ERASMUS+
KA2 –STRATEGIC PARTNERSHIPS FOR ADULT EDUCATION

ELPIDA: "E-learning platform for intellectual disability awareness"

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

Needs Assessment Study: Defining Training Requirements for parents of persons with ID

(*Part A* of Intellectual Output 1 - Two Research Studies)

FINAL VERSION DATE: 30/09/2019

ΙΔΡΥΜΑ ΚΡΑΤΙΚΩΝ ΥΠΟΤΡΟΦΙΩΝ
ΙΚΥ

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

Intellectual Output:	IO1, Two research studies: *Needs Assessment Study (Part A of IO1)*
Authors:	Kasimatis Vasilis & Giannakopoulou Christina Social Enterprise PUZZLE e-mail: info@puzzle-se.eu
Contributors:	CSB, IB, OSLO MET, EPA, FORTH
Status, Version No.	Final of Part A
Submission date:	30/09/2019
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
External Evaluator:	James Crowe

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

This document reports the results of a Needs Assessment Study undertaken in the frame of the ELPIDA project (2017-1-EL01-KA204-036367). These results aimed to inform the axes for the development of resources for the ELPIDA: “E-learning platform for intellectual disability awareness”

Table of Contents

SUMMARY

During the ELPIDA project, a pilot study was designed and carried out in order to determine the need for developing learning material for distance learning for parents of people with intellectual disability (PWID). The study aimed to assess the need and interest of parents on issues concerning people with intellectual disability. More specifically, the study focused on issues around communication, stress management, transition to adulthood, Human Rights, sexuality/personal relationships and ageing. The study had two parts: (a) a literature review looking at the national context of the partner countries as well as the European context and (b) the completion of over 150 questionnaires by parents of PWID across Europe. The findings show that parents of PWID are interested in participating in e-learning and that there is a clear need for this kind of opportunity. Moreover, parents would like to gain more information/training on these issues and receive more in-depth information and practical advice on these topics. The results of this study were taken into consideration and informed the content of the e-learning modules.

Linguistic concise versions of this Intellectual Output are available in Greek, Danish, German, French, Norwegian, and Portuguese, as stand-alone documents labelled as:

- IO1 (PART A) EL
- IO1 (PART A) DA
- IO1 (PART A) DE
- IO1 (PART A) FR
- IO1 (PART A) NO
- IO1 (PART A) PT

INTRODUCTION

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

In Europe, as well as in other parts of the world, the efforts for the social inclusion of people with disability have begun in the second half of the 20th century, having parent associations leading the fight for defending their children's rights. Even today, ***in most countries, it is the parental movement that leads the implementation of actions for people with disability*** and in some cases acts as a pressure group in order to bring changes and safeguard the rights of people with disability.

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***.

The ELPIDA project aims 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. The e-learning platform will not only provide ***support and empower parents of PWID by developing their skills and knowledge***, but it will also have a ***positive knock-on effect on the quality of life of PWID***. Moreover, parents across Europe will have free access to the training material, which will be available in six languages and will offer the flexibility of distance learning.

The importance of adults' life-long learning and also open and distance learning has been repeatedly documented (e.g. Jarvis Peter (1988), Adult and Continuing Education, Theory and Practice, Routledge, London). 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.

In order to ***examine and verify the need for further support and training of parents of PWID***, we conducted a ***literature review*** and collected information from parents, professionals and European organisations, looking at the national context of the partner countries as well as the European context. The results clearly demonstrate the ***need for more parent training***.

By verifying our initial belief that there is insufficient parent education, we went on to ***investigate the parents' real training needs and interests through the use of a questionnaire***. More specifically, the questionnaire contained items on ***parent's previous training and knowledge*** as well as ***items specific to the six topics/modules*** that have been chosen ***to be included in the e-learning platform***, namely: ***stress management, communication, transition to adulthood, human rights, sex education, ageing***. The results of this study aim to inform the content of each module, therefore tailoring it to the interests and needs expressed by the parents.

Definitions / Clarifications

A. Parent education – Adult education

Overall, 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 (Brookfield 1986: 124).

There are many definitions for parent education. Each definition approaches the subject from a different psychological or philosophical point of view. All definitions, however, agree that ***parent education aims to improve the quality of life not only of the children but of parents as well.***

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*** (Hepburn Kathy Seitzinger (2004), Families as Primary Partners in their Child's Development and School Readiness, The Annie E. Casey Foundation, Baltimore).

It is important to note that parent education is part of adult education and that its development during the 20th century has taken place at the same time. What is adult education? ***Adult education refers to any learning activity or programme developed by an education***

organisation, designed specifically to meet a training need or interest that will take place during any stage of a person's life who is over the age of mandatory education and whose main activity is no longer related to education. Thus, its "sphere" covers non-professional, professional, general, formal and non-formal education, as well as education that aims at collective social purpose (Rogers, 1999).

B. E-Learning and Distance learning

Distance learning is an education system that differs from traditional education systems. Its main difference is that there is a ***physical distance between educators/teachers and learners*** and therefore their presence at the same time, at regular intervals, in a specific location (e.g. classroom, university) is not necessary.

In terms of ***e-learning***, the notion of e-learning is quite general and it ***includes any form of distant education, where an e-platform uses the resources of the web/internet or of computers in general***. During the last few years, the popularity of distance learning has increased significantly. A few of the documented advantages of e-learning are flexibility, adaptability, time and money economy, and high knowledge retention rate. In the case of parent education, distance learning could be used to meet a series of educational and real needs of the adult role of each parent. ***Because of its flexibility, it allows participants to participate at their own pace, at a convenient time for them, and choose the topics that are of interest/relevant to them.***

LITERATURE REVIEW – National and European Framework

In the course of the ELPIDA project, we conducted a literature review with an ***aim to record the existing situation in terms of parent support and education in the participating countries – namely Norway, Denmark, Germany and Greece, as well as an overview of Europe*** as a whole through the European Parent Association that participates in this project and has many years of experience in this field on an international level. We, therefore, collected short national reports by each partner country describing what is available to parents of PWID in terms of training and support, how this is provided and by whom (see Annex 1). In addition to the national framework provided by each partner, we have used a range of other resources such as expert interviews, literature reviews, and information from international networks to get a better and fuller picture. Although our recording was not a generalized study of the national and European framework for the education of parents of people with intellectual disabilities, it is of particular interest as it leads to a series of findings. ***The most important finding is the necessity of developing parent education programmes.*** The lack of sufficient parent education available reinforces the need to implement this project.

As evident from the reports on the national and European frameworks, ***despite the fact that, over the last 40 years, a lot of work has been done in terms of education of people with disability as well as the education of professionals, parent education and support has not been equally developed.*** This is particularly interesting when we take into consideration that in all participating countries it is noted that parents are the main people claiming their children’s rights and that the education and support systems for people with disability have mainly been based on parent association initiatives.

The value of family involvement in a person's transition to adulthood is expressed by the theory of a holistic approach in which the family plays a dominant role. *But how prepared are the parents to support their family member?* In the participating countries, ***there is no formal or informal procedure for certifying the family's ability to handle these specific issues.*** Any ***approaches are fragmented*** and are based on the parent's individual anxiety and initiative, or in fragmented efforts by organizations or local authorities, municipalities, etc.

The purpose of the ***Social Welfare system*** in every European country is to support people with disabilities and to try to ensure their autonomy and their equal participation in society. It seems that in most cases, the ***services provided are focused on the needs of people with disability***, e.g. education, housing, financial support (social benefits). ***Families*** may receive guidance and support, but they ***have limited access to training programmes*** for parents and these ***training programmes do not cover the whole range of topics to meet their needs***. Moreover, these services often ***vary on quality and availability of options*** depending on the available resources and funding of each municipality.

In addition, there seems to be a ***difference between the Scandinavian countries and the countries in Northern Europe in general compared to the countries in the South in terms of parent education and support*** as it is also the case in most aspects of the welfare system. The services in ***northern countries*** are better organised and parents are supported by a network of services that protects the whole family from the day a child is diagnosed with a disability. For example, in some northern European countries, like ***Norway***, all parent association offer meetings, conferences and courses. These, however, are based on parents’ initiative and leisure time so they do not always meet the needs of parents of people with disability. In ***Denmark***, it is local authorities that provide the majority of parent support and training. On the other hand, the strength of the family leads most parents from the ***Mediterranean countries*** to look for and take part in expensive educational programmes in order to learn how to better support their child as free training and support is not as widely available.

In terms of the form of these educational programmes and the organisations that offer these, it is noted that most efforts are around ***seminars on specific topics*** that are developed by ***organisations belonging to the parental movement*** or often, as in the case of Germany, by the association of parent organisations (Lebenshilfe). Other organisations that provide similar education programmes are ***local authorities***, integrating them into the general lifelong learning programmes they implement.

An issue where there is no clear information on and which would be interesting to investigate in the future, is whether there is an educational package or educational modules recommended to the participating parents.

Most educational programmes seem to be implemented by ***non-governmental organisations or municipalities*** and are ***offered free of charge***. There are, however, ***specialised training programmes*** (e.g. SIGNET) relevant mainly to parents of people in the autistic spectrum. In fact, our literature review shows that there are several methodologies and training programmes for this specific disability available to parents. These are mainly organised by ***private organisations*** and parents/participants have to pay a fee.

An area that seems to be particularly developed in both ***Norway and Denmark*** but not only in these countries is ***individual parent education and parent support***. Whether these could be defined as counselling or education cannot be clear at this point.

Finally, ***the lack of distance learning, e-learning etc., is also evident***. Although this educational approach has been showing tremendous growth in recent years, according to our research and the information provided by project partners there is a lack of distance learning programmes for parents of people with disability.

It would be interesting in the future to carry out a research study investigating in depth and with scientific objectivity the above observations/findings. We believe that such research would help improve education, quality of life and daily life of people with disabilities and their families

In conclusion, main findings from the literature review on the existing situation in terms of parent support and education in Norway, Denmark, Germany and Greece, as well as an overview of Europe are:

- There is a lack of sufficient parent of PWID education and as such a ***necessity of developing educational programmes for parents of PWID***. The lack of distance learning, e-learning etc. for parents of people with disability is also evident. These findings reinforces the ***need to implement the ELPIDA project***.
- The organisations providing parent training, do not have a holistic approach but rather offer ***fragmented courses/seminars***. Additionally, the courses/seminars often focus on specific topics and ***do not cover the whole range of training needs parents of PWID*** – especially, as these needs change through the person's transition to adulthood. This leads us to ***develop the modules in such a way that they are tailorised to the needs and interests of the participant***, which is also in line with one of the main principal of adult education.
- There is a ***difference between the Scandinavian countries*** (and the countries in the Northern Europe in general) ***compared to the countries in the South Europe*** in terms of parent education and support. ***Contextual differences are needed to be taken into consideration when developing the ELIDA modules***, both from content and mode of delivery perspectives.

In the light of the above findings, a needs assessment study was conducted in the course of the ELPIDA project aiming to inform the content of each module, therefore tailoring it to the interests and needs expressed by the parents. The study is presented in the following section of this report.

NEEDS ASSESSMENT STUDY

The ELPIDA project aims 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 believe this knowledge will have a positive impact on people with ID and will contribute to a better transition to adulthood, social inclusion, and better quality of life in general. ELPIDA will achieve this goal by developing a free-to-use e-learning platform, which will contain interactive educational modules providing more training, awareness raising and/or attitude change on key areas and will be available in six languages (Danish, English, French, German, Greek and Norwegian).

In order to meet the parents’ training needs and interests, we undertook a study investigating previous training/knowledge of parents of PWID focusing on the six topics/modules that have been chosen to be included on the e-learning platform. More specifically, these topics are: stress management, communication, transition to adulthood, human rights, sex education and ageing.

STUDY OBJECTIVES:

The main objectives of the study are:

A. To ***gain insight on previous training/knowledge that parents of PWID already have***

B. ***To explore which aspects of the chosen six topics parents of PWID would be more interested in*** and/or show more need for training/changing attitudes on

METHODOLOGY

The study’s preparation and implementation phases spanned from ***November 2017 to February 2018***. The sample was made up of 167 participants from Norway (N=51), Greece (N=40), Denmark (N=35), Germany (N=22), Hungary (N=8), Austria (N=5) and other European countries (N=6).

STEP 1. PREPARATION

All project partners provided an overview of the content of their chosen topic/module. Taking this into account, a questionnaire was developed focusing on various aspects of the topics. Moreover, the questionnaire was developed in English in order to have an interactive approach where all project partners could provide feedback. The questionnaire was then tested in a small group of experts and parents and was validated. Upon finalisation, the questionnaire underwent translation and localisation into Norwegian, Danish, German and Greek. Partners had the option to administer the questionnaires using an electronic survey tool or use paper versions.

STEP 2. STUDY DESIGN AND IMPLEMENTATION

The questionnaire was constructed using mainly close-ended questions (mainly rating on a 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).

Each partner disseminated the questionnaire in electronic or paper version to parents of PWID either directly or through parent associations, service providers etc.

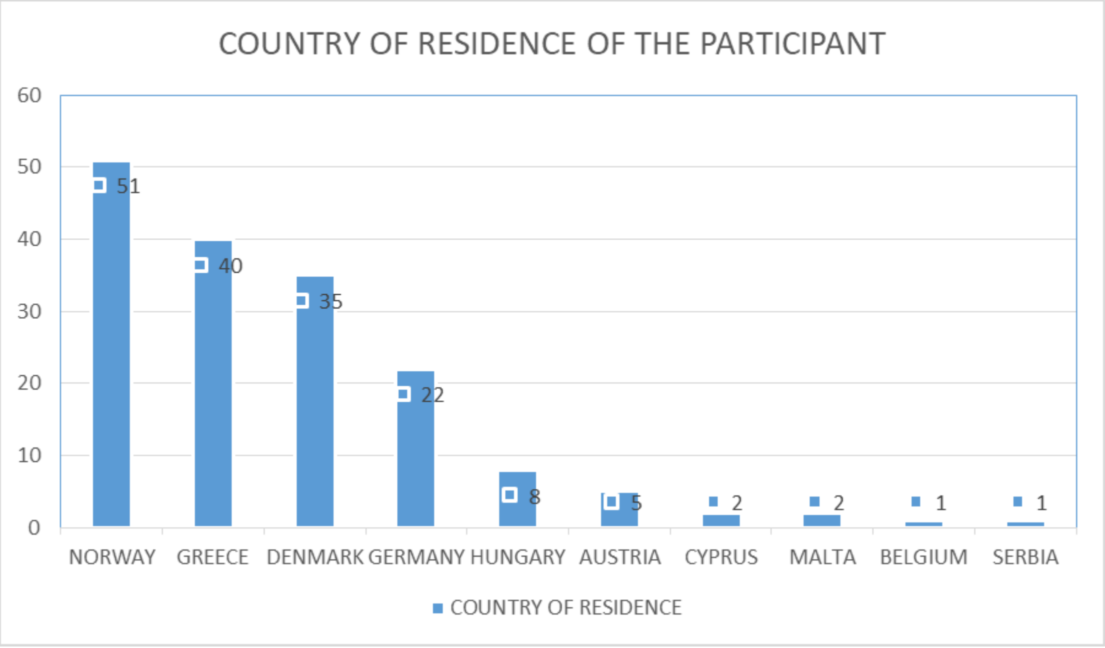
Before the questionnaires were completed, participants were introduced to the notions of the project and were reassured about the confidentiality of their answers through the information provided in the invitation/cover letter.

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

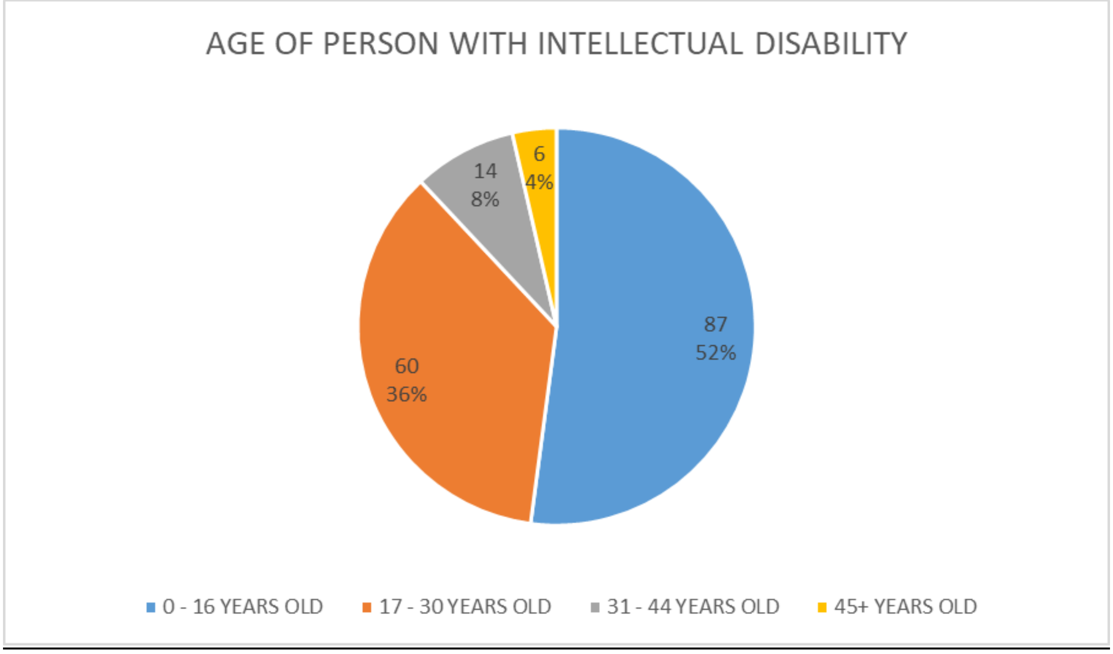
DEMOGRAPHIC INFORMATION

- ***167 people in Europe completed the survey*** looking at their knowledge and interest on six educational subjects. Participants were ***mainly residents in the four project countries (Norway, Denmark, Germany and Greece***) as shown in the chart below.

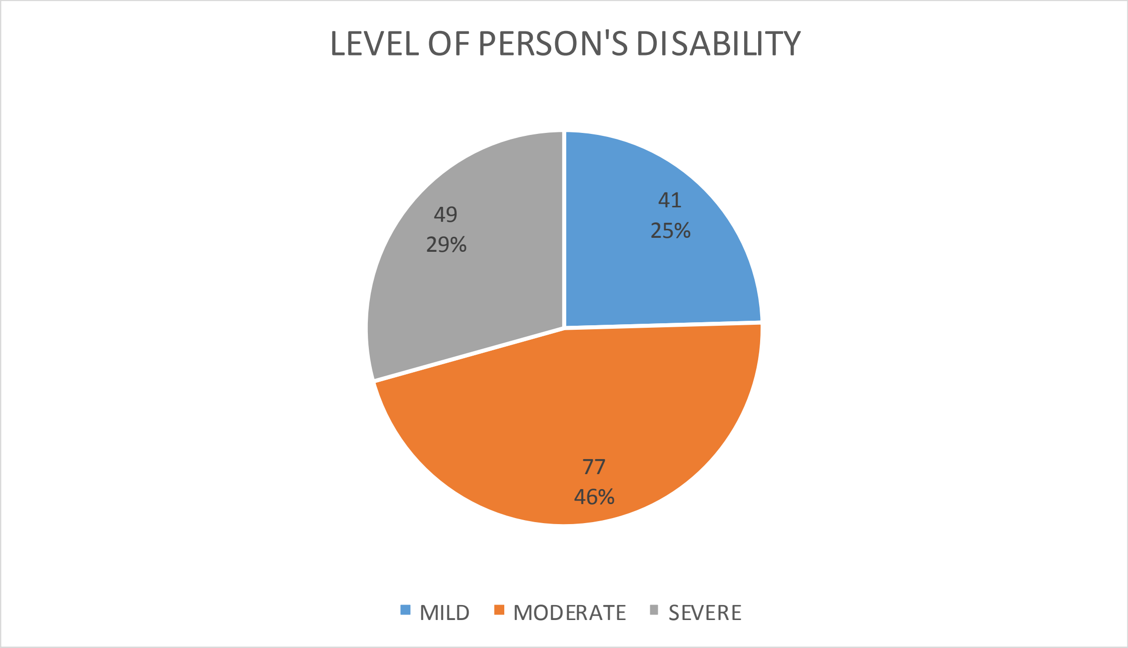


- In terms of the participants' relation to PWID, the ***majority of the participants (74%) was mothers of PWID***, ***17% was fathers of PWID*** and the rest was: sibling, professionals, aunt and foster family.

- In terms ***the PWID*** to which the participants were related to: almost ***half were male (46%) and the other half female (54%)***, the ***vast majority belonging to age the group 0-30 years old,*** as shown in the chart below. It is interesting the fact ***that most of the participants were parents of PWID under 16 years old (52%),*** which may be due to the fact that they are more familiar with technology both for the online completion of the questionnaire as well as more prone to be interested in completing an e-learning course.

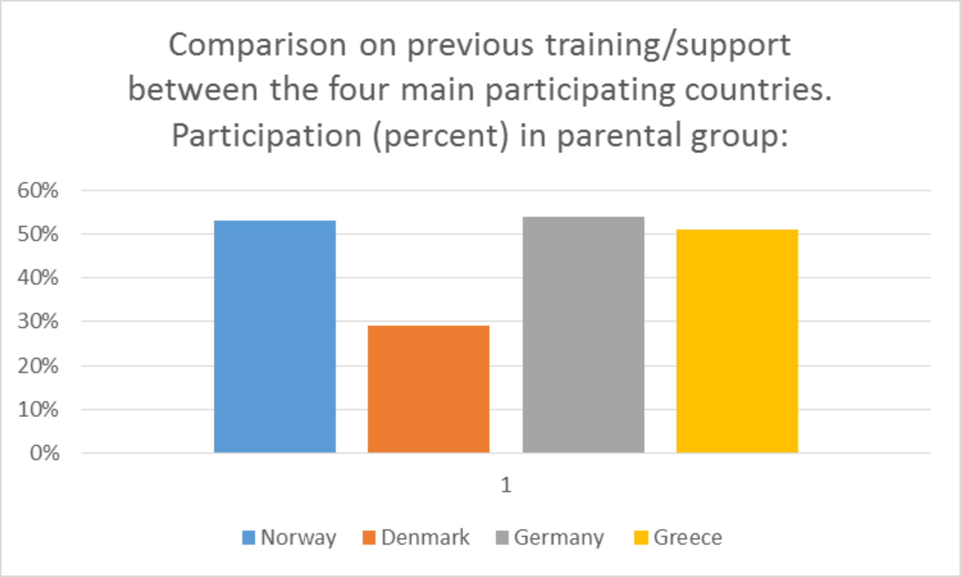


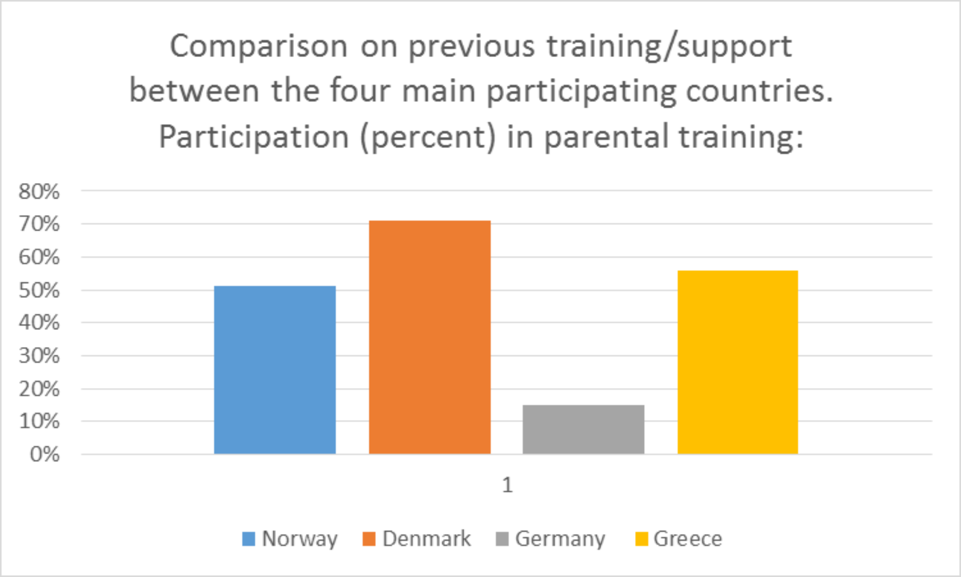
- According to the info provided by the survey participants, the ***level of PWID disability*** mainly falls in a ***moderate level (46%)***, while ***29% reported severe disability*** and ***25% mild disability***.



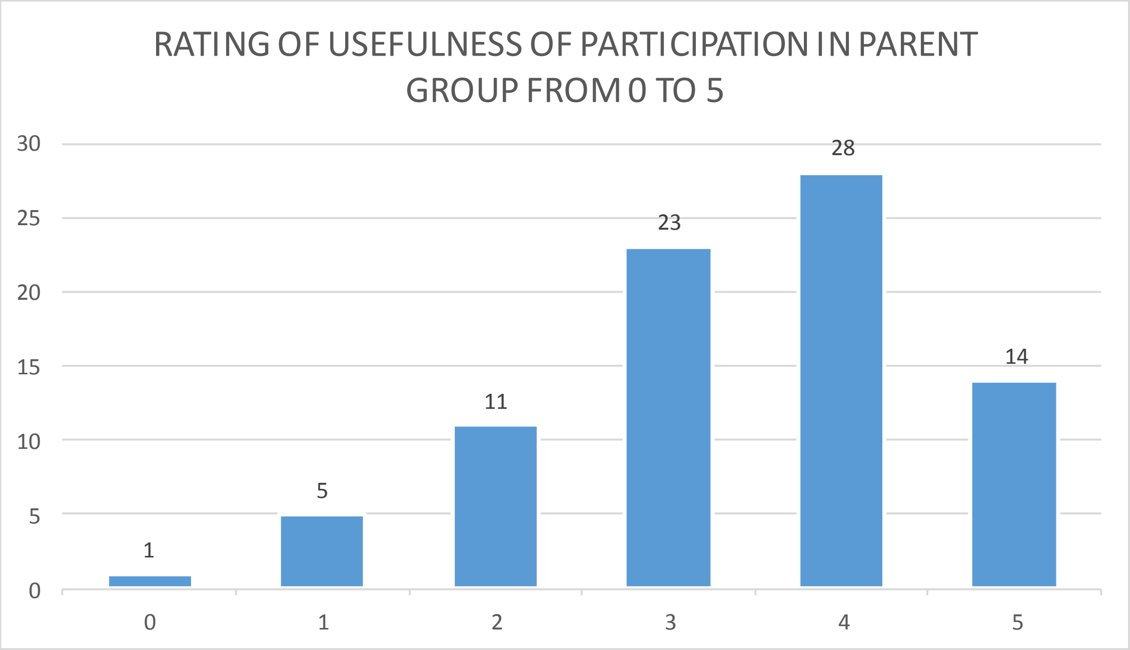
INFORMATION ON PREVIOUS SUPPORT & TRAINING

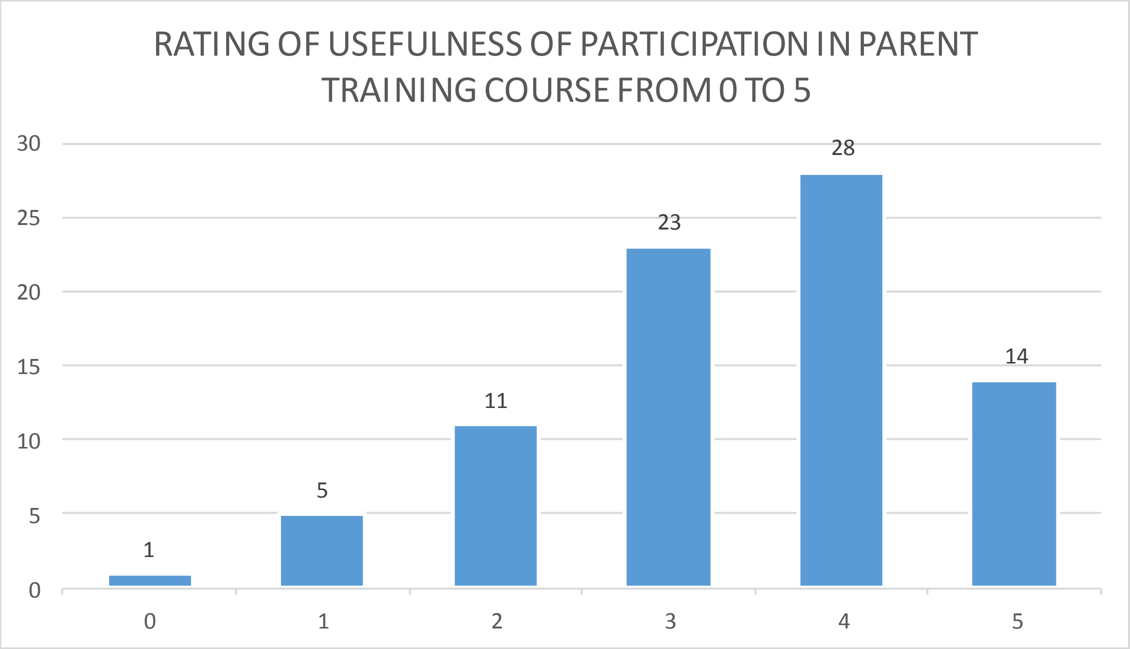
- Almost ***half of the participants (49%)*** had participated in ***a parent group*** and ***(48%)*** had completed ***a training course***. A comparison on participation in parent group and in training course in the past among the four project countries (Norway, Denmark, Germany and Greece) is provided in the charts below. ***Information in the charts may indicate that in Denmark parental training is more popular than parental group, while the contrary might be the case for Germany.*** In Norway and Greece both forms of support seem to be of equal popularity.





- People who have participated in parent group and had completed training course express the view that ***the support provided has been quite useful to them***, as shown in the charts below.





As per participants' open comments in terms of the usefulness of participation in parent group:

- The parents seem to ***appreciate the opportunity*** to share experiences, exchange information and receive information and support from people in similar situation.
- Often though ***parent groups did not meet their expectations due to the different diagnosis/needs of their child***.

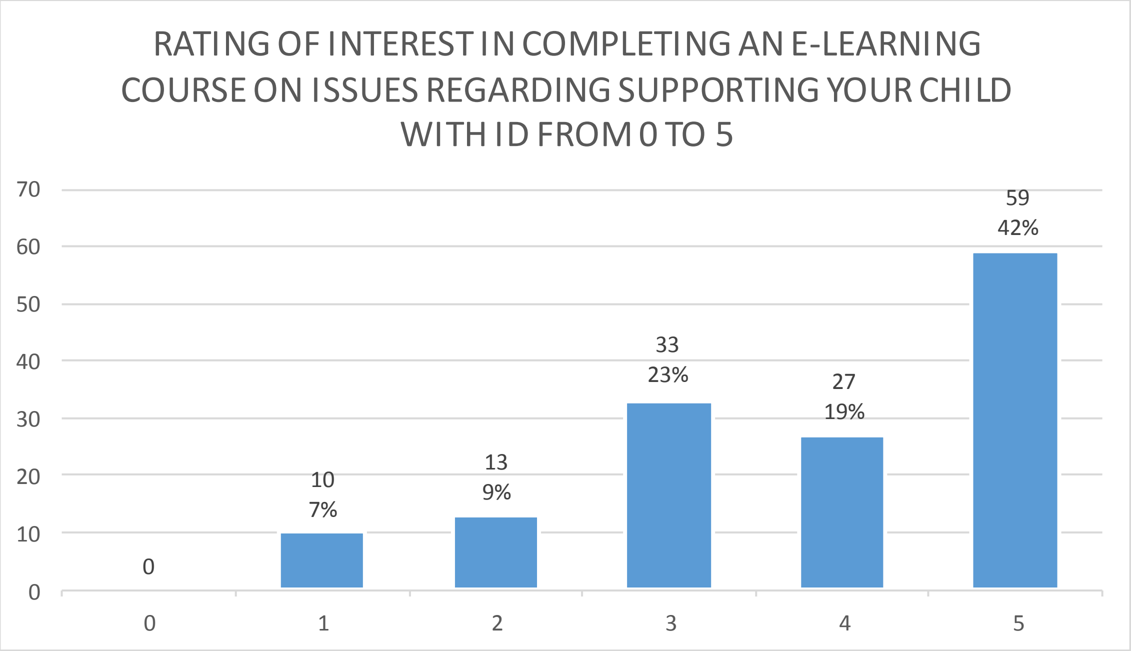
In terms of parents' training course:

- Participants commented that ***the quality of the training courses*** varies and it ***does not always meet the expectations*** of the parents.
- Moreover, ***some training courses mainly provide a theoretical approach and lack practical information/tools***.
- There also seems to be a lack of training courses on ***issues specific to adults with intellectual disability***.
- Finally, parents would also like the ***opportunity to participate in distance learning***.

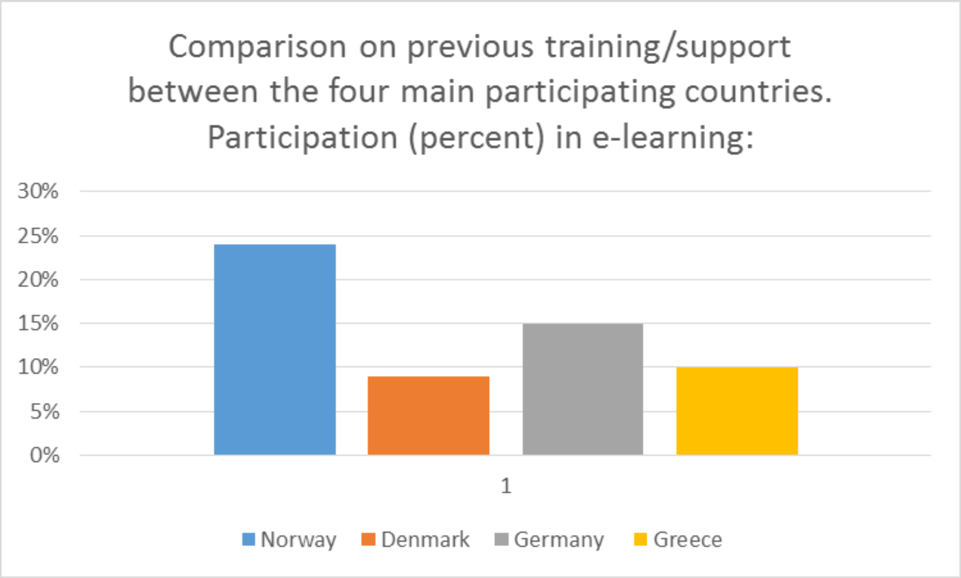
The above indicate that ***parents would like to receive training on subjects not already provided*** by municipalities and parent associations and ***with more practical information/advice.***

The focus on theories and general information in the existing parent training programmes was also documented in the literature review, ***highlighting the need for more practical advice.***

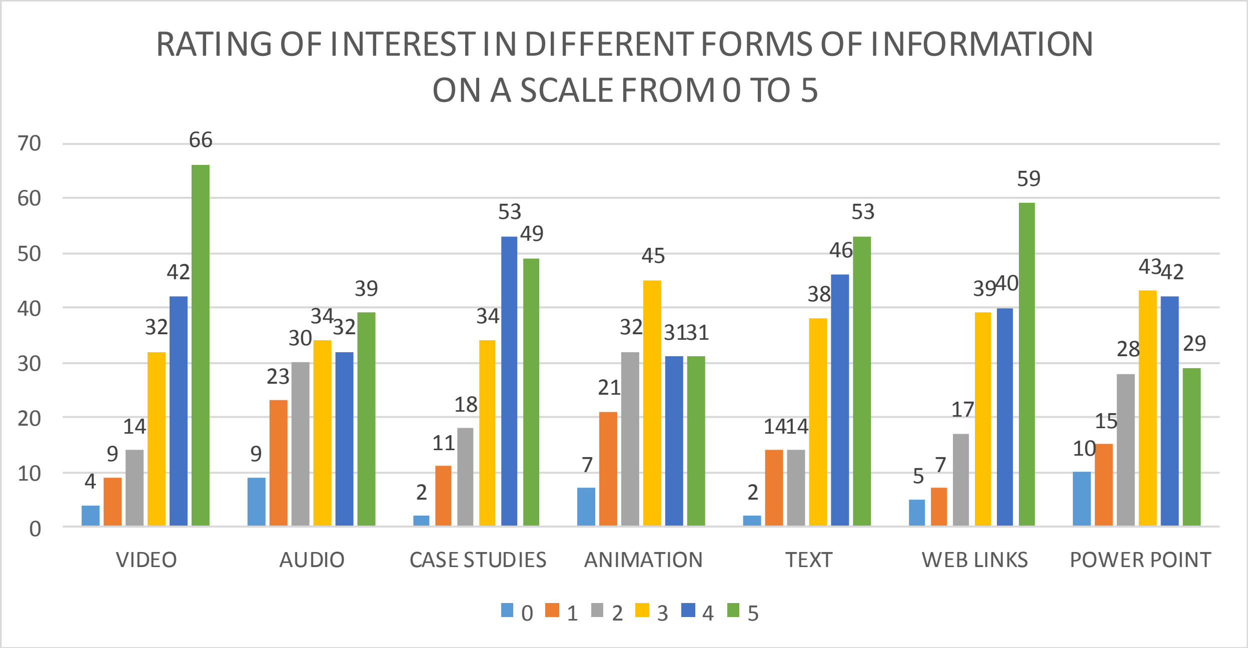
○ ***Only 24% of the participants had completed an e-learning course*** but they indicated ***they would be quite interested in completing an e-learning course on issues regarding supporting their child with intellectual disability*** (42% said they will be very interested, see chart below). The small percentage of participants who had already completed an e-learning course could be explained by the small number of e-learning courses available.



A comparison on previous e-learning participation among the participant counties indicate that ***e-learning support for parents with PWID might be more common in Norway*** and less common in the other three countries.



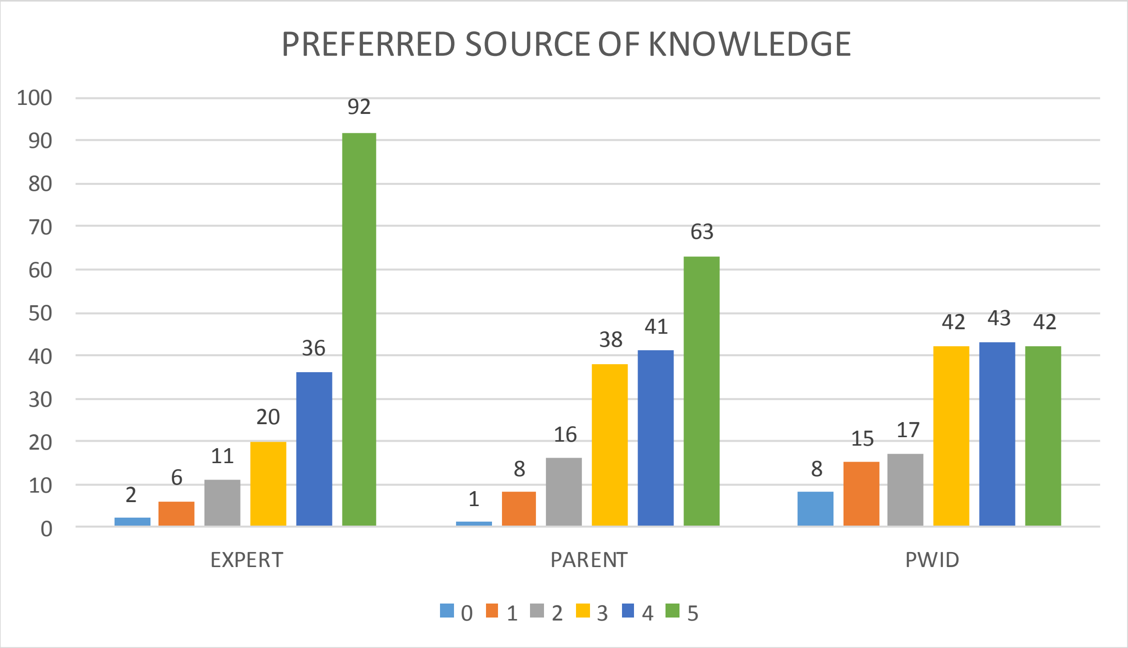
- ***Most forms of information*** seem to be of interest to them***, particularly videos, web-links, text and case studies***.



According to participants’ open comments ***other forms of information*** that could be of interest include:

- *Discussion groups;*
- *Face-to-face support/guidance by professionals*
- *Workshops;*
- *Fairytales/stories;*
- *Illustrations/drawing, personal stories by parents;*
- *Podcasts,*
- *Situation simulation;*
- *Informal parent groups,*
- *Links to organisations*

○ In addition, participants would be ***more interested to receive the information from an expert*** although they ***do place a value on other parents’ and PWID’s experience and knowledge.***



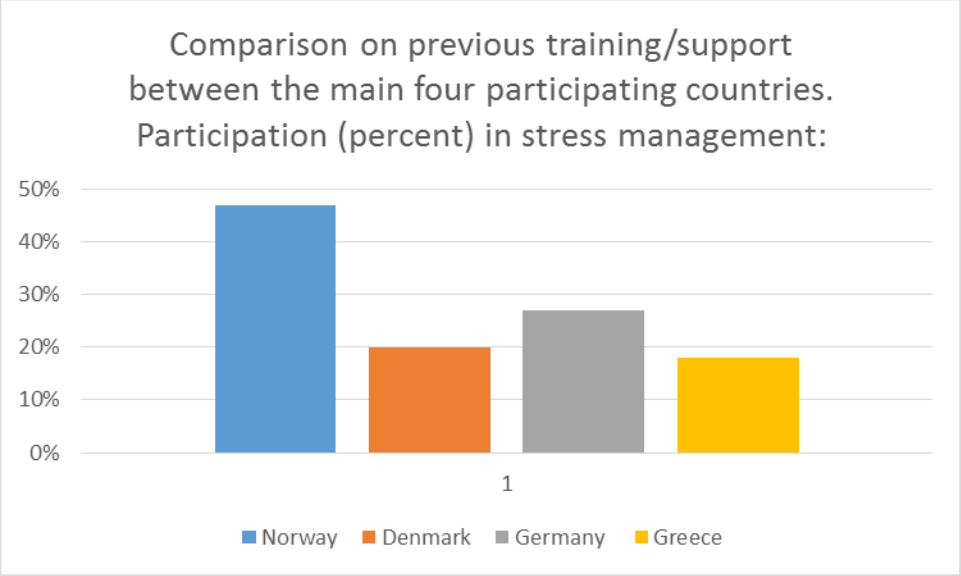
INFORMATION ON TRAINING TOPICS

This section provides information derived from the survey specific to the six topics/modules that have been chosen to be included in the e-learning platform, namely: stress ***management, communication, transition to adulthood, human rights, sex education, ageing.*** For each topic the focus is on: participants' ***previous knowledge*** on the topic; ***usefulness*** and ***content needs***.

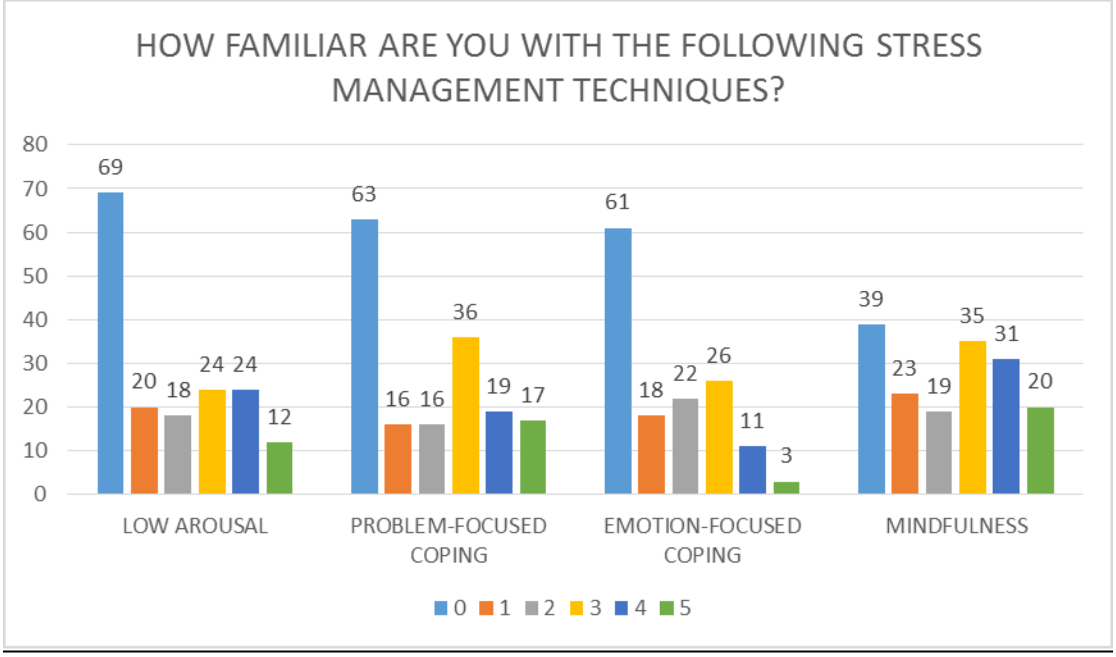
Stress Management

- ***Previous knowledge***

Only 1 of 4 participants (28%) has already taken part in stress management training. According to the survey, there is a big percent of participants from the four main participating countries who has no previous training/support on stress management. Specifically, ***in Norway*** over the half of participants said that they have no previous training/support on this topic. In ***Denmark, Germany and Greece*** the vast majority has no previous training/support on stress management, too (see chart below).



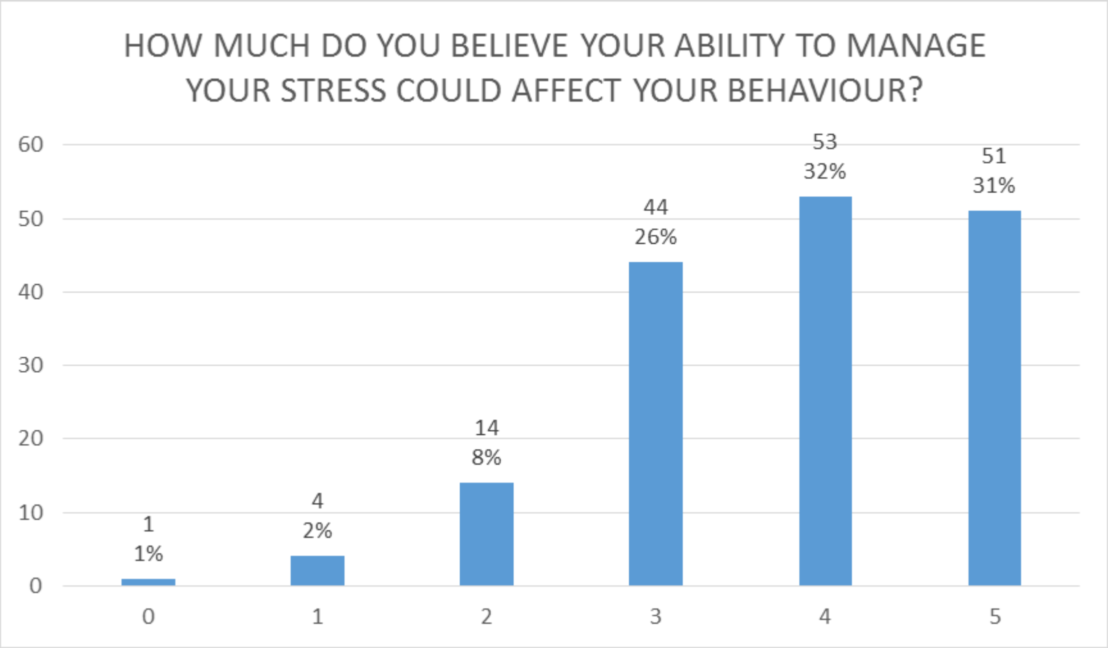
Moreover, ***over half of the participants have little or no knowledge on stress management techniques like low arousal, problem-focused coping and emotion-focused coping***. Participants, on the other hand, seem to be ***quite familiar with mindfulness as a stress management method (***as shown in the chart below).

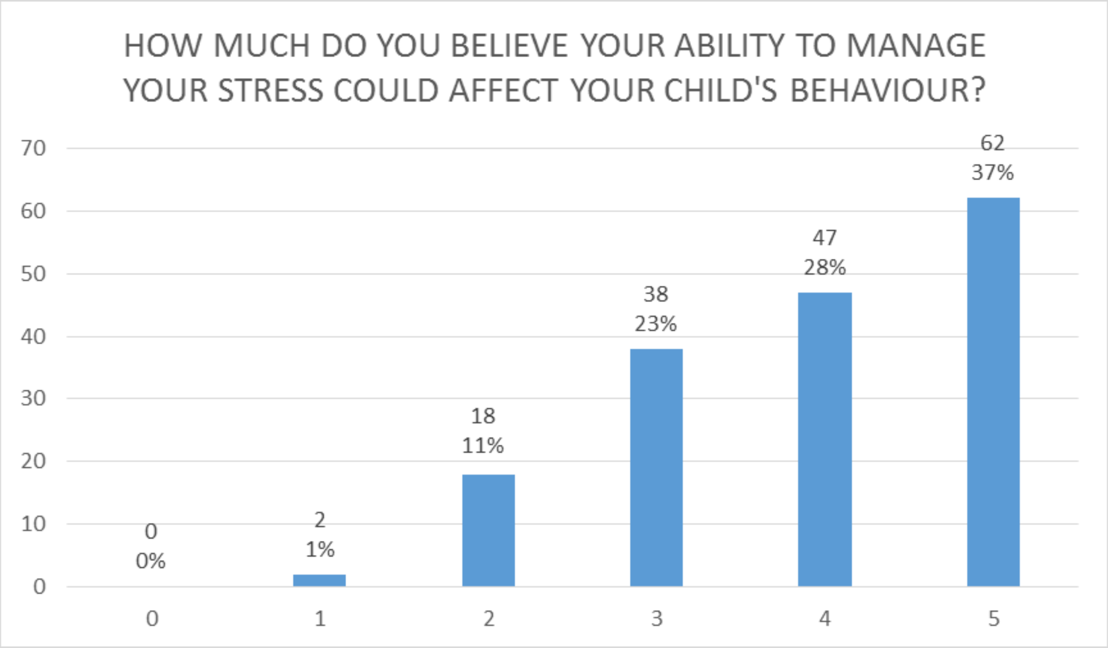


➲ ***<u>Usefulness</u>***

The participation in a stress management training (28%) is inversely proportional to the interest in this topic as ***more than 2/3 of the participants believe it plays an important role and it would be important for them to gain more knowledge on.*** Regarding the usefulness of previous stress management training, most of the participants believe that it was very useful for them.

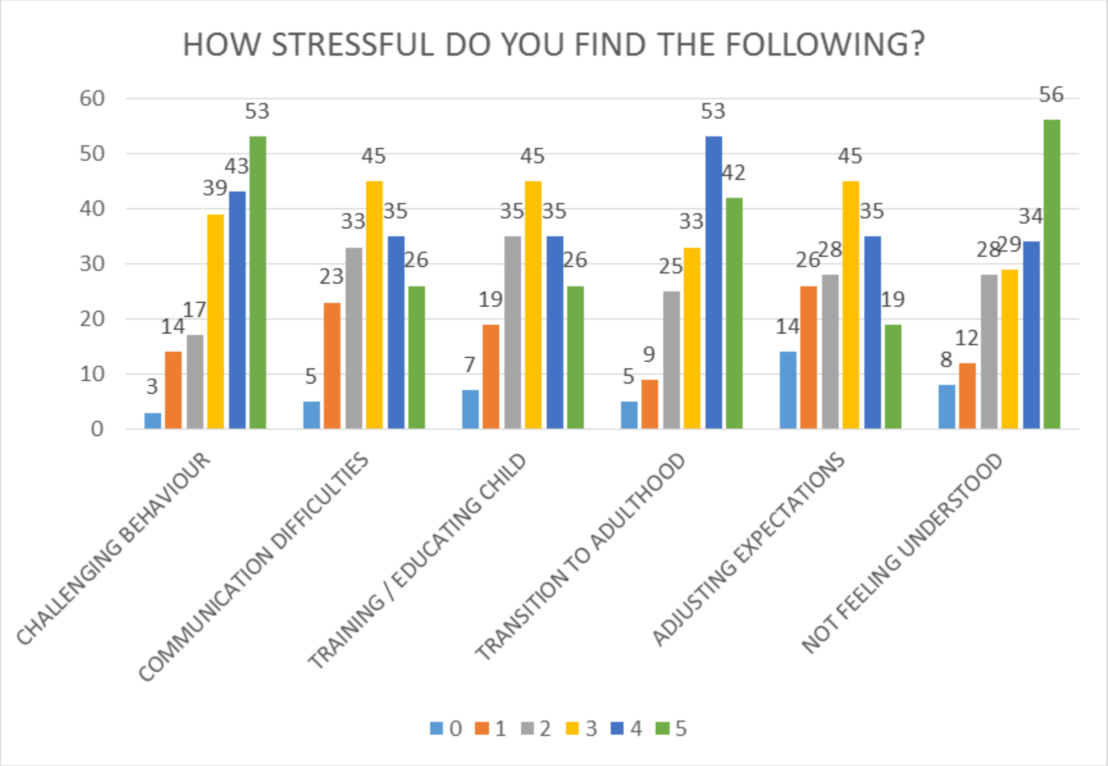
When the participants were asked about how much they believe their ability on stress management could affect their behaviour and their child’s behaviour, ***the majority of participants seem to appreciate the important role their ability to manage stress plays on their behavior*** (32% indicated 4 and 31% indicated 5 on a 0-5 scale) ***and their child’s behavior*** (28% indicated 4 and 37% indicated 5 on a 0-5 scale) – see charts below.





- ***Content needs***

Most of the participants feel ***quite competent to manage their stress, with a small percentage of participants seem to feel confident*** in managing their stress levels (only 13% indicated 5 on a 0-5 scale). However, there are a number of content needs that become evident from the issues that parents feel as more stressful – as shown in the following chart.

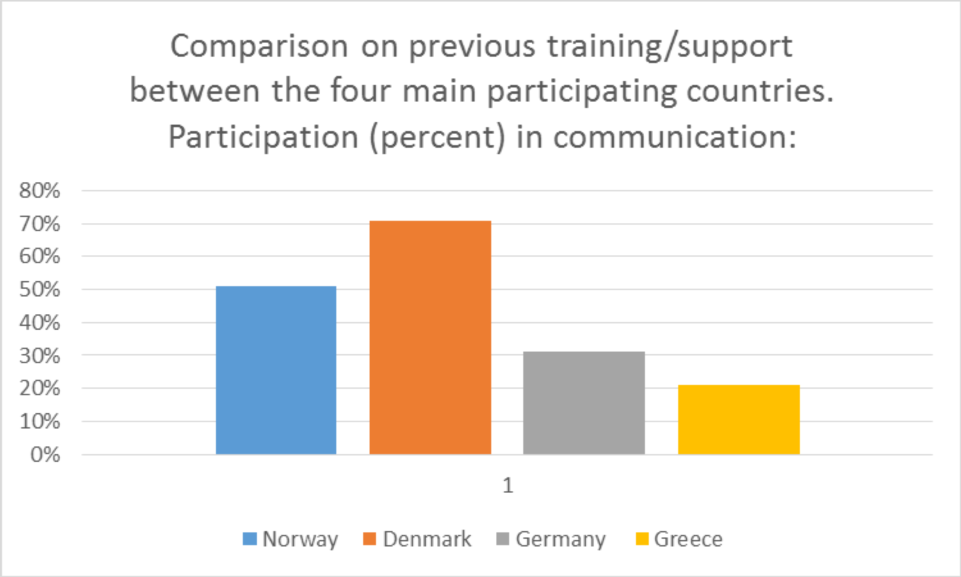


As evident in this chart above, ***over half of participants said that not feeling understood by others***, ***dealing with challenging behavior*** and ***their child's transition to adulthood*** are very stressful for parents. Additionally, ***educating their child***, ***communication difficulties and adjusting their expectations to their child's abilities*** are also stressful for parents but less so.

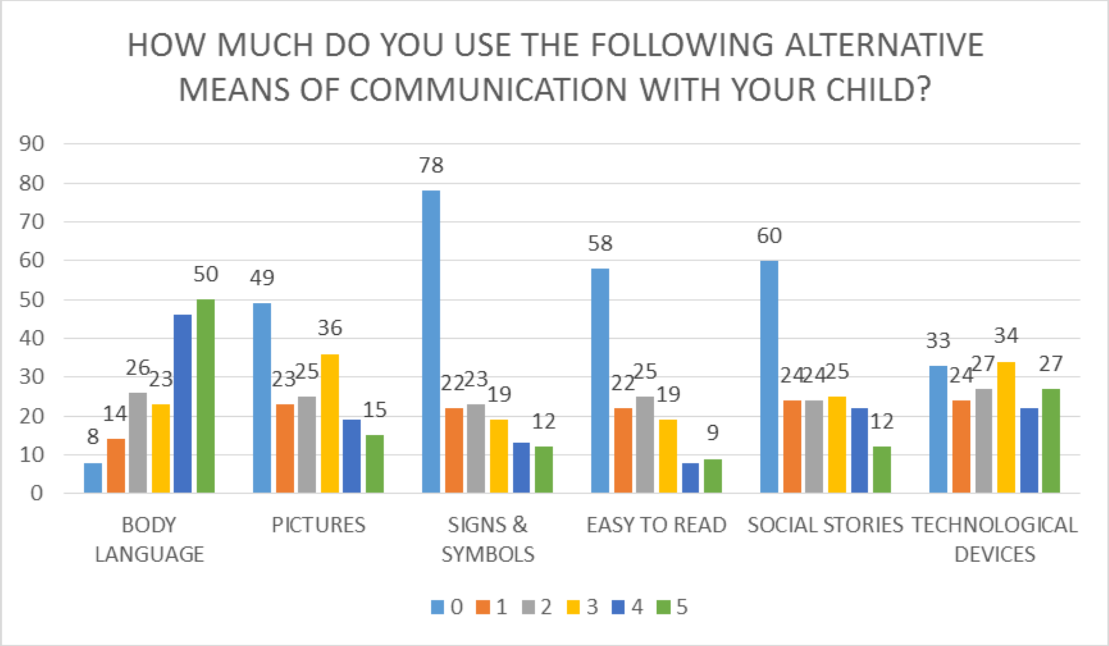
Communication

- ***Previous knowledge***

Over half of the participants have not taken part in communication skills training. According to the survey, there is a big percent of participants from the four main participating countries who has no previous training/support on communication skills. Specifically, in ***Norway*** almost the half of participants said that they have no previous training/support on this topic. In ***Germany and Greece*** the vast majority also has no previous communication skills training, but in ***Denmark*** the vast majority seems to have.



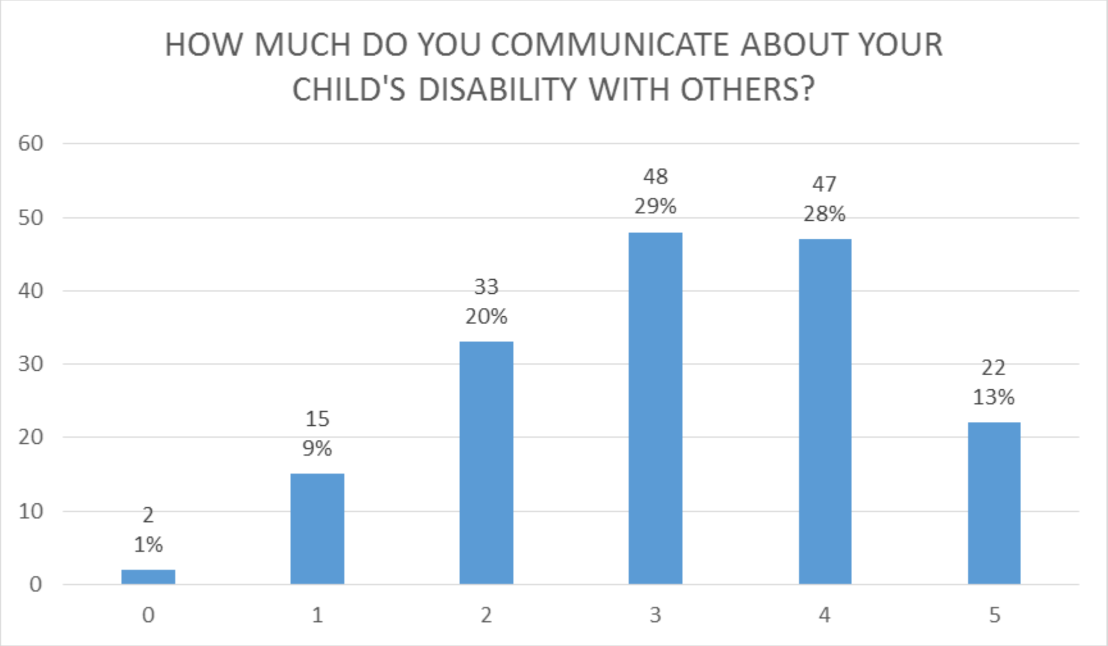
Furthermore**, *in order to overcome the communication difficulties*** with their child, parents seem to mainly use body language and technological devices (such as telephone, tablet, etc.). ***Alternative means of communication such as pictures, social stories, easy-to-read and symbols are not commonly used.***

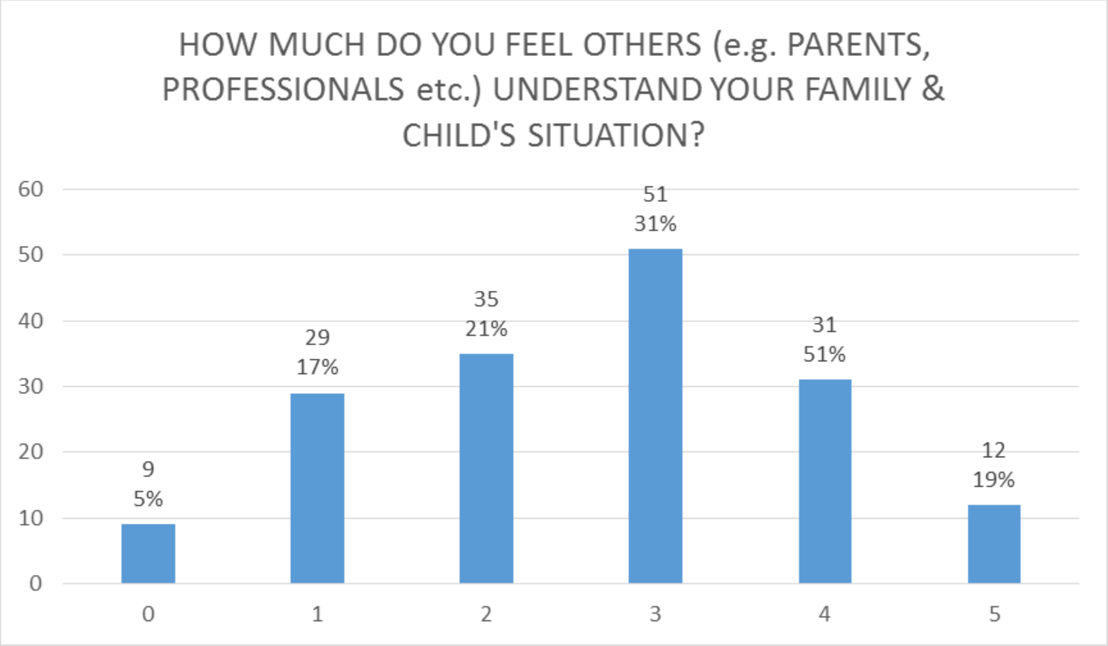


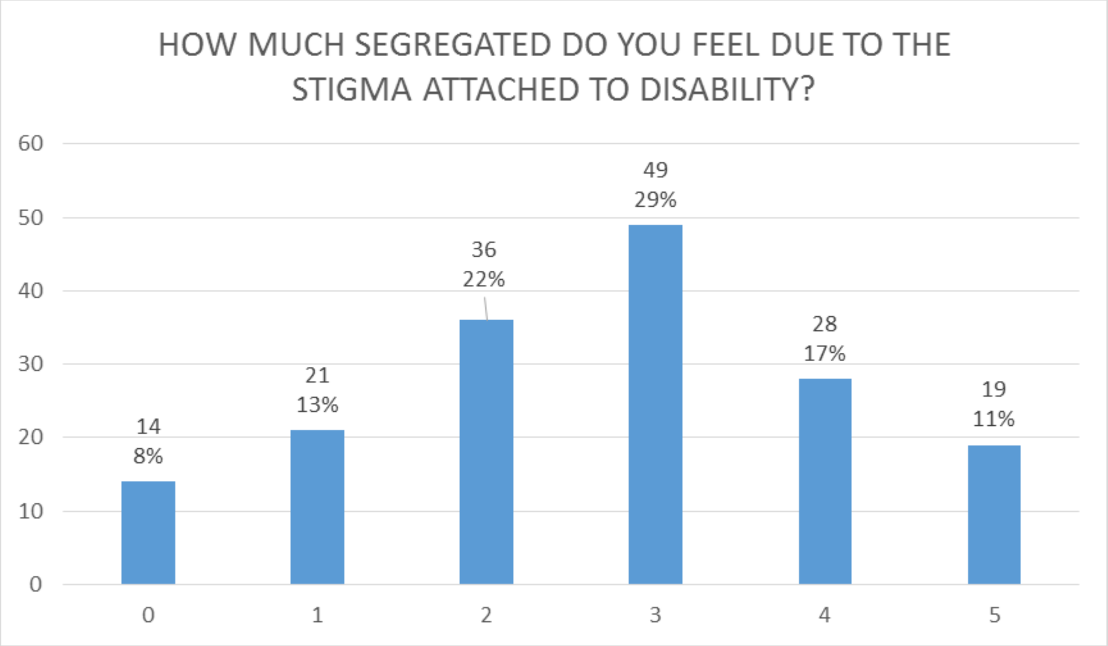
Based on the above findings, it would be interesting to carry out an extensive research study on the use of technology in communication. More specifically, it would be interesting to look at the use of technological devices as means of communication for PWID and whether parents of PWID are familiar with various technological devices. The small average age of the children of the participants implies that they are quite young parents who are familiar with technological devices and applications, and may be less inclined to use printed material such as texts in easy to read methodology.

➲ ***Usefulness***

Regarding the usefulness of previous communication skills training, most of the participants have found it very useful for them. ***The majority of participants also said that they would be very much interested in improving their communication skills***. In terms of how much participants communicate about their child’s disability, they seem to do so but not on a great degree (only 13% indicated 5 on a 0-5 scale). This does not seem to be due to not feeling understood by others or to the stigma attached to disability. The majority of participants, however, would like to have more communication with other parents (77%) as well as service providers (80%). It is a positive finding that parents no longer see their child’s disability as stigmatizing. More than 60% consider their child a little or not stigmatized at all by its disability.

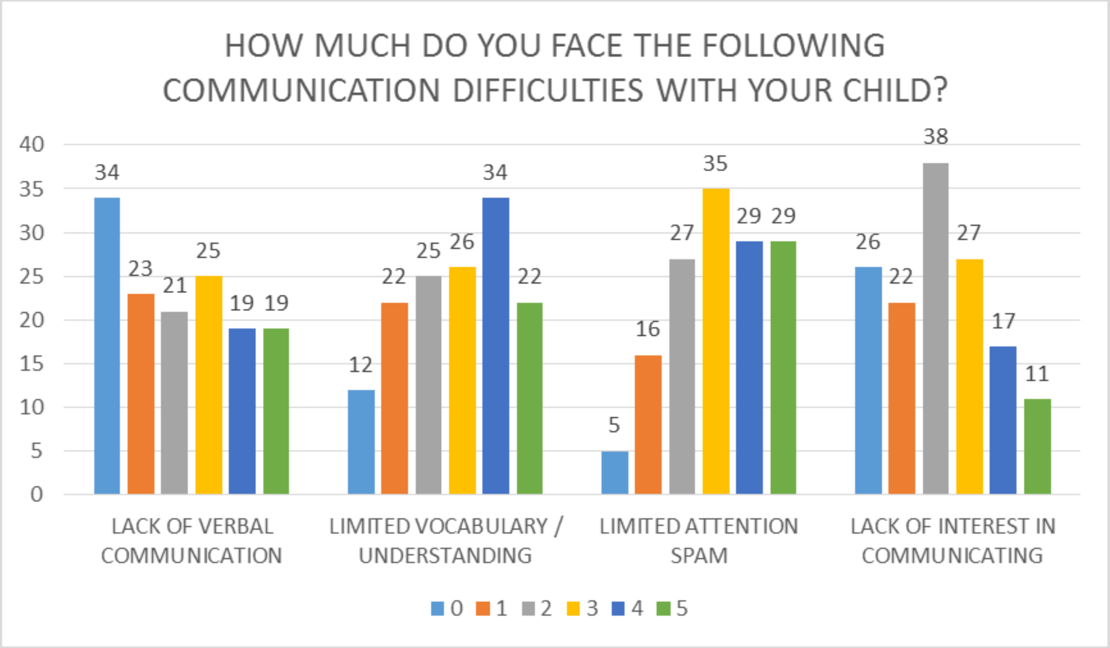



HOW MUCH DO YOU FEEL OTHERS (e.g. PARENTS, PROFESSIONALS etc.) UNDERSTAND YOUR FAMILY & CHILD'S SITUATION?
60
50
40
30
20
10
0
9
5%
29
17%
35
21%
51
31%
31
51%
12
19%
0
1
2
3
4
5


HOW MUCH SEGREGATED DO YOU FEEL DUE TO THE STIGMA ATTACHED TO DISABILITY?
60
50
40
30
20
10
0
14
8%
21
13%
36
22%
49
29%
28
17%
19
11%
0
1
2
3
4
5

- ***Content needs***

As the survey shows, the vast majority of the participants would like to have more communication with other parents (specifically, 3 out of 4) as well as service providers (specifically, 4 out of 5). This shows ***that there are a number of communication difficulties which parents have to face with them concerning their child***. The main difficulties are ***child's limited vocabulary/understanding and its limited attention spam***. ***Lack of interest in communicating***, which their child has, is another important difficulty for parents but less so. Moreover, lack of verbal communication is another communication barrier for parents but even less so.

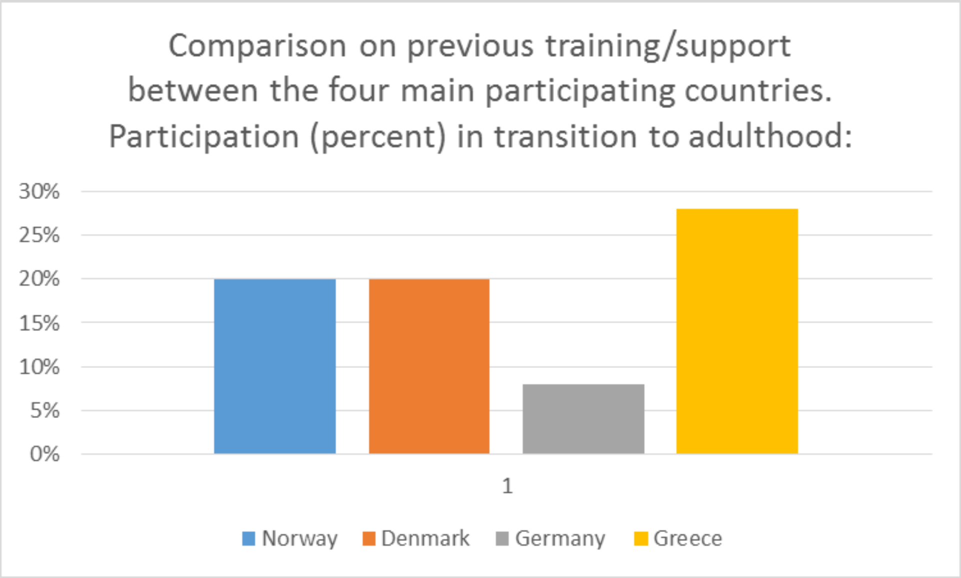


In addition, participants named ***several other communication difficulties with their child***, as: unable to speak, jumping from theme to theme in the middle of sentences (comment: loss of coherence), becomes easily tired, influenced by mood (more difficult when angry), discrepancy between explicit verbal language and understanding, unclear speech, requires that parents ''translate'' to other what child says.

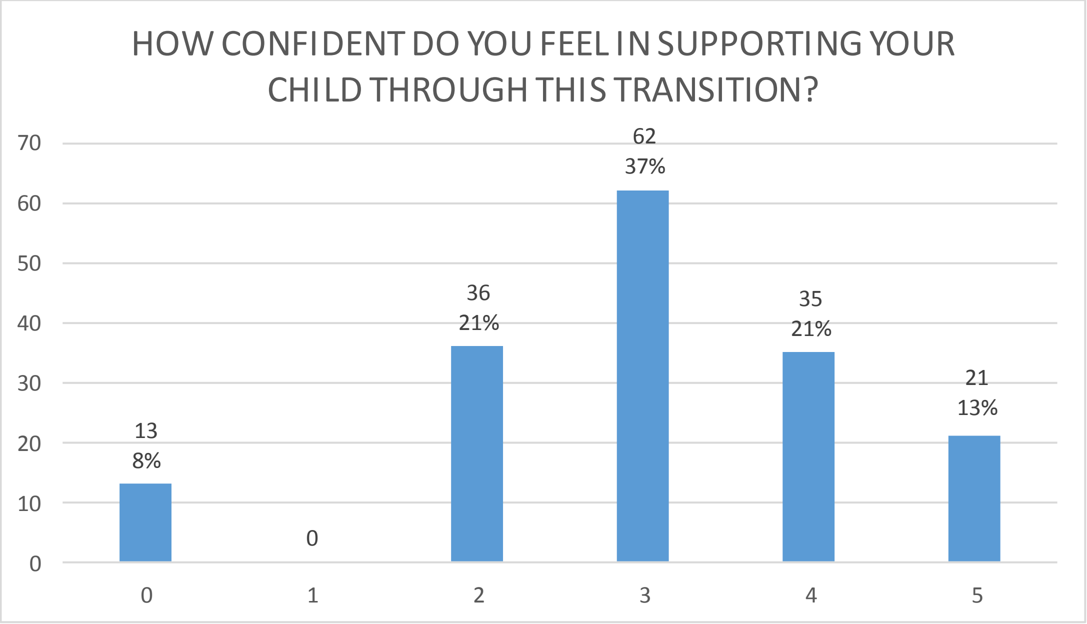
Transition to adulthood

- ***Previous knowledge***

Only 1 of 5 participants has already participated in previous transition to adulthood training. According to the survey, the vast majority of participants from the four main participating countries has no previous training/support on transition to adulthood. Specifically, ***in Norway and Denmark*** 8 out of 10 participants, ***in Germany*** 9 out of 10 participants and ***in Greece*** 7 out of 10 participants have ***not*** taken part in previous training on this topic.

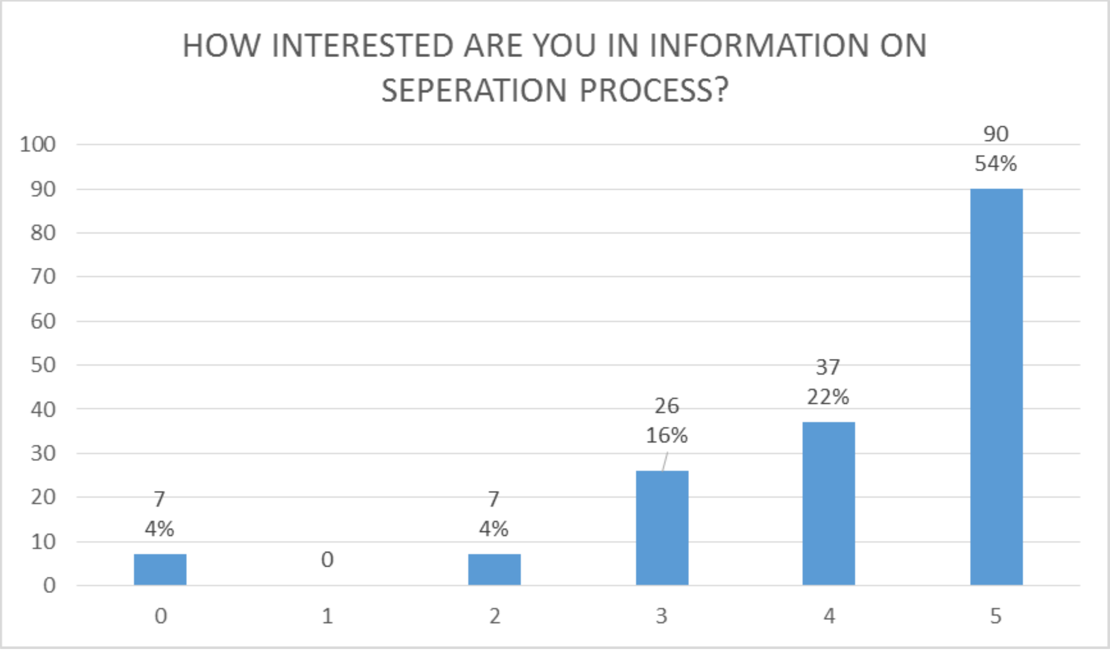


In addition, only 1 out of 3 participants feel very or quite confident in supporting their child through transition to adulthood (21% indicated 4 and 13% indicated 5 on a 0-5 scale).



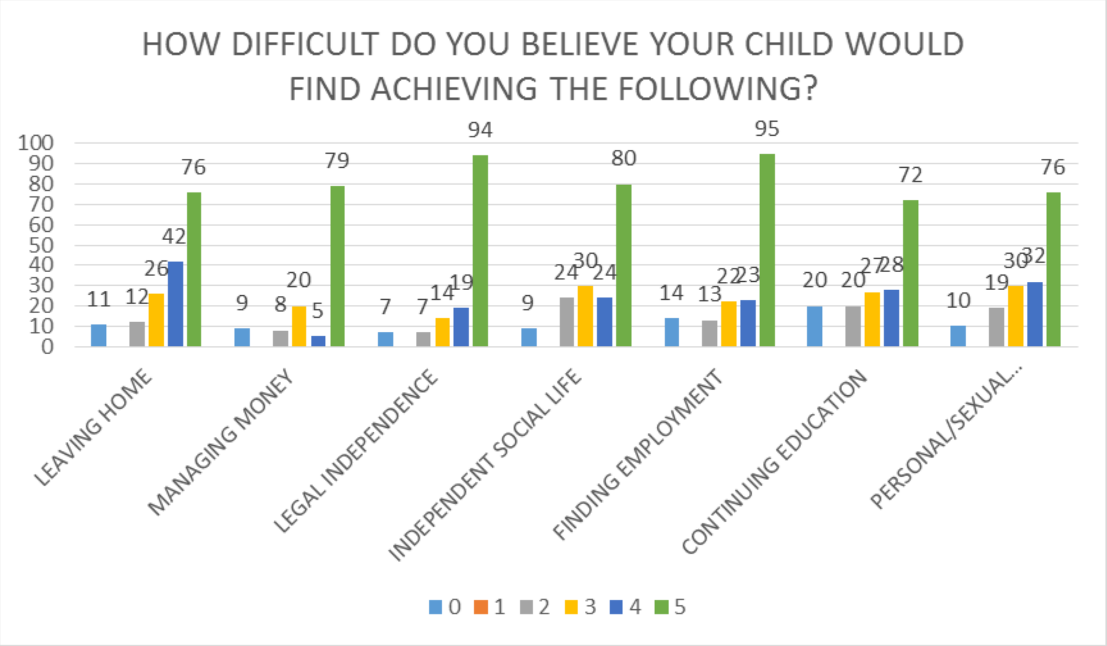
➲ ***Usefulness***

From those participants who have participated in previous corresponding training, the majority said that it was quite useful for them. Furthermore, ***over half of the participants indicated that they are very interested in information on separation process.***



- ***Content needs***

In term of how difficult participants believe that their child would find achieving a number of different goals relevant to their child’s transition to adulthood, ***the vast majority indicated as the most difficult goals finding employment and achieving legal independence***. In addition, the survey shows that they believe that ***it is also very difficult for their child to leave home and have personal/sexual relationships.*** As less difficult goals they consider continuing education, acquiring independent social life and managing their own money.

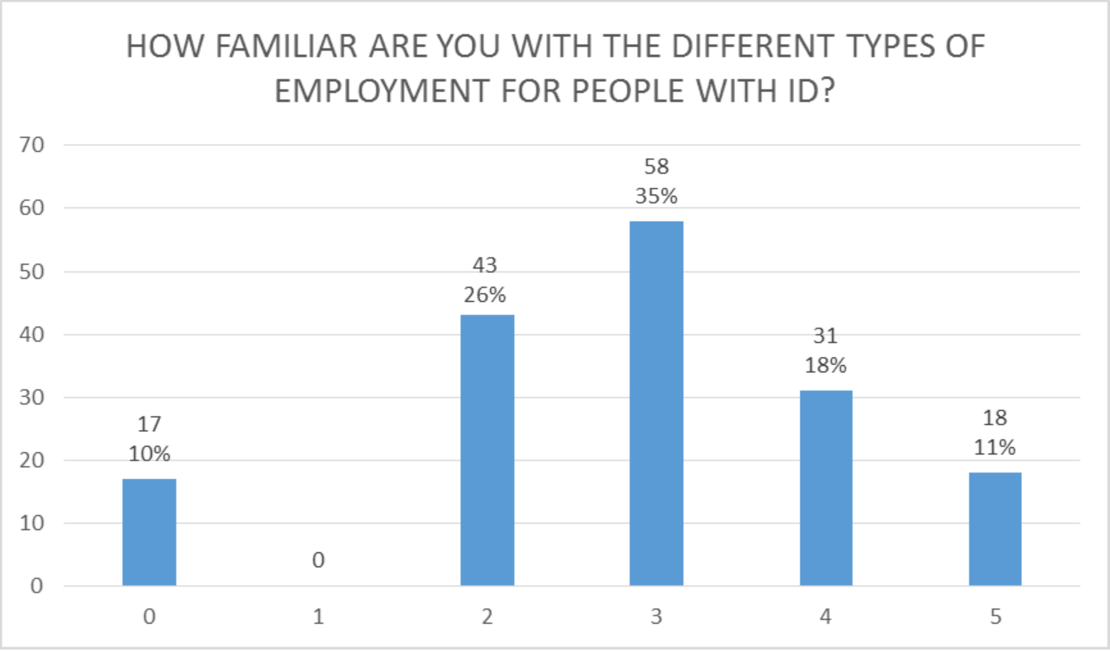


Even though our study is a pilot study, it shows, like in previous published research, that during transition to adulthood the main difficulties parents and PWID face are around education, safeguarding of human rights (in this case it is mentioned as legal independence) and independent living.

Human Rights

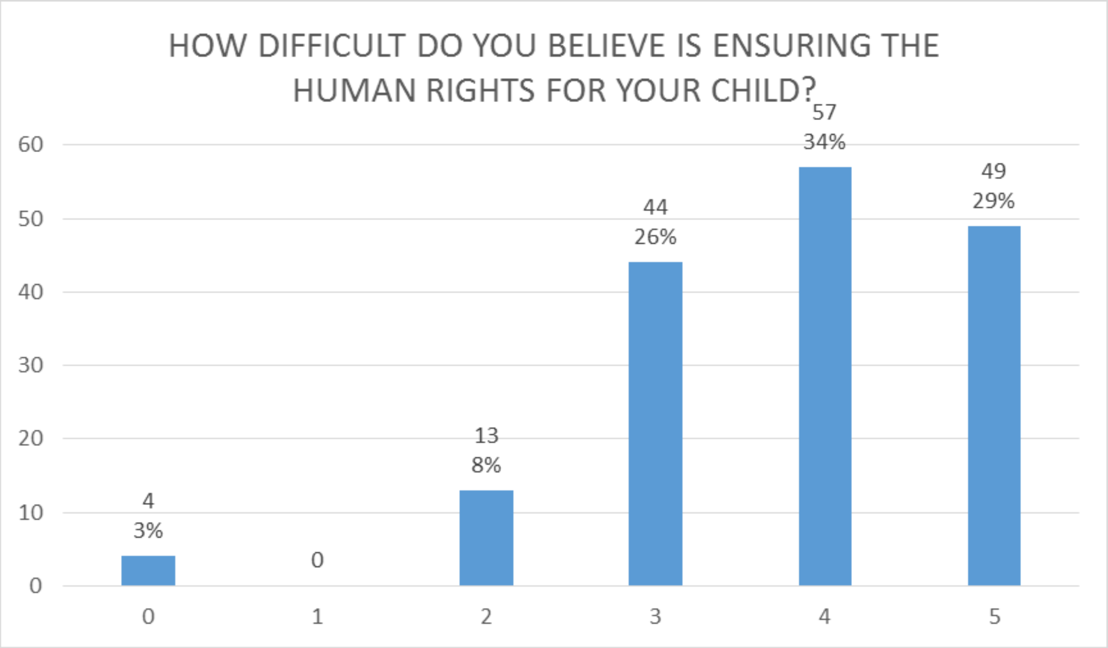
- ***Previous knowledge***

The majority of participants have little or no knowledge at all on the Human Rights Convention (25% indicated 0 and 27% indicated 2 on a 0-5 scale). They also believe that it will be very difficult to ensure the Human Rights for their child (34% indicate 4 and 29% indicated 5 on a 0-5 scale). Apart from this, most of the participants seem to have quite or little familiarity with different types of employment for people with ID.



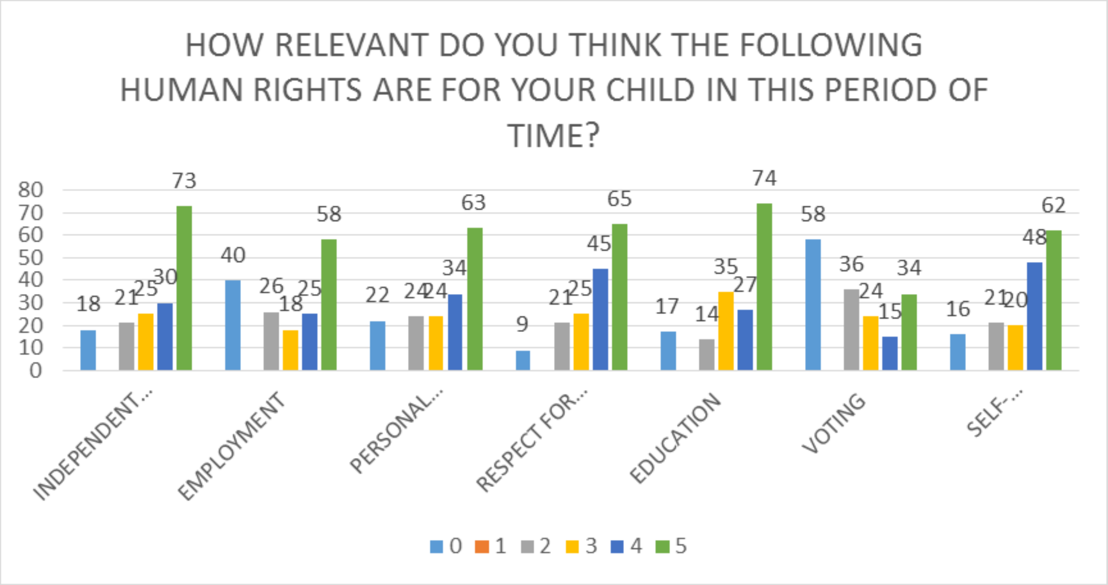
- ***Usefulness***

In terms of how difficult the participants believe is ensuring the human rights for their child, the majority considers that it is very difficult for their child to achieve it.



➲ *Content needs*

Regarding the relevance of some important human rights for their child in this period of time, ***education and independent living were indicated as the most relevant human rights***. Respect of privacy, self-determination and personal relationships were also indicated as quite relevant to the participants' child. Furthermore, the right of employment seems to have less relevance for their child in this period of time, while the voting right seems to be the least relevant to them.



The findings on ***Transition to adulthood*** regarding the interest and need for employment, housing and education are also documented here confirming our initial assumption regarding lack of training and support on these areas/topics. Moreover, the lack of knowledge on the Convention of Human Rights shows limited training on this subject and regardless of the small sample of the study it raises new issues. The right to employment was also indicated as quite relevant to the participants' child. There also seem to lack of knowledge on the different types of employment for people with intellectual disability (10% indicated no knowledge at all and 26% very little knowledge).

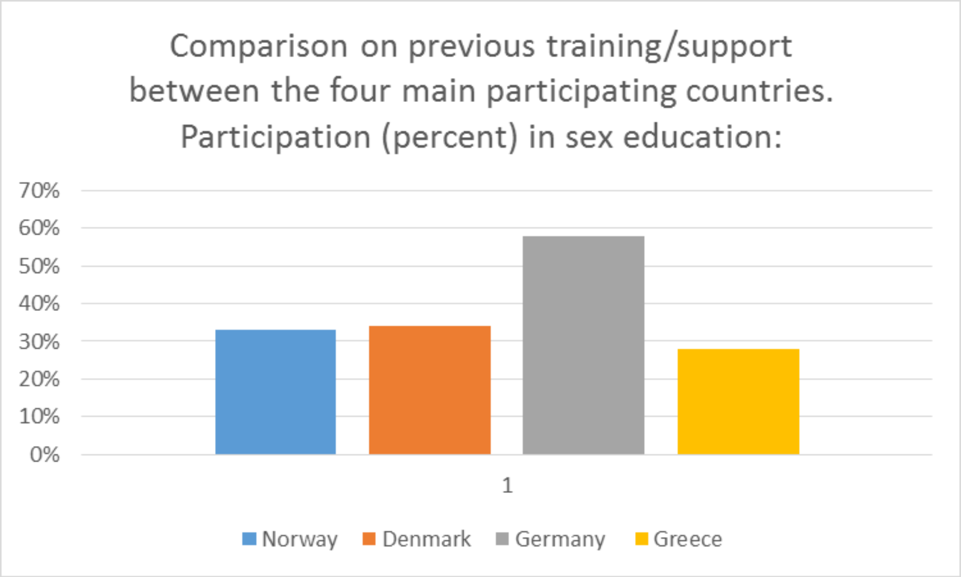
Sex education

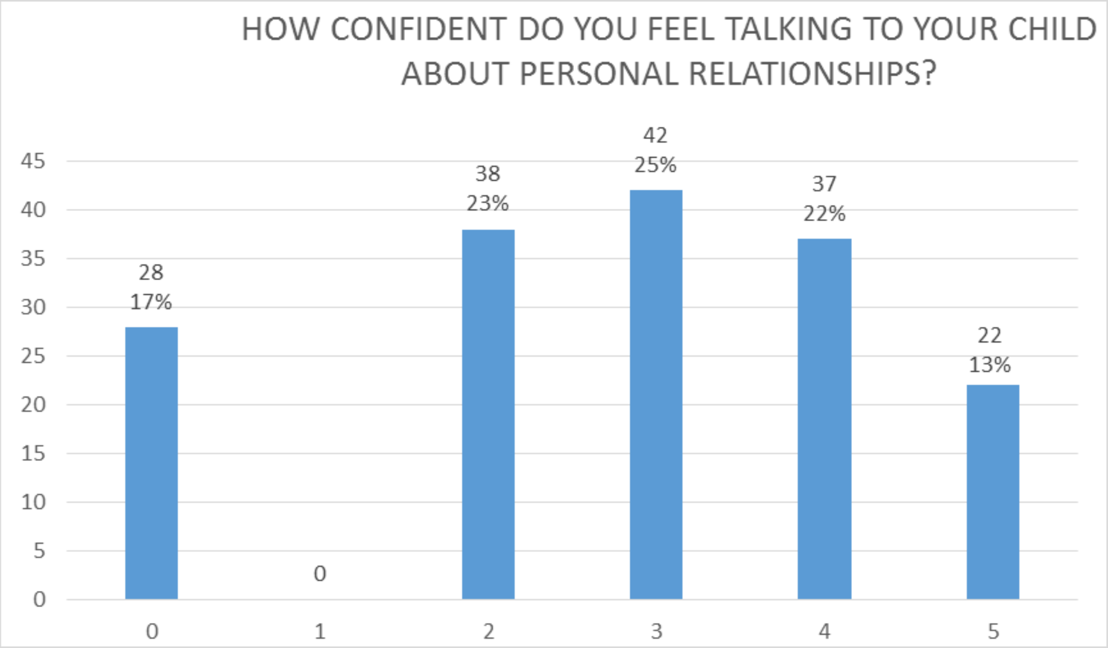
- *Previous knowledge*

Only 1 of 3 participants has already taken part in previous sex education training. According to the survey, the vast majority of participants from the four main participating countries has no previous training/support on sex education.

Specifically, ***in Norway and Denmark*** 2 of 3 participants have not acquired previous knowledge by participation in a training course. In ***Greece*** a bigger percent (almost 72%) of participants seem to have no previous corresponding training, while ***in Germany*** under the half of participants (almost 42%) has not previous training on sex education (see first chart below).

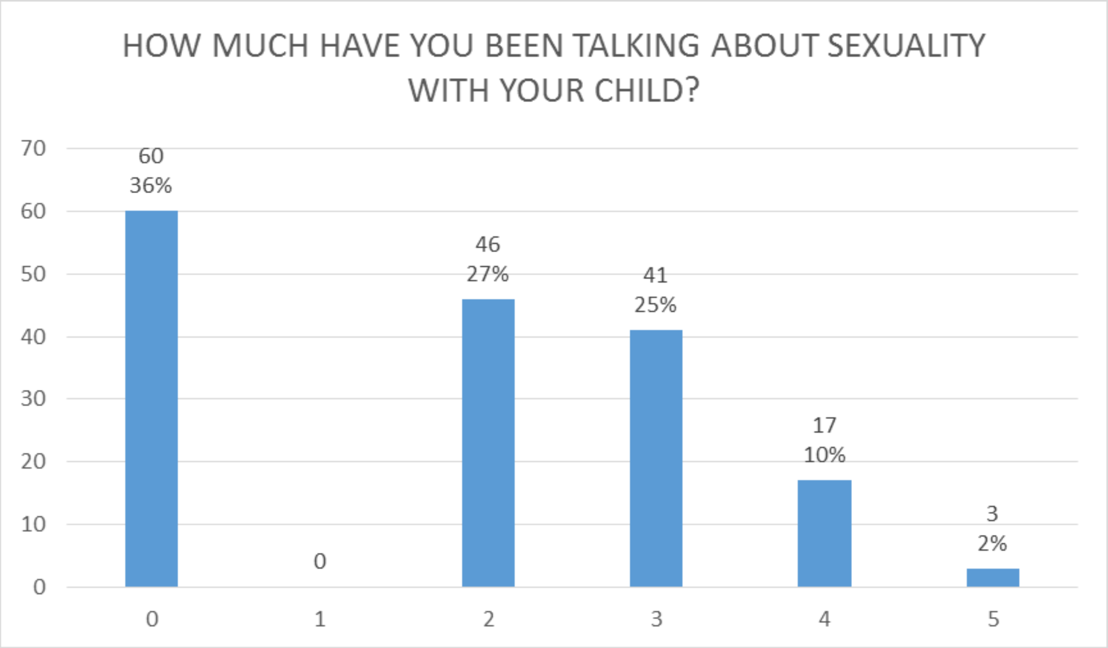
This may be linked to their low confidence in talking to their child about personal relationships (see second chart below).



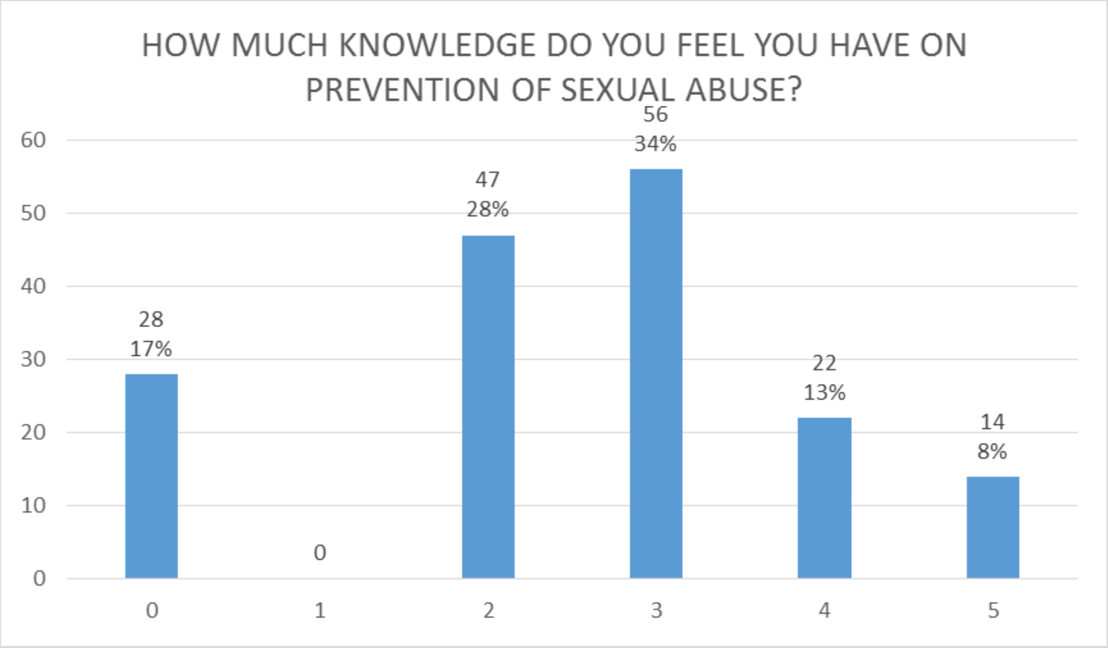


➲ ***Usefulness***

From those participants who have participated in previous corresponding training, the majority said that it ***was very useful for them***. However, ***the majority of parents does not talk at all or talk a little about sexuality with their child***.



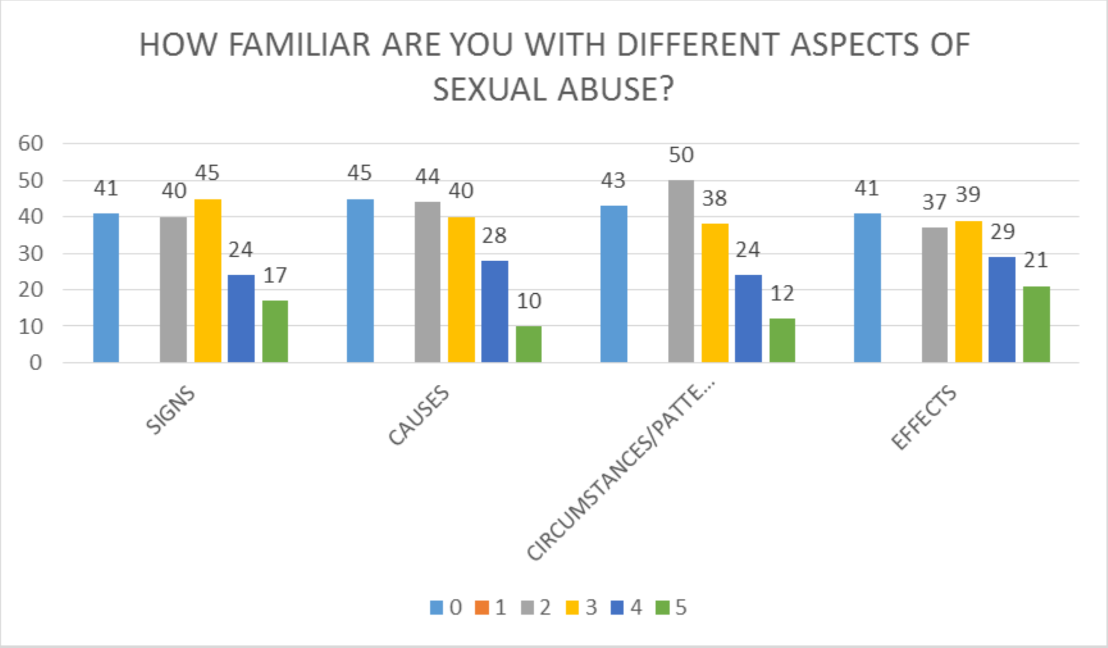
Apart from this, the survey also shows that ***parents feel they have little knowledge on prevention of sexual abuse,*** i.e. signs, causes, circumstances/patterns as well as effects.



It would be interesting to look at differences between different ethnicities and cultures. ***It is likely that in Southern Europe, sexuality is a taboo subject whereas in Northern Europe they may be talking about is more openly.*** A larger sample would be needed though in order to investigate this assumption.

- *Content needs*

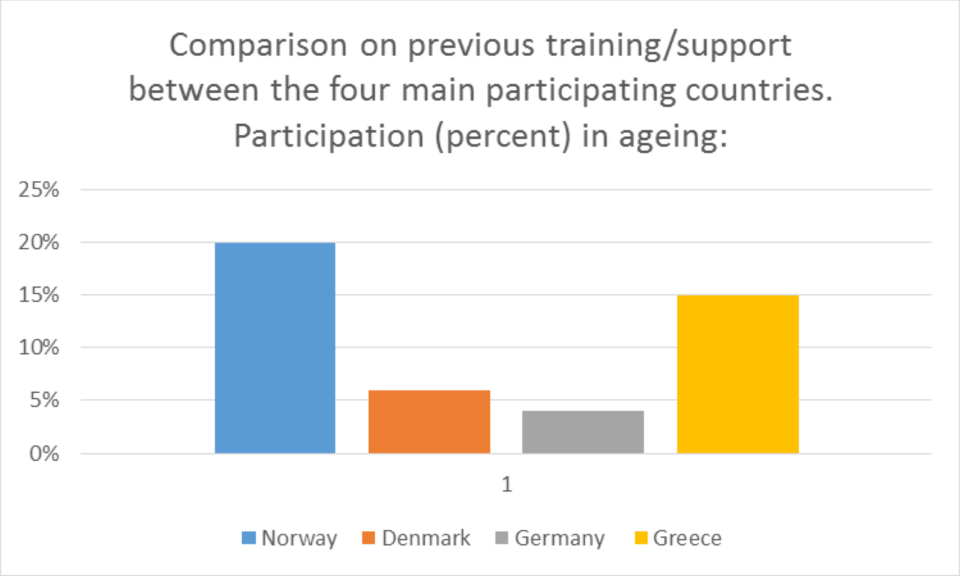
Parents’ little knowledge on prevention of sexual abuse seems to be the reason they are not familiar with all aspects of sexual abuse. Specifically, circumstances/patterns and signs seem to be the two less recognizable by the parents. ***The vast majority of parents are not at all or are a little familiar with other aspects of sexual abuse such as causes of sexual abuse and effects it has in individual’s life.***



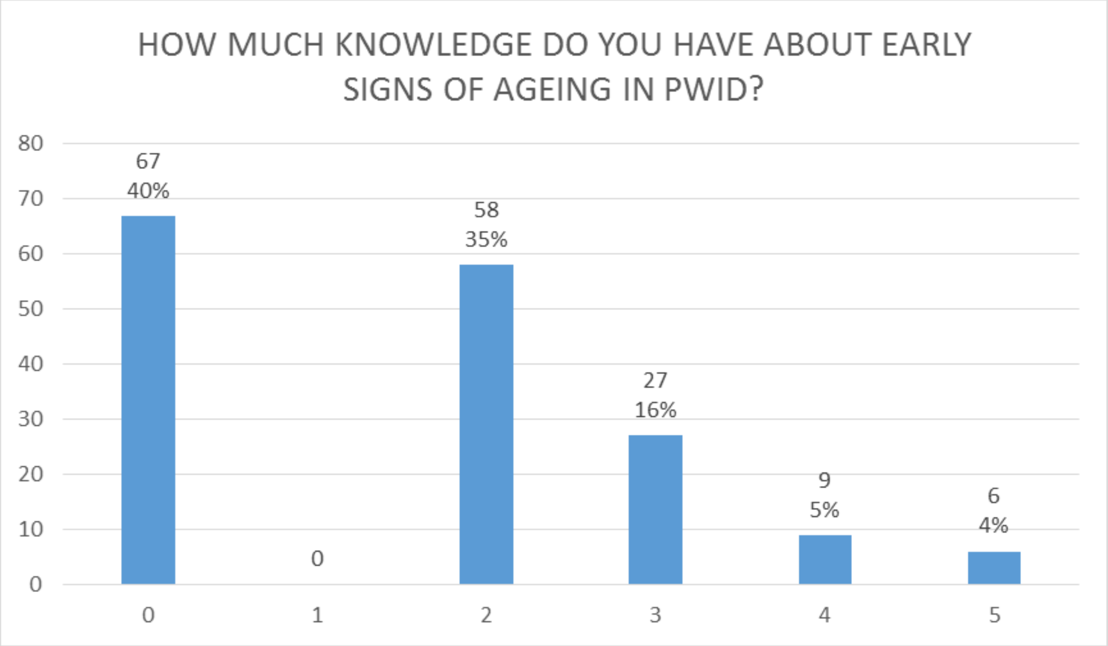
Ageing

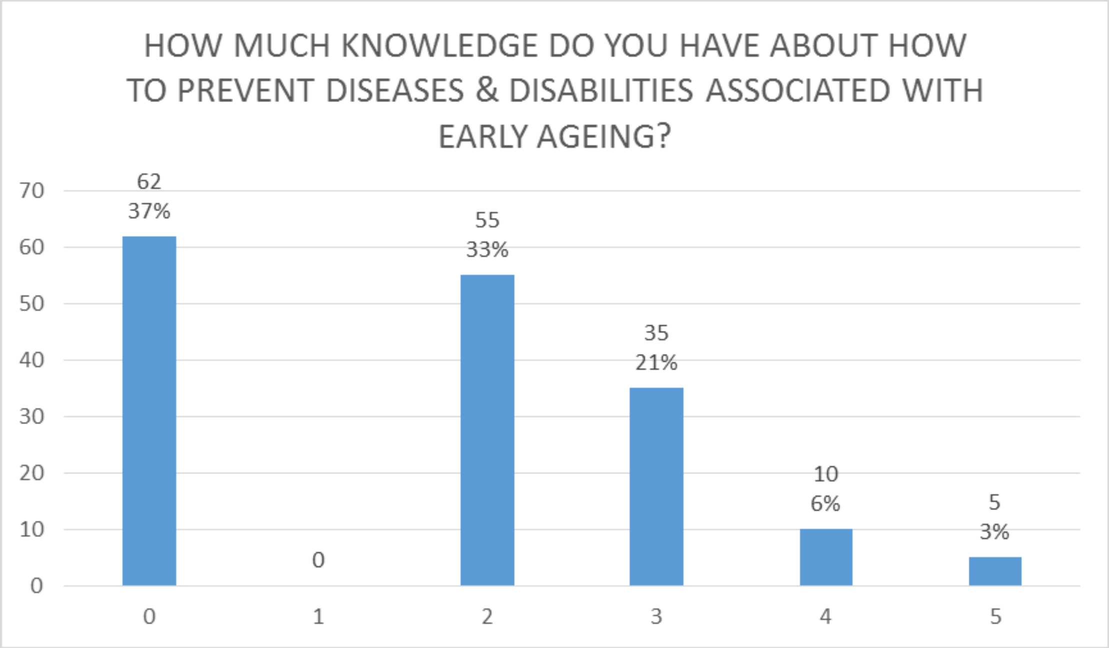
- ***Previous knowledge***

Only 1 of 10 participants has taken part in previous ageing training. According to the survey, the vast majority of participants from the four main participating countries has no previous training/support on ageing. Specifically, ***in Norway*** 8 of 10 participants have **not** acquired corresponding knowledge by training course, in ***Denmark and Germany*** more than 9 of 10 participants and in ***Greece*** more than 8 of 10 (see chart below).

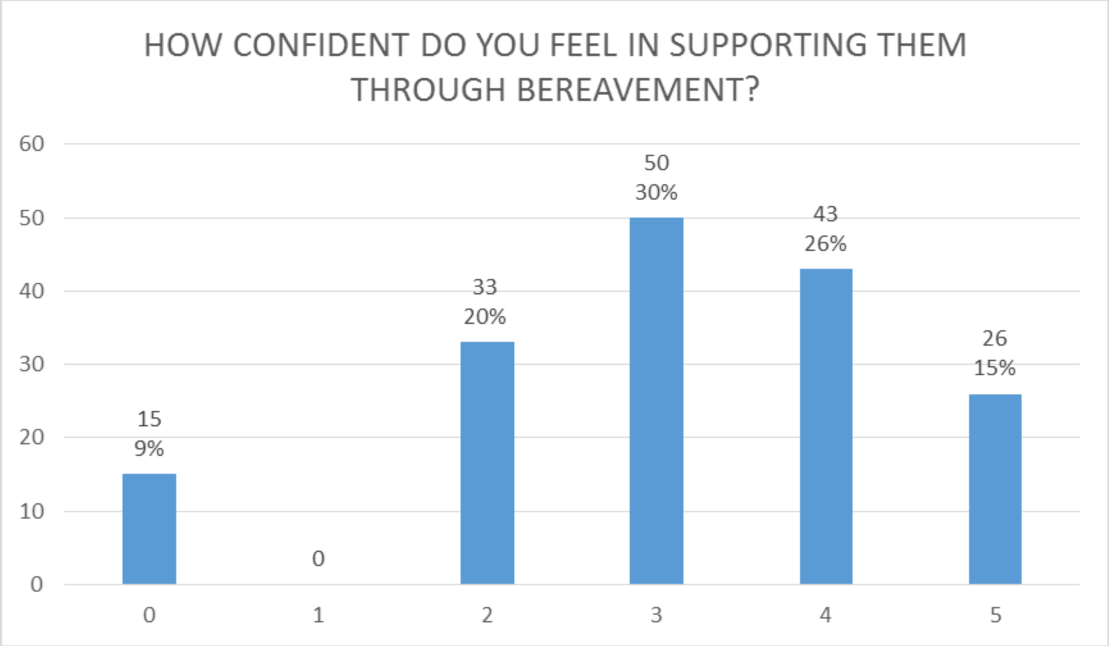


The ***vast majority of participants has no knowledge on early signs of ageing in PWID***. Similarly, the most of them have ***no knowledge or have a little knowledge on preventing diseases and disabilities associated with early ageing***.



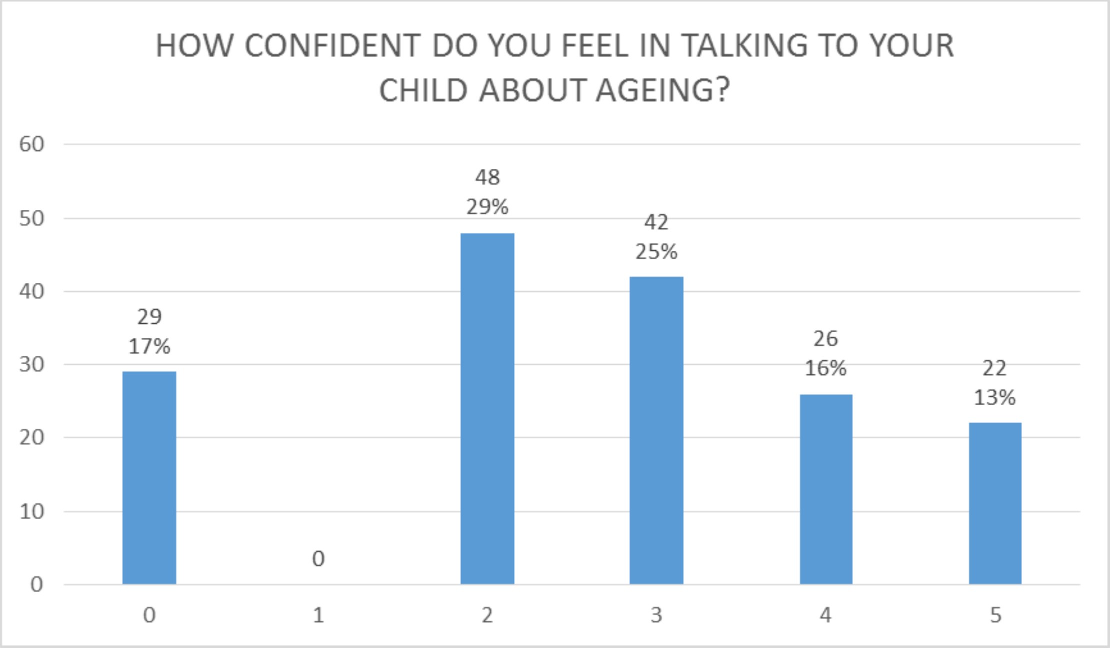


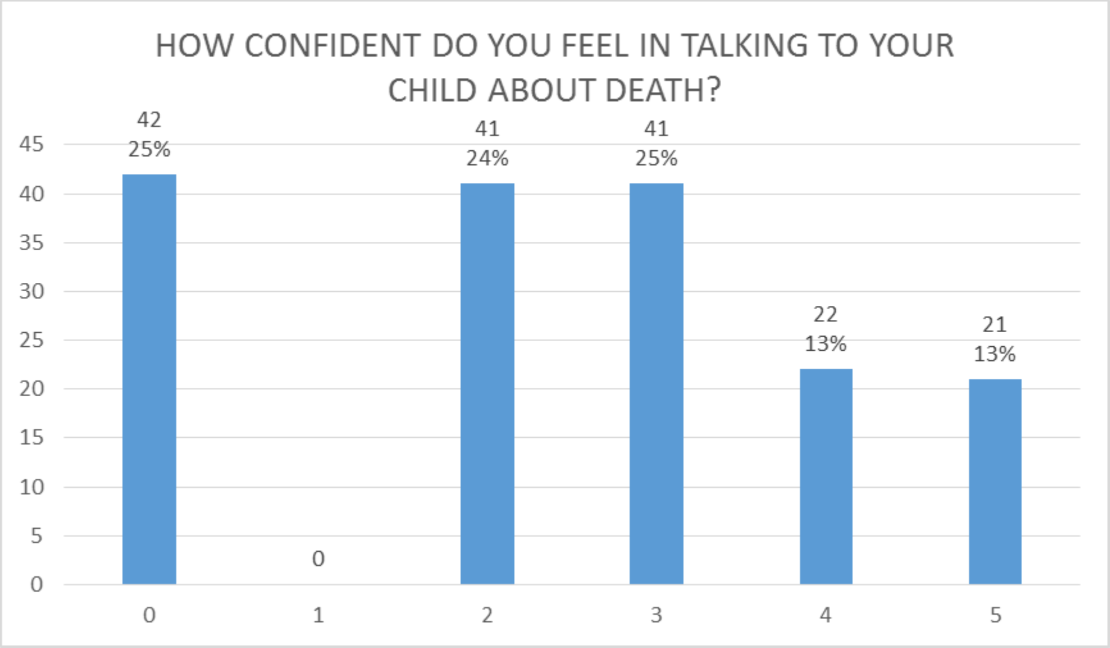
In terms of how confident the participants feel in supporting their child through bereavement, the majority of them seems to feel ***rather confident on this topic***. However, 3 of 10 participants feel very low confidence.



➲ ***Usefulness***

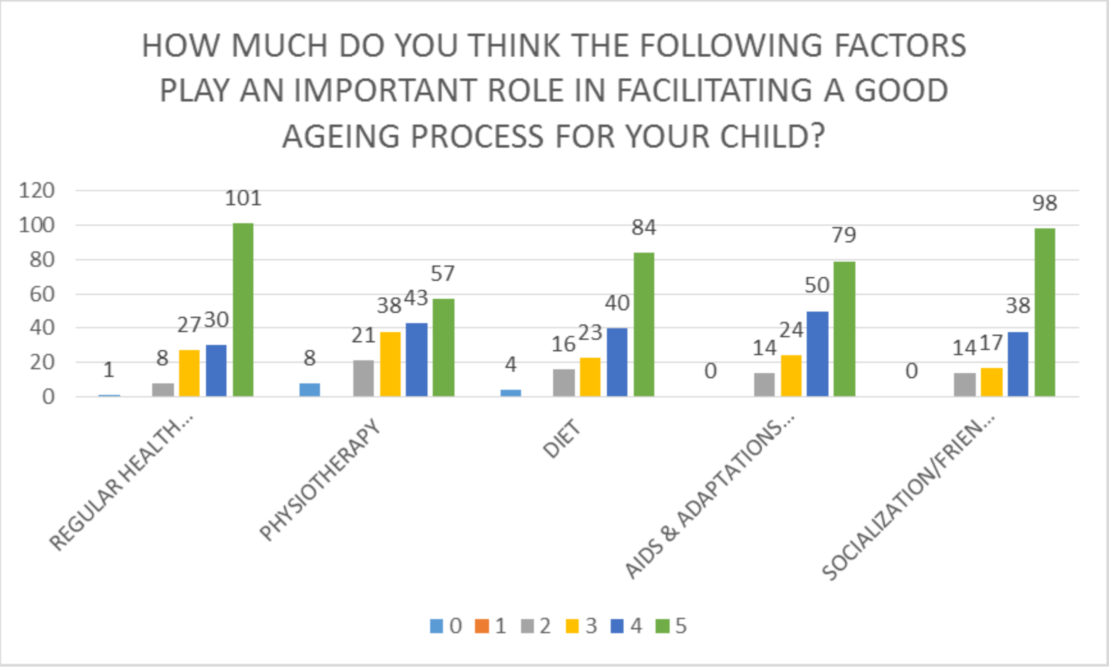
Regarding the usefulness of previous ageing training, most of the participants have found it ***very useful for them***. Nobody said that he/she found that training little, very little or not at all useful. This might be due to their low confidence in talking to their child about ageing. In terms of how confident the participants feel in supporting their child through bereavement, the majority of them seems to have enough confidence on this topic. However, 1 of 10 participants does not feel confident at all.



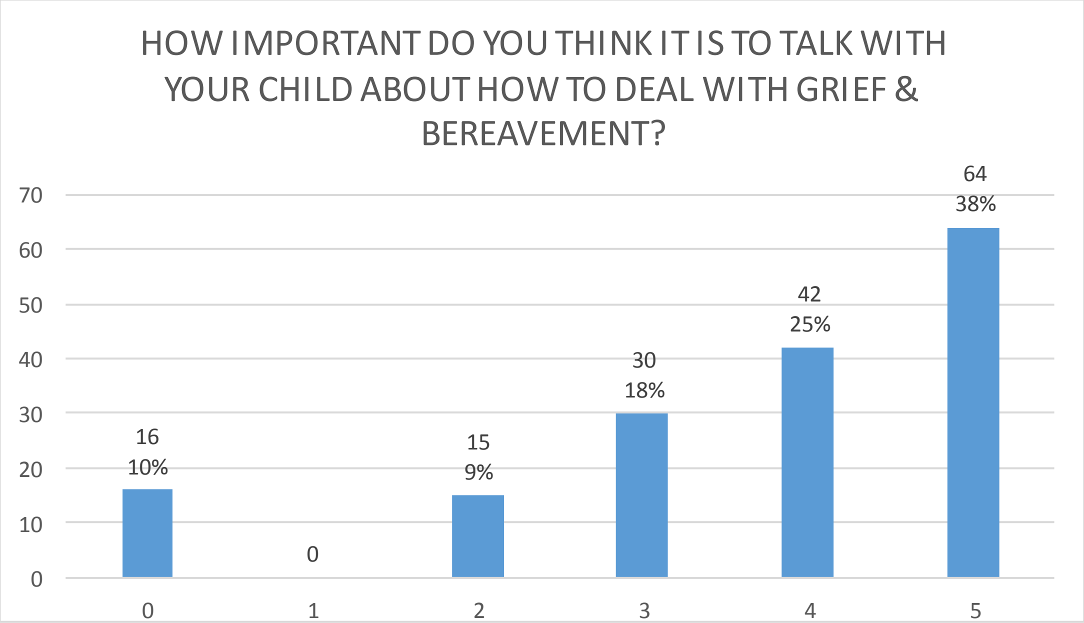


➲ ***Content needs***

The participants seem to appreciate the importance of various factors in ensuring a good ageing process for their child: they place huge importance on regular health checks and they also understand that socialization/friendships, diet as well as aids and adaptations are very much important in a good ageing process for PWID. As the least important one they indicated physiotherapy, but it is also considered as a notable factor in good ageing.



Furthermore, the majority of participants believe that it is very important to talk with their child about how to deal with grief and bereavement. Noted should be though that even though, participants believe it is very important to talk to their child about how to deal with grief and bereavement (38% indicated 5 on a 0-5 scale), ***they do not seem very confident in talking to their child about ageing and about death***. Moreover, they seem to lack confidence in supporting them through bereavement.



Other topics of interest

Participants indicated a number of other issues they would like more training and/or support on. This also supports the belief that the training available is not sufficient and that it does not cover all areas parents of PWID need information and support on. ***The topics that parents indicated in this study they would be interested in are:***

-socialisation,
-supported living / housing opportunities,
-legal protection and representation,
-accepting child’s disability,
-good family relationships,
-education/training people with intellectual disability,
-managing conflict,
-collaboration between family and professionals/service providers,
-puberty,
-dementia,
-ways to maintain good physical and mental health,
-how to talk to them about their diagnosis.

It is important to take this into consideration when developing the modules, in case some of these ***could be embedded in the six chosen topics***. More modules could also be developed at a later stage - maybe after the completion of the project - to meet more of the parents’ training needs.

CONCLUSION

The present study was carried out in the course of the European project Erasmus+ KA2 ELPIDA. It was a small scale study ***aiming to confirm our research assumption that there is need for training parent of people with intellectual disability (PWID)*** and ***to investigate parents' interests and needs regarding the content of six topics/modules***. Even though our study is not a scientific piece of research as that would require a bigger sample, validation and reliability testing of the questionnaire, assessment of other factors etc., it is a small scale pilot study that contains all the elements necessary to record the trends and to obtain an overall picture on the subject we are working on.

Initially, ***our pilot study confirms that on a European level and more specifically in the partner countries of this project there is lack of training for parents of PWID.*** This lack of parent training and support ***regards both training seminars that require physical presence/attendance, as well as distance learning programmes.*** This finding reinforces the need to implement the ELPIDA project.

In addition, as evident from the literature review, most of the existing training programmes have been developed through parent initiatives and that they are ran by non-governmental organisations and municipalities. Moreover, the private sector offers more specialised training programmes on specific methodologies. However, these provisions do not have a holistic approach but rather offer ***fragmented courses/seminars***, while they ***do not cover the whole range of training needs parents of PWID*** – especially, as these needs change through the person's transition to adulthood. This finding reinforces the ***requirement to develop the ELPIDA project modules in such a way that they are tailored to the needs and interests of the participant -*** which is also in line with one of the main principal of ***adult education.***

The questionnaire results provide a general picture in which all the characteristics of an adult learner are described - as mentioned in the main principles of adult education. More specifically, as Knowles (1984) and Rogers (1999) report, ***adults (in our case parents) learn or are interested in learning through the following:***

- ***Discovering and fulfilling his/her potential***
- ***Personal motivation***
- ***His/her needs***

- ***Gaining applied knowledge***

Our results show that t***he majority of parents would like to participate in individual/personal learning process, they have the motivation, the need and are interested to gain practical solutions and knowledge.*** Moreover, as mentioned by Jarvis (2004), adults learn mainly through the unexpected, i.e. through problems they face or needs.

Our results, hence, show that ***the majority of parents had not received some kind of training on issues around the upbringing of their child***. Even those who had received some relevant training, as our literature review and the questionnaire results showed, this was not systematic and holistic but occasional and for a few days. This is also supported ***by the number and the variety of different topics parents indicated*** they would be interested in receiving more training on, clearly underlying the need for more training.

Most of the parents would like to participate, have the desire and motivation and are positive towards ***different ways of education and alternative educational tools*** (e.g. video). It is also clear ***the parents' need for communication***. They seek and wish to communicate with other parents, experts, organizations etc. They seek and value the opinion of specialists more than other parents or PWID themselves.

Even though there was no comparative analysis between different countries due to the small sample, the results show that the problems and needs are similar in all countries. There is a ***clear preference on issues regarding the safeguarding of human rights*** and this is evident both on the questions on human rights as well as in other questions such as those on transition to adulthood and ageing. Overall, in many of the questionnaire items, ***parents’ need to strengthen the adult role of PWID is evident***. As mentioned in research by McLaughlin et al. (2001) and underlined in this pilot study, ***adult roles in areas such as employment, communication, personal relationships, sexual relationships, independent living etc. are really important for PWID.***

Some recommendations for the development of the ELPIDA project modules

- As evident from the literature review, there is a difference between the Scandinavian countries (and the countries in the Northern Europe in general) compared to the countries in the South Europe in terms of parent education and support. ***Contextual differences are needed to be taken into consideration when developing the ELIDA modules***, both from content and mode of delivery perspectives.

- In relation ***to the topics of the modules*** that have been chosen by the ELPIDA partnership to be included in the e-learning platform:

- The ***stress management topic*** might be more relevant for the needs of parents of PWID in ***Denmark and Greece***. Sub-topics that might be of more relevance for stress management are: ***challenging behavior; transition to adulthood and confronting feelings of not being understood***. Stress management techniques that parents with PWID might be less familiar with are: ***low arousal; problem-focus coping; emotion-focus copying.***

- The ***communication topic*** might be more relevant for parents in ***Germany and Greece***. Parents might need more training in alternative modes of communication such as: ***signs and symbols; easy to read; social stories***. Main communication difficulties that parents confront are: ***PWID limited vocabulary and understanding; limited attention spam***.

- The ***transition to adulthood topic*** might be more relevant for the needs of parents of PWID in ***Germany, Norway and Denmark***. Sub-topics that might be of more relevance are: information on separation process; finding employment; achieving legal independence; personal/sexual relationships.

- The ***human rights topic*** is relevant for ***all participant countries***, especially the following sub-topics: independence; employment; respect of privacy; education and self-determination.

- The ***sex-education topic*** might be more relevant for the needs of parents in ***Norway, Denmark and Greece.*** Parents have little knowledge on sub-topics relating to: ***prevention*** on sexual abuse; ***circumstance/patters*** and ***signs*** of sexual abuse.

- The ***ageing topic*** might be more relevant for parents in ***Denmark and Germany***. In all countries though the vast majority of participants in the ELIDA study stated that they have ***no knowledge on early signs ageing in PWID*** and on **how to prevent diseases and disabilities associated with early ageing**. Communicating with the PWID about ageing and death is a subtopic relevant to parent needs.

- Other ***topics of parents’ interest that the ELIPD project needs to take this into consideration when developing the modules, in case some of these could be embedded in the six chosen topics are***: *socialisation, supported living / housing opportunities, legal protection and representation, accepting child’s disability, good family relationships, education/training people with intellectual disability, managing conflict, collaboration between family and professionals/service providers, puberty, dementia, ways to maintain good physical and mental health, how to talk to them about their diagnosis.*

- In relation to the ***mode of content delivery in the ELPIDA e-learning platform***: parents in Norway seem to be more feminized with e-learning support than parents in Greece, Denmark and Germany. Forms of information that might be of more interest are: videos; web-links text and case studies. O***ther forms of information*** that could be of interest include: *Discussion groups; Face-to-face support/guidance by professionals*; *Workshops; Fairytales/stories; Illustrations/drawing, personal stories by parents; Podcasts, Situation simulation; Informal parent groups, Links to organisations*

In conclusion, looking at the results of this study, we believe that the results provide evidence that there is a need for this project and that the chosen themes/topics for the modules to be developed during ELPIDA are of great interest to the parents of PWID. Moreover, there is a need for a modern approach using educational material and methodology suited to the adult role of parents. The use of a free-to-use e-learning platform will provide a flexible distance learning tool, available to a large number of parents across Europe. The educational material will address issues of everyday life and will provide practical solutions, underlying the reasons parents should take part in this process.

Finally, we believe that this study raises the need for a generalised social study looking at various aspects of the lives of families of PWID. Such piece of research would contribute both to a better understanding as well as the improvement of services for PWID.

REFERENCES

Brookfield, S. (1986), Understanding and Facilitating Adult Learning, Σαν Φρανσίσκο: Jossey-Bass.

Hepburn Kathy Seitzinger (2004), Families as Primary Partners in their Child’s Development and School Readiness, The Annie E. Casey Foundation, Baltimore).

Jarvis P. (1988), Adult and Continuing Education, Theory and Practice, Routledge, London.

Jarvis P. (2004) Συνεχιζόμενη Εκπαίδευση και κατάρτιση: Θεωρία και πράξη του εκδ. Μεταίχμιο, μετάφραση: ΑΛΕΞΑΝΔΡΑ ΜΑΝΙΑΤΗ

Knowles, M. (1984). Andragogy in Action.

McLaughlin, J., Monteith, M., Sneddon, H. (2001). A Long and Widing Road to Employment?: Disabled Young People in Northern Ireland Making The Transition to Adulthood. Irish Journal of Applied Social Studies

Rogers, A. (1999), Η εκπαίδευση ενηλίκων, Μετάφραση: Μαρία Κ. Παπαδοπούλου, Μαρία Τόμπρου, Αθήνα.

ANNEX 1: NATIONAL & EUROPEAN FRAMEWORKS

GREECE

The development of training and support of people with disability in Greece begun in the 1960s but flourished in the 1980s with the accession to the European Economic Community. Numerous structures were developed during this decade, most of which relied on the initiative and involvement of parents of people with disability. At the same time, the National Federation of parents of people with disability (POSGAMEA) was established in 1982 aiming to coordinate and strengthen the efforts to secure the rights of people with disability, mainly their right to education.

Even though the importance of education for people with disability but also for professionals was acknowledged and dealt with right at the start, the systematic and holistic training and support of the family was completely omitted. There were some individual efforts by specialized professionals (e.g. Nanakou 1984) who, through collaborations with other European organisations, carried out educational activities and programmes aimed at families, but these addressed specific issues and there was no follow-up. Moreover, these efforts relied on the implementation of European programmes and were never incorporated into the operation of most organisations.

Over time, some of the families, while perceiving the need for family support and education, developed from time to time organized support programs, but these programs were short-lived and never updated existing knowledge.

The increase in the number of people with autism has in recent years given birth to a new need for family education and support. This need is partially met through private initiative - a number of private centers were set up providing educational programs for parents of people in the autistic spectrum. The cost of these programmes is not covered by the state or through the national insurance system and are usually very expensive. The origin of these programs is mainly from Western Europe, Canada and the USA. Some of them, such as Signet, are particularly popular, they consist of a complete training programme and participants obtain a certificate of attendance.

However, the need for training is highlighted in a large percentage in all relevant research.

DENMARK

The Danish Welfare System

In Denmark there are five regions and 98 municipalities. Regions and municipalities are independent politically controlled organisational units.

The basic principle of the Danish welfare system is that all citizens have equal rights to social security. Within the Danish welfare system a number of services are available to citizens, free of charge. This means that for instance the Danish health, social welfare and educational systems are free because they are mainly funded through taxation. Most of the social welfare services are provided by the public sector.

Through legislation the national government establishes the framework for the welfare system on both national, regional and local level. Regions and local authorities cannot finance all their expenditure through local tax-revenues and they are therefore supported by a system of central government grants and reimbursement schemes.

Local government has the authority to provide social services. Local authorities and regions have a wide autonomy when implementing the various social protections schemes. The Danish Social Service Law, is a Danish law which specifies guidelines for advice and support both in order to prevent social problems and to provide services to people with physical or mental disabilities or particular social problems.

The local government may offer temporary stays in residential accommodation. These could take the form of respite care, physical rehabilitation or weekend stays. It could also be in preparation for living independently.

The municipality is responsible for providing the necessary number of habitations in long-term residential accommodation for persons needing extensive help with ordinary daily functions, care or treatment, and whose needs cannot be covered in any other way.

The municipality is also responsible for providing the necessary number of places for temporary stays for training related to the preparation for living more independently. The objective is to improve the individual’s skills through socio-educational activities and treatment.

In Denmark both local authorities and private organisations offer parent groups, parent training and courses for siblings. The private organisations is typically parent-organisation. In Denmark there is no tradition for big-scale private organisation operating in the social arena. There is charity organisations - typically based on a religious and/or humanitarian ground and there is also a variety of consultants offering coaching, support or similar to parents, but the vast majority of support is provided by the local authorities. At our center we offer parent groups, training and courses for siblings as well as e-learning programs (At the moment only in the area of autism. In a few months our e-learning program targeting the ADHD area will be launched).

NORWAY

Parent associations:

The Norwegian association of Autism

This is an association of people with diagnosis within the autism spectrum, parents and other relatives as well as other persons with an interest in Autism spectra.

LUPE - National Association for People with Intellectual disability and Relatives

Is a nationwide and political independent organization working for PWID to be accepted as equal fellow human beings and to have real choices for varied housing, work and leisure facilities.

NFU - Norwegian Federation for people with developmental disability – (LARGEST in Norway).

A nationwide organization for people with intellectual disabilities. The organization's business is based on belonging and equality as basic and universal human rights. NFU is designed to make everyday life easier for people with disabilities and their families. Our vision is a society for all.

NNDS - Norwegian Network for Down Syndrome

Is a standalone network that aims to gather and disseminate information about Down Syndrome.

Ups & Downs

Norwegian support associations for parents of children with Down syndrome.

HBF –Disabled Children's Parent Association

Working to safeguard the interests of children with disabilities, their parents and relatives, and to improve children's upbringing conditions and the whole family's living conditions.

Umbrella associations:

FFO – Association for handicapped people

Is Norway's largest umbrella organization for organizations for people with disabilities and chronically ill.

SAFO - Cooperation Forum of Disabled People's Organizations

The purpose is to contribute to the coordination of member organizations' interests policy efforts through cooperation, interaction and development of the organizations' interest-policy efforts.

NHF - Norwegian Handicap Association

Is an independent interest organization that works for full gender equality and social participation for people with disabilities. The main target group is disabled people.

SOR Foundation

The Coordination Council is a community of many organizations that wish to work for the improvement of living conditions for people with intellectual disability.

Association organized by PWID:

Advisory Group in Bærum (RGB)

Even with disabilities. we both can and will let the experts escape. RGB works with rights and responsibilities, self-determination, user involvement, accessibility and easy-to-read in the areas of home, work and freedom / culture.

Training:

Every parent association have meetings, conferences and courses. But they are based on parents initiative and leisure time, so they are struggling. In their webpages most of the organisations are providing information.

National center for ageing and health (NKAH) are providing courses in ageing for parents and some municipalities are organising this as well. Not sure about other topics.

SOR is a professional NGO that is providing conferences mainly to professionals. In their webpage they are providing course about ID, maybe also parents use this course.

NAKU is a nationwide competence network about ID. In their webpage, they provide a lot of information that may be useful for parents. Presently they published a film about ID from birth to adulthood.

Associations/NGO’s may apply for economic support from the government to arrange conferences, teaching materials and courses.

Support to parents in Norway:

The municipalities supports parents with social security benefits and national law gives their child a right to local schools and activities, such as kindergarden and special education in ordinary schools, as well as aids they may need. They may also receive support with their child in form of local housing that are taking care of their child in periods or personal assistant in own home. In childhood, they are supported by local health center for children, which also provide support to start individual planning and connect the parents to needed services.

Norway have legislations that gives rights to parents as well as their children, but the services are “need-tested” and dependent on the municipality's finances, so there are major differences between the municipalities in terms of what parents receive from support.

In addition to the support parents may receive from local authority, they may also receive services from Re-/Habilitation Centre in the County.

GERMANY

Rehabilitation and participation of people with disabilities in Germany

The Ninth Social Law Code contents the regulations concerning rehabilitation and participation of people with disabilities in Germany. The purpose is to support people with disabilities and people in danger of disability regarding their autonomy and their equal participation in their life in the mainstream of society and to avoid respectively antagonize disadvantages.

The social service institution can provide the rehabilitation and participation services alone or by non-profit or private rehabilitation services or facilities (§ 28 Abs. 1 SGB IX).The right on service providing leads to a social law triangle correlation.

In part 2 of the SGB IX (§§ 90 to 150) the extraordinary services for a self-determined life for people with disabilities (right on inclusion) are described.

The service providing is excluded step by step of the system of German social code (SGB XII). A new service right, as new part 2, will be now part of the Ninth German Social Code – SGB IX - and distinguishes itself especially by its person centered approach and an integral assessment of demands.

The implementation is realized by the Federal Law Code for participation (article law) in the period 2018 – 2020. All services belonging to the right on inclusion for people with disabilities are transferred from social welfare law to rehabilitation law, besides many other things it regulates the benefits granted by inclusion law – also with regards to contents – and modifies the rules for cost absorption by people with disabilities and their relatives.

Due to the federal structure in Germany the frame conditions for service providing depends on the respective states and their financial revenue. For example in the state of Hessen the Landeswohlfahrtsverband / Public Welfare Association of Hesse (LWV Hessen) is the supra-local provider of inclusion services and grants services for social and vocational participation and integration.

Target is that people with disabilities are enabled to lead a life as autonomous and self-determined as possible, e. g. regarding Assisted Living. The LWV is also contact partner for people with disabilities living in residential homes, attending day care centers or/and working in sheltered workshops for people with disabilities.

LWV is service provider for 13 supra-regional special schools and 5 early intervention centers in Hessen. The aim is to foster children and youngsters so that disadvantages caused by disabilities are compensated to the highest possible extent.

All social forces have to engage in the implementation of rehabilitation and participation. The public welfare as pillar of the social state belongs to these forces. All services and institutions in non-profit body and working as organization in the social and health care sector are considered as public welfare. Key feature of their activities are independency and partnership based cooperation with the public social care providers.

Basis of this cooperation is the principle of subsidiarity as far as it is supplied by public and non-profit care providers (for example Internationaler Bund). Non-profit care providers are partly privileged regarding the completion of federal social tasks. The following institutions belong to public welfare: Deutsches Rotes Kreuz (DRK), Caritasverband, Diakonisches Werk, Paritätischer Wohlfahrtsverband, Arbeiterwohlfahrt and the Zentralwohlfahrtsstelle of German Jews. Under their roof and direction of their cooperative organizations most of the services and offers for disabilities are provided.

The greatest provider for services for parents of people with intellectual disability and people with intellectual disabilities in terms of training / support, seminars, e-learning platforms etc. in Germany is the Bundesvereinigung Lebenshilfe e.V.. Their member organizations are often as well member organizations of one of the welfare organizations mentioned above.

Lebenshilfe provides information, advice and further education for mentally disabled people, their relatives and for employees of disabled peoples' support agencies.

Lebenshilfe runs more than 3.200 facilities and mobile or out-patient services throughout Germany to promote people with mental disabilities and to support their relatives, for instance: early learning offices | family-relieving services | kindergartens and schools | workshops for disabled people | residences | leisure offers. Lebenshilfe has more than 135.000

members, who are organized in 527 local and district associations of Lebenshilfe. Every Federal State has its own Lebenshilfe state association. The federal association campaigns nationally for the concerns of people with mental disabilities and their families; its offices are located in Marburg and Berlin.

The Lebenshilfe federal association is managed by an honorary board, of which more than 50 per cent are disabled people, parents and family members under its charter.

The federal board works closely with the Federal Chamber, of which the chairmen of the federal associations are members. In accordance with the self-help idea, these committees are backed up by the council of disabled people and the federal parents' council. Expert committees and project groups develop specific task areas. This democratic structure ensures that the variedness of the members of Lebenshilfe is represented. The work of Lebenshilfe is characterized by the current state-of-the-art of expertise and personal experience of the persons affected. (https://www.lebenshilfe.de).

European context

Statistics

There are about 100 million children in the European Union and about 80 million European persons with disabilities. While the number of children and the number of persons with disabilities is well documented, the same cannot be said of children with disabilities. The only data available[1] concern children with special educational needs (SEN), which cover only a limited number of children with disabilities. It is estimated that 15 million European children have special educational needs[2]. Children with disabilities combine different factors of vulnerability. As children the protection of their rights requires the adoption of special measures that are recognised by the UNCRC[3]. As individuals with disabilities, they are particularly vulnerable EU citizens who deserve specific safeguards and protection as acknowledged by the CRPD[4].

International legislation in place

In December 2010, the European Union became a party to the CRPD. In doing so, the EU recognised the challenges persons with disabilities face in securing the fulfilment of their rights and assumed the responsibility for its implementation alongside Member States. The EU's responsibility towards the implementation of the UNCRC is of a different scale. Despite the lack of ratification by the EU, the UNCRC rights and principles guide the EU policies and action since the EUT[5] recognises the rights of the child as an EU objective.

The CRPD provides a legal framework for the protection of the rights of children with disabilities as particularly vulnerable EU citizens. Its Article 7 is specifically devoted to children with disabilities and requires Member States to take all necessary measures to ensure that children with disabilities can fully enjoy all human rights and fundamental freedoms on equal footing with other children. These obligations relate, inter alia, to the right to education and the respect for the evolving capacities of children with disabilities, the right to family life and care within the community, the right to health and access to goods and services including

---

[1] Support for children with special educational needs – EU policy brief 2013

[2] Data for 2012. European Commission, Press release, Special needs children and disabled adults still getting a raw deal from education, 10 July 2012, IP/12/761, available at <http://europa.eu/rapid/press-release_IP-12761_en.htm>

[3] UN Convention on the Rights of the Child

[4] UN Convention on the Rights of Persons with Disabilities

[5] Treaty on the European Union

leisure activities. In addition, Article 16 requires States Parties to take all necessary measures to protect children with disabilities from exploitation and abuse. The EU, together with Member States in areas of shared competence or national competence, is bound by the CRPD obligations.

While the EU has not concluded the UNCRC, all the EU Member States have ratified the Convention. The UNCRC explicitly recognises the rights of children with disabilities under its Article 23. In addition, Article 2 prohibits discrimination on the grounds of disability and Article 3 calls for the best interests of the child to be at the heart of any decision affecting children, including those with disabilities. Articles 5 and 18 recognises the sole right, duties and obligations of parents for the upbringing of their children and obliges member states to provide support for parents to fulfil this role in forms they require. At EU level, Article 3 TEU defines the protection of the rights of the child as a European Union objective which requires to actively develop appropriate legislative or policy initiatives according to its competences.

European and national legislative frameworks

The current EU legislative and policy framework give recognition to the Conventions’ rights and principles applicable to children with disabilities and a certain degree of implementation. However, the existing EU legislation relevant to this area is mainly sectoral (i.e., employment or immigration). The legislation addresses the situation of persons with disabilities separately from the rights of the child, whereas there is a need to consider children with disabilities as they face multiple discrimination, on the basis of age as well as disability, and to tailor measures to ensure that their rights are respected.

Member States have comprehensive legal frameworks in place reflecting the main aspects of the rights and principles identified under the CRPD and UNCRC. While it may be stated that the rights of children with disabilities are broadly recognised under national legal systems either through general or specific legislation, their practical implementation revealed to be problematic in most Member States. This is especially true in the field of supporting parenting, especially parenting support and education programmes.

The EU has no explicit competence on children with disabilities. However, the EU framework – as said before - contains provisions recognising the EU’s role to promote the protection of the rights of the child as an EU objective as well as its competence to combat discrimination based on disability. Furthermore, the Charter of Fundamental Rights of the European Union, with similar legal value as the Treaties, recognises the right to non-discrimination on ground of disability in Article 21 and the rights of the child under its Article

24. This recognition, while important, cannot extend the competences of the EU as conferred by the Treaties.

No EU legal measures provide for a definition of disability. Prior to the adoption of the CRPD, in a judgment6 in July 2006, the Court of Justice of the European Union (CJEU) defined disability in the same sense as the CRPD within the context of employment policy as 'a limitation which results in particular from physical, mental or psychological impairments and which hinders the participation of the person concerned in professional life'.

Supporting parents

Parenting support is currently on the policy agenda of several Member States. The importance of parenting support has also been acknowledged by European organisations. In 2006, the Council of Europe issued a recommendation[7] encouraging states to recognise the importance of parental responsibilities and the need to provide parents with sufficient support in bringing up their children. In June 2012, the Social Protection Committee adopted an advisory report[8] on tackling and preventing child poverty which underlines the need to strengthen parenting support as part of services for children. At the 7th European Forum on the Rights of the Child, the European Commissioner responsible for Employment, Social Affairs and Inclusion highlighted the role of parenting support services in child protection and coping better with difficult situations[9].

The returns on parenting support measures have been analysed by the Dartington Social Research Unit for OECD[10]. The research project 'Investing in Children' provides advice on the costs and benefits of competing investment options in children's services (including early years and education). The benefits are grouped according to the different beneficiaries, which include benefits to a) taxpayers (savings to the justice system from reduced crime, increased taxes due to higher earnings, savings in costs to child protection and social care services), b) participants (increased earnings due to educational outcomes) and benefits to others..

The development of parental support policy is generally the responsibility of the national/federal government, while the implementation of the programmes through the provision of parenting support activities is, in most cases, a responsibility of the local/municipal agencies. At national level, the central authorities, such as ministries dealing

---

[6] Judgment C-13/05 of the Court (Grand Chamber) of 11 July 2006, *Sonia Chacón Navas v Eurest Colectividades*, pt 43.

[7] https://www.crin.org/en/library/legal-database/council-europe-recommendation-rec200619-policy-support-positive-parenting

[8] http://ec.europa.eu/social/BlobServlet?docId=7849&langId=en

[9] http://europa.eu/rapid/press-release_SPEECH-12-804_en.htm

[10] Doing Better for Families (OECD, 2011)

with child protection, families or social inclusion issues, are responsible for the legislative framework and regulations, the drafting of national action plans and for financial support[11].

---

[11] Eurofund 2013

ANNEX 2: QUESTIONNAIRE FOR NEEDS ASSESSMENT STUDY

Dear Parents,

Project ELPIDA aims 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). ELPIDA will achieve this goal by developing a free-to-use e-learning platform, which will contain interactive educational modules providing more training, awareness raising and/or attitude change on key areas. More specifically, the modules will cover issues such as stress management, communication, transition to adulthood, human rights, sexuality and ageing. We believe this knowledge will have a positive impact on people with ID and will contribute to a better transition to adulthood, social inclusion, and better quality of life in general. These modules will be available in six languages (English, French, Danish, Norwegian, German and Greek) on the project's website www.elpida-project.eu in the next coming months.
In order for this e-learning platform to better meet the interests and needs of the target group, we are inviting parents of people with Intellectual Disability to take the time to fill in the following questionnaire by February 4th 2018. The completion of the questionnaire can be done on-line by clicking on the following link ___________or by completing a printed copy. It takes about 15 minutes to complete and it is anonymous.

If you would like more information on the ELPIDA project and/or you would be interested in completing the e-learning module(s) in the future, please contact the participant organisations.

Thank you
The ELPIDA Consortium:

- Foundation for Research and Technology Hellas (Greece) – www.forth.gr
- European Parent Association (Belgium) – euparents.eu
- Oslo Metropolitan University (Norway) – www.hioa.no
- Internationaler Bund (IB) Südwest gGmbH Region Mitte (Germany) – www.ib-suedwest.de
- Center for Specialpaedagogiske Boernetilbud (Denmark) – specialpaedboernetilbud@aarhus.dk
- Social Enterprise Puzzle (Greece) – info@puzzle-se.eu

1. Country of residence:

   - Greece ☐
   - Norway ☐
   - Germany ☐
   - Denmark ☐
   - Other ____________

2. Your relation to the person with Intellectual Disability. You are:
   Mother ☐ Father ☐ Other (please specify)____________

3. Gender of person with Intellectual Disabilities (ID) Male ☐
   Female ☐

4. Age of person with Intellectual Disabilities (ID)

   0 - 16 years old ☐
   17 - 30 years old ☐
   30 - 44 years old ☐
   45+ years old ☐

5. Level of person's disability

   Mild ☐
   Moderate ☐
   Severe ☐

6. Have you ever participated in a parent group? Yes ☐ No ☐

7. If "yes", on a scale from 0 to 5 (0 = not at all and 5 = very), how useful was it for you?

   0 1 2 3 4 5
   Comment box ___________________

8. Have you ever completed a parent training course? Yes ☐ No ☐

9. If "yes", on a scale from 0 to 5 (0 = not at all and 5 = very), how useful was it for you?

   0 1 2 3 4 5
   Comment box ____________________

10. Have you ever completed an e-learning course? Yes ☐ No ☐

11. On a scale from 0 to 5 (0 = not at all and 5 = very), how interested are you in completing an e-learning course on issues regarding supporting your child with ID?

    0 1 2 3 4 5

12. <u>On a scale from 0 to 5 (0 = not at all and 5 = very), how interesting would you find the following forms of information?</u>

Video	0	1	2	3	4	5
Audio	0	1	2	3	4	5
Case studies	0	1	2	3	4	5
Animation	0	1	2	3	4	5
Text	0	1	2	3	4	5
Web links for more information	0	1	2	3	4	5
Power Point presentations	0	1	2	3	4	5
Other ______________________						

13. <u>On a scale from 0 to 5 (0 = not at all and 5 = very), who would you prefer gave you the knowledge?</u>

An expert	0	1	2	3	4	5
Another parent	0	1	2	3	4	5
A person with ID	0	1	2	3	4	5

14. <u>There are several techniques developing skills aiming to reduce stress levels. Have you ever had any training on stress management?</u>
Yes ☐ No ☐

15. <u>If "yes", on a scale from 0 to 5 (0 = not at all and 5 = very), how useful was it for you?</u>

0 1 2 3 4 5

16. <u>On a scale from 0 to 5 (0 = not at all and 5 = very), how stressful do you find the following situations?</u>

Dealing with challenging behavior	0	1	2	3	4	5
Communication difficulties	0	1	2	3	4	5
Training/educating your child	0	1	2	3	4	5
Your child's transition to adulthood	0	1	2	3	4	5
Adjusting your expectations to your child's abilities	0	1	2	3	4	5
Not feeling understood by others	0	1	2	3	4	5

17. <u>On a scale from 0 to 5 (0 = not at all and 5 = very), how well do you feel you manage your level of stress?</u>

0 1 2 3 4 5

18. On a scale from 0 to 5 (0 = not at all and 5 = very), how familiar are you with the following stress management techniques?

Low arousal	0	1	2	3	4	5
Problem-focused coping	0	1	2	3	4	5
Emotion-focused coping	0	1	2	3	4	5
Mindfulness	0	1	2	3	4	5

19. On a scale from 0 to 5 (0 = not at all and 5 = very), how much do you believe your ability to manage your stress could affect your behavior?

0 1 2 3 4 5

20. On a scale from 0 to 5 (0 = not at all and 5 = very), how much do you believe your ability to manage your stress could affect your child’s behavior?

0 1 2 3 4 5

21. There are many ways of communication besides oral speech and some have been specifically developed to assist people with ID. Have you ever had any training on communication skills?

Yes ☐ No ☐

22. If “yes”, on a scale from 0 to 5 (0 = not at all and 5 = very), how useful was it for you?

0 1 2 3 4 5

23. On a scale from 0 to 5 (0 = not at all and 5 = very), how much do you face the following communication difficulties with your child?

Lack of verbal communication	0	1	2	3	4	5
Limited vocabulary/understanding	0	1	2	3	4	5
Limited attention spam	0	1	2	3	4	5
Lack of interest in communicating	0	1	2	3	4	5
Other ___________________________						

24. On a scale from 0 to 5 (0 = not at all and 5 = very), how much do you use the following alternative means of communication with your child?

Body language	0	1	2	3	4	5
Pictures (e.g. PECS)	0	1	2	3	4	5
Signs and symbols (e.g. Makaton)	0	1	2	3	4	5
Easy-to-read	0	1	2	3	4	5
Social stories	0	1	2	3	4	5
Technological devices	0	1	2	3	4	5
Other ______________________						

25. On a scale from 0 to 5 (0 = not at all and 5 = very), how interested are you in improving your communication skills?

    0 1 2 3 4 5

26. On a scale from 0 to 5 (0 = not at all and 5 = very), how much do you communicate about your child’s disability with others?

    0 1 2 3 4 5

27. On a scale from 0 to 5 (0 = not at all and 5 = very), how much do you feel others (e.g. other parents, professionals etc.) understand your family and child’s situation?

    0 1 2 3 4 5

28. On a scale from 0 to 5 (0 = not at all and 5 = very), how much segregated do you feel due to the stigma attached to disability?

    0 1 2 3 4 5

29. Would you like to have more communication with other parents?

    Yes ☐ No ☐

30. Would you like to have more communication with service providers?

    Yes ☐ No ☐

31. Transition to adulthood can be a challenging process for young people with ID. Have you ever had any training on issues around transition to adulthood?
    Yes ☐ No ☐

32. If “yes”, on a scale from 0 to 5 (0 = not at all and 5 = very), how useful was it for you?

    0 1 2 3 4 5

33. In relation to transition to adulthood, on a scale from 0 to 5 (0 = not at all and 5 = very), how difficult do you believe your child would find achieving the following?

Leaving home	0	1	2	3	4	5
Managing money	0	1	2	3	4	5
Legal independence	0	1	2	3	4	5
Independent social life	0	1	2	3	4	5
Finding employment	0	1	2	3	4	5
Continuing education	0	1	2	3	4	5
Personal/sexual relationships	0	1	2	3	4	5

34. On a scale from 0 to 5 (0 = not at all and 5 = very), how confident do you feel in supporting your child through this transition?

    0 1 2 3 4 5

35. On a scale from 0 to 5 (0 = not at all and 5 = very), how interested are you in information on separation process?

    0 1 2 3 4 5

36. On a scale from 0 to 5 (0 = not at all and 5 = very), how familiar are you with the Human Rights Convention?

    0 1 2 3 4 5

37. On a scale from 0 to 5 (0 = not at all and 5 = very), how relevant do you think the following human rights are for your child in this period of time?

Independent living	0	1	2	3	4	5
Employment	0	1	2	3	4	5
Personal relationships	0	1	2	3	4	5
Respect for privacy	0	1	2	3	4	5
Education	0	1	2	3	4	5
Voting	0	1	2	3	4	5
Self-determination	0	1	2	3	4	5

38. On a scale from 0 to 5 (0 = not at all and 5 = very), how difficult do you believe is ensuring the Human Rights for your child?

    0 1 2 3 4 5

39. On a scale from 0 to 5 (0 = not at all and 5 = very), how familiar are you with the different types of employment for people with ID?

    0 1 2 3 4 5

40. Have you ever had any training on sex education? Yes ☐ No ☐

41. If “yes”, on a scale from 0 to 5 (0 = not at all and 5 = very), how useful was it for you?

    0 1 2 3 4 5

42. On a scale from 0 to 5 (0 = not at all and 5 = very), how much have you been talking about sexuality with your child?

    0 1 2 3 4 5

43. On a scale from 0 to 5 (0 = not at all and 5 = very), how confident do you feel talking to your child about personal relationships?

    0 1 2 3 4 5

44. On a scale from 0 to 5 (0 = not at all and 5 = very), how much knowledge do you feel you have on prevention of sexual abuse?

0 1 2 3 4 5

45. On a scale from 0 to 5 (0 = not at all and 5 = very), how familiar are you with sexual abuse in terms of:

Signs	0	1	2	3	4	5
Causes	0	1	2	3	4	5
Circumstances/patterns	0	1	2	3	4	5
Effects	0	1	2	3	4	5

46. Have you had any training on ageing for people with intellectual disabilities?
Yes ☐ No ☐

47. If “yes”, on a scale from 0 to 5 (0 = not at all and 5 = very), how useful was it for you?

0 1 2 3 4 5

48. On a scale from 0 to 5 (0 = not at all and 5 = very), how much knowledge do you have about early signs of ageing in people with ID?

0 1 2 3 4 5

49. On a scale from 0 to 5 (0 = not at all and 5 = very), how much knowledge do you have about how to prevent diseases and disabilities associated with early ageing?

0 1 2 3 4 5

50. On a scale from 0 to 5 (0 = not at all and 5 = very), how much do you think that the following factors play an important role in facilitating a good ageing process for your child?

Regular health checks	0	1	2	3	4	5
Physiotherapy	0	1	2	3	4	5
Diet	0	1	2	3	4	5
Aids and adaptations in the surroundings	0	1	2	3	4	5
Socialization/Friendships	0	1	2	3	4	5

51. On a scale from 0 to 5 (0 = not at all and 5 = very), how confident do you feel in talking to your child about ageing?

0 1 2 3 4 5

52. On a scale from 0 to 5 (0 = not at all and 5 = very), how confident do you feel in talking to your child about death?

0 1 2 3 4 5

53. On a scale from 0 to 5 (0 = not at all and 5 = very), how important do you think it is to talk with your child about how to deal with grief and bereavement?

    0 1 2 3 4 5

54. On a scale from 0 to 5 (0 = not at all and 5 = very), how confident do you feel in supporting them through bereavement?

    0 1 2 3 4 5

55. Are there any other areas/topics you would be interested obtaining more information/training on?

1. ______________________________

2. ______________________________

3. ______________________________

4. ______________________________

ANNEX 3: RESULTS OF THE SURVEY

This section refers to the results from the survey looking at demographic information and assessing participants’ previous training and knowledge on the six main topics. The diagrams below show in quantity and/or percentage how the situation looks as a whole. The title refers to the survey question, and the legend details the given answers. Some comparisons between the countries are also presented.

DEMOGRAPHICS

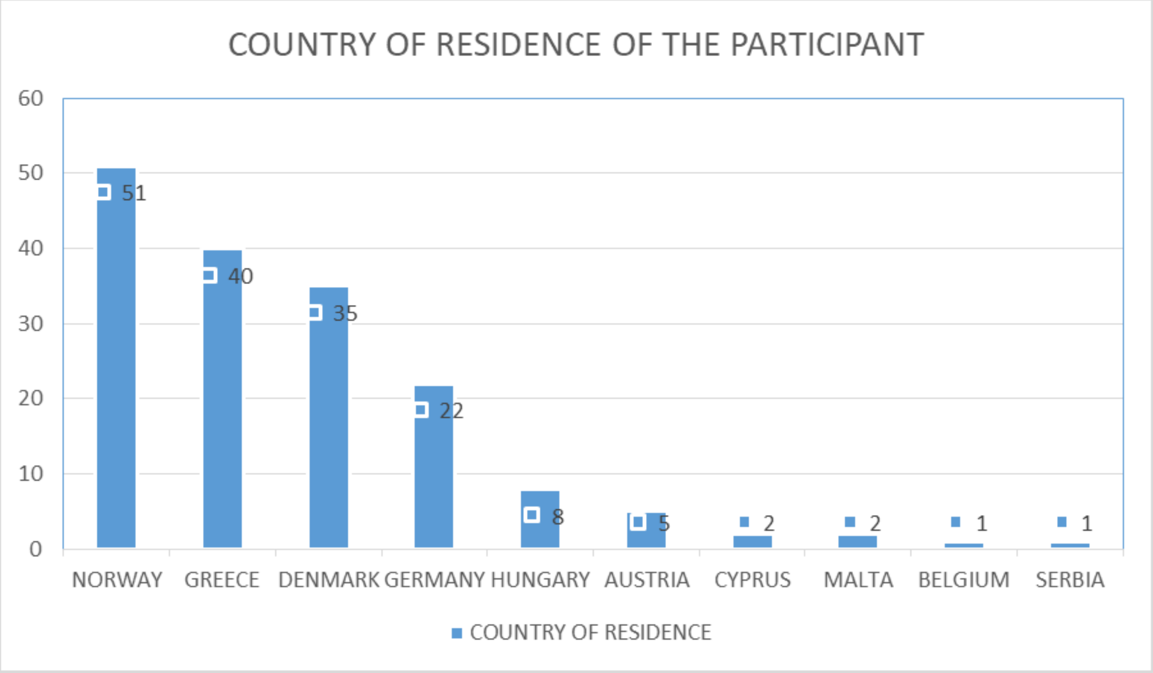


CHART 1: COUNTRY OF RESIDENCE

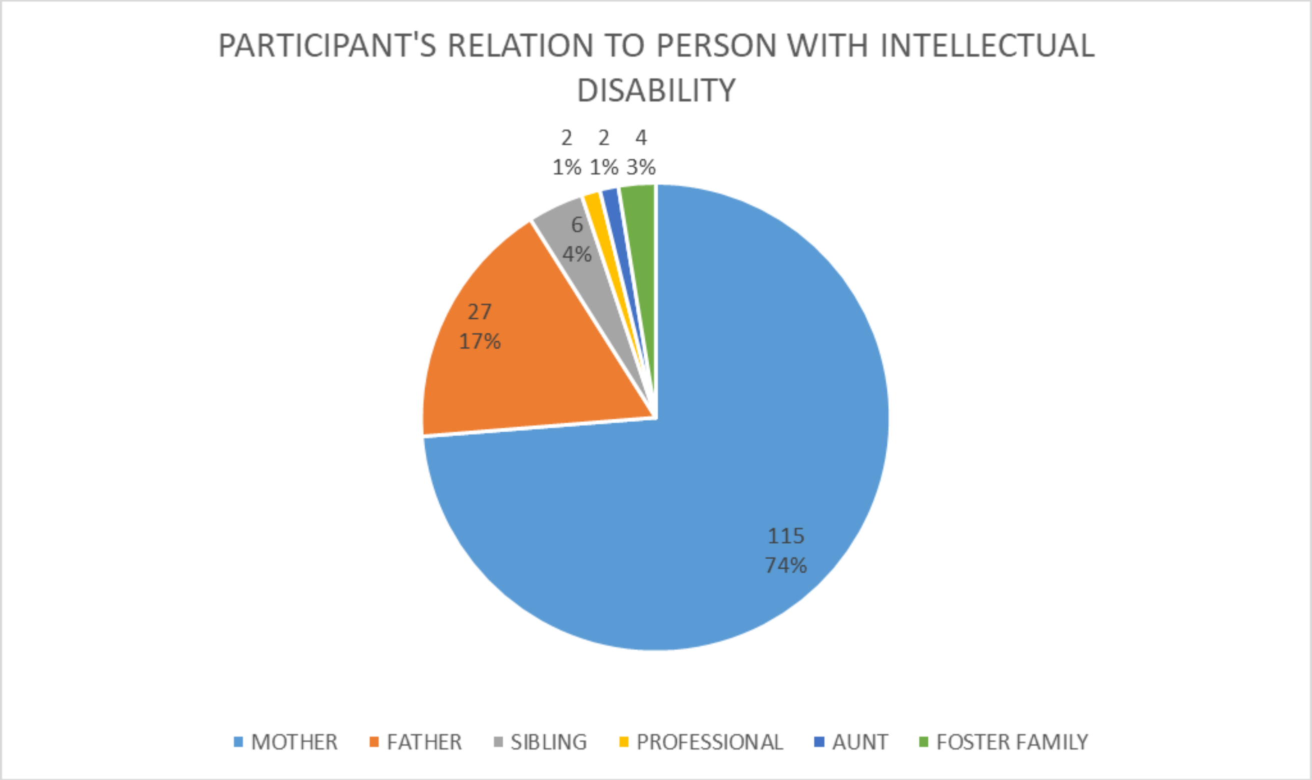


CHART 2: RELATION TO PWID

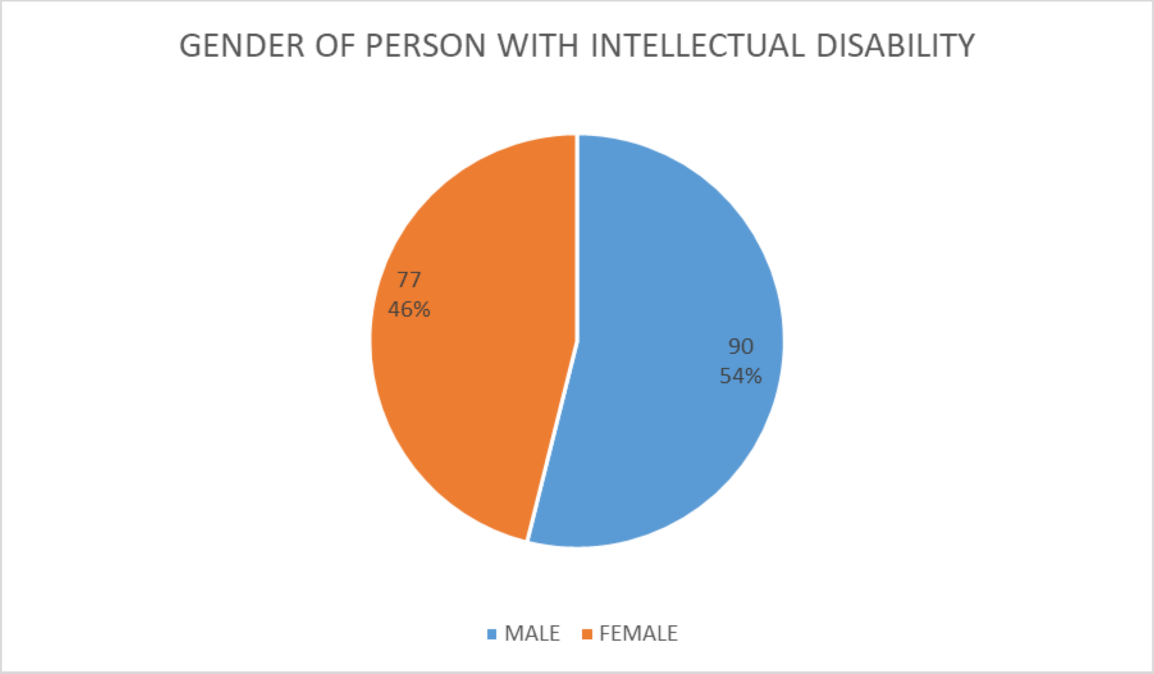


CHART 3: GENDER OF PWID

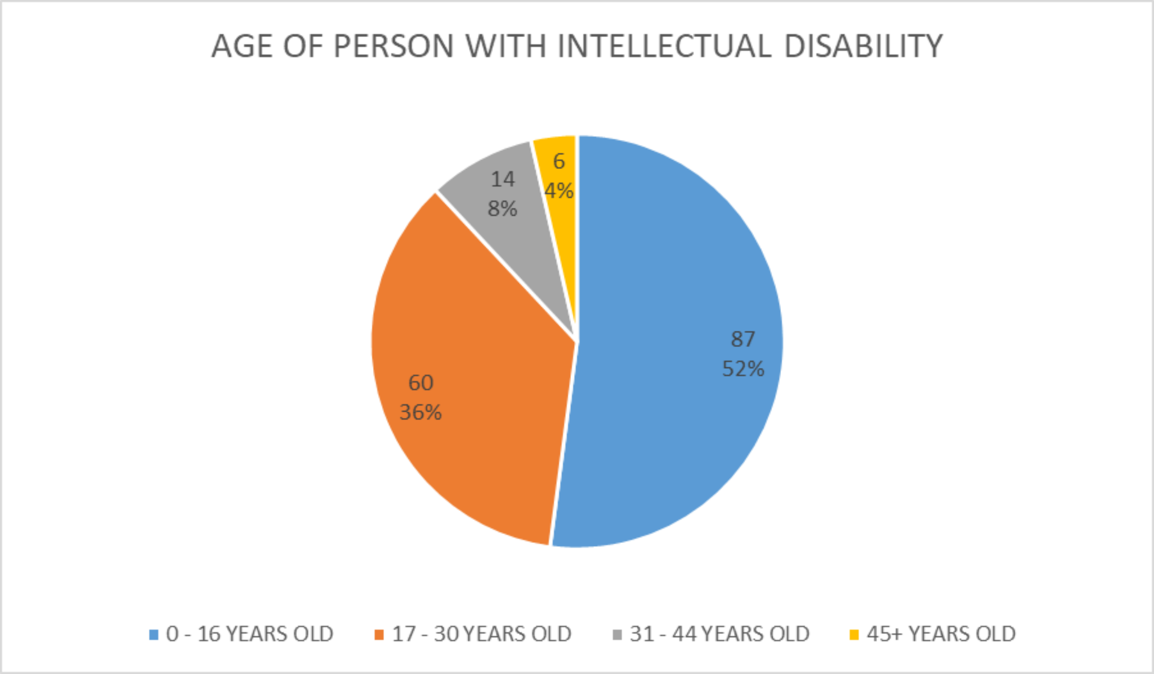


CHART 4: AGE OF PWID

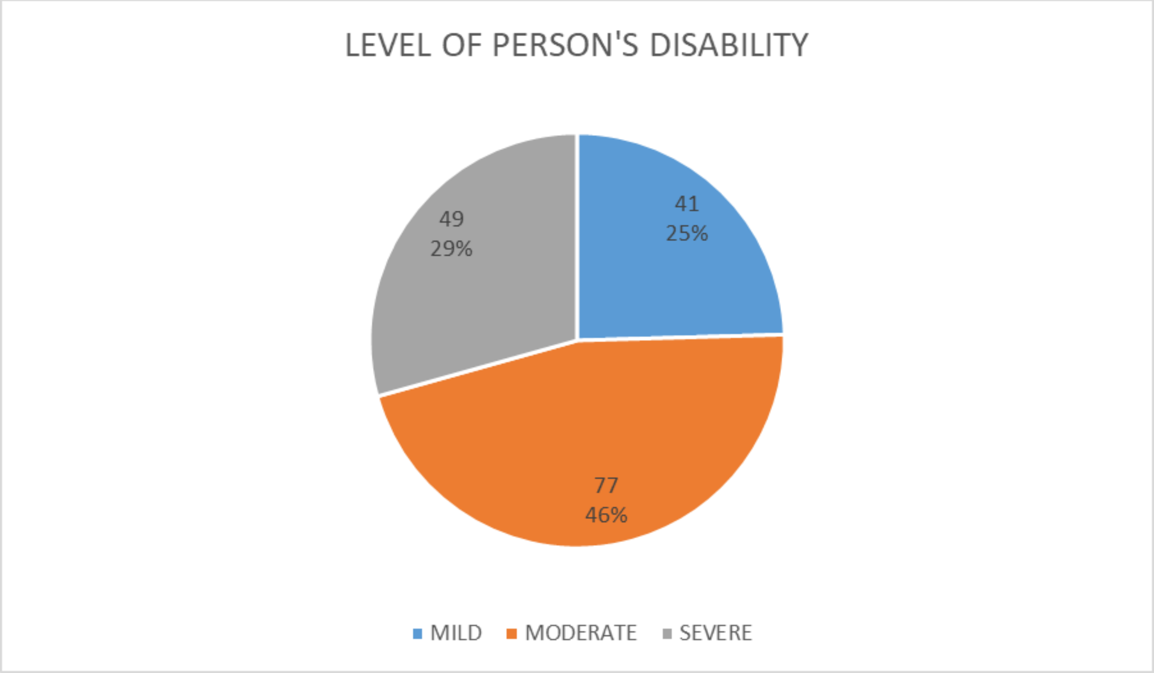


CHART 5: LEVEL OF PERSON'S DISABILITY

INFORMATION ON PREVIOUS SUPPORT/TRAINING

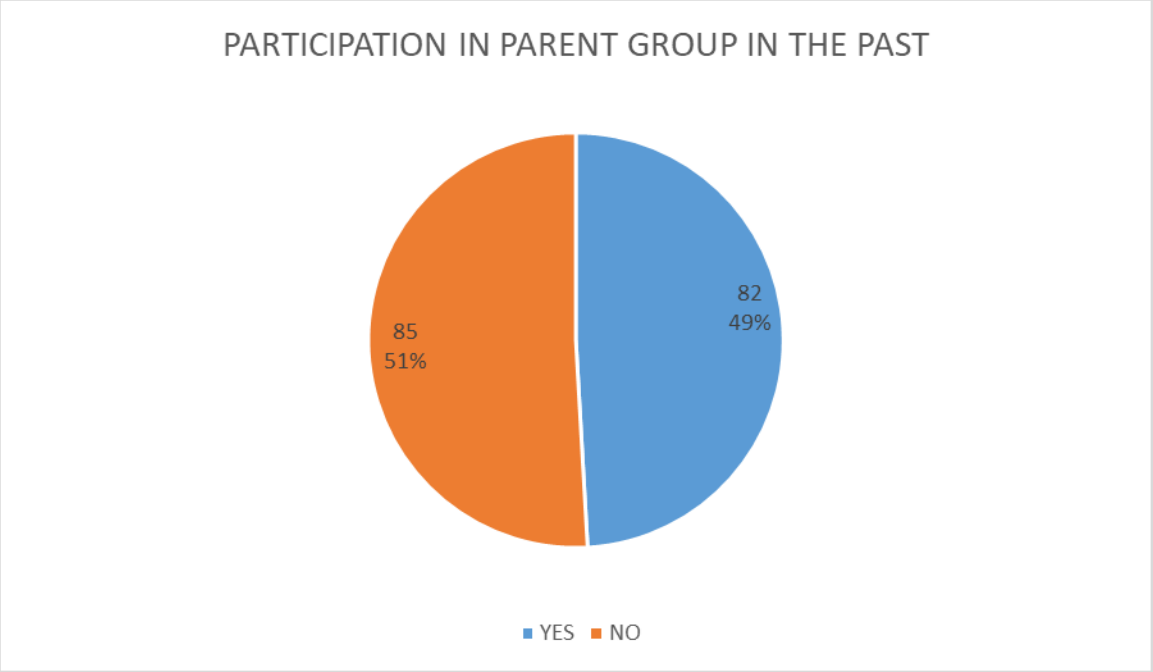


CHART 1: PARTICIPATION IN PARENT GROUP

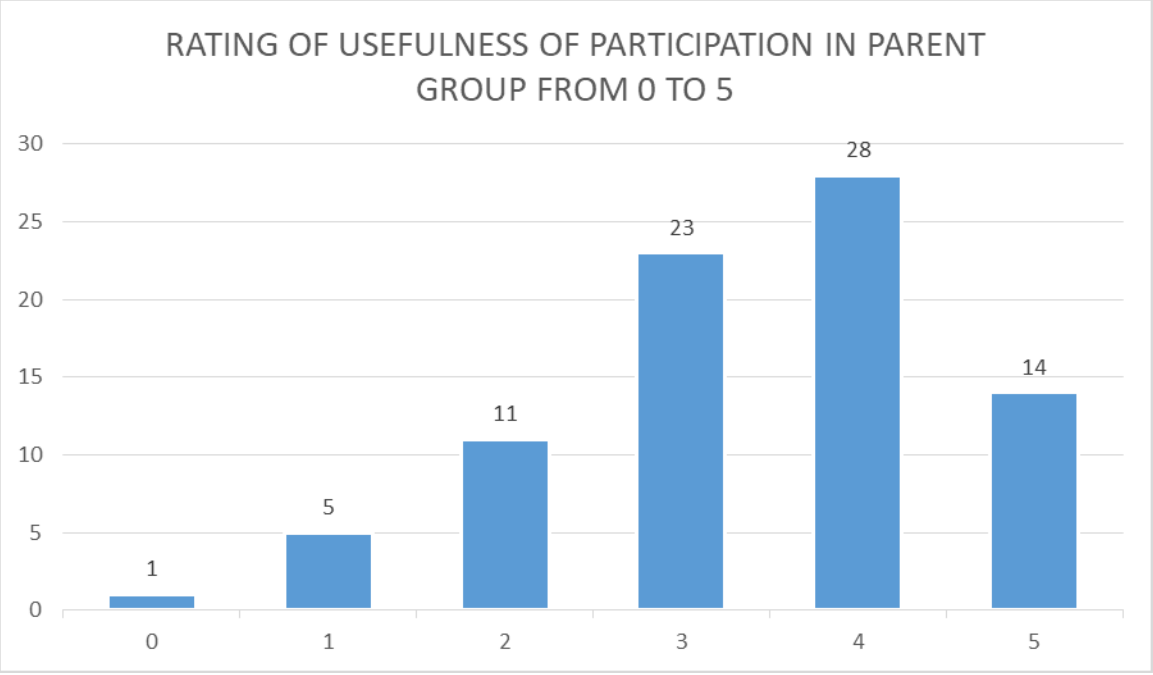


CHART 2: USEFULNESS OF PARTICIPATION IN PARENT GROUP

Summary of Comments:

Parents seem to appreciate the opportunity to share experiences, exchange information and receive information and support from people in similar situation. Often though parent groups did not meet their expectations due to the different diagnosis/needs of their child.

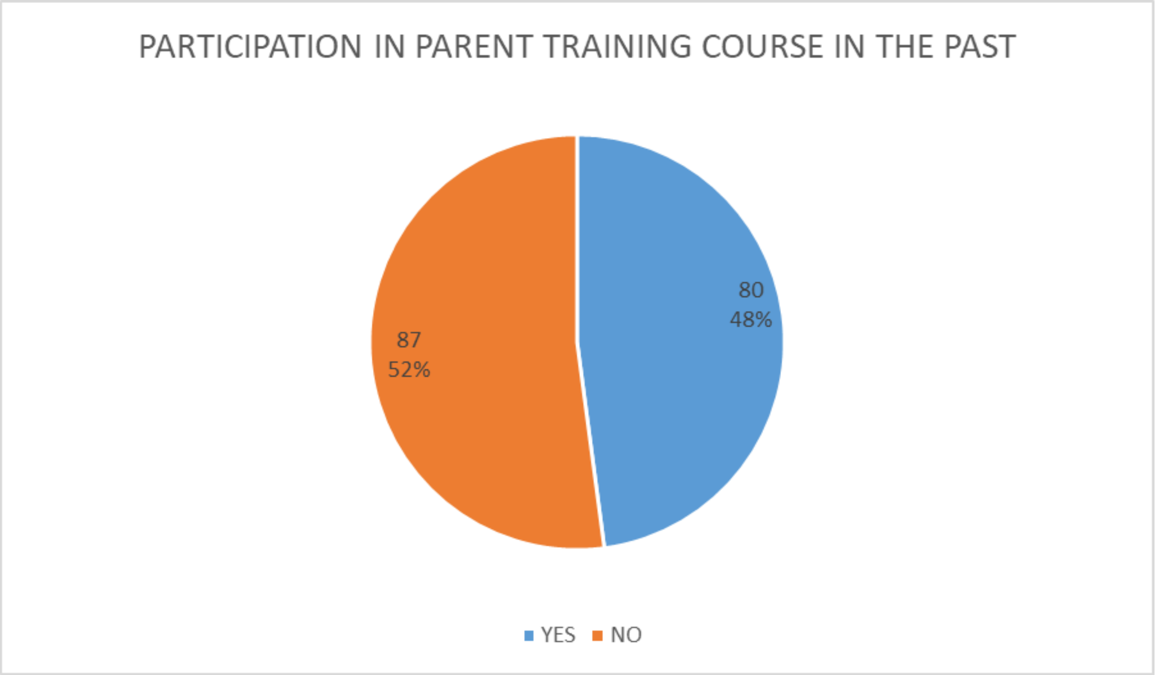


CHART 3: PARTICIPATION IN PARENT TRAINING COURSE

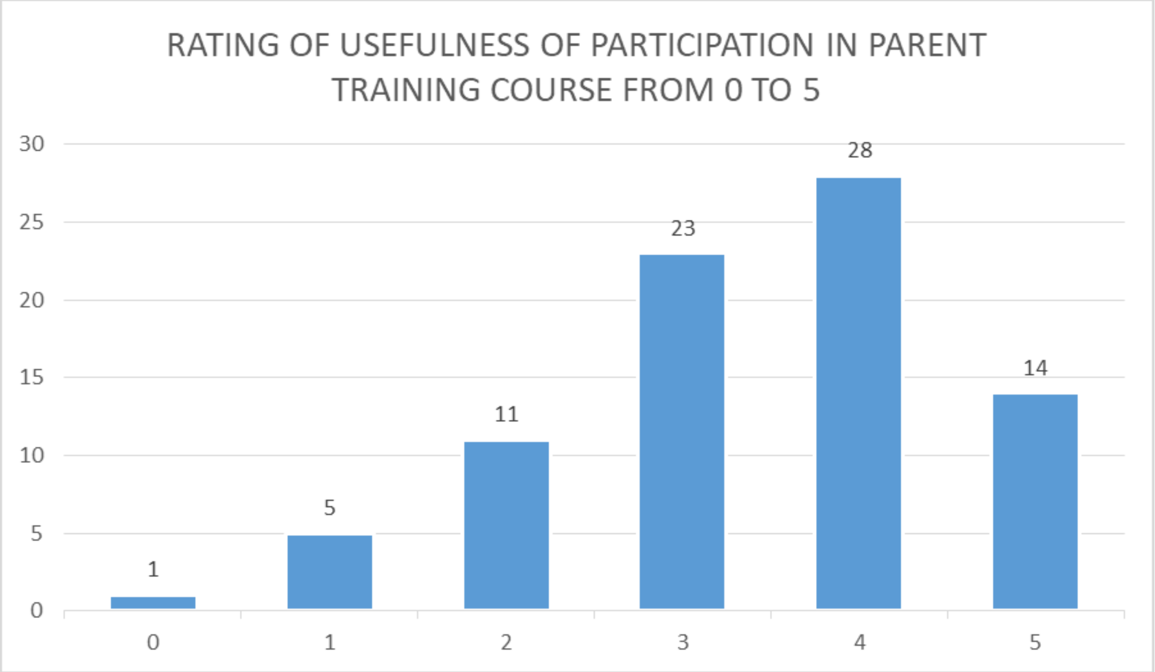


CHART 4: USEFULNESS OF PARTICIPATION IN PARENT TRAINING COURSE

Summary of Comments:

The quality of the training courses varies and it does not always meet the expectations of the parents. Moreover, some training courses mainly provide a theoretical approach and lack practical information/tools. There also seems to be a lack of training courses on issues specific to adults with intellectual disability. Finally, parents would also like the opportunity to participate in distance learning.

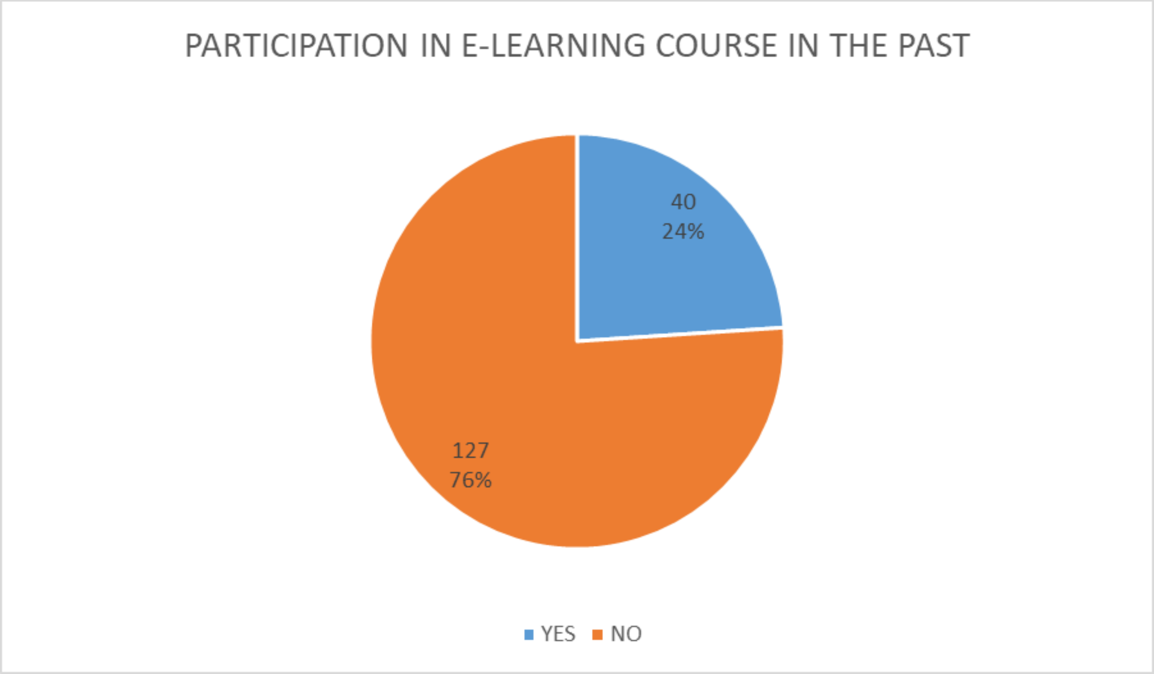


CHART 5: PARTICIPATION IN E-LEARNING COURSE

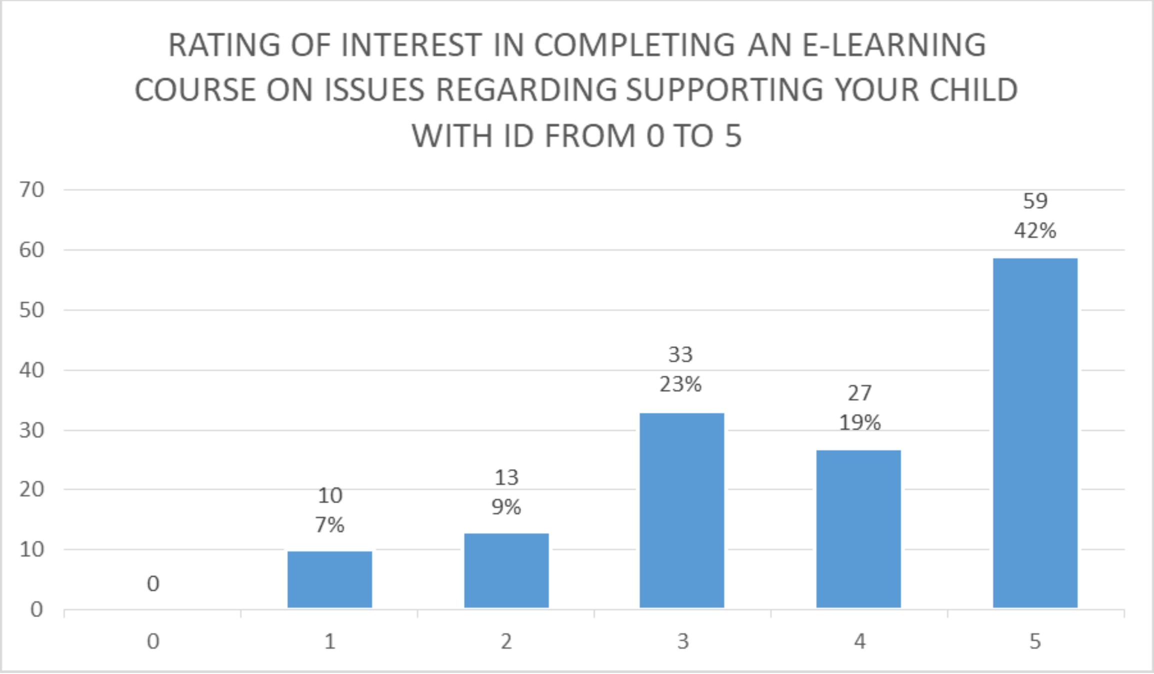


CHART 6: RATING OF INTEREST IN COMPLETING E-LEARNING COURSE

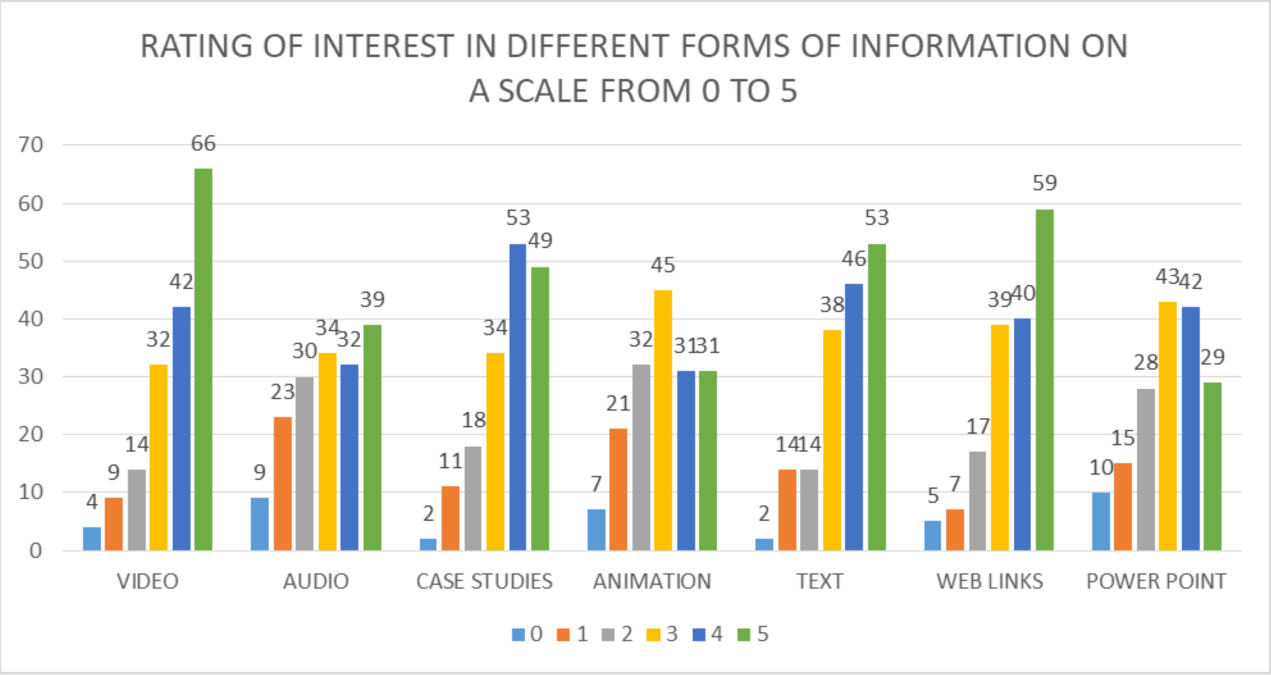


CHART 7: RATING OF INTEREST IN DIFFERENT FORMS OF INFORMATION

Other forms of information:

Discussion groups, face-to-face support/guidance by professionals, workshops, fairytales/stories, illustrations/drawing, personal stories by parents, podcasts, situation simulation, informal parent groups, links to organisations

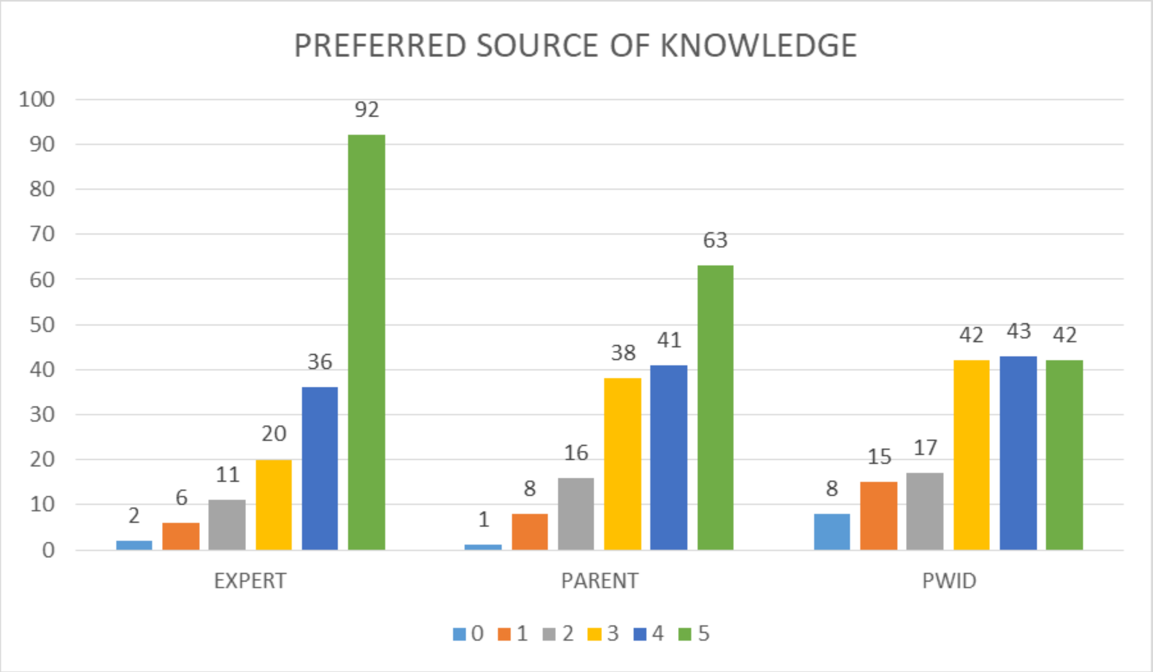


CHART 8: PREFERRED SOURCE OF KNOWLEDGE

STRESS MANAGEMENT

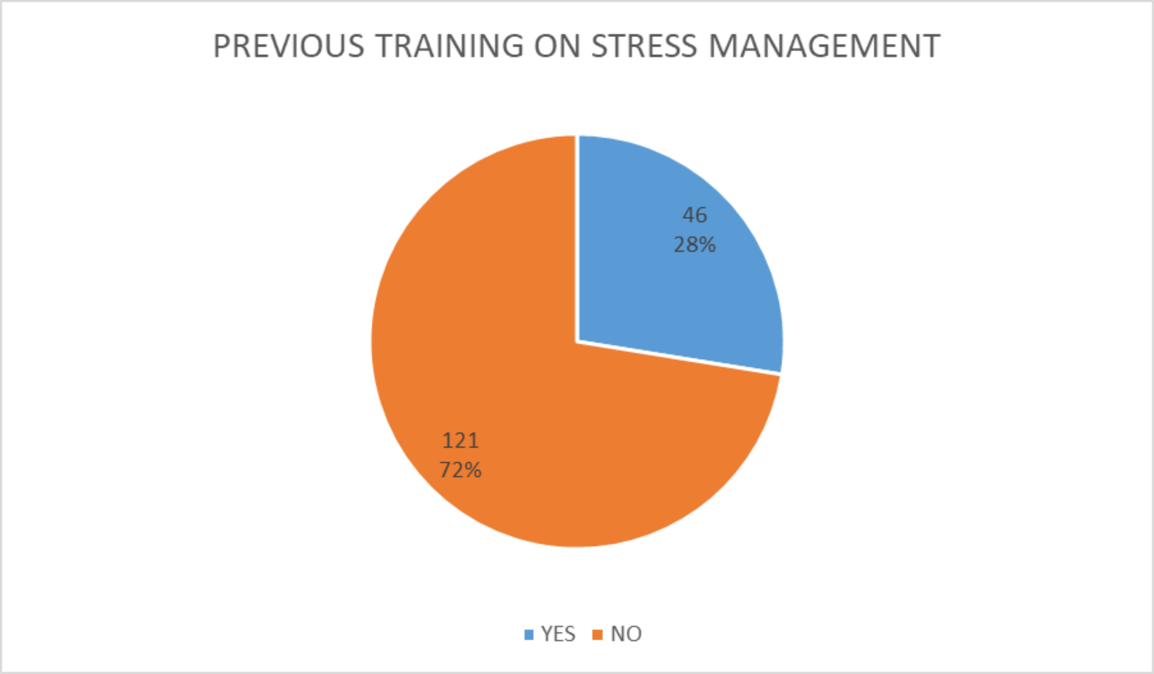


CHART 1: TRAINING ON STRESS MANAGEMENT

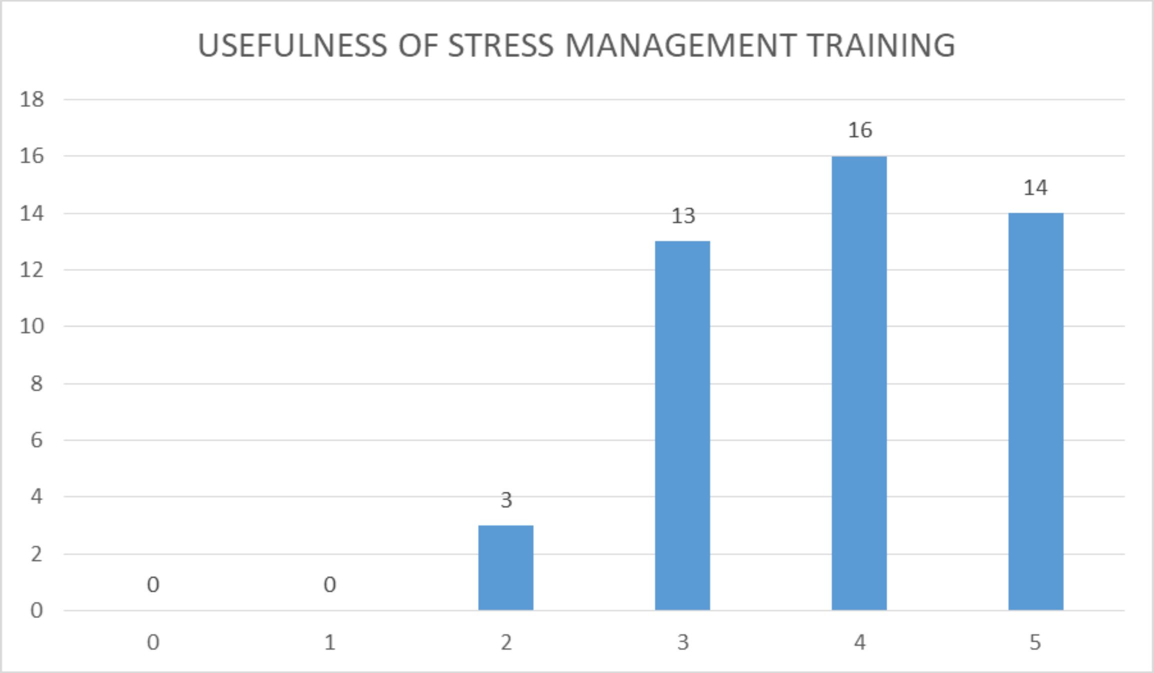


CHART 2: USEFULNESS OF STRESS MANAGEMENT TRAINING

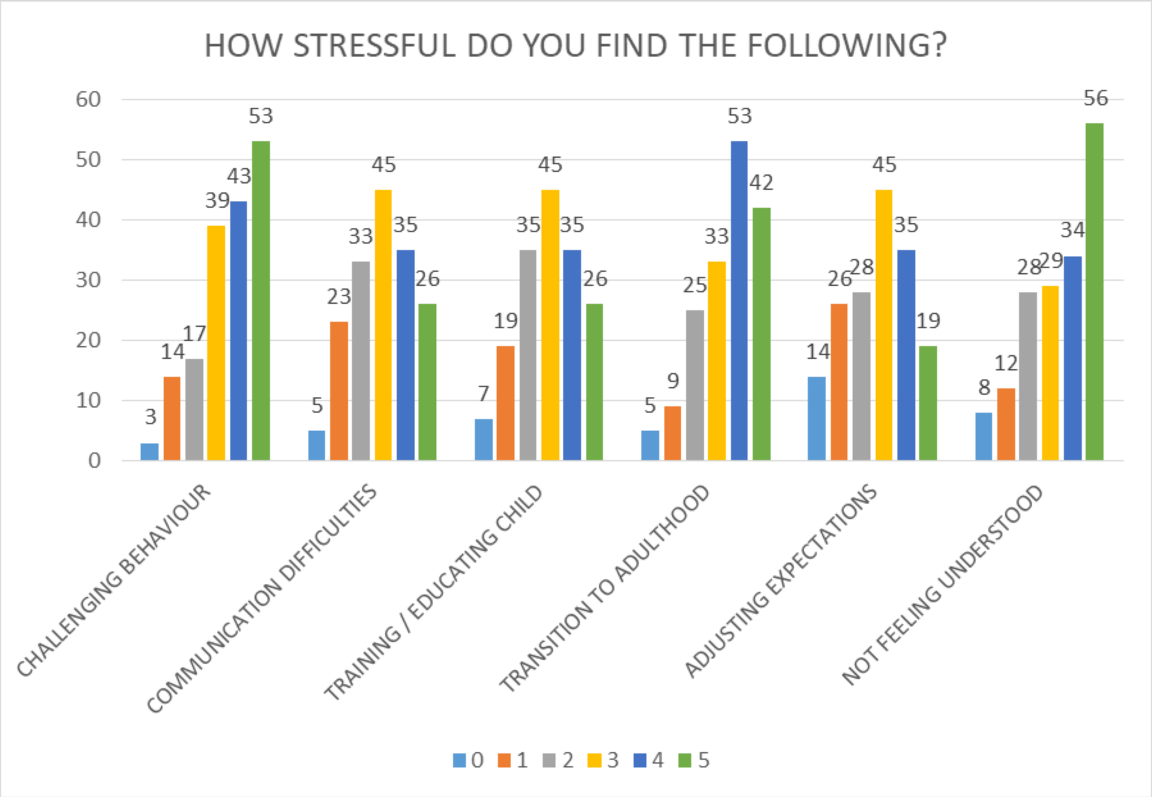


CHART 3: RATING HOW STRESSFUL ARE SOME SITUATIONS

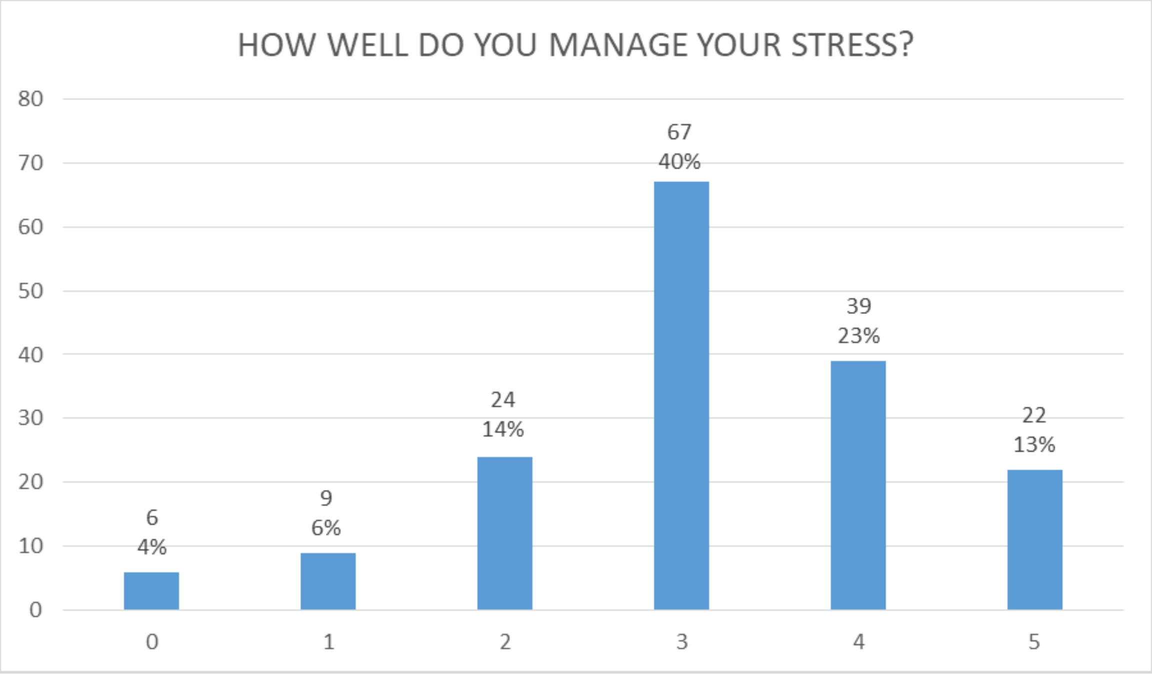


CHART 4: RATING HOW WELL PARTICIPANTS MANAGE THEIR STRESS

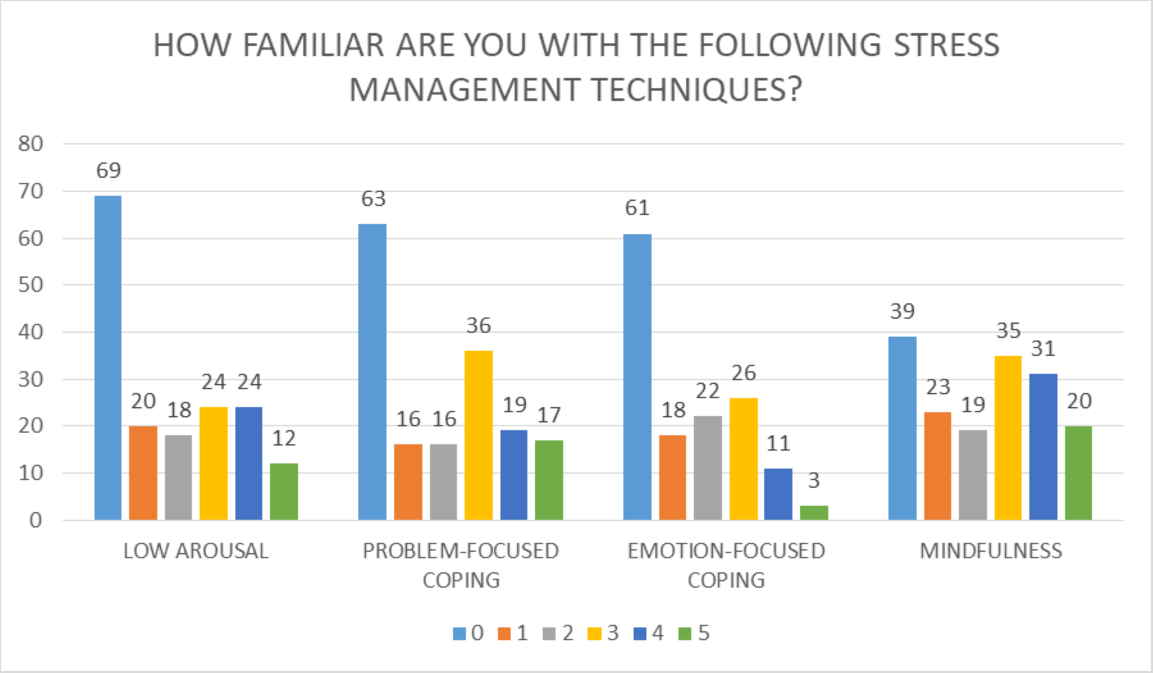


CHART 5: FAMILIARITY WITH DIFFERENT STRESS MANAGEMENT TECHNIQUES

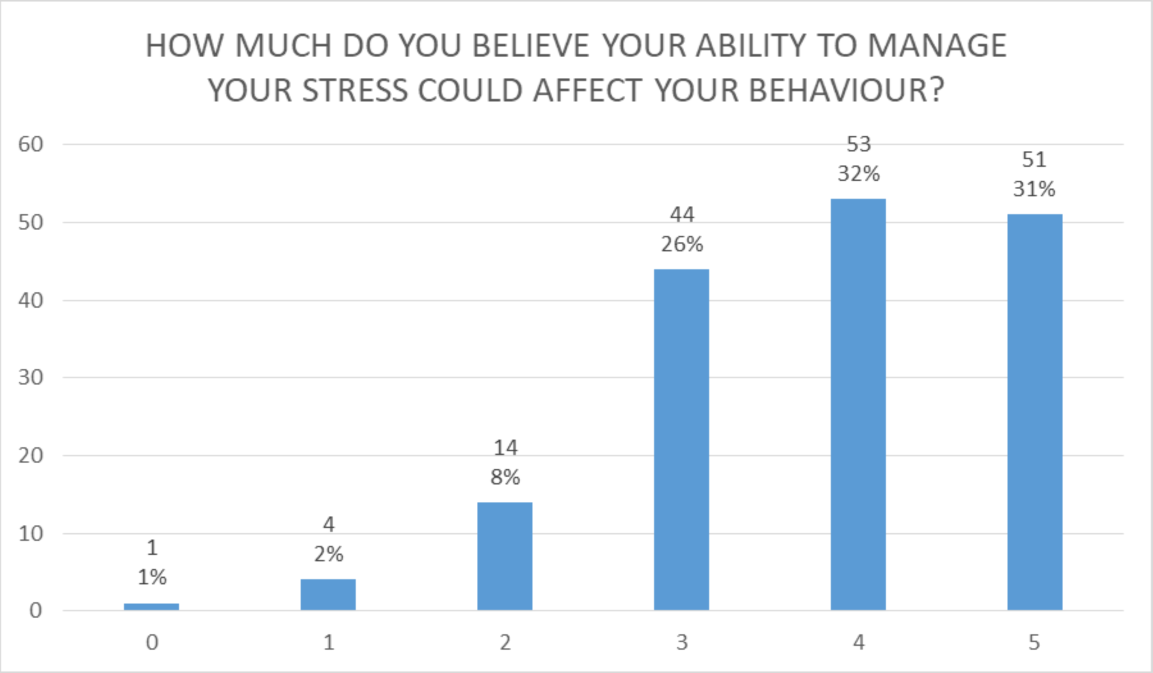


CHART 6: ABILITY TO MANAGE STRESS HAS AFFECTS YOUR BEHAVIOUR

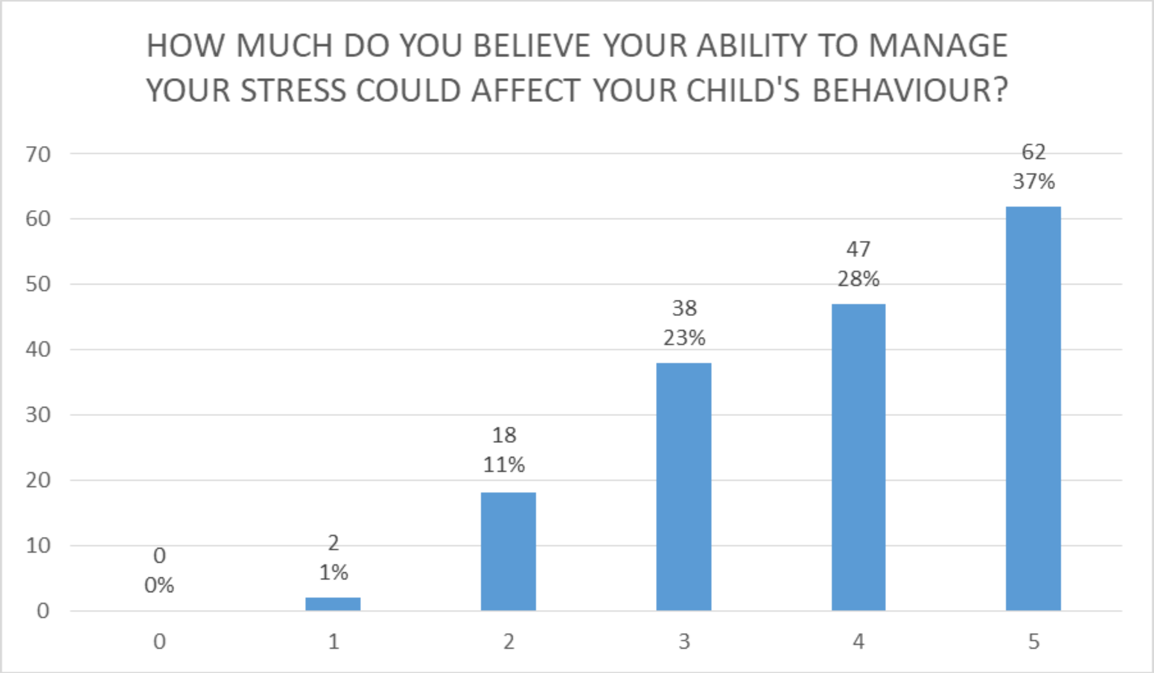


CHART 7: ABILITY TO MANAGE STRESS HAS AFFECTS YOUR CHILD’S BEHAVIOUR

COMMUNICATION

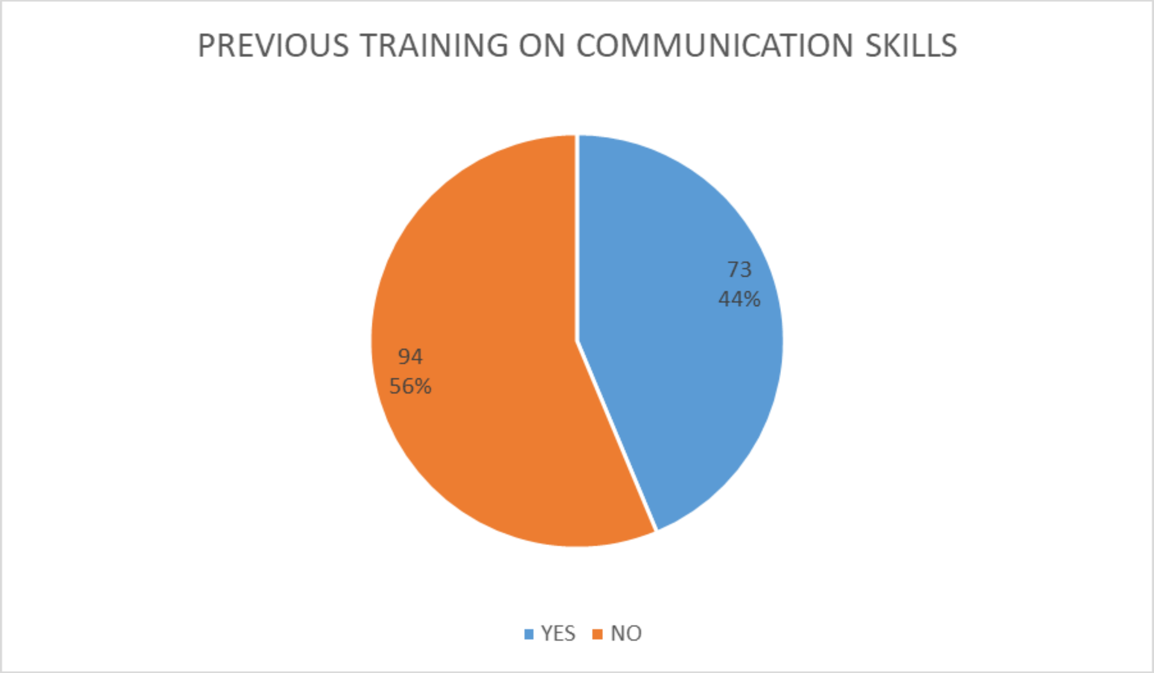


CHART 1: PREVIOUS TRAINING ON COMMUNICATION SKILLS

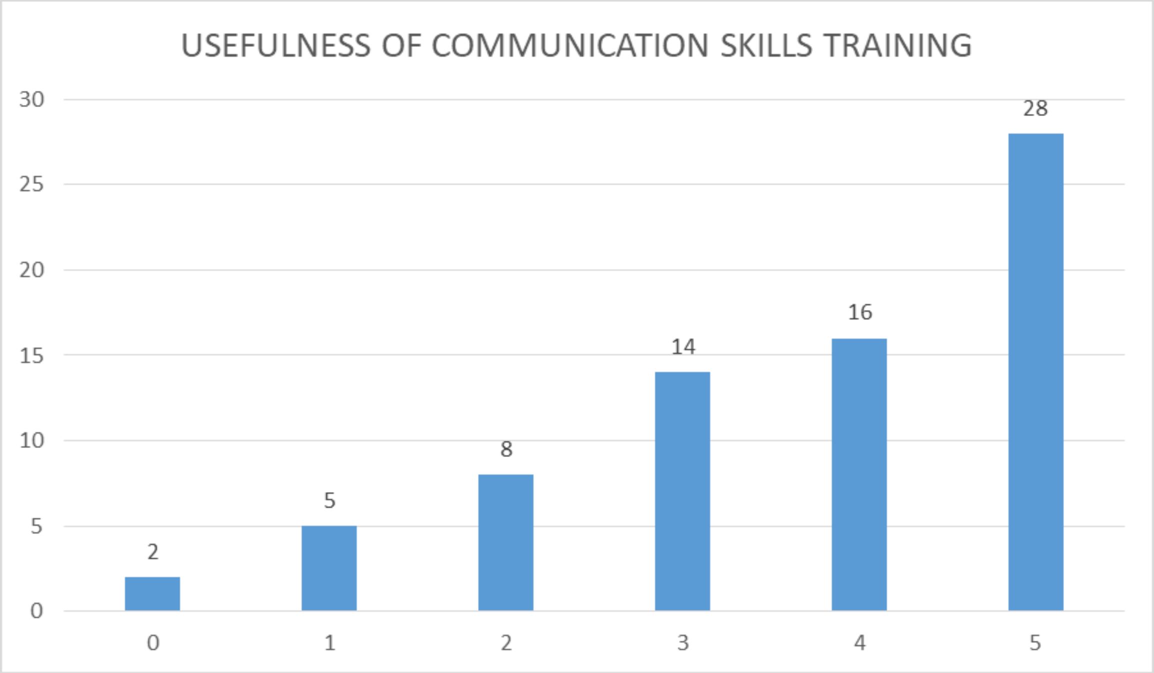


CHART 2: USEFULNESS OF COMMUNICATION SKILLS TRAINING

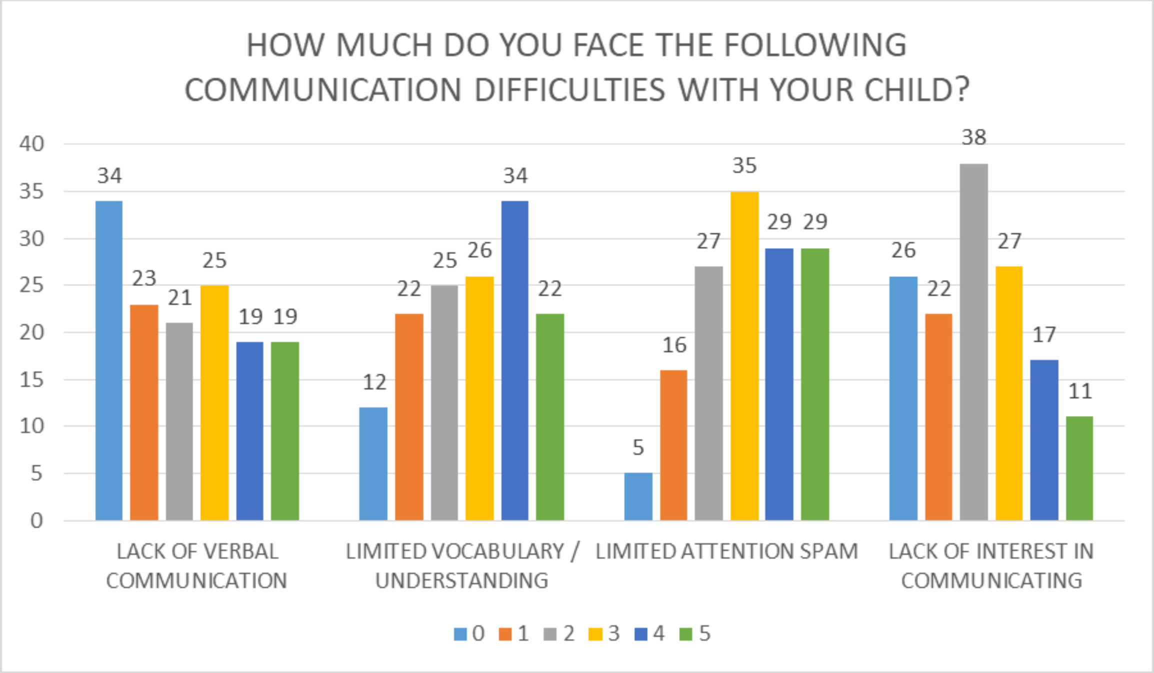


CHART 3: DIFFERENT COMMUNICATION DIFFICULTIES WITH CHILD

Other communication difficulties:

Unable to speak, jumping from theme to theme in the middle of sentences, becomes easily tired, influenced by mood (more difficult when angry), discrepancy between explicit verbal language and understanding, unclear speech, requires that parent «translates» to others what child says

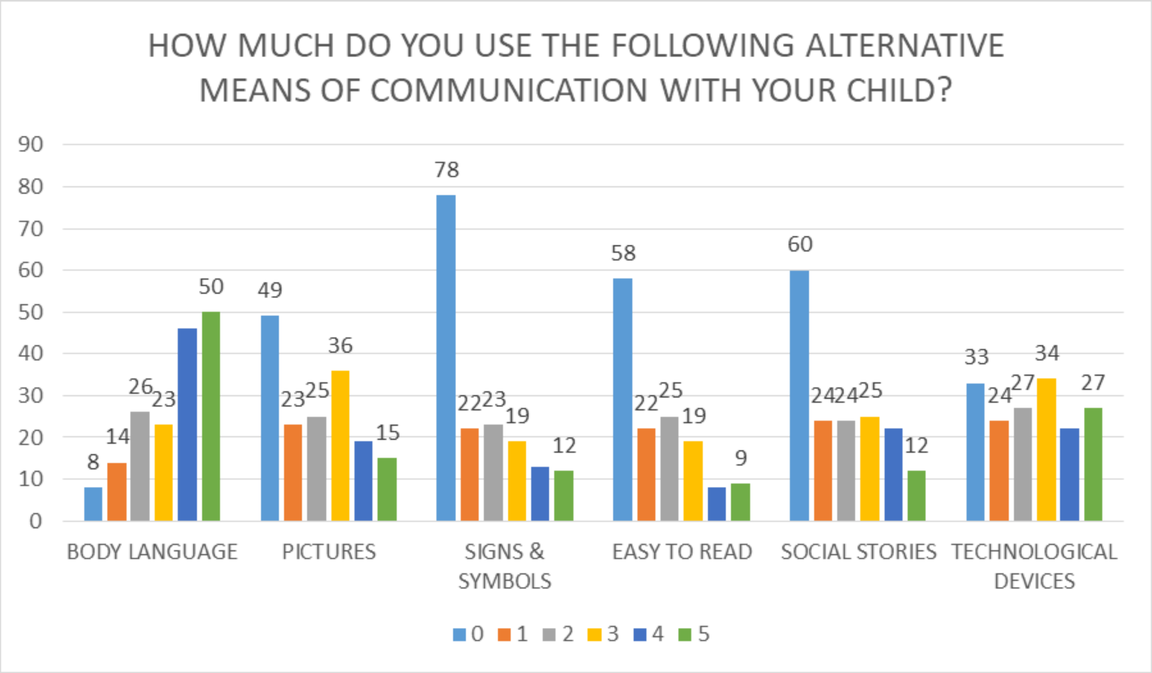


CHART 4: USE OF ALTERNATIVE MEANS OF COMMUNICATION

Other means of communication:
Actions/activities (e.g. getting ready to go out, setting the table), rhymes/songs, ASK, technology (telephone, speech machine, tablet, amplifier), text to speech

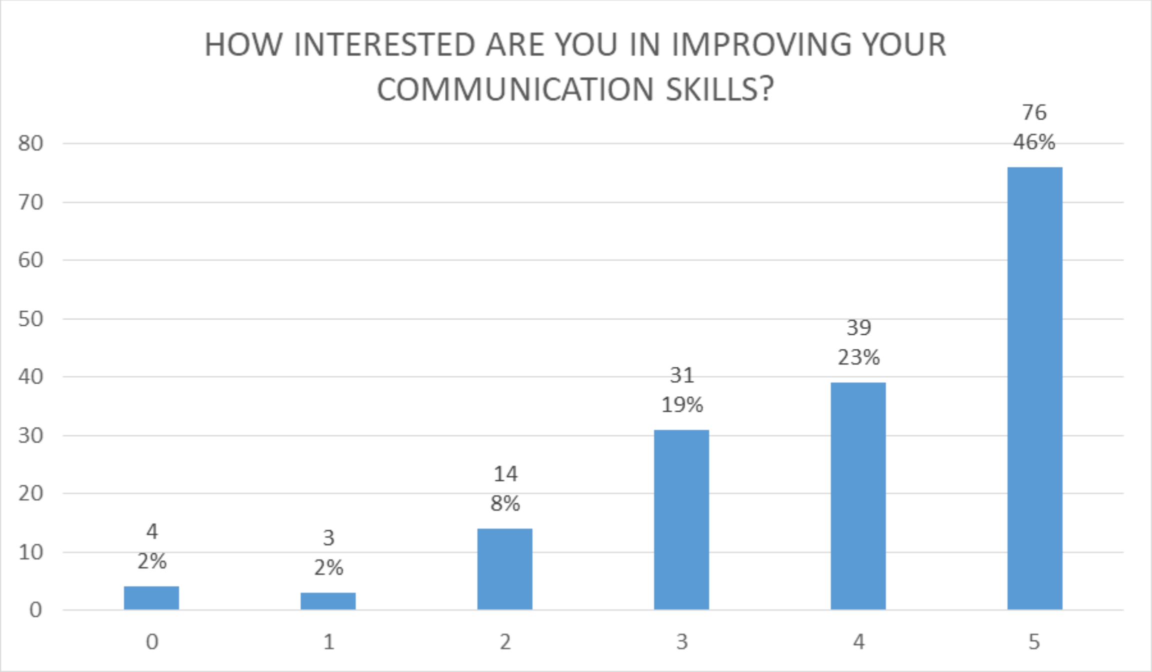


CHART 5: INTEREST IN IMPROVING COMMUNICATION SKILLS

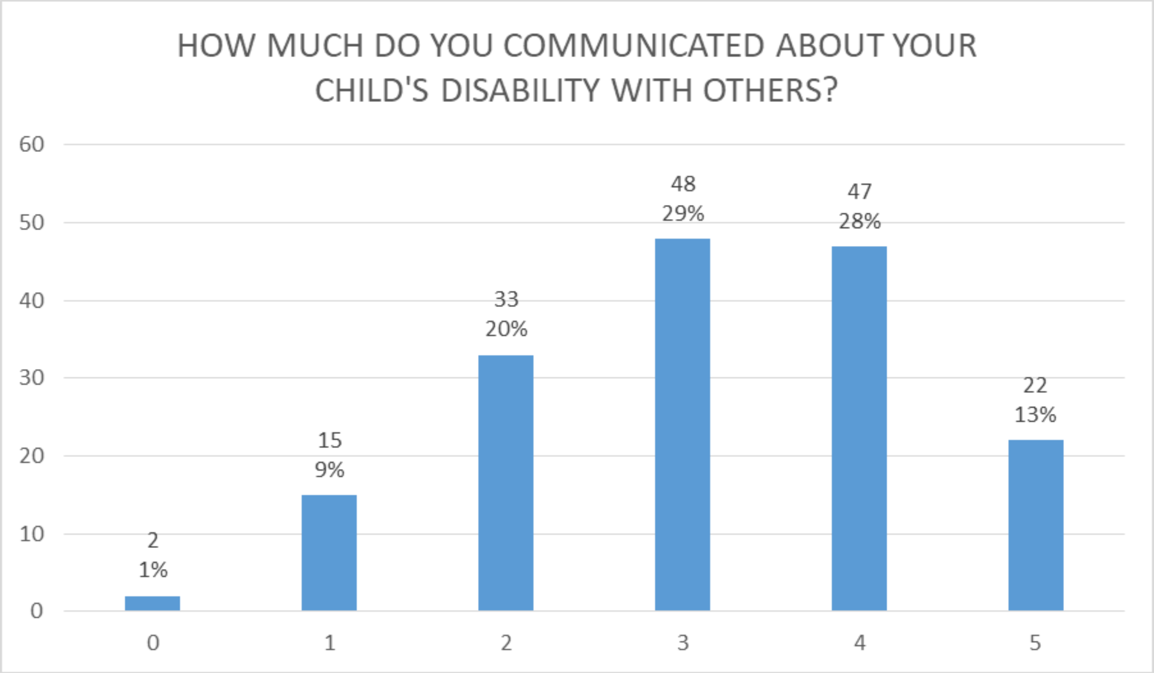


CHART 6: COMMUNICATING CHILD'S DISABILITY WITH OTHERS

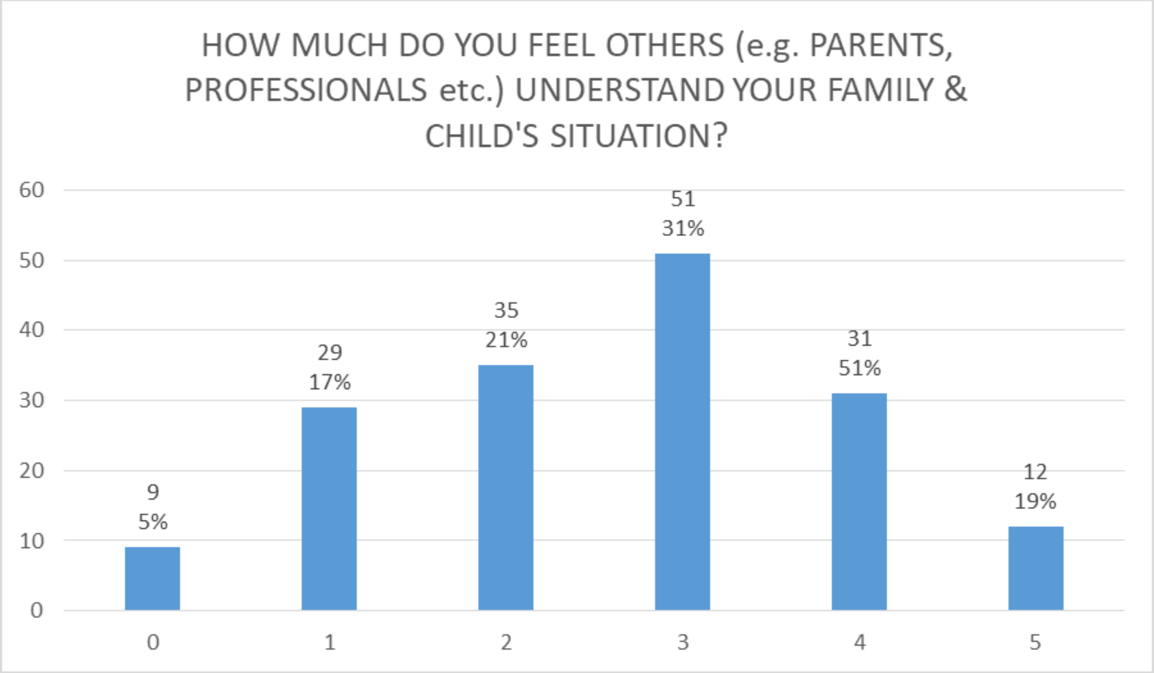


CHART 7: FEELING UNDERSTOOD BY OTHERS

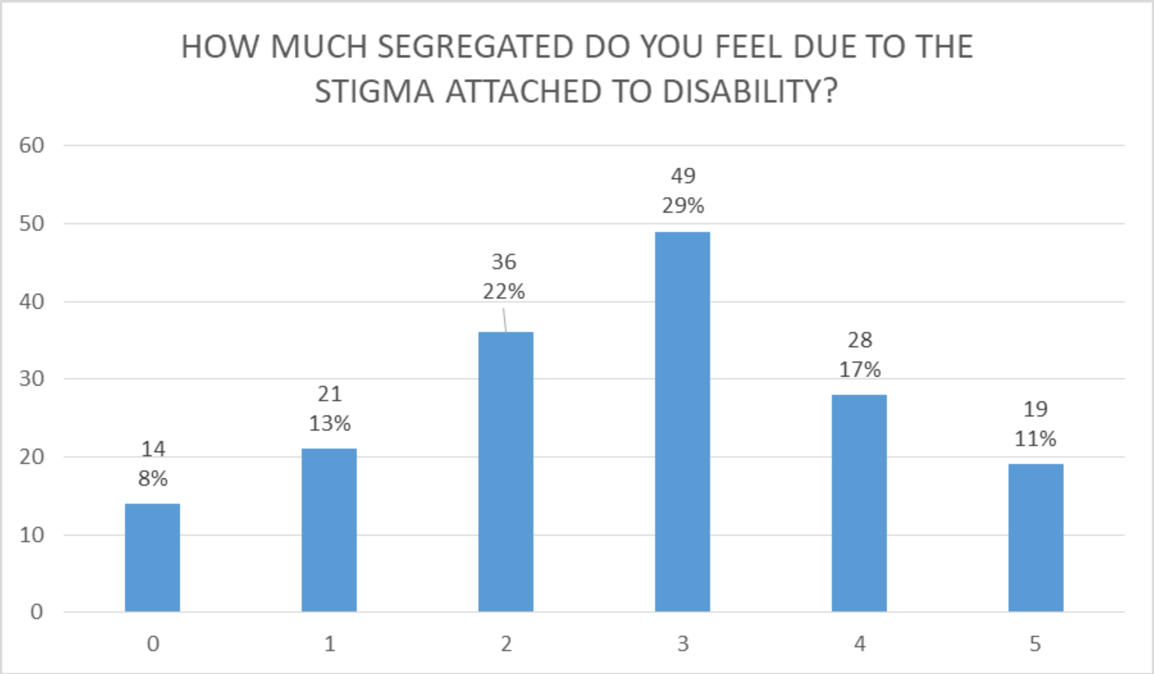


CHART 8: SEGREGATED DUE TO THE STIGMA ATTACHED TO DISABILITY

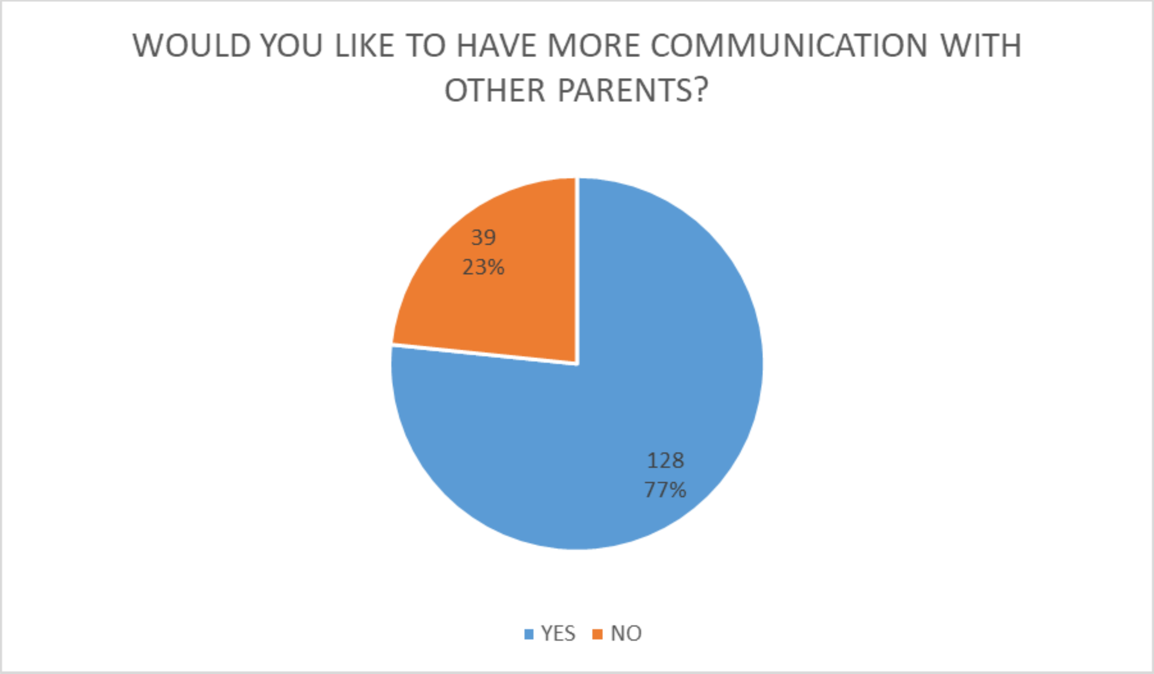


CHART 9: MORE COMMUNICATION WITH OTHER PARENTS

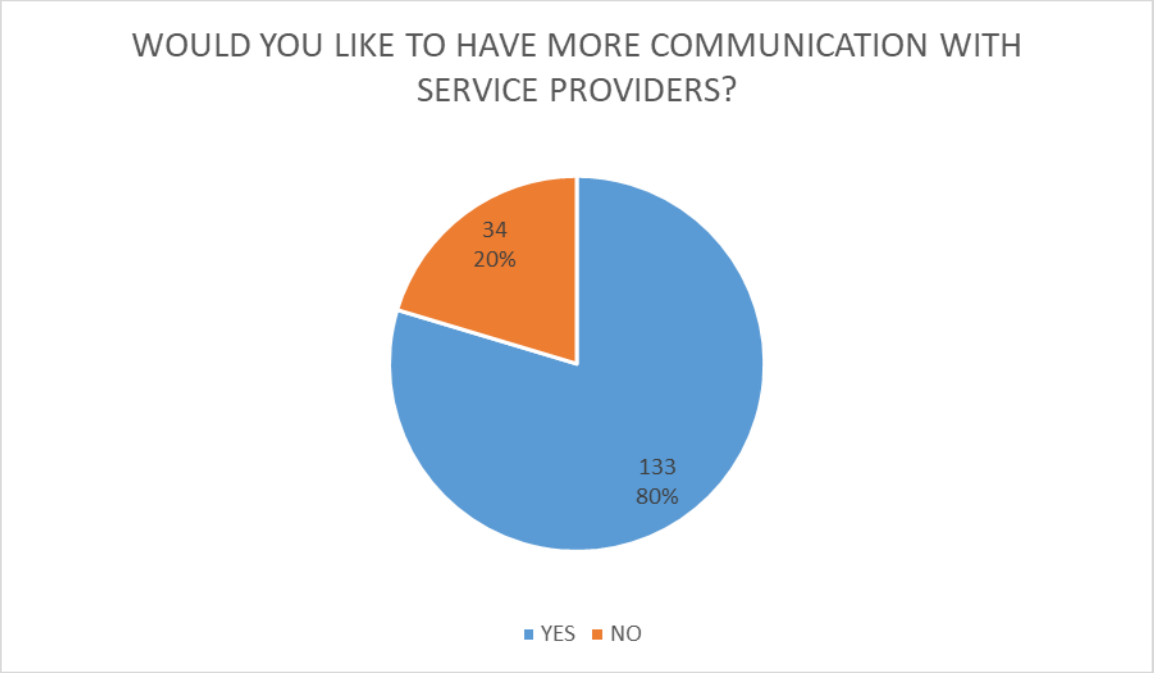


CHART 10: MORE COMMUNICATION WITH SERVICE PROVIDERS

TRANSITION TO ADULTHOOD

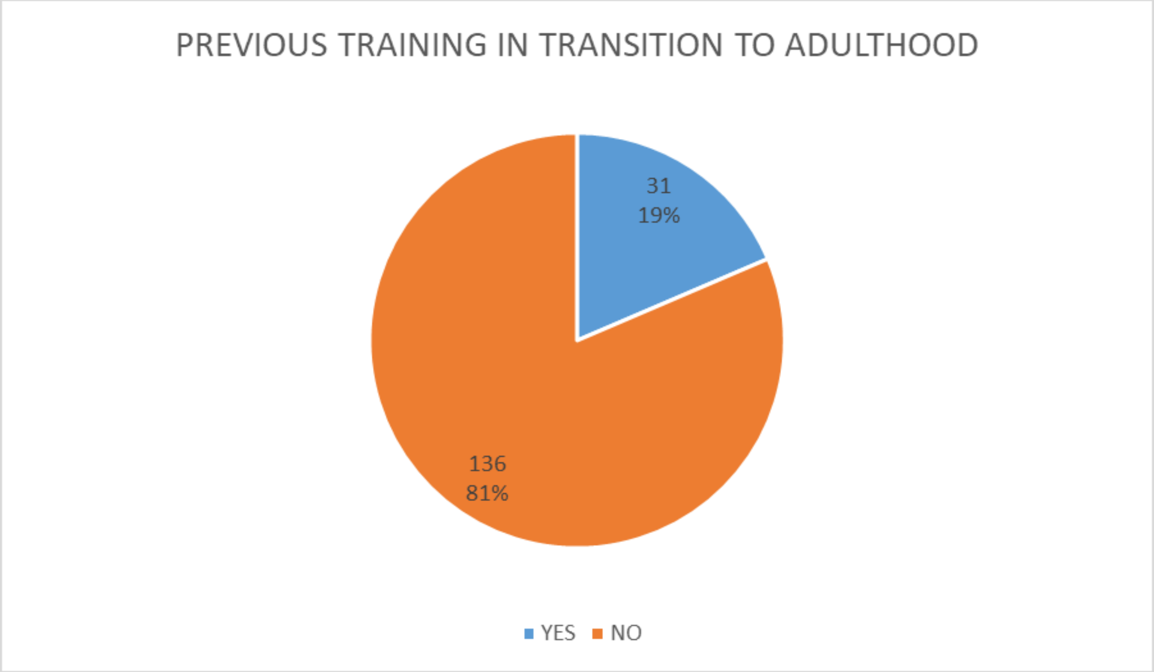


CHART 1: PREVIOUS TRAINING IN TRANSITION TO ADULTHOOD

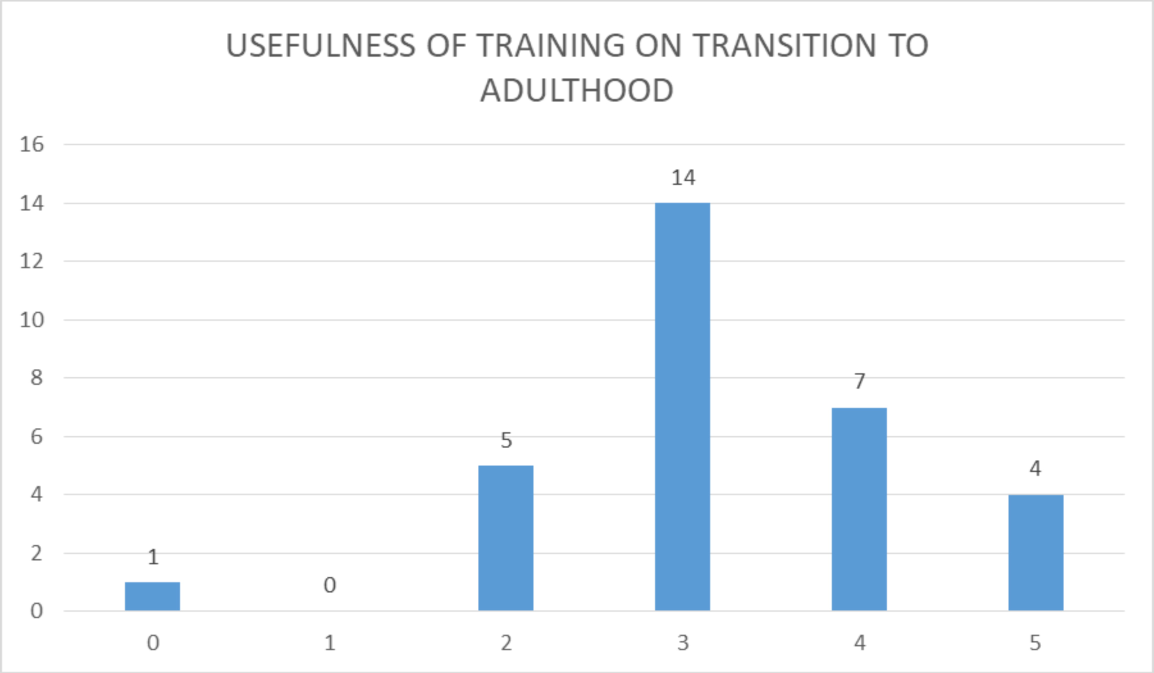


CHART 2: USEFULNESS OF TRAINING ON TRANSITION TO ADULTHOOD

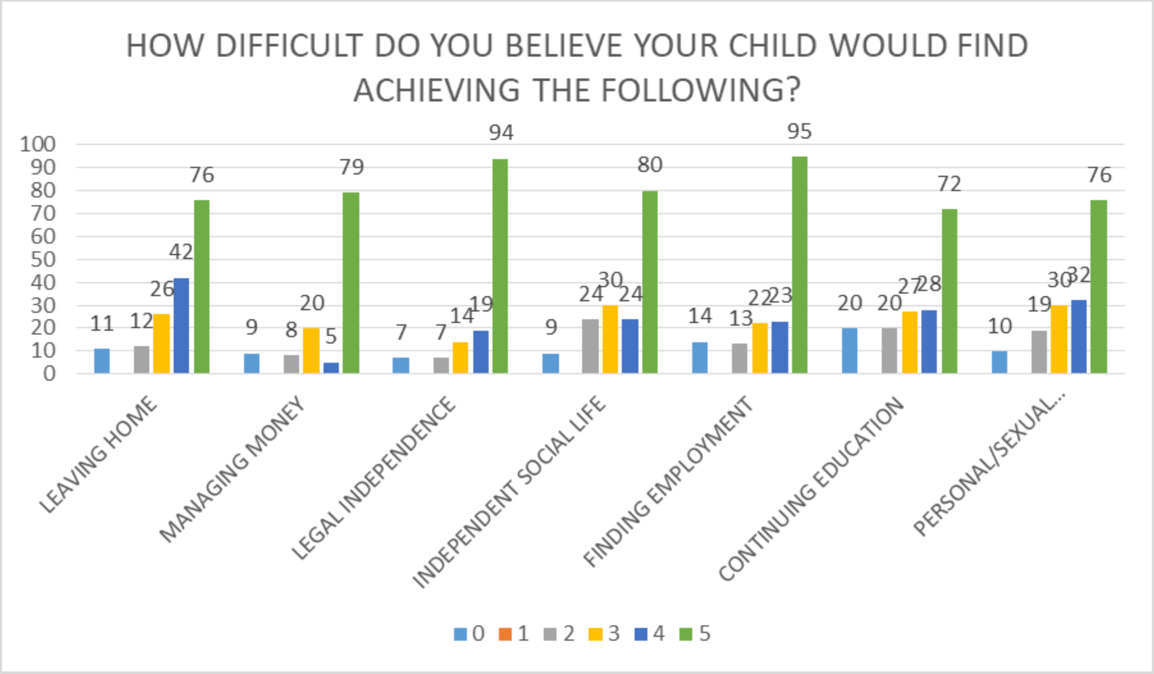


CHART 3: DIFFICULTY FOR THE CHILD TO ACHIEVE DIFFERENT GOALS

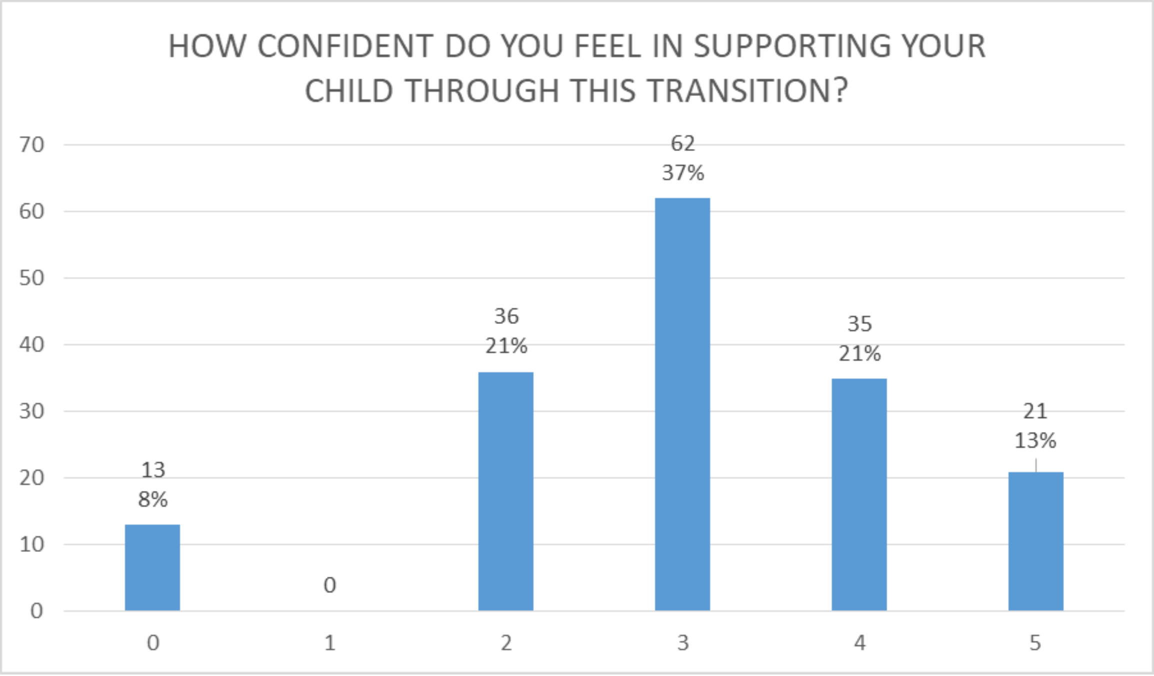


CHART 4: CONFIDENCE IN SUPPORTING CHILD THROUGH TRANSITION

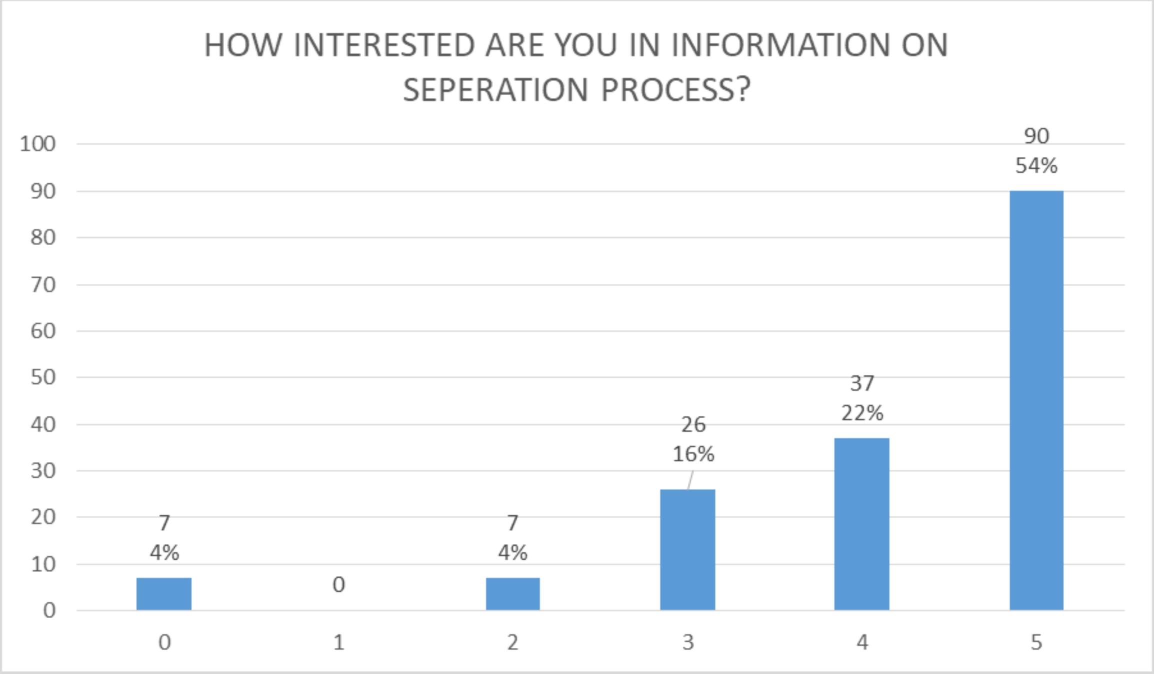


CHART 5: INTERESTED IN INFORMATION ON SEPARATION PROCESS

HUMAN RIGHTS

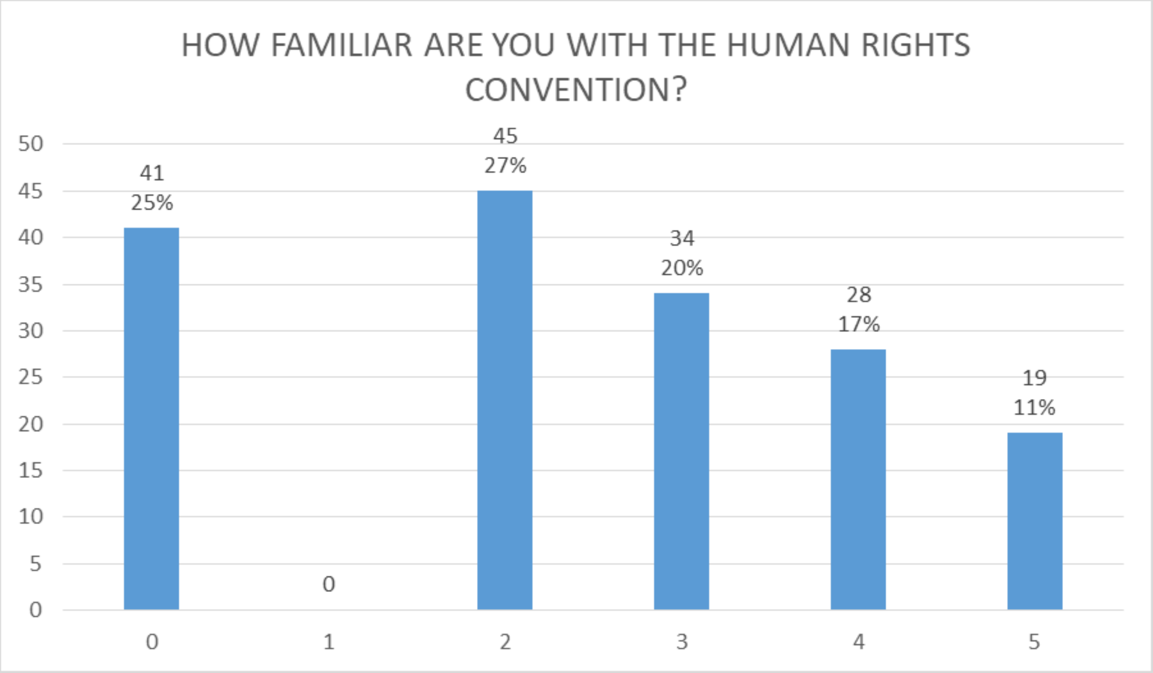


CHART 1: FAMILIARITY WITH THE HUMAN RIGHTS CONVENTION

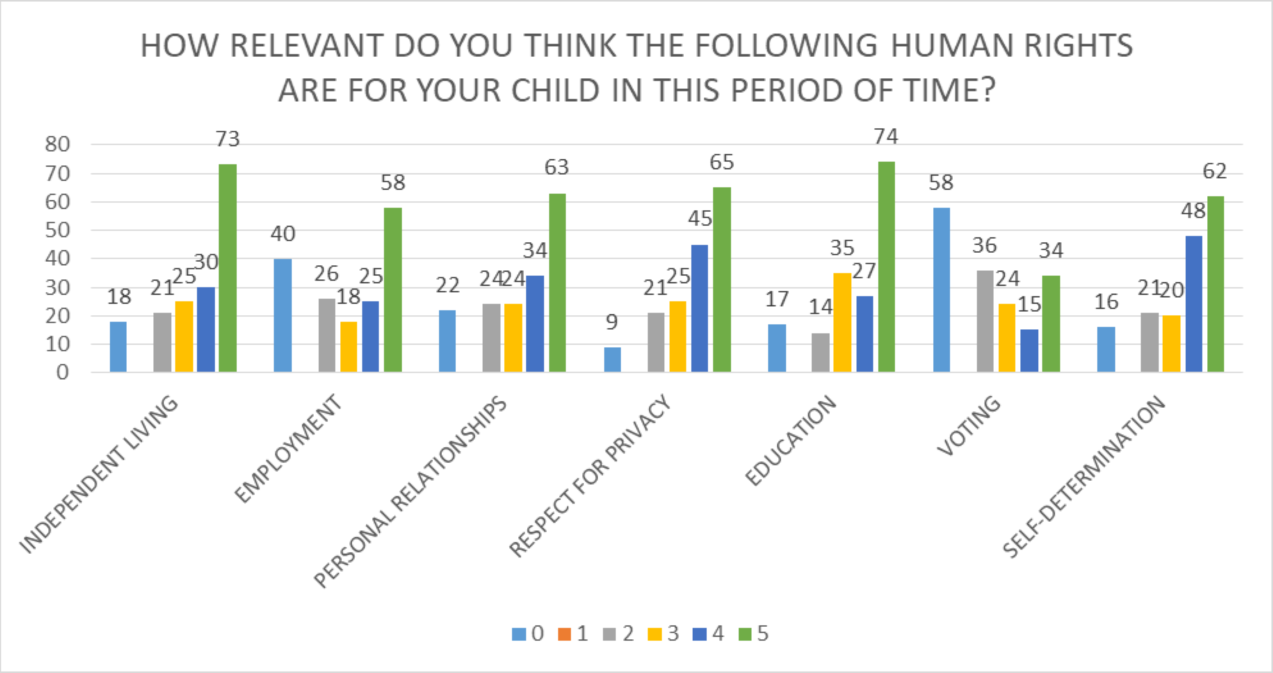


CHART 2: RELEVANCE OF THE FOLLOWING HUMAN RIGHTS IN THIS PERIOD OF TIME

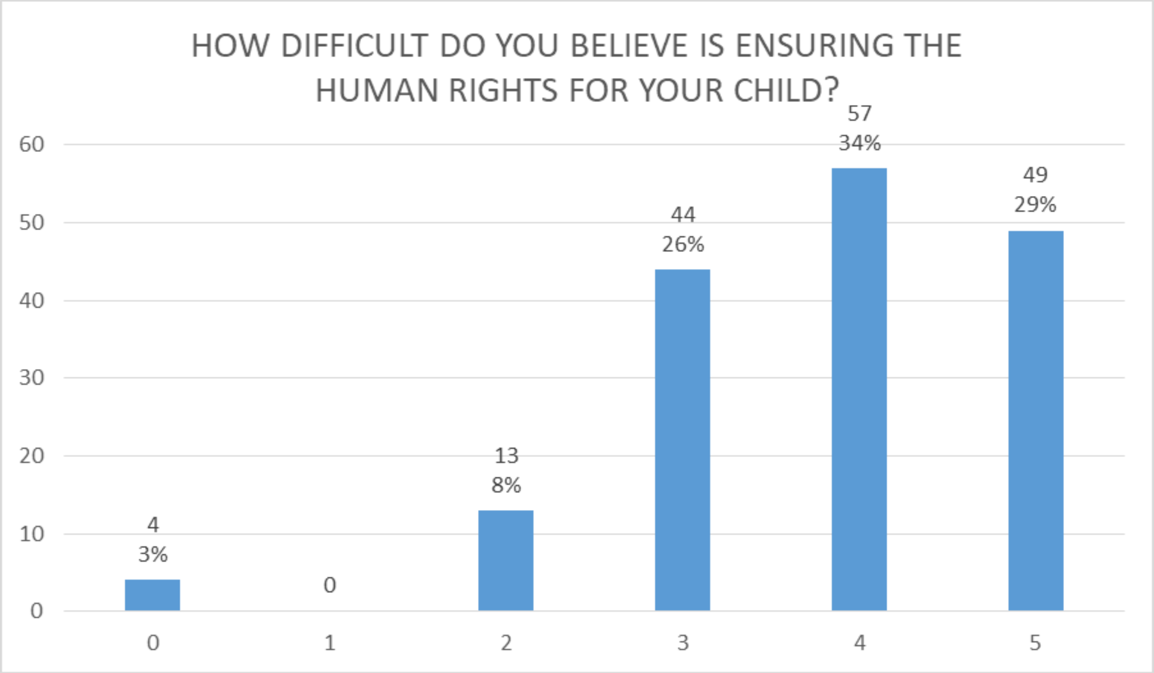


CHART 3: DIFFICULTY IN ENSURING HUMAN RIGHTS

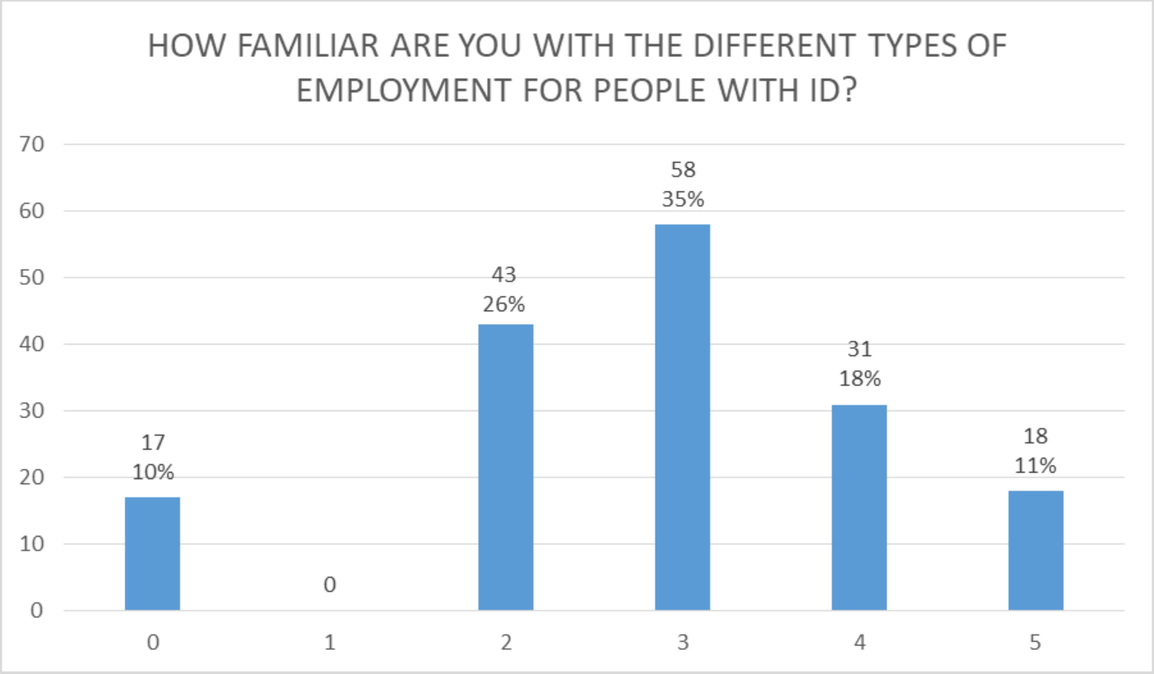


CHART 4: FAMILIARITY WITH DIFFERENT TYPES OF EMPLOYMENT

SEX EDUCATION

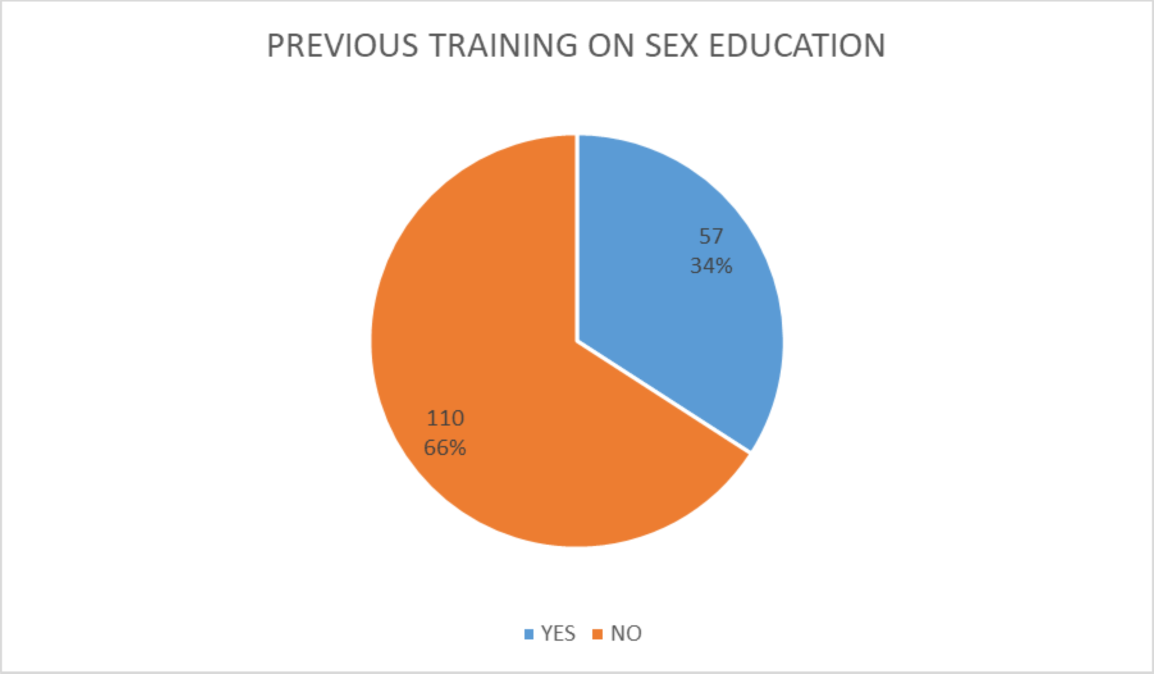


CHART 1: PREVIOUS TRAINING ON SEX EDUCATION

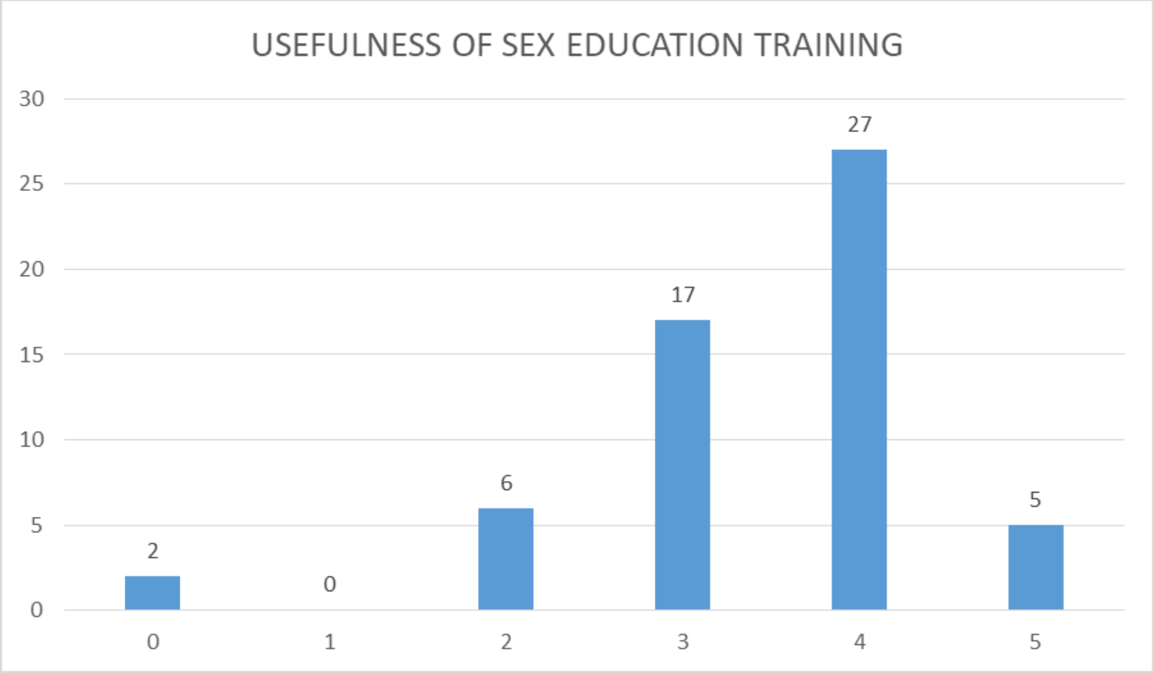


CHART 2: RATING USEFULNESS OF SEX EDUCATION TRAINING

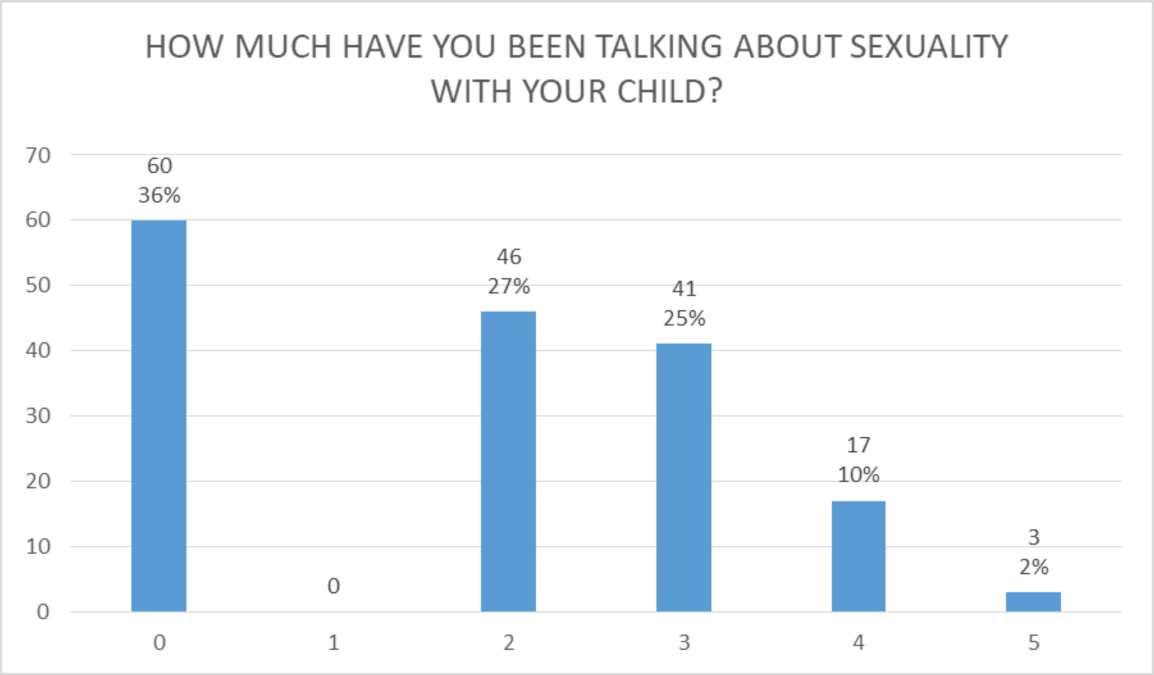


CHART 3: DISCUSSION ABOUT SEXUALITY WITH CHILD

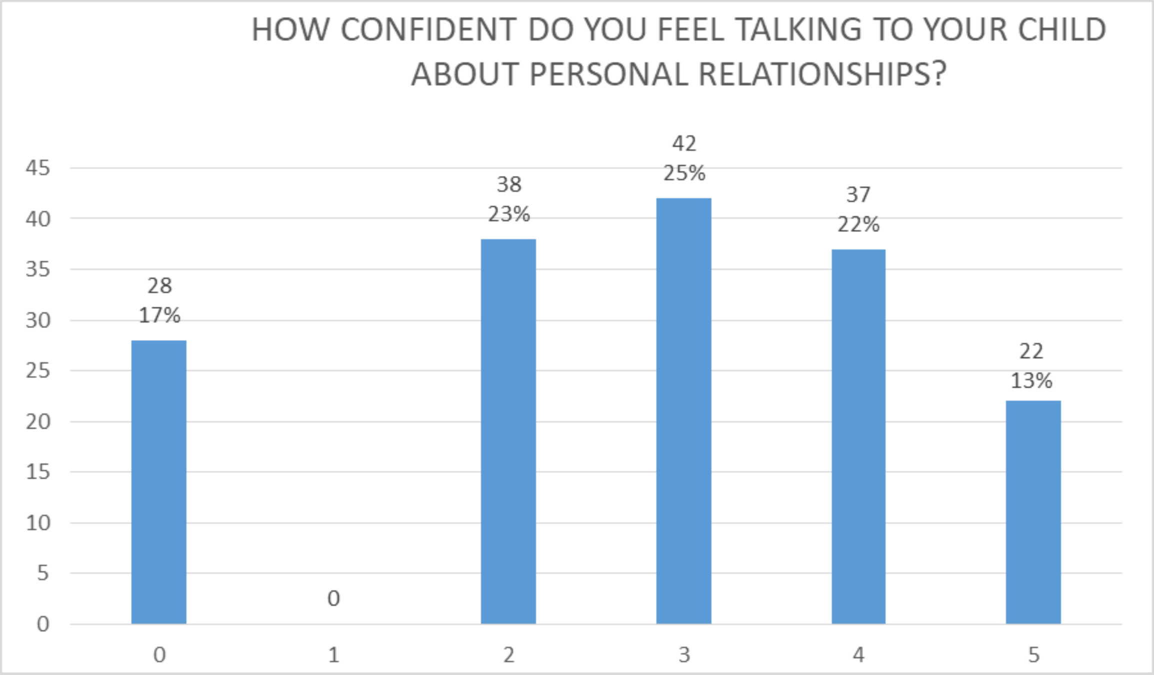


CHART 4: CONFIDENCE IN TALKING TO CHILD ABOUT PERSONAL RELATIONSHIPS

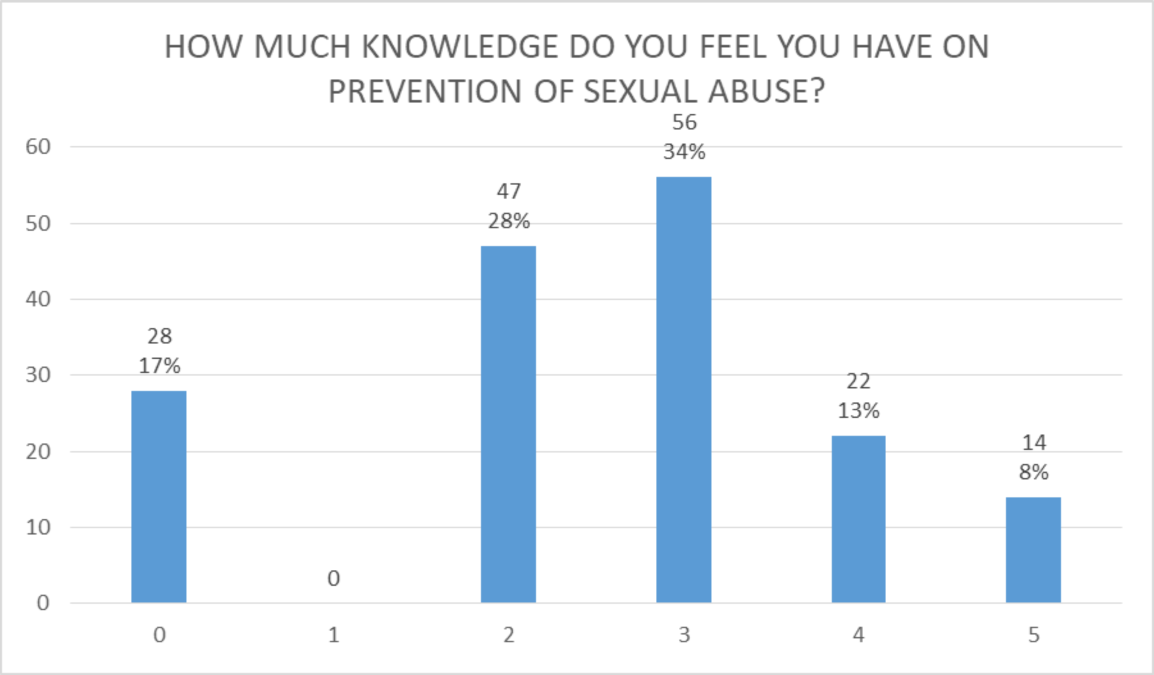


CHART 5: KNOWLEDGE ON PREVENTION OF SEXUAL ABUSE

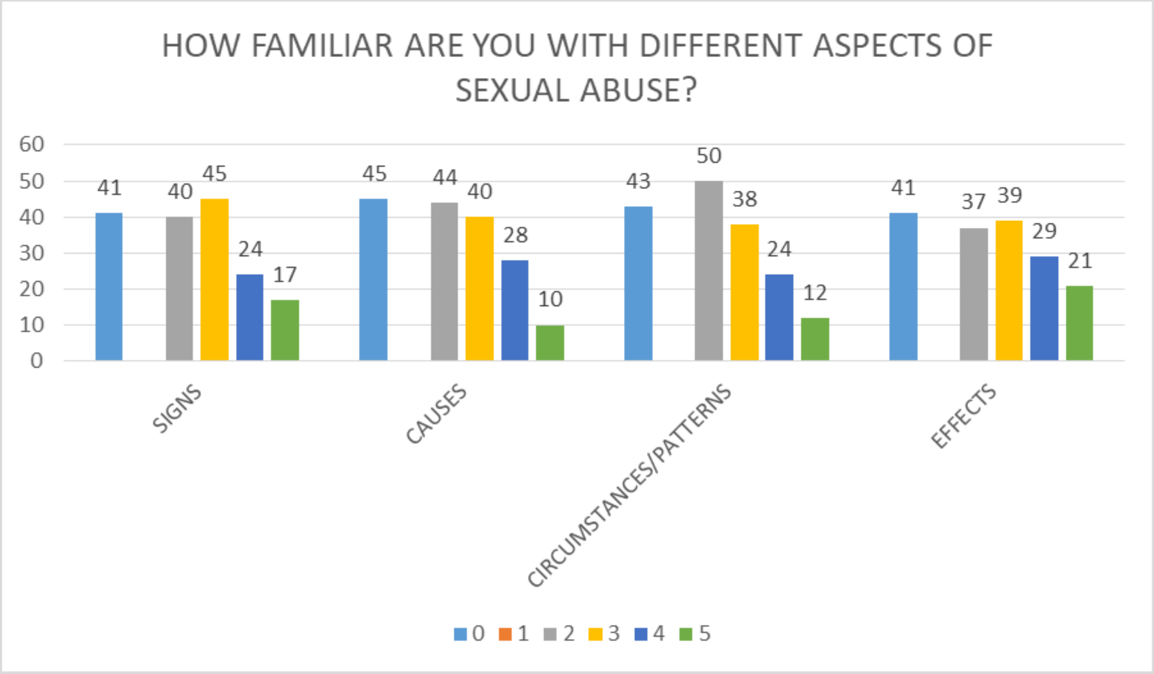


CHART 6: FAMILIARITY WITH SEXUAL ABUSE

AGEING

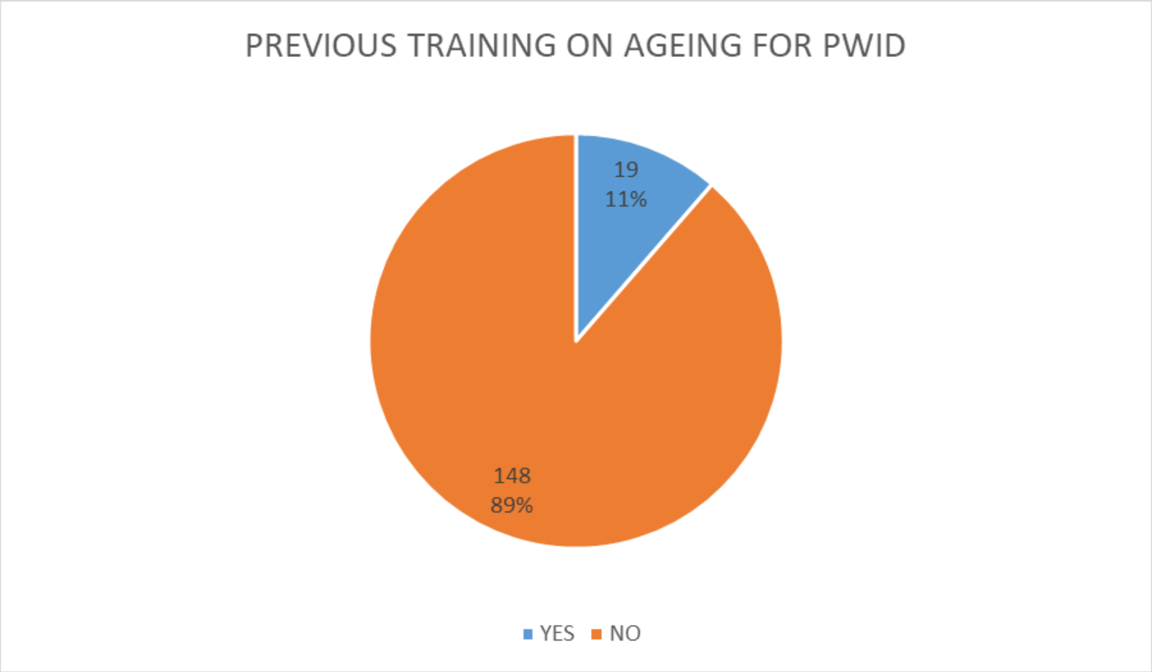


CHART 1: PREVIOUS TRAINING ON AGEING

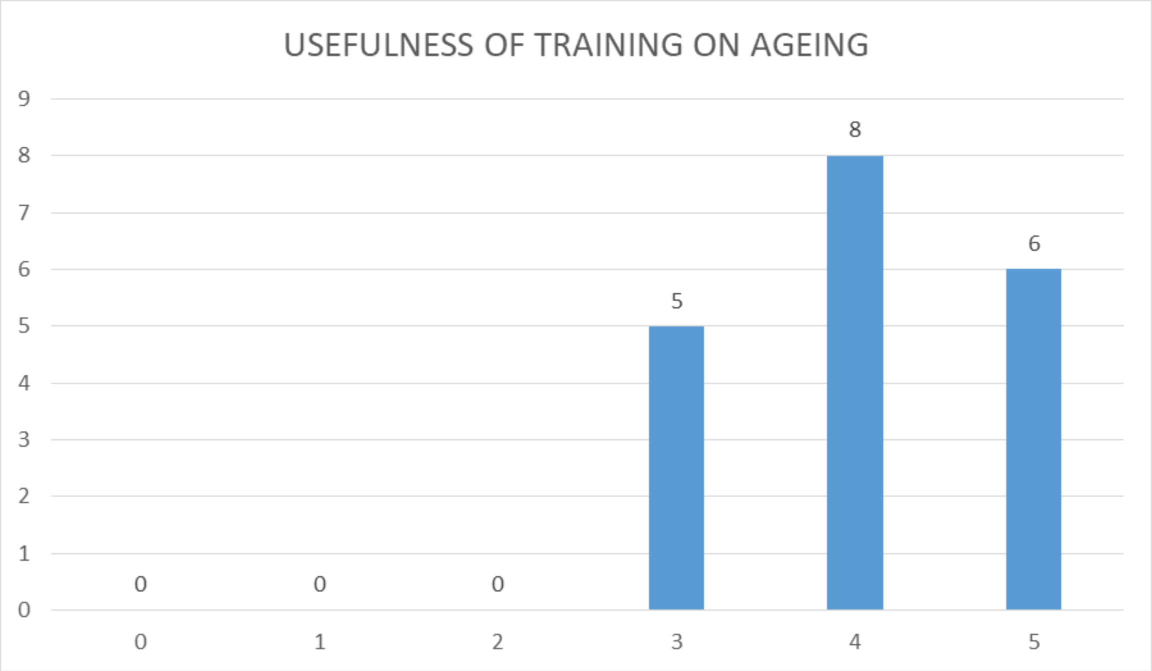


CHART 2: USEFULNESS OF TRAINING ON AGEING

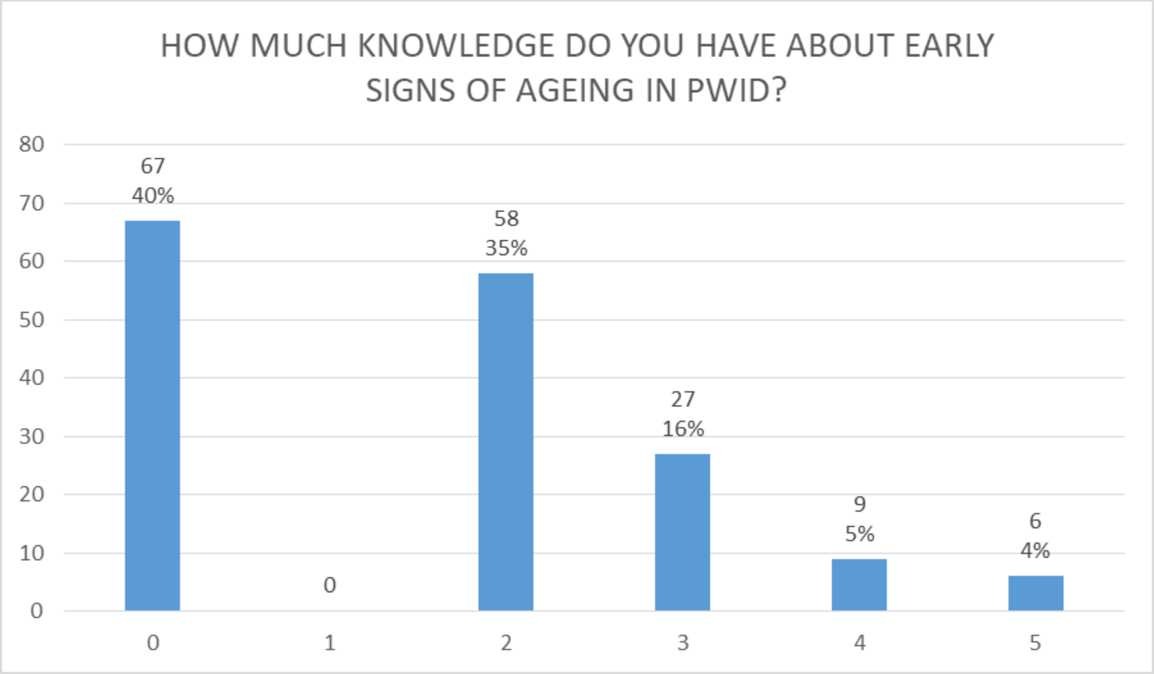


CHART 3: KNOWLEDGE ON EARLY SIGNS OF AGEING

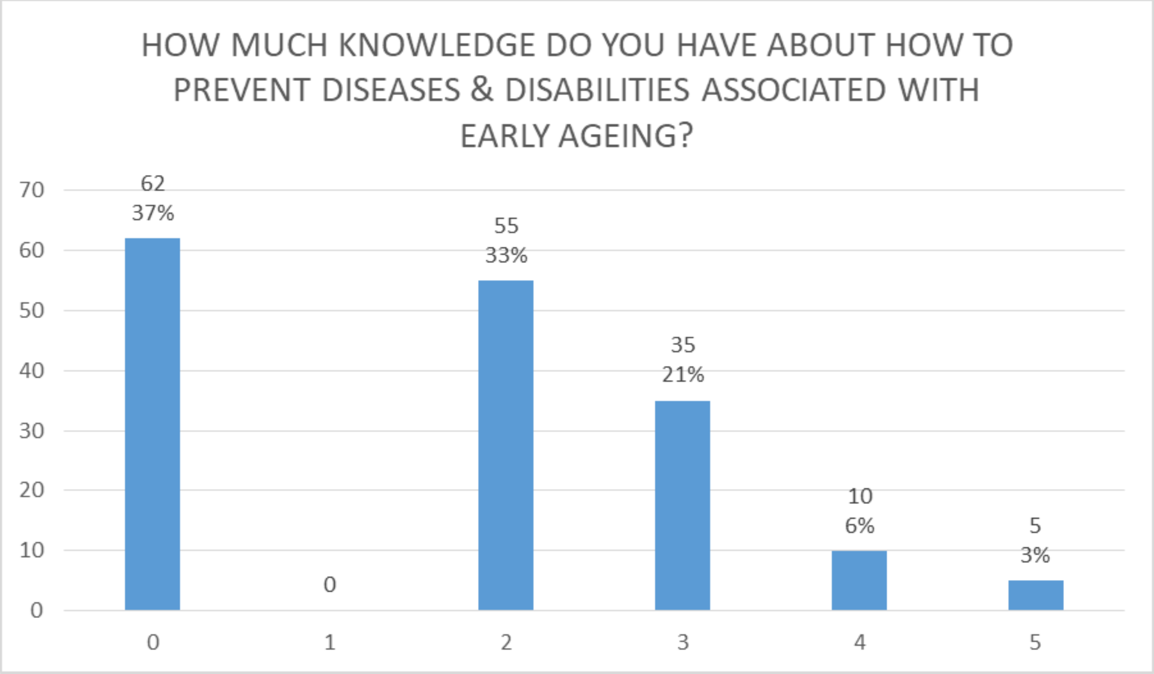


CHART 4: KNOWLEDGE ON PREVENTING DISEASES AND DISABILITIES ASSOCIATED WITH EARLY AGEING

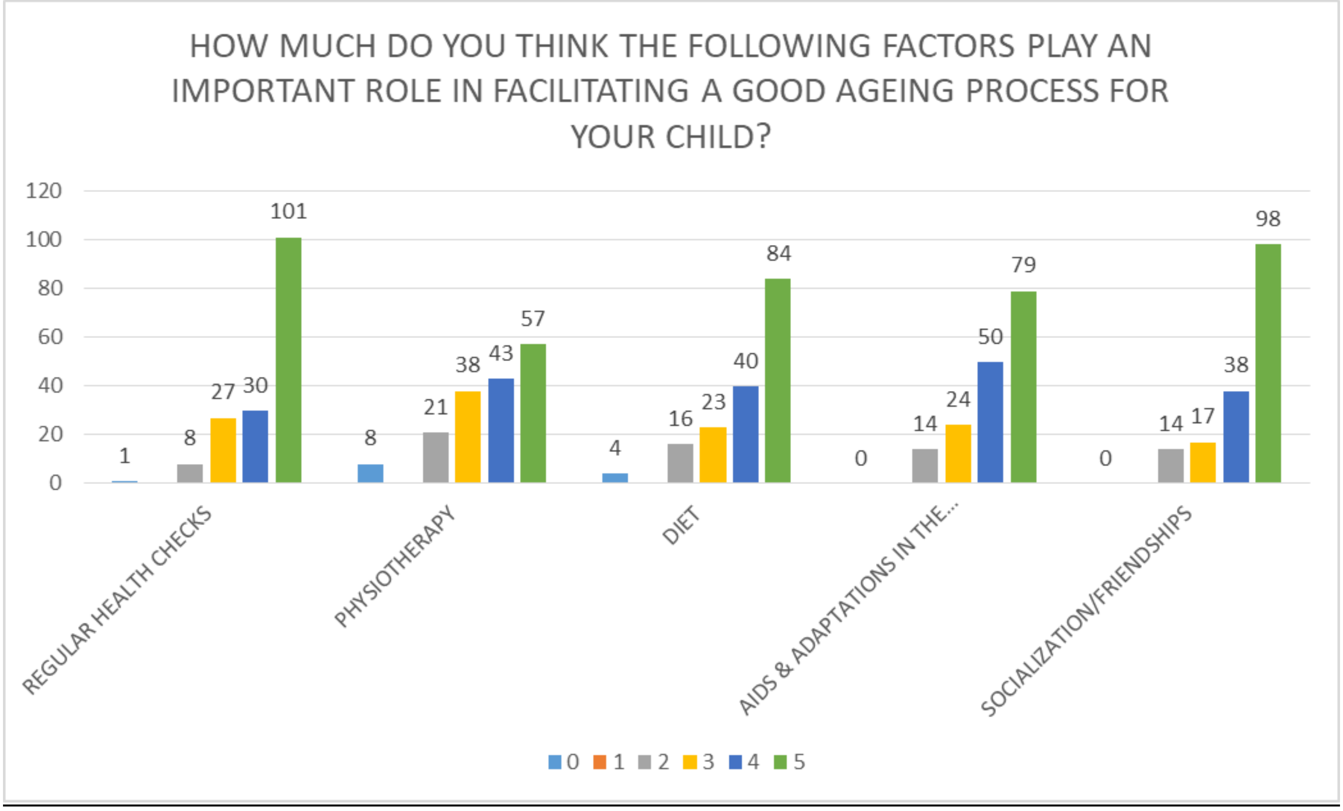


CHART 5: IMPORTANCE OF DIFFERENT FACTORS IN FACILITATING GOOD AGEING PROCESS

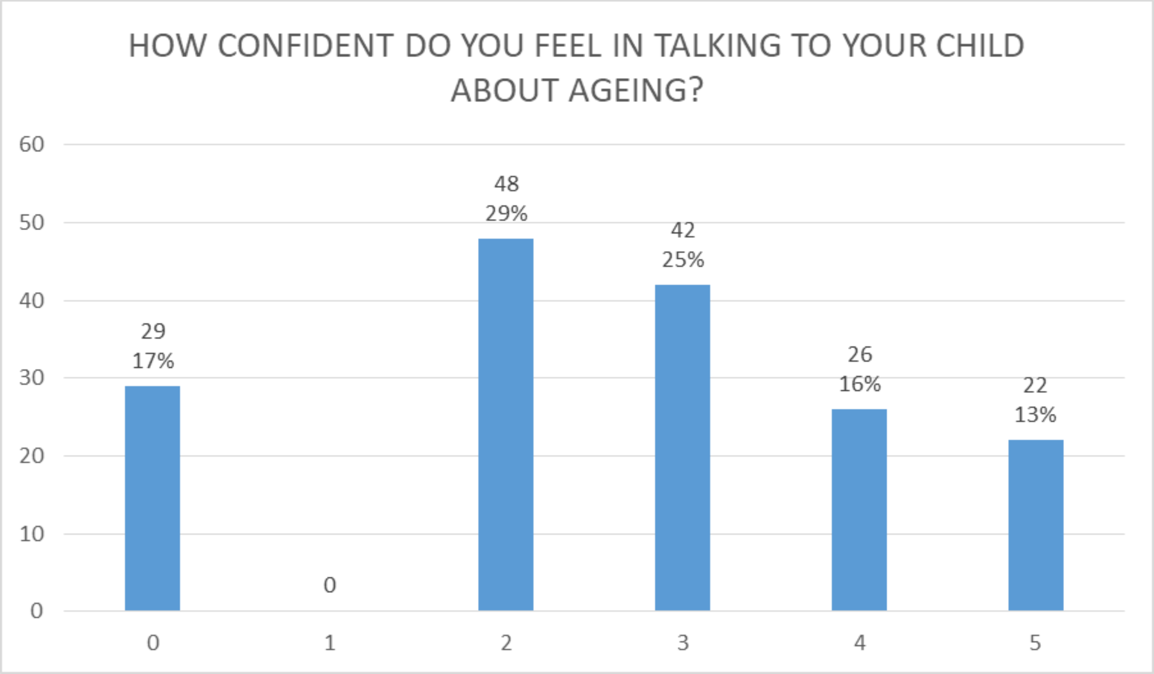


CHART 6: CONFIDENCE IN TALKING ABOUT AGEING

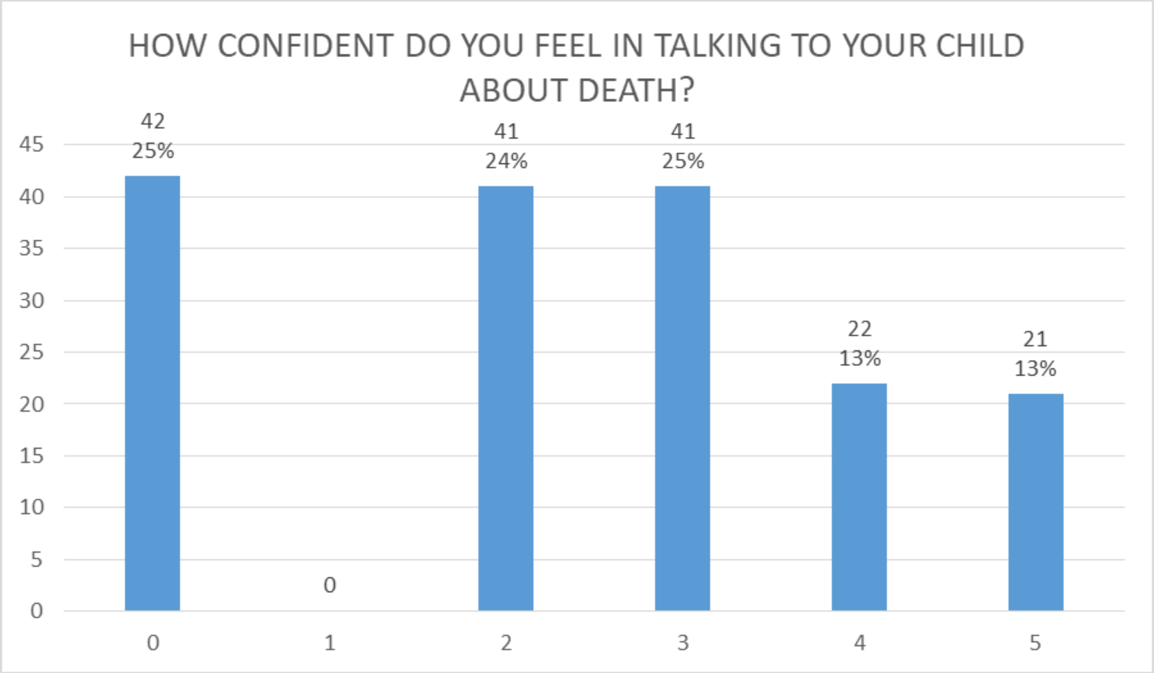


CHART 7: CONFIDENCE IN TALKING ABOUT DEATH

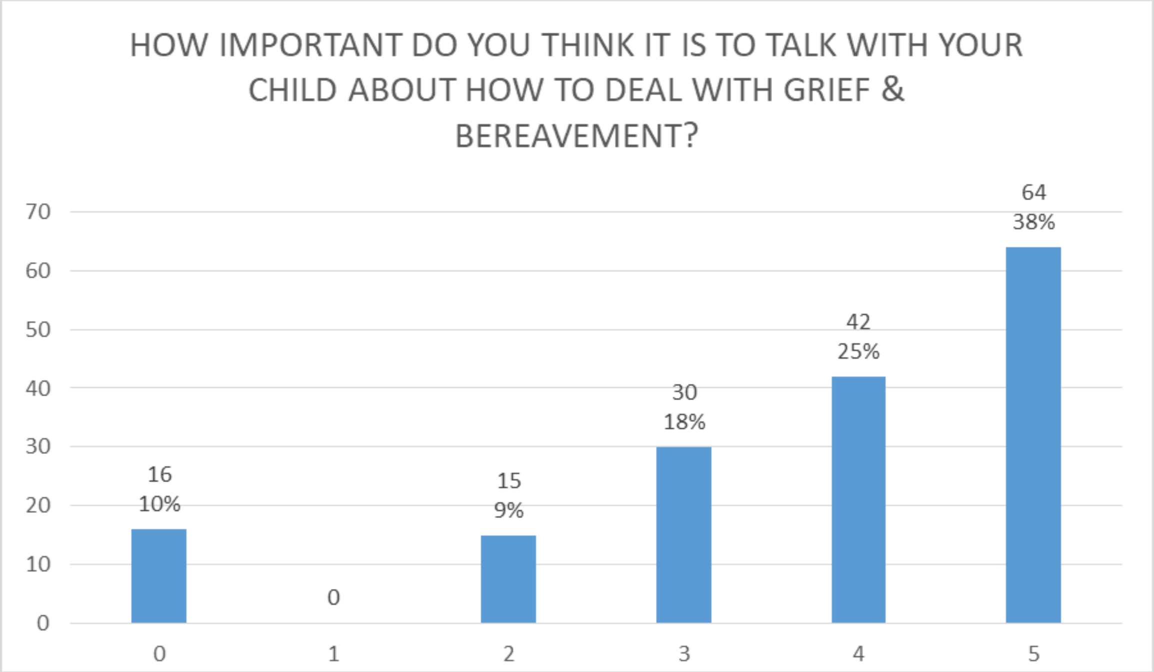


CHART 8: IMPORTANCE IN TALKING TO CHILD HOW TO DEAL WITH GRIEF AND BEREAVEMENT

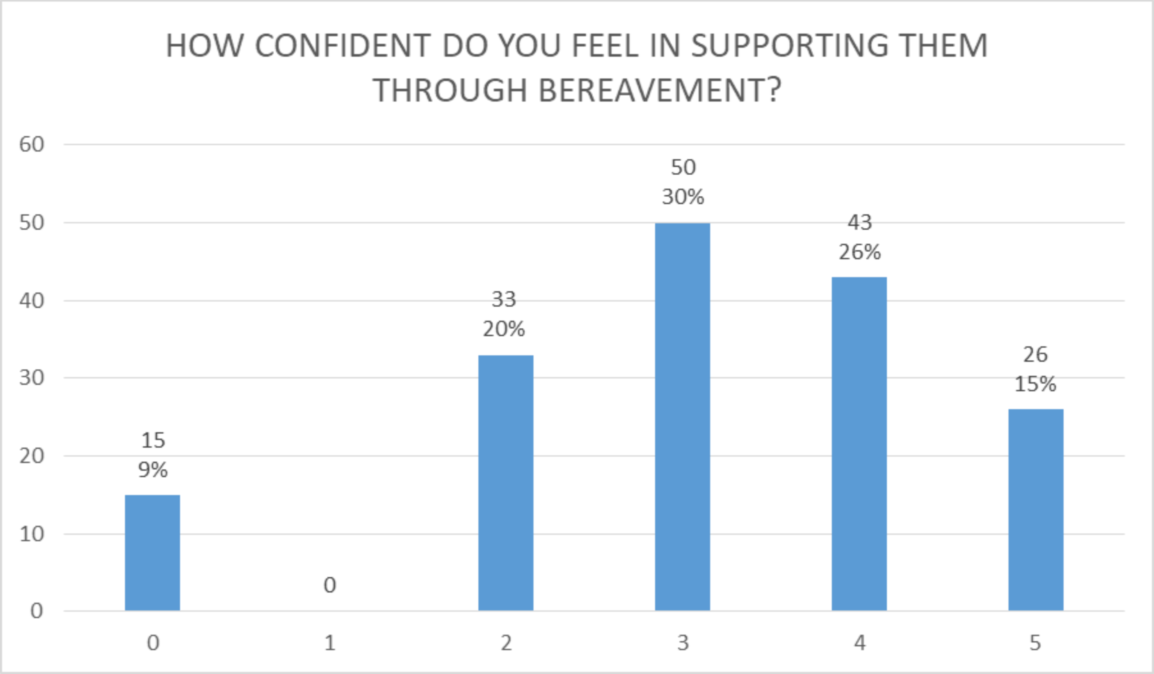


CHART 9: CONFIDENCE IN SUPPORTING CHILD THROUGH BEREAVEMENT

OTHER TOPICS PARENTS WOULD LIKE MORE INFORMATION/TRAINING ON:
Socialisation, supported living / housing opportunities, legal protection and representation, accepting child's disability, good family relationships, education/training people with intellectual disability, managing conflict, collaboration between family and professionals/service providers, puberty, dementia, ways to maintain good physical and mental health, how to talk to them about their diagnosis

Table 1: Comparison on previous training/support between the four main participating countries

Participation in:	**NORWAY**		**DENMARK**		**GERMANY**		**GREECE**	
	Yes	*No*	*Yes*	*No*	*Yes*	*No*	*Yes*	*No*
Parent Group	52,9% (N=27)	47,1% (N=24)	28,6% (N=10)	71,4% (N=25)	53,8% (N=14)	46,2% (N=12)	51,3% (N=20)	48,7% (N=19)
Parent Training	51% (N=26)	49% (N=25)	71,4% (N=25)	28,6% (N=10)	15,4% (N=4)	84,6% (N=22)	56,4% (N=22)	43,6% (N=17)
E-Learning	23,5% (N=12)	76,5% (N=39)	8,6% (N=3)	91,4% (N=32)	15,4% (N=4)	84,6% (N=22)	10,3% (N=4)	89,7% (N=35)
Stress Management	47% (N=24)	52,9% (N=27)	20% (N=7)	80% (N=28)	26,7% (N=7)	73,1% (N=19)	17,9% (N=7)	82,1% (N=32)
Communication	51% (N=26)	49% (N=25)	71,4% (N=25)	28,6% (N=10)	30,8% (N=8)	69,2% (N=18)	20,5% (N=8)	79,5% (N=31)
Transition to adulthood	19,6% (N=10)	80,4% (N=41)	20% (N=7)	80% (N=28)	7,7% (N=2)	92,3% (N=24)	28,2% (N=11)	71,8% (N=28)
Sex Education	33,3% (N=17)	66,7% (N=34)	34,3% (N=12)	65,7% (N=23)	57,7% (N=15)	42,3% (N=11)	28,2% (N=11)	71,8% (N=28)
Ageing	19,6% (N=10)	80,4% (N=41)	5,7% (N=2)	94,3% (N=33)	3,8% (N=1)	96,2% (N=25)	15,4% (N=6)	84,6% (N=33)

ANNEX 4: EXTERNAL EVALUATION ON THE NEEDS ASSESSMENT STUDY

After having reviewed the upgraded IO1 report, I am pleased to note that an additional section has been added to the report 'Other resources for Literature Review' where a number of experts who were consulted have been identified. These experts were consulted through exploratory interviews. This ensures that the main point identified in the evaluation report has been addressed.
I have no other remarks to make.

My original review Report of 30.06.2018 follows

J. Crowe

External Evaluator

19.09.18

Erasmus+
KA2 –Strategic Partnerships for adult education

ELPIDA: "E-learning platform for intellectual disability awareness"

External evaluation of *Part A* of Intellectual Output 1 Two Research Studies

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

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

Table of contents

1. Evaluation aims and evidence

The intention of evaluation activity for the ELPIDA project is to provide an external expert view to assess the extent to which the project meets its aims and objectives.

In this report, Part A of Intellectual Output 1 is assessed to determine whether it was completed in accordance with the plans detailed in the successful project application and expectations for IO1 were fulfilled. Feedback is provided on the activities that were undertaken and the coherence, effectiveness, quality and relevance of the output. Conclusions will be drawn about how the outputs will influence subsequent activities of the Project and conclusions are given.

This evaluation is based on the following activities:

- Analysis of the literature review that was conducted as a first stage in planning the Needs Assessment Study
- Analysis of the methodology of the NAS, the construction of the NAS questionnaire and the conclusions drawn by the project partners from the survey responses
- Review of the final IO1 Needs Assessment Report, the original application and other relevant materials

2. Project aim & details

This project is funded by the Erasmus + programme. It responds to the Erasmus+ objective of 'Development of Innovation.'

The project aim is to improve the quality of life of people with an intellectual disability, by providing parents with the necessary knowledge and skills to help them better support the needs of children and young adults with ID.

It will achieve its aim by developing an e-learning platform. This will contain 6 interactive educational modules on topics identified through consultation with families and parents.

This project wants to provide parents of children and adults with ID with the necessary skills and knowledge so they can be competent and confident to provide the right support and empowerment to their children.

The project seeks to have a direct, positive impact on people with ID and to result in a better transition to adulthood, social inclusion, and better quality of life in general.

The partners also hope the project will lead to the creation of an active community of practice that fosters the high-quality exchange of knowledge.

The e-platform will be freely available to all parents across Europe and beyond. It will be maintained for at least 5 years after the project finishes and it is anticipated that additional e-learning modules on key issues will be added over time.

3. Description of Part A, Intellectual Output 1

Part A is concerned with conducting an initial Needs Assessment Study. The responsibilities for designing and leading implementation of IO1 rested with Puzzle, one of the Greek partners. All partners contributed to disseminating the NAS survey, assisting parents in completing it where necessary and considering its results.

The work undertaken to create the NAS and the results gained were described in a 'Needs Assessment Report.'

This NAS section of IO1 is designed to:

- test and confirm the logic and usefulness to parents of relatives with ID of developing an e-learning platform.
- gain feedback from beneficiaries about what subjects the proposed e-learning modules should cover and therefore inform their content

The first element of the NAS is a literature review. Key reference works mainly concerned with theories of learning were reviewed and research papers were commissioned on the national context in each partner country and more broadly across Europe.

The second element was a survey of parents, using a specially designed questionnaire.

Literature Review

Through the literature review the project partners sought to check whether educational experts could confirm the validity of e-learning approaches in assisting adult learning and the extent and type of learning opportunities that had been developed for parents.

In the second element of the review the project sought to establish the existing situation regarding parent support and education in the participating countries –

Denmark, Germany, Greece and Norway, as well as an overview of Europe as a whole.

For this second element the project commissioned and reviewed short national and Europe wide reports prepared by project partners. These described what is available to parents in terms of training and support, how this is provided and by whom. These studies were included as an appendix to the Needs Assessment Report.

In addition to these papers, the project "used a range of other resources, including expert interviews, published literature, and information from international networks to get a better and fuller picture."

The conclusions drawn from the literature review by the partners were that:

- There is a lack of educational opportunities for parent of people with ID to help them support their relatives. In some respects, provision for parents had fallen behind, when compared to the development of training for professionals and people with ID themselves. Therefore, there is scope to provide appropriate educational programmes for parents.
- There is a particular absence of e-learning materials to assist parents. This confirmed the need to implement the ELPIDA project.
- Organisations providing parent training, do not take a holistic approach, and fragmented courses/seminars are offered. They do not cover the whole range of training needs of parents, where the demands that their relatives will place on them change as the person grows to adulthood. This suggested that modules should be developed by the project that can be tailored to the needs and interests of the individual participant.
- There is a difference in the availability of parent education and support between the Scandinavian countries and the countries in South Europe. In developing the content and delivery plans for the ELPIDA modules the project should consider these contextual differences.

NAS survey

The projects intention in undertaking the NAS survey was to 'confirm our research assumption that there is need for training parent of people with ID and to investigate parents' interests and needs regarding the content of six topics/modules.'

Partners agreed which organization would lead on the development of each module. All project partners then provided an overview of the content of their chosen topic/module. The topics that were agreed to be consulted upon and developed into e-learning modules were:

- stress management
- communication
- transition to adulthood

- human rights
- sex education
- ageing

To prepare the consultation with parents, Puzzle developed a draft questionnaire, focusing on various aspects of each of the topics. The working language for this development activity was English, to encourage a collaborative and interactive process so all project partners were able to contribute to an almost final version.

The survey questionnaire was designed to gain insights and advice to improve the usefulness of each module. For each module questions were asked of respondents about their previous knowledge on the topic, their exposure to training, how the module could be made as useful as possible and what was needed in content.

The questionnaire was then tested with a small group of experts and parents to validate it. The finalized questionnaire was translated into Danish, German, Greek and Norwegian.

Partners invited beneficiaries in their own countries and elsewhere to complete the questionnaire using an on line or paper version. 167 beneficiaries completed the survey, drawn in descending order from the following countries:

Norway: 51
Greece: 40
Denmark: 35
Germany:22
Hungary:8
Austria:5
Other countries:6

The data gathered from the survey was analyzed by Puzzle.

52% of the respondents were parents to relatives with ID who were under 16 years of age, a group who are most likely to be seeking practical advice and assistance.

The conclusions made by the project, drawn from analyzing the NAS were that:

- at European and partner country level there is a lack of training and support for parents of relatives with ID, either training that requires physical presence, as well as distance learning programmes.

- most existing training programmes have been developed through parent initiatives and are run by non-governmental organisations and municipalities. In some cases, the private sector offers more specialised training programmes on specific methodologies but at high cost. They do not take a holistic approach, however, offering fragmented courses/seminars, which do not cover the whole range of training needs of parents

- a majority of parents would like to participate in personal learning opportunities. They are motivated, have needs and are interested to gain practical solutions and knowledge.

- the majority of parents had not received any kind of training on issues around the upbringing of their child. Even those who had received some relevant training, felt it was irregular, not systematic or holistic.

- Parents identified a number and variety of different topics that they would be interested in receiving more training on, demonstrating the need for training.

- Most of the parents surveyed would like to participate in training, have desire and motivation and are positive towards different education approaches and alternative educational tools (e.g. video). Parents would also appreciate more opportunities to communicate: with other parents, experts and provider organizations. They seek and value the opinion of specialists over and above that of other parents or people with ID.

- The problems and needs highlighted by parents in the survey were similar across all partner countries. They had a clear preference to learn more about issues regarding the safeguarding of human rights.

The survey also enabled the project to make several recommendations about the content of specific modules.

In their report on Part A, Intellectual Output 1, Puzzle conclude that:

"The findings show that parents of PWID are interested in participating in e-learning and that there is a clear need for this kind of opportunity. Moreover, parents would like to gain more information/training on these issues and receive more in-depth information and practical advice on these topics. The results of this study will be taken into consideration and will inform the content of the e-learning modules."

4. Key Achievements of Part A IO1

To evaluate Part A IO1, the first step is to consider it in the light of each of the criteria underpinning appropriate evaluation activity. These evaluation criteria have been identified by the OECD as representing best practice and were described in the ELPIDA Evaluation Plan.

So as to evaluate the success of the ELPIDA project against each of the evaluation criteria, main evaluation questions were identified for each criterion in the Evaluation Plan.

We now consider the success of Part A, measured against each criteria and the respective main evaluation questions:

Relevance

Did Part A do the right things as interventions?

The activities undertaken as part of Part A, Intellectual Output 1 were fully in line with the plans set out in the project application. Undertaking the literature review and the survey of parents and analysing the results from both have given the project partners:

- Confirmation that there was strong support from the sample of parents for the topics that the project partners had identified that the e- learning modules should focus on
- Confirmation that delivering learning by the projects favoured tool of developing e-learning modules is seen as useful and user friendly
- Useful advice on what the sample of parents want to see covered in the e -learning modules.

It is noted that the sample size for the survey was quite small, so care needs to be exercised with extrapolating the results. The survey did nonetheless prove very useful in checking that the findings from the literature review and the assumptions of the project partners about parent concerns and interests were correct.

Effectiveness

Were the aims and objectives for this part of the project achieved? To what extent?

The evidence gathered by the Literature Review and the NAS supports a conclusion that the project aims, and objectives related to Part A of Intellectual Output 1 were achieved.

Through Part A the partners wished to establish:

- What learning topics should be developed for project partners
- Whether e-learning was viewed positively by parents as a way that they could use to develop their skills.

The findings from the Literature Review and the NAS are sufficiently robust to confirm the appropriateness of the project proceeding with its plans as they will benefit parents.

Were activities adjusted or amended in the light of feedback? To what extent?

No adjustment or amendments proved necessary during the development of IO1. The original application suggested that findings to inform the e-learning module approach would be secured through either conducting a questionnaire- based survey with parents and/or holding meetings with them. The project opted to concentrate on the survey, probably recognising that meetings would not have yielded any information that differed from the findings of the survey.

Did the transnational aspect of the project contribute to its effectiveness?

The transnational aspect of the project did contribute to its effectiveness.

The Literature Review and the NAS each served a complementary function in helping the project benefit at this early stage from its transnational nature.
The Literature Review provided a snapshot of the assistance available to parents in each partner country and across Europe and identified the gaps and variations that exist in currently available training opportunities.

The NAS enabled the project to check on whether there were any transnational variations in the concerns of parents, whether there was transnational support for the proposed modules and whether the final products of the project would be of interest to parents living in countries beyond the catchment of the project partners.

The results from Part A confirmed the partners view that the e-learning modules will be relevant to parents across the partner countries.

The two activities, taken together, would indicate, given the diversity and geographical spread of the partner countries, that the project outputs will be of benefit to and assist parents in many other countries.

Is e-learning an effective intervention for stakeholders?

The two activities carried out in Part A do provide strong evidence that e-learning will be a popular and accessible medium for parents to gain more information and guidance in supporting their relative.

Efficiency

Were the aims and objectives of the project achieved economically? Did the interventions represent value for money?

The NAS was completed, using the survey only. Since it is unlikely that holding meetings with parents would have yielded any differing findings, this was a sensible decision, to secure value for money.

There was some slippage in the deadline for the completion of Part A. However, the partners do not anticipate that this will have an adverse impact on the development of subsequent project products or endanger completing the project within its agreed duration.

Were intellectual outputs, training and dissemination activities efficiently conducted? Were they adjusted or amended to improve efficiency? Did they do so?

Part A of IO1, in its planning and implementation, was efficiently conducted, yielded the necessary data to inform the subsequent activities of the project and was completed in a timely fashion, adhering to the project timelines.

One sensible adjustment was made, described above, that contributed to the efficient implementation of Part A.

Impact

Have the aims & objectives of the project been met?

The project is at a very early stage, but Part A of IO1 was designed and implemented in such a way that a key milestone has been met to ensure that the ELPIDA project meets its aims and objectives. A very good foundation has been laid in providing the necessary data to inform future planned activities.

Did the project interventions help the stakeholders to better help their relatives?
Have professionals benefited from the project, and if so, to what extent?

These questions can only be examined and assessed when subsequent IO's and actions planned by the project are undertaken and completed.

Has the transnational aspect of the project contributed to its impact?

This question can only be examined and assessed when subsequent IO's and actions planned by the project are undertaken and completed.

Sustainability

Are the positive impacts of the project sustainable?

This question can only be examined and assessed when subsequent IO's and actions planned by the project are undertaken and completed.

It is, however, evident that even at this early stage, the project partners are giving a priority to ensuring that the impacts of the project are very relevant to project beneficiaries and will therefore are more likely to be sustainable.

An example of this is the care that has been taken in Part A in ensuring that the e-learning modules that will be developed meet the priority needs of parents. The more relevant to parents needs that the modules are, the more likely they are to have an extended life and to continue to be utilised.

The Project partners continue to support the intention stated in the application to maintain the e-learning platform for at least 5 years after the ending of the project.

Will the transnational aspect of the project contribute to it being sustained?

This question can only be examined and assessed when subsequent IO's and actions planned by the project are undertaken and completed.

Logic does, however, suggest that the transnational nature of the project can only enhance its sustainability. This is to some extent supported by the findings of Part A.

There were some variations across national boundaries about the needs that parents expressed. Nonetheless, there was a very substantial correlation in both the literature review and in the NAS study about parental willingness to use e-learning and about the issues that parents in each country identified should be addressed by the e-learning modules.

5. Findings

Accessibility and design

The Report on Part A was clearly written, in a good standard of accessible English. It was logical in its description of the activities undertaken, findings and recommendations made. It was interesting and engaging to read. The layout of the report was attractive. To analyse the data from the NAS study, very good use was made of well-designed and clear tables.

To further enhance clarity, it might be sensible to move some of the comments about the findings from the literature review that currently appear in the Introduction, to the Literature Review section

Content

Part A of IO1 was an essential activity that needed to be undertaken to test out the judgement of the project partners about the applicability and usefulness to parents of the

Despite some differences between countries in Northern and Southern Europe, the Literature Review and the NAS survey both served to confirm the loneliness of parents, the limits to the practical support that they receive and the stigma that having a relative with a disability can bring.

Regarding the Literature Review, the country reviews that are contained in the Appendix formed a substantial element of this are generally of a good, analytical standard. Relevant Literature Review findings are usefully identified against the Report conclusions.

The Report notes that the Literature Review was supplemented by a range of other resources such as expert interviews, literature reviews, and information from international networks. It would be useful to list the most significant of these resources in the Appendix alongside the publications that are cited.

The sample of 167 beneficiaries who completed the NAS survey, spread across more than 6 countries, was somewhat greater than the figure proposed in the application of 150, but there had been an intention to secure responses from 30 respondents from countries outside the partnership.

Whilst the project engaged with a relatively small sample of parents, this was broadly in line with the application. Taken together with the findings from the Literature Review, it provided enough evidence to successfully allow the project partners to confirm “our research assumption that there is need for training parent of people with ID and to investigate parents’ interests and needs regarding the content of six topics/modules.”

6. Conclusions

Part A of IO1 was an essential activity that needed to be undertaken. It was designed to test the judgement of the project partners about the applicability and usefulness to parents of e-learning tools, whether the topics identified were appropriate and to seek advice on their content.

Part A of IO1 fully met its design objectives.
The findings of the Literature Review and of the NAS study were meaningful, despite the relatively small sample of parents surveyed. They effectively:

- validated the experience of the project partners and the emphasis that they placed in the ELPIDA project application that parents can access little in the way of training to support their relatives
- validated the experience of the project partners and the emphasis that they placed in the ELPIDA project application and in the project design
  that using e-learning will be a popular way to give more advice and information to parents in how they can help their relatives.
- validated the subject topics that partners had identified for each of the planned e-learning modules
- provided very useful advice to the partners on the content of each pro- posed e-learning module.
- Identified some national variations in parental concerns that should be addressed as the modules are written.

Though caution would need to be exercised, it seems very likely that the findings from Part A provide an accurate reflection of parental attitudes to e-learning across national boundaries and that the ELPIDA project has identified module themes that will have a transnational appeal, beyond the countries represented by partners.

It would therefore be appropriate that the findings from Part A are more widely disseminated by the project and could usefully inform other initiatives and pro- jects to support parents.

J. Crowe
External Evaluator
30.06.18

External Evaluator's CV

James Crowe has a B.A. and M.A. from University College of Wales, Aberystwyth. For 30 years, he was Director of Learning Disability Wales, an umbrella body for organisations working with children, young people and adults with an intellectual disability. He led several national and European transnational pro- jects to improve the quality of support to people with I.D. He has acted as an adviser to the Welsh Government on many advisory bodies and expert groups. Since 2016 he has been President of EASPD, the European Association of Service Providers for Persons with Disabilities.

Concise linguistic versions of Intellectual Output 1 (PART A) are provided under separate cover in the following languages: Greek (EL), Danish (DA), German (DE), French (FR), Norwegian (NO), and Portuguese (PT).