part of the corrective activity that did not work.

Recommendation for change when planning future projects

The COVID-19 pandemic confronted us with an unexpected challenge, but also gave us a valuable lesson for another risk before the implementation of a project, which we should anticipate when developing future projects, as well as to bet at the level of project proposal development. action in the event of such a risk.

LESSON LEARNED 7 – JOINT PLANNING OF TRAININGS WITH THE TARGET GROUP HELPS TO RESPECT THE REAL LEARNING NEEDS OF DIRECT USERS.

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Activity 4 - Empowerment of people with rare diseases through training

Brief description of the context

The trainings in the project were planned on the basis of a previous study of the training needs of the direct users. Nevertheless, in the period between the development of the project, its approval for funding and the start of its implementation, the dynamics of continued provision of information and changes in the legal framework and provision of services introduced changes in the need for targeted information and training needs.

The problem

From the conversations with the direct users before the beginning of the trainings and during the first training their desire for more detailed acquaintance with the occurred legal changes and discussion of the practice of their application, as well as their desire for more detailed acquaintance with the good foreign practices on time of conducting the trainings and bilateral events empowering them, as well as acquainting them with their possibility and rights to demand equal integration in the social policy and services, and meeting their specific and urgent needs.

Solution found

In order to achieve real empowerment of the target group of the project, which undoubtedly requires the best possible coverage of their stated training needs, it was decided to stimulate feedback after each training by announcing and complying with the content of future trainings with the identified educational desires of direct users. In response to the stated desire of people

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with rare diseases to expand the sharing of experiences and practices with other people living with rare diseases, it was decided to include in the project trainings as trainers and people with rare diseases as experts in practice.

What worked well?

What worked well in the project was the mobilization of all participants - both experts and direct users - for joint training planning.

What didn't work well?

In principle, the decision worked well with the stipulation that due to the large age range of the participants in the trainings and their different level of preliminary training, it was not always possible to plan and conduct trainings equally interesting for everyone.

Recommendation

To plan at the beginning of a training project a new study of the training needs to identify changes in the priority interests of the trainees and their attitude to the proposed training topics. To be used in the future for joint planning of trainings with direct users in areas in which they have expertise, as in the case of this project. And in future projects to be involved as trainers experts in practice

LESSON LEARNED 8 - STIMULATING ACTIVITY IN TRAINING AND FEEDBACK IS NECESSARY FOR CHANGING IN THE CONTEXT

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**Number and title of the activity in which the "lesson learned" was identified
Activity 4 - Empowerment of people with rare diseases through training**

Brief description of the context

The problem

Although the group of our direct users is the people with rare diseases, in the project proposal we have written that the participants in the trainings will be selected according to their degree of disability, which will allow them to be active. Unfortunately, the COVID-19 pandemic prevented us from conducting the planned motivating and evaluating trips in the country and our invitations to participate in trainings and motivating messages to direct users had to be addressed individually, which helped us to know this specific vulnerable group of our previous many years of work with them. In the circumstances of the state of emergency, some of the

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direct users, who in normal training in 3 settlements with participants selected and motivated on a regional basis, would be covered in the training, now could not join for technical reasons - lack of personal computers and / or internet connection, which we had planned to allow provided that part of our project - the technical and information equipment of the users for telerehabilitation, was denied funding. The trainings conducted by the project are a practical test of how the existing offline techniques can be applied in an online context, but there is still not enough experience in this area.

Solution found

The solution found for identifying active and interested people in training for empowerment of direct users worked well, although it somewhat limited the access of some possible representatives of the vulnerable group to the training. The implementation of motivating activities was done through additional work of the project staff with telephone calls, e-mail and other Internet methods such as Skype discussions to clarify the possibilities for inclusion of individual users and stimulate their interest in empowering training.

What worked well?

The result of our motivating and activating activity is extremely good. All participants in our trainings show a high level of activity in case studies and discussions and provide very valuable information with their feedback through their answers to the rather long and detailed evaluation questionnaires filled out after each training. The inclusion as trainers in the project of experts from the direct users proved both the great potential of the vulnerable group of people with rare diseases and the importance of their participation as trainers, because with the extremely small number of specialists in rare diseases in Bulgaria, educated and intelligent users often have in-depth knowledge of their disease from self-education and monitoring the development of research and advances in treatment in the field directly affecting them.

What didn't work well?

The well-planned wide inclusion of direct users from all planning regions in the country and in particular the desired widest possible inclusion of users from minority groups, including Roma, from remote geographically disadvantaged regions could not work. However, we must take into account that representatives of ethnic minorities also took part in the trainings and we managed to provide participants in the trainings from 7 districts of the country, who provide us with valuable data on local conditions with access to information and social services.

Recommendations:

When developing future similar projects, both actions should be planned to overcome risks such as the coronavirus pandemic with its subsequent limitations, and active participation of representatives of the direct users as trainers in project trainings. And in future projects to encourage the use of techniques that ensure effective exchange of thoughts and ideas. Learners to participate in the creation of online content.

The transition from knowledge to action is essential, as people who are relevant to the topic often have a desire to act. As in this project, avoid focusing only on legal issues, which is not enough to activate a vulnerable group. Using real-life stories of real people to solve cases stimulates empathy, evokes emotions, provides a shared context, triggers memories, and creates a desire for protection and counteraction through advocacy. To provide an opportunity

for participants to contribute to the training, thus contributing to mutual learning and encouraging further activities. A scientific lesson from the feedback is that many participants expect to have access to more resources after the training. It is therefore advisable to create and supplement a digital platform of appropriate resources available before the training, as in this project, to be regularly updated.

LESSON LEARNED 9 - ADVOCACY THROUGH ADVOCACY STIMULATES THE CREATIVE THINKING OF SERVICE USERS AND ENCOURAGES THEM TO ANALYZE OWNERSHIP

Name of the project (Project No ACF-231, Call Topic: SEC-12-FCT-2017)
Empowerment of people with rare diseases (EMPOWERare), financially supported by the FOUNDATIVE CITIZENS FUND BULGARIA UNDER EEA FM 2014-2021
Duration of the project / activity (dates from - to)
October 2019 - May 2021
The activity in which the "lesson learned" is identified is implemented during the second part of the project implementation.

Brief description of the context

The problem:

Difficulties in the implementation of Activity 5 in compliance with its set time schedule were reported during the development of the project proposal with its dependence on external factors, such as: difficulties in agreeing on convenient dates and times for working meetings of the Consumer Advisory Board, weak activity of involving the trained users in their advocacy campaign. With the onset of the COVID-19 pandemic, which required mostly online work, fortunately the members of the Advisory Consumer Council, planned as the target group's organizational center, had the technical means and skills to use them to conduct online meetings, thus avoiding the danger of untimely collection at key moments of implementation. However, the problem with the impossibility to guarantee the inclusion in advocacy of trained users from all regions of the country without holding the planned motivational meetings in places and trainings in all regions.

Our invitations to join the advocacy campaign and our motivational messages to direct users had to be addressed individually, which became possible only thanks to our knowledge of our specific target group of previous activities with people with rare diseases. The activity envisages activating people with rare diseases in an advocacy campaign for their rights to equality, initiated and implemented by them, with the support of the project team to further develop their capacity for social activity and supportive motivation in case of difficulties.

The Advisory Board, supported by the project team, initiated an advocacy campaign for the rights of people with rare diseases by encouraging people with rare diseases to participate in the development of advocacy materials and the preparation of materials for project and social media publications as part of the advocacy campaign, incl. . told stories about the practice of

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receiving services from institutions (good practices and negative experiences) and preparation of presentations by the end users of the Final Round Table. In the circumstances of the state of emergency, a part of the direct users, who in normal trainings in 3 settlements with participants selected and motivated on a regional basis, would be covered in the trainings and prepared for advocacy, now could not participate technically. reasons - lack of personal computers and / or internet connection or poor online skills.

Solution found

The solution found for the activity in the changed context was to keep the maximum possible for implementation in the changed social conditions and to strengthen the motivational activity Online to pass those parts of the activity that are impossible to carry out as planned as the Consumer Advisory Council as organizer and coordinator. The Advocacy Campaign has stepped up its efforts to mobilize people with rare diseases to engage with their experiences and experiences with institutions so far in discussing obstacles to their equality and what could help to improve their situation as measures adopted by responsible institutions. It was agreed that parents, young people - children of people with rare diseases, other relatives and NGO activists will be invited to join the campaign.

What worked well?

With the joint efforts of the Consumer Advisory Council and the project implementation team, an advocacy campaign was successfully organized and conducted, with people with rare diseases actively participating in it, working on the preparation of advocacy materials and submitting their requests to institutions. The involvement of practical experts from direct users in the advocacy campaign proved both the great potential of the vulnerable group of people with rare diseases and the importance of their participation as people living with rare diseases and directly experiencing large deficits in the support provided due to the extremely small number. specialists in the field of rare diseases in Bulgaria, who have often acquired in-depth knowledge of their disease through self-education and monitoring the development of research and achievements in treatment in the field directly affecting them. The expected two-pronged result of the advocacy campaign was achieved: (1) to increase the capacity of consumers to disseminate information about a problem concerning them, to build support and find allies, and (2) to provide useful feedback to public institutions. Consumers learned the skills needed for the 5 steps of advocacy: identifying, researching, planning, acting, and evaluating, and how to build a support coalition after identifying stakeholders as opponents, neutrals, or opponents of their cause.

What didn't work well?

The well-planned wide inclusion of direct users from all planning regions in the country and in particular the desired widest possible inclusion of users from minority groups, including Roma, from remote geographically disadvantaged regions could not work, as they did not have the technical tools and knowledge to work online. However, we must take into account that representatives of ethnic minorities also joined the project and we managed to provide participants from 7 districts of the country to provide us with their experience and valuable data on local conditions of access to information and social services.

Recommendation

In the development of future similar projects to continue to plan advocacy activities with the active involvement of direct users, if necessary with prior preparation for advocacy and the transition from knowledge to action. Ensure maximum publicity of advocacy so that not only public institutions and other stakeholders, but also the general public are made aware of the issues that have created the need for an advocacy campaign.

LESSON LEARNED 10 - ANALYTICAL ACTIVITIES SHOULD INCLUDE THE ASSESSMENT OF DIRECT USERS.

Name of the project (Project No ACF-231, Call Topic: SEC-12-FCT-2017)

Empowerment of people with rare diseases (EMPOWERare), financially supported by the ACTIVE CITIZENS FOUNDATION BULGARIA EEA FM 2014-2021

Duration of the project / activity (dates from - to)

October 2019 - May 2021

The activity in which the "lesson learned" is identified is implemented during the second part of the project implementation.

Number and title of the activity in which the "lesson learned" was identified

Activity 6 - Analytical activities - research and reports

Brief description of the context

The problem

The greatly changed context of project implementation with the onset of the COVID-19 pandemic and the resulting restrictions on travel and gatherings became an unforeseen external risk to the project's implementation according to its planned methods. To achieve the expected results, it became necessary to plan corrective actions. Initially, the study of consumer needs was planned to be conducted with a survey and in-depth interviews conducted with trips to all areas of the country and followed by comparison and analysis of data to develop the planned analytical reports. Subsequently, it was necessary to significantly reduce the planned trips and meetings with final beneficiaries and the implementation of short and planned ones. The anticipated risks in the development of the project were possible low level of activity of users to answer the surveys and to participate in in-depth interviews and low activity to express opinions about their level of satisfaction with access to services and the quality of available services, as well as reluctance. for inclusion in the Consumer Assessment Report.

Unfortunately, the COVID-19 pandemic prevented all planned motivating and evaluative trips in the country from taking place and invitations to participate in the research and motivational messages to direct users had to be addressed individually, which helped us to know this specific vulnerable group of our previous many years of work with them. In the circumstances of the state of emergency, some of the direct users could not join for technical reasons - lack of personal computers and / or internet connection, which we had planned to resolve given that part of our project - the technical equipment of users for telerehabilitation, funding was denied.

Solution found

The management decision found and taken to overcome the negative impact of the changed public context with the pandemic was to stimulate the maximum online involvement of consumers in the assessment of the areas to be analyzed. In order to provide more answers from activated users, questions from the areas of research of the analytical reports were asked after the trainings with a very detailed evaluation questionnaire. Meetings in the country to conduct in-depth interviews were difficult due to the pandemic, but several meetings with individual users were pre-directed, and most of the data was collected online. A management decision was made to collect feedback from users online after the trainings and through targeted interviews seeking the widest possible geographical coverage from the respondents.

What worked well?

The collection of data from users worked well with the long and detailed questionnaires after the trainings and their activation for participation in an online survey through a survey to assess the needs for support and services. There has also been a successful inclusion of experts in practice to contribute to the report on the study and assessment of the availability of services and support, as well as to contribute to the formulation of recommendations to the Opinion with recommendations on the need for health and social support reforms. people with rare diseases.

What didn't work well?

The well-planned wide inclusion of direct users from all planning regions in the country and in particular the desired widest possible inclusion of users from minority groups, including Roma, from remote geographically disadvantaged regions could not work, as they did not have the technical tools and knowledge to work online.

However, we must take into account that the project involved representatives of ethnic minorities and we managed to provide participants from 7 districts of the country to provide us with valuable data on local conditions of access to information and social services. Despite the pandemic, the team also held several live meetings, which were pre-planned in three regional cities with interested representatives of end users.

Recommendations:

When developing future similar projects, continue to plan the chosen methodological approach for research with active involvement of users, which ensures equal access of project participants, availability of Internet-based and paper questionnaires and a variety of respondents with the most comprehensive presentation of feedback. link for satisfaction with the activities, providing for the possibility of its application online.

To plan in other future projects when involving the participants by the users to evaluate their activity and the proven during the consultation period ability for analytical evaluation of information. The target group to participate in the transition from knowledge to action. To ensure the maximum opportunity for the contribution of the authorized participants, thus contributing to mutual learning and encouraging further activities. To continue to provide for the publication of research reports as well as the general public through the online presentation of the reports, to hear the voice of people with disabilities in advocacy for access to their desired changes.

CONCLUSION

Identifying, documenting, storing and future use of lessons learned from any organizational activity is crucial for any organization that wishes to develop by avoiding the repetition of its mistakes and applying practices that have proven to be good. At the beginning of the project, the two partner organizations in the implementation of the project reached an agreement on the organizational culture of collecting, analyzing and subsequent use of lessons learned and that the activity of documenting lessons learned from successes and possible failures in organizing and conducting project activities is one of the important activities in the EMPOWERare project.

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