

ELPIDA: “E-learning platform for intellectual disability awareness”

Grant Agreement: 2017-1-EL01-KA204-036367



Evaluation Study

Part B of Intellectual Output 1 *Two Research Studies*

FINAL VERSION (of Part B)

DATE: 15/08/2019

ERASMUS+

KA2 –STRATEGIC PARTNERSHIPS FOR ADULT EDUCATION



Co-funded by the
Erasmus+ Programme
of the European Union



Intellectual Output:	IO1, Two research studies: <i>Evaluation Study (Part B of IO1)</i>
Authors:	Kasimatis Vasilis & Giannakopoulou Christina Social Enterprise PUZZLE e-mail: info@puzzle-se.eu
Contributors:	CSB, IB, OSLOMET, EPA, FORTH
Status, Version No.	Final of Part B
Submission date:	15/08/2019
Start Date of the Agreement:	1 October 2017
Duration of the Specific Agreement	24 Months
Project coordinator:	Kathy Kikis-Papadakis, FORTH/IACM katerina@iacm.forth.gr
Financing:	With the support of the Erasmus+ programme of the European Union

This project has been co-funded from the Erasmus+ programme of the European Union.

The European Commission support for the production of this publication does not constitute an endorsement of the contents which reflects the views only of the authors, and the Commission cannot be held responsible for any use which may be made of the information contained therein

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SUMMARY

During the ELPIDA project, an e-learning platform was produced for parents of people with intellectual disability (PWID). The topics of the learning material were chosen based on a needs assessment study that was carried out at the beginning of the project. Six modules were developed focusing on issues around human rights, communication, stress management, transition to adulthood, sexual health and ageing. Several actions were taken in order to evaluate the usefulness of the ELPIDA e-learning platform, including registered users activity, questionnaires, focus groups and collecting feedback from parents and professionals who had used the platform. The results suggest that the training material available on the e-learning platform is useful not only to parents/carers but also for professionals and that it is presented in an interesting and engaging way.

INTRODUCTION

The importance of parents’ participation in the upbringing, training and in the overall support of people with intellectual disability has been repeatedly reported.

Despite the value and importance of *parents’* participation, their *education and support, as well as their overall training is insufficient in relation to the significance of their role but also in terms of the better functioning of the family and the support of people with disability.*

Parents’ education aims to meet specific needs, difficulties or questions that families face every day in the upbringing of their child. Among its goals, it is to deal with real needs and work on these so that children can become integrated adults. More specifically, parent education *refers to activities that enhance parents’ knowledge on their child’s development, help parents acquire skills in order to strengthen parent-child relationships and promote appropriate care and support to enhance a child’s health, and to support a child develop social and psychological skills throughout his/her life. Overall, parent education aims to improve the quality of life not only of the children but of parents as well.*

The ELPIDA project aimed to meet the training and support needs of parents of people with intellectual disability (PWID) by creating an educational e-learning platform containing educational material on six areas of interest.

A needs assessment study was initially carried out in order to examine and verify the need for further support and training for parents of PWID. It also looked at *the parents’ real training needs and interests through the use of a questionnaire.* The results of this study informed the content of each module, therefore tailoring it to the interests and needs expressed by the parents. The topics of *the six modules* that were developed and *included in the e-learning platform* were: *stress management, communication, transition to adulthood, human rights, sexual health, and ageing.*

Taking into account the needs of every adult parent, who has limited free time, we decided to *approach parents’ education through e-learning* so they can begin, take part and complete their training at their own pace and at a convenient time for them rather than through conventional ways of education (e.g. seminars) that they might find difficult to attend. Moreover, e-learning offers the flexibility to choose the topics that are of interest/relevant to



each participant. Finally, it can be accessed from across Europe and the material was made available in six languages (Danish, English, German, Greek, Norwegian, and Portuguese).

EVALUATION STUDY

The ELPIDA project aimed to provide parents of people with Intellectual Disability (PWID) skills and knowledge in order for them to feel more confident and competent to provide support and empowerment to their children with intellectual disability (ID). We believed this knowledge would have a positive impact on people with ID and would contribute to a better transition to adulthood, social inclusion, and better quality of life in general. ELPIDA aimed to achieve this goal by developing a free-to-use e-learning platform, which contains interactive educational modules providing more training, awareness raising and/or attitude change on key areas and are available in six languages (Danish, English, German, Greek, Norwegian, and Portuguese).

In order to evaluate the usefulness and effectiveness of the e-learning platform, we undertook various actions aiming at collecting quantitative and qualitative data. More specifically, data was collected through registered users activity, questionnaires, focus groups and discussions with parents and professionals who had used the platform.

STUDY OBJECTIVES:

The main objectives of the study are:

- A. To explore to which extent the e-learning platform met the needs and expectations of the participants*
- B. To explore the effectiveness of the e-learning platform at increasing knowledge level and/or changing attitudes*
- C. To explore ways the e-learning platform could be improved*

INFORMATION ON REGISTERED PLATFORM USERS

Looking at the number of people who registered in the ELPIDA e-learning platform (see Table 1), there are over 375 participants across Europe. The big percentage of Norwegian participants might be due to the fact that they are more familiar with distance learning courses and the use of computers/internet. Moreover, it seems that all modules attracted participants and that overall, the e-learning platform reached across to a quite large number of people who wanted to gain more knowledge and acquire new skills to better support people with intellectual disability.

This is also confirmed looking at the activity logs, showing that the majority of users accessed the material several times, going back either to complete a module or to participate in a new one (see Table 2).

LANGUAGE	HUMAN RIGHTS	COMMUNICATION SKILLS	STRESS MANAGEMENT	TRANSITION TO ADULTHOOD	SEXUAL HEALTH	AGEING	TOTAL NO OF REGISTERED USERS
DANISH	4	6	11	1	1	1	13
ENGLISH	24	16	18	18	19	17	34
GERMAN	7	8	6	4	4	5	28
GREEK	15	9	15	9	11	3	45
NORWEGIAN	52	28	19	102	92	14	241
PORTUGUESE	2	1	3	2	1	1	18
TOTAL							379

TABLE 1: NUMBER OF REGISTERED USERS

	English	Greek	Norwegian	Danish	German	Portuguese	TOTAL
Pre-course questionnaire	34 views 9 users	24 views 15 users	105 views 73 users	11 views 6 users	13 views 9 users	7 views 3 users	194 views 115 users
Course discussion forum	2 views 2 users	-	-	-		-	2 views 2 users
Glossary	58 views 6 users	149 views 13 users	85 views 40 users	5 views 2 users	5 views 3 users	2 views 1 user	304 views 65 users
Announcements	31 views 15 users	12 views 9 users	31 views 30 users	3 views 1 user	9 views 4 users	4 views 1 user	90 views 60 users
Human Rights & Employment	2490 views 24 users	365 views 15 users	837 views 52 users	239 views 4 users	326 views 7 users	123 views 2 user	4380 views 104 users
Communication	2613 views 16 users	523 views 9 users	513 views 28 users	249 views 6 users	252 views 8 users	114 views 1 user	4264 views 68 users
Stress Management	2326 views 18 users	397 views 15 users	227 views 19 users	526 views 11 users	301 views 6 users	52 views 3 users	3829 views 72 users
Transition to adulthood	2957 views 18 users	230 views 9 users	1995 views 102 users	152 views 1 user	418 views 4 users	143 views 2 users	5895 views 136 users
Sexual Health	2923 views 19 users	326 views 11 users	1700 views 92 users	280 views 1 user	309 views 4 users	10 views 1 user	5548 views 128 users
Ageing	2426 views 17 users	162 views 3 users	519 views 14 users	203 views 1 user	332 views 5 users	78 views 1 user	3720 views 41 users

TABLE 2: NUMBER OF USERS AND VIEWS

QUESTIONNAIRES

METHODOLOGY

The study’s preparation and implementation phases spanned from *February 2019 to July 2019*. The sample was made up of 50 participants from Norway (N=33), Greece (N=14), Denmark (N=2), Germany (N=3), Romania (N=1), Austria (N=1), Croatia (N=1) and Serbia (N=1).

STEP 1. PREPARATION

Three questionnaires were developed to be filled in by each participant at different stages. These questionnaires aimed at collecting data on the knowledge level and/or attitudes of the participants before and after the completion of the module(s). More specifically, the participants were asked to complete a questionnaire before starting a module, after the completion of the module(s) and at 3-month follow-up. The questionnaires were developed in English in order to have an interactive approach where all project partners could provide feedback. Upon finalisation, the questionnaires were translated into Norwegian, Danish, German, Portuguese and Greek and were incorporated into the e-learning platform.

In order to comply with the General Data Protection Regulation (GDPR), as part of the process of creating an account in the e-learning platform and before completing the questionnaires, participants were given information regarding the processing of personal data and were then asked to give their consent if they chose to proceed (see Annex 1).

STEP 2. STUDY DESIGN AND IMPLEMENTATION

The questionnaires were constructed using mainly close-ended questions (mainly rating on a 5 or 6-point Likert scale) in order to facilitate data collection through an electronic survey tool and in various European languages. In addition, we included some open-ended questions to enrich the results with qualitative data (see Annex 2).

In the sections that follow, the data is presented and discussed. Although considerable care has been taken in interpreting the obtained data, due to the relatively small sample size, the results should not be considered as definitive generalisations that can be applied to parents of PWID in the participating countries.

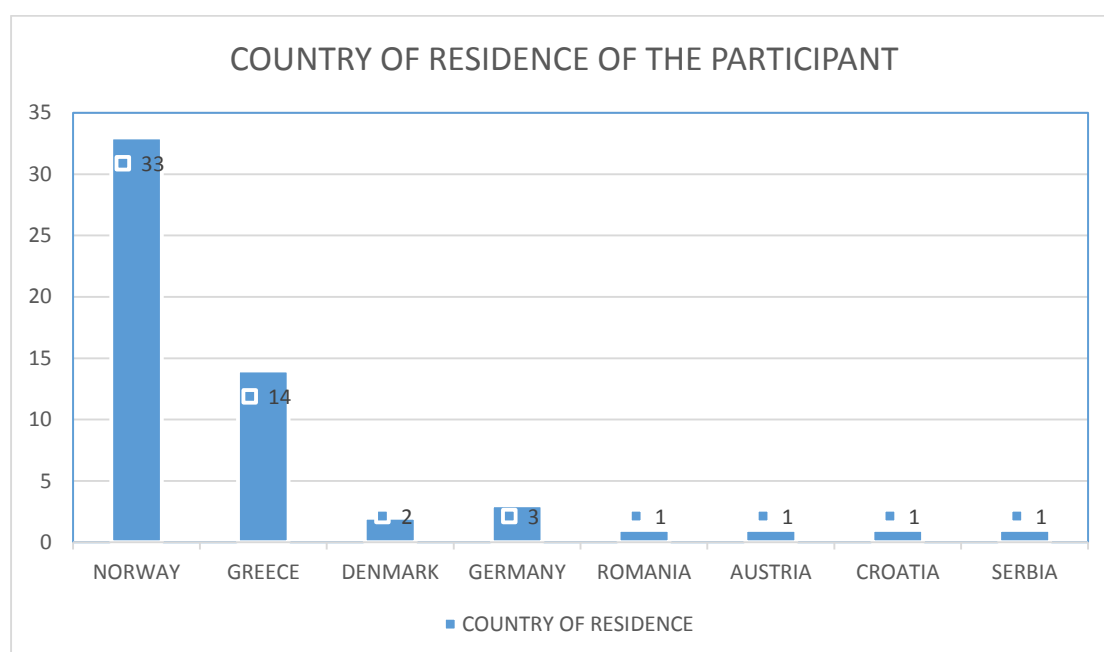
RESULTS & DISCUSSION

DEMOGRAPHIC INFORMATION

Fifty six (56) people begun the process of creating an account, but only fifty (50) consented and proceeded with filling in the pre-course questionnaire.

The sample was therefore made up of 50 participants from Norway (N=33), Greece (N=14), Denmark (N=2), Germany (N=3), Romania (N=1), Austria (N=1), Croatia (N=1) and Serbia (N=1). Only 4 participants filled in the post-course questionnaire.

No other demographic information was collected due to the GDPR compliance.



RESULTS FROM THE PRE-COURSE QUESTIONNAIRE

1. Have you had any previous training on the following topics?

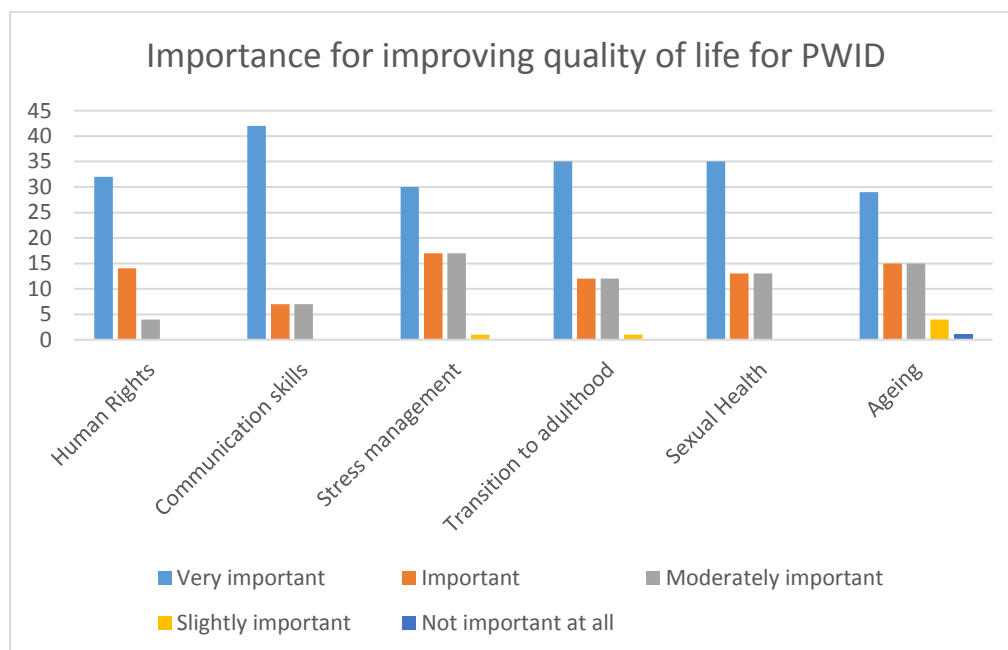
	Yes	No	Not sure
a. human rights	25	25	0
b. communication skills	35	13	2
c. stress management	23	23	4
d. transition to adulthood	19	30	1
e. sexual health for PWID	21	26	3
f. ageing for PWID	22	25	3



A big percentage of the participants had no previous training on the six topics. This was especially the case for Transition to Adulthood (only 19 out of the 50 participants) but also for other topics such as Sexual Health (21/50), Ageing (22/50) and Stress Management (23/50). Half of the participants had received previous training on Human Rights whilst 35 out of the 50 participants had previous training on Communication Skills. This confirms both the need for parent education but also the fact that the existing training programs available do not cover all areas of interest.

2. How important are the following topics to help/support a person with ID to improve his/her quality of life?

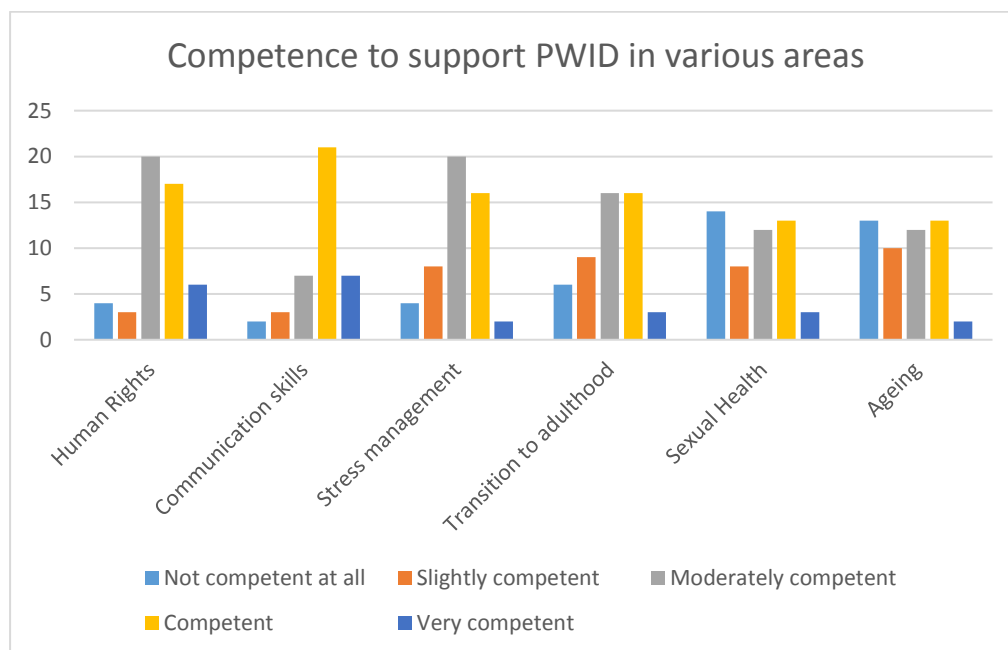
	Not important at all	Slightly important	Moderately important	Important	Very important	AVERAGE
a. human rights	0	0	4	14	32	4.6
b. communication skills	0	0	1	7	42	4.8
c. stress management	0	1	2	17	30	4.5
d. transition to adulthood	0	1	2	12	35	4.6
e. sexual health	0	0	2	13	35	4.7
f. ageing	1	4	1	15	29	4.3



All average scores range from 4.3 to 4.8 out of 5. The above results clearly demonstrate that all six topics are valued of high importance for the quality of life of PWID.

3. How competent do you feel in supporting the needs of a person with ID related to the following topics?

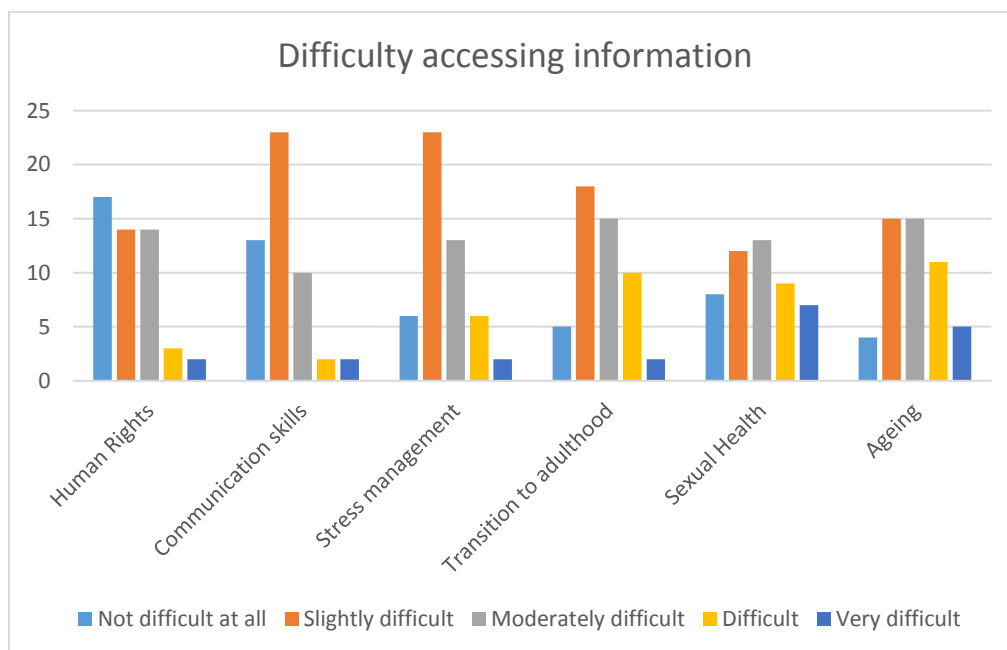
	Not competent at all	Slightly competent	Moderately competent	Competent	Very competent	AVERAGE
a. human rights	4	3	20	17	6	3.3
b. communication skills	2	3	17	21	7	3.5
c. stress management	4	8	20	16	2	3.1
d. transition to adulthood	6	9	16	16	3	3
e. sexual health	14	8	12	13	3	2.6
f. ageing	13	10	12	13	2	2.6



Participants seem to feel moderately competent at supporting their child’s need. Despite the fact that some participants have already received some training, there is clear need for further education and support in these areas, especially around sexual health and ageing.

4. How difficult have you found it to access information/support about the following topics?

	Not difficult at all	Slightly difficult	Moderately difficult	Difficult	Very difficult	AVERAGE
a. human rights	17	14	14	3	2	2.1
b. communication skills	13	23	10	2	2	2.1
c. stress management	6	23	13	6	2	2.5
d. transition to adulthood	5	18	15	10	2	2.7
e. sexual health	8	12	13	9	7	2.8
f. ageing	4	15	15	11	5	3



Participants seem to find that information is not easily available on all areas of interest, especially on Ageing, Sexual Health and Transition to Adulthood.

Overall, the results from the pre-course questionnaire demonstrate that although some participants have received previous training on issues important for the quality of life of people with intellectual disability, there is a need for further training and support as information is not always easily accessible and participants need more education in order to feel more competent at dealing with certain issues.

RESULTS FROM THE POST-COURSE QUESTIONNAIRE

Despite our efforts, only four (4) people completed the post-course questionnaire. As the size of the sample is too small, the results are seen just as an indication.

How much did this course help you to improve your understanding on (scale 0-5):

Human Rights	4.5
Communication Skills	4.25
Stress Management	4.5
Transition to Adulthood	4.5
Sexual Health	4.5
Ageing	4.5

1. Please rate the following statements (scale 0-5):

I discussed what I learnt with others (parents, professionals, people involved in PWID care)	4.25
I will recommend and I am willing to invite others to use this e-learning platform	4.5
It was useful having this content available in an e-learning platform	5
The navigation through the material provided was easy	4.5

HUMAN RIGHTS (N=3)

This module changed my views/attitudes on the subject	4.6
After completing the module, I feel competent to support persons with ID to understand and take care of own rights, or advocate the person in human rights	5
After completing the module, I am familiar with the employment options for people with ID	5
I found useful the information provided as text.	4.6
I found useful the provided videos	5
The provided activities increased my engagement with the module	4.6
The knowledge I have gained will have a positive impact on the quality of life of people with ID	5

COMMUNICATION SKILLS (N=2)

This module changed my views/attitudes on the subject	3.5
This module will help me improve communication with people with ID	5
This module will help me improve communication with other parents	4.5
This module will help me improve my communication with service providers and professionals	4.5
I found useful the information provided as text	5

I found useful the provided videos	5
The provided activities increased my engagement with the module	4.5
The knowledge I have gained will have a positive impact on the quality of life of people with ID	4.5

STRESS MANAGEMENT (N=2)

This module changed my views/attitudes on the subject	4.5
This module improved my understanding on the different ways of stress coping	5
This module improved my understanding on the connection between stress and health	4.5
This module will help me improve my ability to cope with your stress	4.5
This module will help me improve my ability to cope with stress of people with ID	5
I found useful the information provided as tex	5
I found useful the provided videos	5
The provided activities increased my engagement with the module	4.5
The knowledge I have gained will have a positive impact on the quality of life of people with ID	4.5

TRANSITION TO ADULTHOOD (N=2)

This module changed my views/attitudes on the subject	4.5
This module improved your understanding on ways to support people with ID through his/her transition to adulthood	4.5
This module helped me feel more comfortable sharing responsibilities in terms of life of people with ID as they are getting older	3.5
I feel competent to support people with ID through his/her transition to adulthood	5

I found useful the information provided as text	5
I found useful the provided videos	4
The provided activities increased my engagement with the module	4.5
The knowledge I have gained will have a positive impact on the quality of life of people with ID	5

SEXUAL HEALTH (N=3)

This module changed my views/attitudes on the subject	3
This module will help me improve my ability to support people with ID during his/her sexual development	4
This module will help me improve my ability to cooperate with professionals to provide support on sexual education of people with ID	4.3
This module will help me improve my ability to detect signs of sexual abuse and provide adequate support	4
I found useful the information provided as text	4.3
I found useful the provided videos	3.6
The provided activities increased my engagement with the module	4
The knowledge I have gained will have a positive impact on the quality of life of people with ID	4.3

AGEING (N=2)

This module changed my views/attitudes on the subject	4.5
This module will help me improve my ability to support people with ID when he/she experiences challenges related to the ageing process	5

This module will help me improve my ability to talk to people with ID about life ending and death	5
This module will help me improve my ability to support people with ID when he/she experiences grief	4.5
I found useful the information provided as text	4.5
I found useful the provided videos	4.5
The provided activities increased my engagement with the module	4.5
The knowledge I have gained will have a positive impact on the quality of life of people with ID	5

Overall, the feedback from this small sample was very positive. Participants indicated that the modules improved their knowledge significantly and that the newly gained knowledge will help improve their skills. They also indicated that they feel a lot more competent in supporting their child's needs. Moreover, they did discuss what they learnt with others (parents, professionals etc.) and they did recommend this course to others. Finally, they thought it was very useful that it was available on an e-learning platform and that the information was presented in various forms (text, videos, activities).

RESULTS FROM THE 3-MONTH FOLLOW-UP QUESTIONNAIRE

Due to the very small participation in the post-course questionnaire, it was decided not to proceed with inviting participants to fill in the 3-month follow-up questionnaire.

QUALITATIVE DATA

More evidence on the usefulness of the ELPIDA e-learning platform was collected through focus groups and by receiving feedback from people who had used the platform. Each partner contacted groups of parents and professionals and invited them to evaluate the training material and the platform as a whole (see Annex 3 for Short national reports).

Overall, the feedback received was very positive. Below are some statements:

THE PLATFORM IN GENERAL

“it is a very useful tool for carers and professionals”

“parts of the course are very practical and give examples on how to interact and communicate in a way that is beneficial for the family as a whole”

“it is a valuable aid to the work of parents and helps the interaction with professionals”

THE CONTENT

“it provides basic knowledge that will give them more confidence to address these issues”

“the activities in the course encourages the family to interact and discuss important issues”

“it is engaging and it encouraged the participant to examine and reflect upon their own views and attitudes towards PWID, their rights and needs”

“though the ELPIDA program is designed to meet the needs of parents, it can also be used in staff training”

“it can be used in everyday work and as a frame of reference”

THE STRUCTURE

“the course is user friendly... and it is easy to navigate within the course structure”

“it is easy to access and easy to navigate through it”

SUGGESTIONS

Make the language less “academic”

Use videos with better quality

Add information of safeguarding of vulnerable adults (SOVA)

Break down long modules in shorter sections



CONCLUSION

The present study was carried out in the course of the European project Erasmus+ KA2 ELPIDA. It aimed to *evaluate the usefulness and impact of the e-learning platform* that was developed during this project.

The evaluation study was based on the acquired from registered users/participants. The number of registered users although it is quite large (over 375 participants) it is still smaller than that anticipated. This may be due to the fact that some people may not have wanted to go through the registration stage and provide personal information. Moreover, the Consent Form which was a necessary part of the process and compulsory for completing the registration and accessing the learning material might have also acted as an inhibiting factor, making the process longer and more time-consuming for perspective participants. This is also the case for the online questionnaires – the majority of the participants did not take the time to complete the questionnaires and therefore provide feedback on the modules/platform. As a small percentage of people who used the educational material went on to complete the questionnaires, the report was enriched with qualitative data.

According to the evaluation study, *the learning material on the ELPIDA e-learning platform helped increase knowledge level of the participants. In addition, participants believe that this will help improve the quality of life of PWID. This was the case both for parents of PWID as well as professionals working in the field of intellectual disability.* Moreover, participants found the structure and presentation of the material easy to use and engaging.

In addition, the learning material produced and presented in the e-learning platform will be of great use both for parents/carers as well as for professionals. Moreover, it can be used to encourage more interaction between them. It could also be useful for structured parent educational programmes or support groups. In addition, it can be incorporated in staff training programmes.

“Trainings that are rights-based will result in an increased capacity of persons with disabilities and their families in terms of knowing and claiming their own rights, more autonomy and ability for persons with disabilities to decide upon their own lives, and more knowledge for the families to know how to advocate for more support in all areas of life”



In conclusion, looking at the results of this study, we believe that the results provide evidence that the e-learning platform met its goals and will be a useful tool for everyone involved in the care and support of people with intellectual disability. This will have a positive knock-on effect on the quality of life of PWID and their families. It is, therefore, important to carry on the dissemination of this project and the enrichment of the training material.

ANNEX 1: CONSENT FORM

Before you start this e-learning course, we would like to have some information regarding your knowledge and understanding of the modules’ themes. This will prepare you for the content of the course, as well as gathering data on what the participants learn in the e-learning course, assuming that you also complete the evaluation at the end of the course. Please rest assured that any information you provide us with will be treated confidentially.

GDPR compliance statement

Please take time to read and understand the following information, and if you agree with the content, continue to the online questionnaire. Please feel free to ask any questions if there is anything that you require an explanation on. (Contact person: Yorgis Androulakis, FORTH, giorgos@iacm.forth.gr).

The ELPIDA project consortium consists of six organisations: Foundation of Research and Technology - Hellas (FORTH – Greece - coordinator), European Parents Association (EPA - Belgium), Puzzle S.E. (Greece), Center for Specialpædagogiske Børnetilbud (CSB - Denmark), Internationaler Bund Südwest gGmbH Region Mitte (IB – Germany) and Oslo Metropolitan University (OsloMet, Norway).

ELPIDA project, through this e-course, aims to provide family members of PWID with the necessary skills and knowledge in order for them to feel more confident to provide support and empowerment to children of all ages with ID. The e-course consists of six stand-alone interactive educational modules providing more training, awareness raising and/or attitude change on the key areas of Human Rights, Communication, Stress Management, Transition to Adulthood, Sexual Health and Ageing.

In order to evaluate the effectiveness of the learners' interaction with the modules contents, short questionnaires are used to gather participants’ feedback before and after their engagement with each module. Learners' responses to these short questionnaires will be used to upgrade the contents, the method of presentation and the method of delivery of the ELPIDA Course. We collect and further process only personal data that is strictly necessary to fulfil the purpose of our research, namely your email address and your country of residence. Data collected will be used only for the purposes of research and proof-of-concept validation. All necessary and adequate measures will be taken to ensure the security of data collected. The ELPIDA project assures you that any data you provide will be kept strictly confidential and will be deleted after the project has ended (October 2019). Your data will be accessed and processed by authorized researchers and from the consortium partners and the European Commission, to the extent that is necessary for the purposes of the project. Your data will not be shared with any parties outside of the project.

Your participation in this activity is completely voluntary. Participants are free without negative consequences, to decline to take part or withdraw consents and participation to the research without providing an explanation at any time up until the end of the project. If participants choose to withdraw any data collected will be destroyed. Participants have the right to access to data pertaining/related to them that are collected and processed in the context and for the purposes of the project. Participants have the right to request

information, access, rectification, erasure (right to be forgotten) of their personal data or restriction of processing of personal data or to object to further processing as well as the right to lodge a complaint to the Data Protection Authority.

Consent Statement

The purpose of the project, the respective activities and my rights have been explained to me. I am participating voluntarily and understand that I can withdraw from the research activities without repercussions, at any time and have my data deleted. I am satisfied that the assurances of responsible and strict data governance, given by the ELPIDA project, will be upheld.

I understand that my participation and my personal data will be kept confidential. I understand that my data will be kept in a secure environment by the ELPIDA project partners according to data protection legislation and the relevant guidelines.

By clicking on “I agree” button, I agree to participate in this activity.

(In the next step, you will have to provide your email address and your country of residence)

I agree to participate in this activity *

I agree

I disagree

ANNEX 2: QUESTIONNAIRES

1. Have you had any previous training on the following topics?

	Yes	No	Not sure
g. human rights			
h. communication skills			
i. stress management			
j. transition to adulthood			
k. sexual health for PWID			
l. ageing for PWID			

2. How important are the following topics to help/support a person with ID to improve his/her quality of life?

	Not important at all	Slightly important	Moderately important	Important	Very important
g. human rights					
h. communication skills					
i. stress management					
j. transition to adulthood					
k. sexual health					
l. ageing					

3. How competent do you feel in supporting the needs of a person with ID related to the following topics?

	Not competent at all	Slightly competent	Moderately competent	Competent	Very competent
g. human rights					
h. communication skills					
i. stress management					
j. transition to adulthood					
k. sexual health					
l. ageing					

4. How difficult have you found it to access information/support about the following topics?

	Not difficult at all	Slightly difficult	Moderately difficult	Difficult	Very difficult
m. human rights					
n. communication skills					
o. stress management					
p. transition to adulthood					
q. sexual health					
r. ageing					

B. POST-COURSE QUESTIONNAIRE

1. How much did the module improve your knowledge on the subject?
On a scale from 0 to 5 (0 = not at all and 5 = very much)

0 1 2 3 4 5

2. After completing the module, how much do you think it will improve your skills on the subject?
On a scale from 0 to 5 (0 = not at all and 5 = very much)

0 1 2 3 4 5

3. How much did it change your views/attitudes on the subject?
On a scale from 0 to 5 (0 = not at all and 5 = very much)

0 1 2 3 4 5

4. After completing the module, how competent do you will feel in supporting the needs of a person with ID?
On a scale from 0 to 5 (0 = not at all and 5 = very much)

0 1 2 3 4 5

5. How much did you discuss what you have learnt with others (parents, professionals, people involved in the person's (with ID) care)?
On a scale from 0 to 5 (0 = not at all and 5 = very much)

0 1 2 3 4 5

6. How likely is it that you will recommend this course to others and invite them to use this platform?
On a scale from 0 to 5 (0 = not at all and 5 = very much)

0 1 2 3 4 5

7. How useful was having this content available on an e-learning platform?
On a scale from 0 to 5 (0 = not at all and 5 = very much)

0 1 2 3 4 5

8. How easy was it to navigate through the material provided?
On a scale from 0 to 5 (0 = not at all and 5 = very much)

0 1 2 3 4 5

9. How useful did you find the information provided in text form?
On a scale from 0 to 5 (0 = not at all and 5 = very much)

0 1 2 3 4 5

10. How useful did you find the videos?
On a scale from 0 to 5 (0 = not at all and 5 = very much)

0 1 2 3 4 5

11. To what degree did the activities increase your engagement with the topics in this module?
On a scale from 0 to 5 (0 = not at all and 5 = very much)

0 1 2 3 4 5

12. How much do you feel the knowledge you have gained will have a positive impact on the person's (with ID) quality of life?
On a scale from 0 to 5 (0 = not at all and 5 = very much)

0 1 2 3 4 5

13. What changes would you recommend to improve this module?

.....
.....

14. Other comments

.....
.....

C. 3-MONTH FOLLOW-UP QUESTIONNAIRE

1. How much did you put into practice the things you learned during the module?
On a scale from 0 to 5 (0 = not at all and 5 = very much)

0 1 2 3 4 5

2. How much did the module improve your ability to support your child with intellectual disability when he/she experiences challenges related to the ageing process?
On a scale from 0 to 5 (0 = not at all and 5 = very much)

0 1 2 3 4 5

3. How much did the module improve your ability to talk to your child with intellectual disability about life ending and death?
On a scale from 0 to 5 (0 = not at all and 5 = very much)

0 1 2 3 4 5

4. How much did the module improve your ability to support your child with intellectual disability when he/she experiences grief?
On a scale from 0 to 5 (0 = not at all and 5 = very much)

0 1 2 3 4 5

5. How much did you discuss what you learnt with others (parents, professionals, people involved in your child's care)?
On a scale from 0 to 5 (0 = not at all and 5 = very much)

0 1 2 3 4 5

6. How much was the module a starting point for you to search for more information/guidance on these issues?
On a scale from 0 to 5 (0 = not at all and 5 = very much)

0 1 2 3 4 5

7. How much do you think the completion of the module had a positive impact on your relationship with your child?
On a scale from 0 to 5 (0 = not at all and 5 = very much)

0 1 2 3 4 5

8. How much do you feel the knowledge you have gained will have a positive impact on your child's quality of life?
On a scale from 0 to 5 (0 = not at all and 5 = very much)

0 1 2 3 4 5

ANNEX 3: SHORT NATIONAL REPORTS

DENMARK

Data describing the usefulness of the ELPIDA platform, Denmark

The following report describes the status and activities regarding the collection of data supporting the usefulness of the ELPIDA platform. The report is structured in relation to the 4 activities decided by the partners at the Skype meeting the 9 of July.

The actual status is characterized by the fact that July is holiday season in Denmark and it is therefore very difficult to arrange meetings or to get people to respond to e-mail or otherwise.

All partners need to try to get their participants to fill in the post-course

An e-mail has been sent to all the Danish participants in the program asking them to fill in the post-course questionnaire. Hopefully some of the will react to the e-mail.

In February and March more than 300 parents to children with intellectual disabilities and 200 staff members working with people with intellectual disabilities were invited by mail to take part in the program. A reminder has been sent to them and hopefully more will respond to the request.

Partners can gather qualitative data either by running focus groups (around 5 parents/participants) asking their views on the content of the modules, the structure of the platform etc.

As mentioned before it is difficult to arrange meetings in July and also there are very few Danish participants in the program. Instead the Parents Council at CSB, which consists of 7 parents, have been invited to discuss the platform at the next meeting, which will be held at the 17 of September 2019. In order to prepare the discussion the members will be enlisted as students in the program. The Chairman has been contacted directly and has been asked to have a view of the program and to give his feed-back as quickly as possible. I will contact him again this week.

Partners can collect qualitative data from other professionals/participants who used the platform either for their own use or as a teaching tool.

The platform has been discussed by the consultant Team at CSB. The Team consists of specially trained staff members provides consultancy to the rest of the CSB as well as to other programs, other municipalities and to parents.

The discussion concluded that:



- The ELPIDA program is easy to access and it is easy to navigate through the program.
- The ELPIDA program consist of relevant information which is useful to the consultant team.
- The information in the ELPIDA program can be used in everyday work and as a frame of reference.
- Though The ELPIDA program is designed to meet the needs of parents it also can be used in staff training.
- From the perspective of consultants and based on their experience in working with parents to children with intellectual disabilities, the ELPIDA program will be useful for parents as well.
- The ELPIDA program could benefit from an overall introduction to the content and especially in regard to the modules chosen for the program - why where they selected to be a part of the program/what is the overall logic of the program. This point might not apply to a parents' point of view.
- The modules differ in form and length and from a consultant point of view the longest of the modules could be difficult to parents to access. In that respect the division of the modules in short sections is appropriate

Partners should try to get as many questionnaires filled in as possible to increase quantitative data.

Please see the first bullet.

Aarhus, 29. juli 2019
/Mikael Carlsen

GERMANY

IB Short Report on the usefulness of the ELPIDA platform

The current state of the activities is – a situation that all other ELPIDA partners face - very quiet due to the summer break. We can report the following:

In April and May, we contacted around 600 people in various national networks, parent associations, special needs schools and IB institutions and promoted participation in the ELPIDA platform. In addition, a large number of parents and IB colleagues were directly approached to test the platform. In various print publications of Internationaler Bund as well as on our websites and the network “Caravan 2000” we regularly reported about ELPIDA and advertised the testing of the platform.

Since we have also written to many international partners, the return is difficult to verify. However, due to the limitation of languages, the transfer and participation was difficult or even impossible. So for example for our Turkish, Polish, Italian and French partners, we have received this feedback from some partners.

Overall, the return was very low in view of the many broadcasts and mailings, which was certainly related to the season (in May and June we had many holidays in Germany and the summer break began in early July), but also to the lack of staff resources. Due to the high shortage of staff experts in the social work in both Hessen and Germany, fewer and fewer colleagues have the time and willingness to turn to projects and forums or, as in this case, help parents to test the platform.

In the project team, we discussed the work on the platform and the feedback from colleagues and parents who have registered but did not complete a questionnaire, and can list the following feedback and conclusions:

- The individual modules are well designed and clearly arranged, the platform is very nicely designed and illustrated
- The ELPIDA-platform is very interesting and informative
- The information on the platform can be well used in the day-to-day work of staff who work with people with disabilities as well as parents with regard to individual modules that they currently use depending on the age of their child with disability
- Many of our IB supported people with disabilities are older and accordingly have older parents. These parents were often unwilling, despite a personal invitation, to register for the ELPIDA platform in order to be informed and consulted in this technical way. In part, this target group has no computer or cannot operate it well, so is technically unable to use the platform without assistance.
- The use of the ELPIDA platform is very time-consuming. Watching movies, doing exercises and reading long texts is far beyond the normal time frame of each one. Parents of people with disabilities are very tight-lipped anyway and, moreover, they have even less time to take this effort, even if it brings them added value.

All partners have put a lot of work into the platform and both parents of people with disabilities and staff could benefit from it, but this requires more and longer education to reach more people in the target groups.

Perhaps it would be useful to develop a short version where parents can get a first overview, and if needed, they can work more intensively on those modules that affect them personally. We expect that over the next few months we can certainly reach some more participants, but it will take more time and resources to increase the number of participants.

Christiane Lensch, Bianka Winterscheid, Chiara Welker
August 2019

GREECE

ELPIDA EVALUATION – SHORT REPORT (GREECE)

In the Erasmus+ KA2 project ELPIDA, Social Enterprise Puzzle was responsible for two research projects – the needs assessment carried out at the beginning of the project and the evaluation of the e-learning platform based on the feedback obtained from the participants at the end of the project.

In the application, it was described that the evaluation would be carried out in three stages. Before completing the module(s), after completion and at three month follow-up. Through this process we wanted to find out whether the e-learning platform met the participants’ needs, whether it was easy to use, whether the information it contained was useful, and whether the participation led to a change in their views and had a positive effect on the quality of life of the participants.

For various reasons, the initial research plan could not be implemented the way it was initially conceptualized. The new European law on data protection (GDPR) which was implemented in 2018 did not allow the record keeping of all the necessary information. Moreover, the participants, like all adult learners following the “defense of the adult”, did not show an interest in participating in the evaluation process.

In order to overcome the difficulty of the low number of participants in the evaluation process incorporated in the e-learning platform (online questionnaires), Puzzle, in collaboration with the coordinating partner (FORTH) and all partners, discussed and assessed a series of possible solutions/options to complete the evaluation process. It was hence suggested to carry out some focus groups in order to obtain reliable, qualitative data.

Puzzle, in order to obtain more data from Greek participants, decided to carry out two focus groups – one with parents/family members of people with intellectual disability and the other with professionals working in the field of disability. The only pre-requisite for taking part in the focus groups was to have completed at least one module on the ELPIDA e-learning platform and all the relevant activities.

The participants in the focus groups were people who had already contacted us, expressing their views on the project (parts of it or as a whole), and were therefore familiar with the ELPIDA e-learning platform.

An effort was made so that participants were from different cities, organisations etc., to include both men and women (although despite our efforts, 80% of the participants were women) and finally to maintain a diversity in other characteristics (e.g. age, level of education etc.).

Overall, even though this was not a scientific research project, but rather a recording of the level of satisfaction of the participation in a European distance learning project, every effort was made to take into account some parameters in order to ensure reliability and validity of the data.



In terms of the structure, every focus group had two parts: the first one was semi-structured with questions such as “would you participate in other modules like this?” and the second part was an open discussion where participants were invited to describe their experience and express their views/thoughts.

Two focus groups took place: six professionals took part in the first focus group which took place in Athens and 5 parents took part in the second focus group which took place online. All participants had completed at least one module. The overall feedback was very positive.

Parents stated that the choice of topics/modules was satisfactory whilst some modules were more interesting/useful for them. Professionals commented that the six modules included in the platform are among the ten topics of their choice. Parents mentioned that the content of the modules was satisfactory, whereas professionals would have liked more in depth information.

When asked whether they would prefer a distance learning programme or in person, the participants were divided. About half, would prefer to take part in an educational programme in person in order to have the opportunity to exchange views and communicate with other participants, whereas the other half prefer distance learning as it is easier to fit it into their busy schedule, do it at their own pace, not having to travel etc.

In terms of the setup of the platform, its design and user-friendly navigation, all participants were quite satisfied. Most of the participants stated that the presentation of the information was good, and they particularly liked that they were enriched with videos, activities, photos etc. They would have liked though a more unified presentation across all modules and at the activity sections. Moreover, some of the participants (mainly parents) would have liked subtitles/translation added to the videos.

The modules the participants found more useful were Communication, Human Rights and Sexual Health. The majority (75%) thought that the text and the translation were good.

Most of the participants stated that they most likely going to go back to the module(s) they completed to look over some of the material they found useful.

Finally, the average number of modules completed by each participant was nearly 2 (1,7). Overall, through the participants’ feedback and the focus group results, it seems that the participants were satisfied with the e-learning platform and they expressed interest for its continuation.

NORWAY

A summary report of feedback from Norway on the usefulness of the ELPIDA platform

The following report describes the status and activities regarding the collection of data supporting the usefulness of the ELPIDA platform. The report describes four evaluation actions decided by the PMC meeting July 9th 2019.

The content of the report is influenced by the facts that end of June, whole July and beginning of August, most people have summer holyday. This means that it is difficult to ask people to respond to some e-mail or attend any focus group.

Post-course questionnaire

32 persons in Norway have so far answered pre- questionnaire in the platform. 26 persons confirmed to participate in the evaluation and one person have answered post- questionnaire.

July 25th FORTH instructed us in how we could find emails to those who had confirmed to evaluate the course and July 29th every one of these were contacted by a personal e-mail. It seems that more of the persons that have answered the pre- questionnaire are professionals. Automatic answers on the request indicates that many of these participants are on holyday until mid of August. This means that we may not have more evaluations before the end of August.

Gathering qualitative data by running focus groups (around 5 parents/participants) asking their views on the content of the modules, the structure of the platform etc.

Right after the PMC meeting July 9th 2019, staff in two group homes was asked to participate in focus groups. Their answer were that during summer holidays staff are reduced to much use of holiday substitutes, which often are young students. The situation with few ordinary staff and less time to activities out of ordinary routines did not make it possible to run focus groups. Focus groups are more possible in e.g. September.

Collecting qualitative data from other professionals/participants who used the platform either for their own use or as a teaching tool.

One user-organisations, with one professional as a counselor, was asked to give an “open feedback” of the use of ELPIDA course. This user-organisation wrote following:

“The ELPIDA e-learning course is a very useful tool for carers and professionals alike.

The way the course is built up is engaging, and it encourages the participant to examine and reflect upon their own views and attitudes towards PWID, their rights and needs.

Parts of the course is very practical and gives you examples on how to interact and communicate in a way that is beneficial for the family as a whole.



In addition, the activities in the course encourages the family to interact and discuss important issues.

However, parts of the course comes across as a bit to «academic» when it comes to the language used. This might stop some participants from completing the course. Also, some of the videos are of lesser quality picture wise. Also, a couple of the lecturers could benefit from livening up their talk a bit, make more engaging to the participant.

Lastly, the English edition should contain information about safeguarding of vulnerable adults (SOVA) and the Norwegian version should contain information about TryggEst, the Norwegian SOVA system.

But overall the course is user friendly, contains engaging and informative content and it is easy to navigate within the course structure."

The e-learning course have been included as a resource in the BC program of disability nurses (social educator) at Oslo Metropolitan University. The use, the benefit and evaluation from about 700 student will be possible to assess after about two-three years' time (because they have different courses during their education). The use of ELPIDA will start this autumn, and about 150 -300 students will be introduced for the e-learning platform and asked to use some of the modules.

Partners should try to get as many questionnaires filled in as possible to increase quantitative data.

From the beginning of May-19 we have worked with PR of ELPIDA course. We have:

- sent information to every user-organisations in Norway and attended some of their courses and conferences.
- been interviewed and the interview have been published at Facebook in a network of in professionals with 12 393 members (<https://vernepleier.no/2019/05/elpida-e-laeringskurs-om-personer-med-utviklingshemming/>)
- sent out information about ELPIDA in a National webpage that professional, parents and people with ID use (<https://naku.no/kunnskapsbanken/e-l%C3%A6ring-familiemedlemmer#main-content>)
- give information of ELPIDA at a one webpage/workplace containing 42 managers in services for people with ID in the larges municipality in Norway – Oslo.
- used private and public network we have as professional at the University (OsloMet).

To do this kind of work, we have made two films, one poster, flyers and other kind of information that we use when we talk about ELPIDA e.g. at the IASSIDD conference (Glasgow 5-9 August), which is a world conference we are going to present ELPIDA in a poster session.

We suppose that these activities will results in more participants at the e-learning course during this year and next years. It seems to us that people are attending the course when they think they need it, or when ELPIDA is related to teaching. We think this, as well as the "slow" way to introduce something new in this field, may explain why participants are attending the course little by little and not in the speed we expected.



Ref.

Britt-Evy Westergård

July 30th 2019

PORTUGAL

MEETING REPORT

On June 19, a meeting was held to present the European project ELPIDA. There were present 30 organizations involved in the “Promotion and Protection of the Child’s Rights” some of which work exclusively with disabled children.

Following a presentation of the objectives, methodology and constitution of the consortium, through the website, the project was launched.

Each of the modules and their table of contents, deserved special attention, as well as some of the exercises available. Almost all the present associations showed great interest in the project because of their originality, since they were unaware of the existence of a project for parents in this area. Hence the great enthusiasm and participation in some of the exercises that were presented.

The communication module, because of its importance and the modules of Sexual Health and Aging, being the most sensitive, were the ones that aroused the greatest interest.

Several comments were raised regarding:

1º The Modules:

In general, all participants acknowledged the good quality of the modules and the important information contained in. The course is very well structured and is an innovation in the field. One of the issues addressed was the length of some modules, (Communication and Sexual Health) which may be a negative factor in their choice. However, in the case of the Communication its length is compensated by a strong bet in the practical part of the subject, with a lot of attractive exercises.

In some of the videos, the speakers speak too quickly (for instance in 2. Transition for adulthood). Since captions must keep pace with the conversation, their reading and understanding becomes difficult. The videos help a lot in learning, but they should be short, varied and concise with appealing contents. Round tables and interviews are well accepted, but the use of classroom-type videos, raise some doubts of their effectiveness.

Practical cases, good practice and testimonials are very well accepted

With respect to the bibliography presented in the modules, some of them very extensive, for the common of parents not used to dealing with this type of literature, it becomes difficult to discover simple ways of accessing it. The Bibliography should be shorter and incisive, it means to present five or six important books that could easily be bought in a bookstore. Otherwise parents feel lost.

Some modules, due the sensitivity of the topic they address, should merit a first joint explanatory approach between parents and professionals (for instance Sexual Health and Ageing)

The modules are a huge help especially the more specific ones, such as Transition to Adulthood, Sexual Health and Ageing because they are realities difficult to approach by some parents. The course is a great help because it provides them with the basic knowledge that will give them more confidence to address these issues and to remove their doubts with the professionals.

2° The general comments.

- What is meant by ID? What type of disability is included?
- Does the course address only the case of children with ID? There are children with another type of disability who are mentally lucid, whose parents could learn a lot from this course.
- Many teachers are not trained in this field, not knowing how to deal with a child ID.
- It is very important that the parents have some time each year for them to work alone, since during the year the relationship, undergoes normal stress
- We must stop many prejudices that still exist in our society.
- Lack of support policies for these parents, namely the Statute of Caregivers.
- How to mobilize these parents, in this case?
- This course is a valuable aid to the work of parents and helps the interaction with professionals.
- It was interesting to address other issues in another phase of the course, such as how to helping the parents of these children to manage their marital relationship since in a significant number of cases still ends up separating.

At the end of the meeting everyone was asked to join the project, signing up and asking for their password.

Some institutions requested a presentation to be made for the professionals and the parents of the institution's children.

The organizers of “Olivais in Holidays+”, also invited me to go visit their project that is to be held again this year and talk with the parents about the project.

Within the theme of our project I was also invited to attend a doctoral thesis defence on the theme "Sexuality in Cerebral Paralysis" by Margarida Gomes, who was in Brussels at the meeting of our project.

Lisbon 19, June 2019

Hermínio Corrêa

ELIPDA

‘Reflection of the potential impact of training parents on the lives of people with intellectual disabilities’

What? The impact of training parents for intellectual disability awareness, Multiplier event of the ELPIDA project, hosted by MEP Martina Werner (S&D) (DE)

When? 19 March 2019 16:00-18:00 (your intervention from 16:50-17:00)

Where? European Parliament, ASP 5G30

First of all, I would like to thank you for inviting the European Disability Forum to this interesting event and we are happy to support an important project as ELPIDA.

The European Disability Forum is an umbrella organisation of persons with disabilities that defends the rights of over 80 million Europeans with disabilities. We are a unique platform which brings together representative organisations of persons with disabilities from across Europe, including organisations representing the rights of persons with intellectual disabilities. We are run by persons with disabilities and their families.

EDF is always looking for initiatives that can help improve the living conditions of people with disabilities and their families, while respecting their rights, as advocated by the UN Convention on the Rights of Persons with Disabilities. The project we are talking about seems to me to fit perfectly into this prospect and I warmly congratulate the promoters.

I am pleased to be with you today for at least two reasons : first because this project is about families and parents, which is not common – parents have a hard time making themselves heard by organisations today, the tendency being for self-representation and independent living, then because this project is about people with intellectual and cognitive disability, which is not frequent either -- people with intellectual disabilities have difficulty to be heard because they often cannot speak of and for themselves.

By the way, it is interesting to see the initiative recently born in the United States of creating a new organisation for those people who cannot represent themselves.

As a parent, myself, of a 43-year-old adult, "polyhandicapé", as we say in France, with a significant intellectual disability, I would have much appreciated being accompanied by a training like the one you propose. But when my son was born, we were in prehistoric times of the concept of disability and of the type of assistance that could be given to the person with disabilities and his or her parents.

Disability was only a health problem and not a rights issue.

There is, in my opinion, an important moment when parent training can play a major role. This is the moment following the announcement of the intellectual disability of their child. The psychological preparation of parents is crucial. It must be conducted with respect and empathy, while being sincere and scientifically accurate.

But the experience shared with other parents, a good accompaniment of the family and professional entourage can make this irruption of the handicap in the ordinary life a unique and rewarding experience of life.

Training can help and it is why your project looks so much important for EDF.

By showing that nothing is definitively lost, that a life, even with a severe intellectual disability, is always worth living with its moments of joy and sorrow.

In this regard, the simple fact of knowing that there is training for them and that others have shared their difficulties is a powerful comfort and encouragement for new parents who are discovering disability with fear and angry. It's a way of saying, "yes, you can".

And you see how important the role of peer helpers is: parents helping other parents, parents training other parents. Parental involvement in training should, in my opinion, be fundamental, as well as the contribution of people with disabilities themselves, if they are able to do it.

In this regard, training should also be offered to all care and support staff, especially medical staff. The effort to be made in this direction in France, for example, is very important and the announcement of a disability by doctors is often very careless vis-à-vis parents and is the cause of a real trauma. Training parents of children with intellectual disabilities must be accompanied by equivalent and parallel training of health staff.

This training of parents is therefore essential and we welcome your initiative. But what should be the strengths of this training? For EDF, things are clear and all the training work must be based on the principles of the CRPD. The UN Convention on the Rights of Persons with Disabilities provides the pillars of the training to be implemented.

In our view, the training should remind parents of some key recommendations of the Convention:

- The convention celebrates **human diversity and human dignity**. Its main message is that persons with disabilities, are entitled to the full spectrum of human rights and fundamental freedoms without discrimination
- In **prohibiting discrimination** on the basis of disability and establishing that **reasonable accommodation** shall be provided to persons with disabilities with a view to ensuring equality, the Convention promotes the full participation of persons with disabilities in all spheres of life.
- The CRPD reaffirms that persons with disabilities have the right to recognition everywhere as persons before the law. States parties shall therefore recognise that persons with disabilities enjoy **legal capacity on an equal basis** with others in all aspects of life.
- **An individual's right to decision making** should not be replaced by decisions of someone else. Persons with disabilities have the right to make **choices** that affect all issues in their own life, for example deciding where to live, to vote, whom to marry, to buy a house, to find a job, to make decision on one's own health.
- Measures should be taken as to support the **person in making his or her own decision**. **Support** could take the form of one trusted person or a network of people and

alternative/augmentative means of communications, for example for people with autism. Safeguards should be introduced against abuse of that support.

We think that trainings that are rights-based will result in an increased capacity of persons with disabilities and their families in terms of knowing and claiming their own rights, more autonomy and ability for persons with disabilities to decide upon their own lives, and more knowledge for the families to know how to advocate for more support in all areas of life.

At the same time, rights-based trainings will have, as you point out with the ELPIDA project, a positive impact on the lives of persons with disabilities and their families as it will empower and enable them to learn about their rights under the CRPD and to claim them.

Albert PREVOS