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Diagnosis of comprehension difficulties of informative texts and texts related to human rights by people with intellectual disabilities in Greece, Poland and Lithuania

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INTRODUCTION

Diagnosis of comprehension difficulties of informative texts and texts related to human rights by people with intellectual disabilities in Greece, Poland and Lithuania was carried out as part of the European Erasmus+ project: “*Puzzle. Developing easy to read formats for people with intellectual disabilities*”. Puzzle’s overall aim is to facilitate the access to information, education and training of people with Intellectual Disabilities (ID) in following European countries: Poland, Greece and Lithuania. The project takes actions to improve the quality and accessibility of information provided for people with ID, and to raise their knowledge and understanding about their basic human rights. The first aim was to review the availability of materials in Europe concerning basic human rights that are ‘easy-to-read’. Secondly, we aimed to provide evidence of what people with ID already know about their human rights, and how they find this information. This document has been divided into two parts; part one presents the Literature Review of easy-to-read materials, and part two outlines an Empirical Study investigating the awareness of the human rights within the communities of people with ID in Poland, Lithuania and Greece.

The literature review gives an overview of what information about the human rights for people with ID exists, what format it is in, how easy it is to access and are people with ID aware it exists. Furthermore, it suggests what can be done to improve the availability and accessibility of this information for people with ID, to ensure they not only have the awareness of their human rights but also more importantly, have the necessary skills and knowledge to exercise these rights.

The study was conducted with communities of people with ID in Poland (100 participants), Greece (80 participants), and Lithuania (40 participants). At the beginning of the study, surveys were used to assess participants’ prior awareness of their human rights, how they learned about their human rights and, how useful is the information they have accessed. We then held training sessions using multimedia such as pictures, videos, sound and a RIX Wikis, an easy to use website designed for people with ID, whereby participants were supported to create their own website about their human rights. At the end of the study, post-study surveys were applied to evaluate the impact of the intervention.



ABBREVIATIONS AND DESCRIPTION

Abbreviation/Acronym	Description
Advocacy	Speaking up
CRPD	Convention on the Rights of Persons with Disabilities
Easy-to-read	Linguistic adaptation of the text that makes it both easier to read and comprehend
GR	Greece
HR	Human Rights
ID	Intellectual Disability
LT	Lithuania
PCP	Person-Centred Practice
PL	Poland
Self-advocacy	Speaking up for yourself
Supported advocacy	Speaking up for or on behalf of a person with ID
UK	United Kingdom
UN	United Nations
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities

PART 1. LITERATURE REVIEW

INTRODUCTION

The United Nation Convention on the Rights of Persons with Disabilities (UNCRPD) promotes the full and equal enjoyment of all human rights and freedoms by all persons with disabilities. However, access, skills, and knowledge of rights by people with intellectual disabilities (ID), is impaired by information that is not easily available, and often presented in a format that is difficult to understand (Northfield, 2009).

Although the rights of people with disabilities date back to early 1970, (Declaration on the Rights of Mentally Retarded Persons 1971; United Nations Declaration on the Rights of Disabled Persons 1975) providing easy-to-read information and exercising human rights for people with ID is relatively new (United Nations Convention on the Rights of Persons with Disabilities, 2006). In most countries, the provision of easy-to-read information for this is still in its infancy as the updated UN conventions are not legally binding. A person's knowledge of their human rights cannot be obtained if the person with ID does not know that they exist, cannot access the information, cannot comprehend the information or it is dependent on support of others (Fyson, Cromby 2013). Creating easy-to-read information is the first step that countries need to take in order to reach people with ID and inform them of their rights, but it is not enough. More needs to be done to ensure that people have opportunities to engage with their human rights and exercise them on a daily basis.

The aim of this literature review is to evaluate the availability and accessibility of existing easy-to-read information and materials about human rights, written from the perspective of a person with ID. We have highlighted some of the positive and negative aspects of information provided by three partner countries, Greece, Lithuania and Poland, in the hope of providing clearer guidance on creating easy-to-read information in the future.

EASY-TO-READ

There are two different definitions of the 'easy-to-read' term. The first definition refers to the linguistic adaptation of a text to make it easier to read but not necessarily easier to understand. (Nomura et al. 2010). The second definition states that information needs to be both easier to read and comprehend (ibid). For the purpose of this research we are looking for information that is both easy-to-read and understand.



EASY-TO-READ INFORMATION ABOUT BASIC HUMAN RIGHTS

Easy-to-read is a method of adapting text so it can be both easily read, and easily understood, by a person who has reading difficulties. For information to be easy-to-read, it needs to be clearly presented, the text needs to be easily understood by the target group and the content, language, illustrations, and graphical layout must all be considered (Nomura, Nielsen, Tronbacke, 2010). If the target group has severe difficulties with written information, the text must be supported by illustrations that are easy for the reader to correctly interpret. The combination of short, easy-to-read texts and illustrations that the reader finds familiar, is important when producing information for people with ID. For easy-to-read information, it is crucial to take into consideration the background knowledge, the frames of reference, and the interest the reader has in the topic.

Easy-to-read information is not new; in England, in 1993 the Government's Central Office for Information (COI) established an Informability Unit which published an 'Informability Guide' to improve information provision for people with 'literacy problems' and disabilities (Inclecomms, 2014). Hasler (1993) conducted research on what makes information easy-to-read and what principles could be applied when providing information for different age groups. His guidelines include information on types of paper, typeface, font size, spacing, colour, grammar, symbols, images, terminology and many other aspects that should be taken into consideration when creating easy-to-read (Barrow, 2011). Despite the fact that guidelines for preparing easy-to-read information exist, however, there are no set rules that must be followed. It is very hard, if not impossible, to design easy-to-read materials that would meet the needs of all people with various disabilities.

With the introduction of the Disability Discrimination Act (1995), Human Rights Act (1998), Equality Act (2010), the Personalisation Agenda (2010), the European Convention of Human Rights in England, and, similar legislations in partner countries, the need for easy-to-read information became law. Organisations are now required to provide information in formats that are appropriate for all individuals, including those with ID. Article 9 of the UN Convention on the Rights of Persons with Disabilities (2009) states that, "State Parties shall take appropriate measures to ensure persons with disabilities have access, on an equal basis with others to the physical environment, transportation and, information and communications (including technologies and systems associated with these)". Accessibility should, therefore, be seen as a fundamental right of all persons.

The United Nations Convention on the Rights of Persons with Disabilities exists in all partner countries. A short literature review by our partners from Poland, Lithuania and Greece suggests that the simplest



definition of easy-to-read is generally applied where easy-to-read information is made available, but it is often not easy to understand by the ID community. It appears that the easy-to-read text is often too complex and the accompanying images do not always help to support the understanding of the people with ID. The following examples show where some improvements could be made.

Figure 1 below shows the existing information of the UNCRPD in Greek in easy-to-read which is generally of high quality, however, the pictures and text are not clearly connected to each other and therefore difficult to understand.

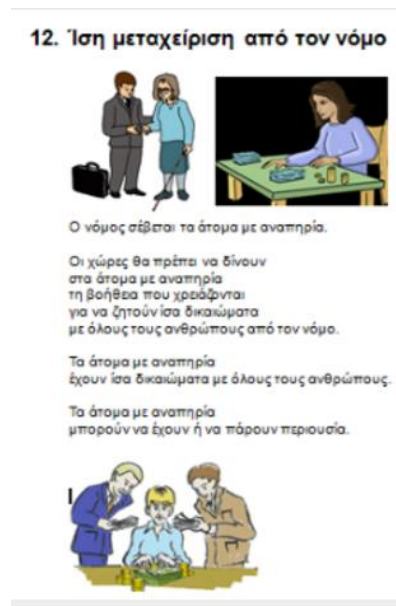


FIGURE 1- GREEK EXAMPLE FROM THE EASY-TO-READ VERSION OF THE CONVENTION, (ARTICLE 12)

Another example from Greece is article 16 (Figure 2), which discusses freedom from exploitation, violence and abuse (page 27 in the Greek version). Here again, there is too much text on one page and the use of abstract pictures does not aid the reader's understanding.

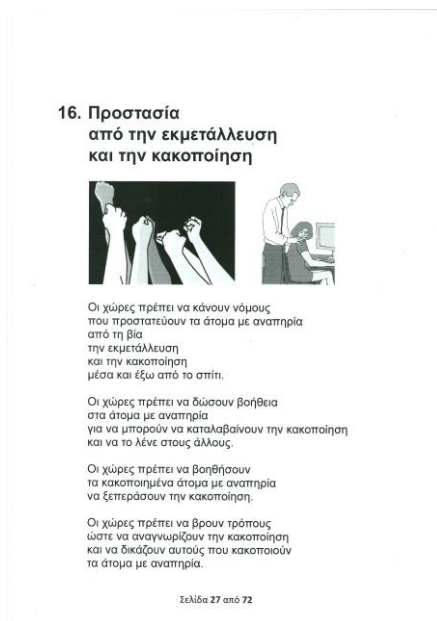


FIGURE 2- GREEK EXAMPLE FROM THE EASY-TO-READ VERSION OF THE CONVENTION - ARTICLE 16

In Poland, we found that the easy-to-read information is not always, easy to comprehend for people with complex needs. For example, a point made in an easy-to-read version of the United Nations Convention on the Rights of Persons with Disabilities (Figure 3), cannot be easily understood by a person with ID. The picture says, ‘Rules’, and the text reads: “If a person needs someone, who will be speaking on their behalf, the rules of support should be clearly identified. It needs to be done so that you can be sure that everything will follow correctly.” Clearly, this is not appropriate for someone with ID as the text is still very complex and the individual is required to have a high level of literacy and comprehension skills in order to understand it.



Jeżeli osoba potrzebuje kogoś, kto będzie mówił w jej imieniu, należy jasno określić zasady wspierania. Trzeba to zrobić, żeby mieć pewność, że wszystko będzie przebiegało prawidłowo.

FIGURE 3- POLISH EXAMPLE FROM THE EASY-TO-READ VERSION OF THE CONVENTION

Another example from Poland demonstrates some effort of local governments to provide easy-to-read information where the text is simplified but still not easy-to-read and understand (Figure4). Figure 4 below shows an easy-to-read document outlining how a person can vote in their local elections. It is clear that the information is difficult for the reader to comprehend due to lack of images and the text being much too long and complex. The use of images would improve this information greatly and would help to break down to text into smaller meaningful chunks of useful information.



Zasady:

Jeśli chcesz głosować zgłoś to wcześniej – 21 dni przed wyborami

zgłoś to do urzędu miasta lub gminy.

Możesz tam napisać list, wysłać e-mail lub zadzwonić telefonicznie

przed wyborami – 7 dni – dostaniesz z urzędu dokumenty.

Nikt poza tobą nie może ich odebrać.

Żeby je odebrać musisz pokazać dowód osobisty.

Przy odbieraniu przesyłki musisz:

- pokazać dowód osobisty

- musisz się podpisać

Jeśli masz problem z podpisaniem odbioru przesyłki poinformuj o tym osobę

dostarczającą przesyłkę.

Listonosz zapisze że nie możesz się podpisać.

Jeśli nie będzie cię w domu otrzymasz dokument z informacją kiedy

ponownie listonosz ją przyniesie.

Będziesz czekać najdłużej trzy dni.

Jeśli dodatkowo nie widzisz możesz poprosić o nakładkę z alfabetem

Braille'a

UWAGA! Nie możesz głosować korespondencyjnie jeśli masz osobę, która cię reprezentuje

FIGURE 4 - 'HOW TO VOTE' EXAMPLE FROM POLAND

In Lithuania easy to read information is also available; however, the documents use a lot of difficult words and expressions which can impede the understanding by people with ID. For example, in Article 8 (Figure 5), even the title is complicated as, 'visuomenė', is a difficult word and, 'švietimas', has a double meaning. This particular problem is consistent across other many articles of UNCRPD.

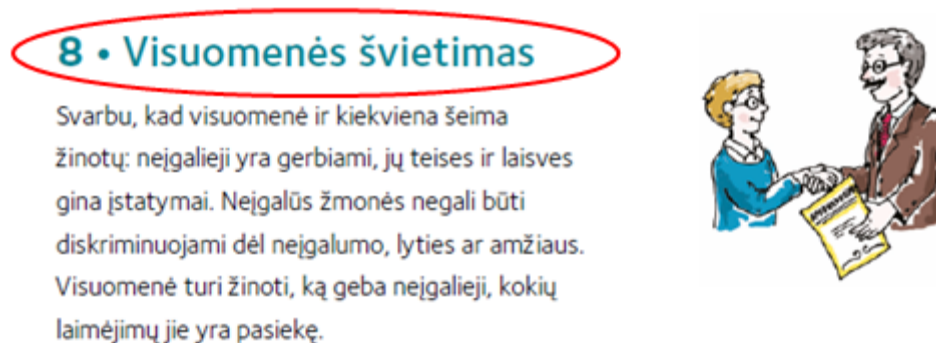


FIGURE 5 - LITHUANIAN EXAMPLE FROM THE EASY-TO-READ VERSION OF THE CONVENTION

The use of images in easy-to-read versions of the UNCRPD in Greek, Polish and Lithuanian has been applied and it makes the information clearer and easier to read, but not necessarily easier to understand. It is important that the text and the pictures used are connected to each other and the message is very clear. Breaking down complex information into easy-to-read chunks supported by meaningful illustrations would make the information much more useful for our target audience.

During our research, we also found that access to information on basic human rights is not easy. People with ID do not have the sufficient literacy skills that would enable them to actively search and find relevant information online, or in their local libraries. It is therefore, required that educators, parents and carers supporting people with intellectual disabilities, engage and support individuals, not only to have awareness of their rights but also to have opportunities to apply them in their daily lives.

Research carried out in the United Kingdom that included people with ID, also suggested that easy-to-read information provision needs further consideration. Despite the existence of relatively clear guidelines, easy-to-read information on the rights of people with disabilities are not always easy to understand (Norfield 2009; Nomura, Nielsen, Tronbacke 2010) or to exercise (Verdugo, Navas, Gomez & Schalock 2012). Information about human rights for people with ID could be presented in other formats, as text no matter how simple is often too difficult to understand for those with most complex communication needs.

ADVOCACY

Although the United Nations Convention states the conditions for achieving equality, autonomy, non-discrimination, participation and inclusion in society, it does not specify how to use the information to enhance a person's human rights (Verdugo et al 2012). Many academics argue that rights can be brought to life through advocacy efforts (Brolan et al 2012; Cocks & Duffy 1993; Rapaport et al 2006; Chambers 2007).

Brolan et al (2012) argue that there are many dimensions of advocacy, as different adults supporting an individual will come from different standing points. For example, parents might express the needs of caring for their child, while support workers might be motivated by their duty of care to protect the individual's rights. It could be argued that the best form of advocacy is self-advocacy (Miller & Keys 1996; Goodley et al 2003). Test et al (2006) argues that advocacy skills do not come naturally, and persons with ID have to acquire them first. According to Test and his colleagues, there are four stages to self-advocacy: developing knowledge of self, knowledge of rights, communication and leadership. Multimedia Advocacy, a co-production approach that uses multimedia tools and guiding principles, can be used to enhance this process.



Multimedia Advocacy is an inclusive approach that uses pictures, text, sound, video, art and play to help people with intellectual disabilities to communicate effectively their wishes, wants, ideas and preferences (RIX Research and Media 2016). It has been developed by the RIX Research and Media organisation and is successfully used by the ID community both nationally, and internationally. The approach is guided by the person-centred principles that ensure that the person with ID is in control of the process and understands the media being used. This approach is used for person-centred planning as well as for creating clear, easy-to-read information.

The Multimedia Advocacy approach is not a panacea for persons with ID to be able to access, understand and exercise their human rights, but it can certainly help in meaningfully engaging this user group and could be a starting point for individuals' self-advocacy. However, where communication is a challenge, Multimedia Advocacy might work best in conjunction with supported advocacy (Reinders 2002; Ziviani et al 2004; McConkey & Alant 2005).

CONCLUSION

Despite the existence of guidance and supporting legislation, easy-to-read information about the UNCRPD is not easily achievable. The main reason for this is that UNCRPD conventions are created as a legal text. In some countries when a convention is ratified, it means it is the law. Therefore, the text cannot be too simplistic since it might exclude something. It is also important to remember that the official easy-to-read versions of the Convention are more of a technical translation into easier language for the general public than an easy-to-read text accessible for people with ID. For people with ID, the easy-to-read version of the UNCRPD must take into consideration the group's prior knowledge and frames of references. The text should be clear, provide examples that are familiar to the reader and at the end, the reader should not have to interpret "what does this mean for me".

The review of the existing literature suggest that creating accessible, easy-to-read information about the human rights, for individuals with ID may not be possible without additional engagement of those who support them. Multimedia Advocacy approach could be used to directly engage the individuals and simplify the information about human rights without losing or changing the meaning. However, there is still a significant gap in the opportunities that young adults and adults with intellectual disabilities have access to. In European countries such as Greece, Poland and Lithuania, this gap lies in the participation of, education and training, and, in the social and economic spheres of life. Among the contributing factors are: a) the lack of educators or other staff working with people with intellectual



disabilities, who are trained on text transformation processes in forms that are adapted to the needs and language skills of such persons, and b) the low utilization of ICT for learning purposes with the use of adapted materials, both because of lack of educators' awareness about suitable digital tools, and because they lack appropriate knowledge and skills.

A commended list of reviewed easy-to-read resources on human rights are included in the Appendix.



PART 2. EMPIRICAL STUDY

INTRODUCTION

Following the literature review, the project partners developed training for staff that covered the Multimedia Advocacy approach and how to create easy-to-read information for person with ID. The training covered the theory behind easy-to-read, advocacy and person-centred practice and the technical expertise of using multimedia and RIX Wiki software to create easy-to-read content for our individuals with ID. The trained staff was acting as facilitators in the empirical study.

The English, easy-to-read version of the UNCRPD Article 19 has been simplified and translated into different European languages with use of multimedia tools and the RIX Wiki software.

This information, alongside the Multimedia Advocacy tools, could help people with ID to engage not only in the creation of easy-to-read information but also give them the voice and the agency required to exercise their human rights.

The Puzzle project aims to investigate how people with ID engage with information, specifically on the topic of human rights. To do so, we undertook a study involving people with ID from Greece, Lithuania and Poland who attend schools, day or residential services (with the ability to understand simple text). The study was facilitated in each country by staff members of these schools and services who had participated in the Puzzle' training activities.

STUDY OBJECTIVES:

The main objectives of the study are:

- A. To gain insights on what people with ID already know about their basic human rights
- B. To explore where people with ID access information about their basic human rights and whether this information is easily accessible and understandable
- C. To identify possible changes in a person's knowledge and understanding of human rights, as a result of the project's intervention

METHODOLOGY

The study's preparation and implementation phases spanned from February to June in 2016.

The sample was made up of 220 persons with ID from Greece (N=80), Lithuania (N=40), and Poland (N=100), who attended schools, day or residential services. Their facilitators for the study were staff members of these services (N=18), who had already participated in Puzzle project activities and training Greece (N=8), Lithuania (N=4) and, Poland (N=6).



STEP 1. PREPARATION

Due to the nature of persons with ID to which the study pertains, we deemed it necessary to outline a set of actions to ensure that reliable and meaningful results.

From the start of the project we actioned:

- the undertaking of a training session for facilitators involved in the study, to support them to engage persons with ID in the research
- the construction of modular instrumentation in easy-to-read format to accommodate data collection
- the organisation of workshops and focus group discussions with persons with ID who participate in the empirical study.

The training session for facilitators aimed to acquaint the trainers with an awareness of methodological issues that could occur (for example, during focus group discussions), and equip them with knowledge that would facilitate the engagement of persons with ID in the study processes and activities.

The evaluation instruments were developed in English by the project partners following an iterative approach where feedback was provided by the facilitators. The set of instruments developed comprise of five questionnaires outlined below:

- *Demographic questionnaire*: to collect data of personal nature on the participants (Annex I)
- *Basic Human Rights Questionnaire (Survey 1)*: to address Objective A. A sixteen item, closed questionnaire referring to Articles 3 (General Principles), 5 (Equality and non-discrimination), 9 (Accessibility), 19 (Independent living and inclusion / participation in community), 21 (Freedom of expression), 23 (Respect for home and family) and 27 (Right to work equal with others) of UNCRPD (Annex II)
- *My Human Rights Questionnaire (Survey 2)*: to address Objective B. A six item, multiple choice questionnaire referring to sources of information, accessibility and appropriate presentation aspects (Annex III)
- *Basic Human Rights Questionnaire (Survey 3)*: to address Objective C. A twenty-one item, closed questionnaire aiming to capture a participant's understanding of human rights after the intervention, and the aspects of the intervention that are most helpful to them (Annex IV).
- *Staff Feedback (Survey 4)*: for staff, to capture trainers' perceptions, experiences and viewpoints on the intervention (Annex V)



The questionnaires were validated by the facilitators engaged in the study. Upon finalisation, these underwent translation and localisation into Greek, Lithuanian and Polish. Partners had the option to administer the questionnaires using an electronic survey tool, or use paper versions. For the latter case, Excel templates were provided to collate the collected data.

STEP 2. STUDY DESIGN AND IMPLEMENTATION

To facilitate the study, the 'Puzzle Evaluation Protocol', was drafted (see Annex VI). Provided in this document are: a) the empirical study design for data collection, to guide partners through the study activities, and b) guidelines for the trainers of the target population.

In short, the empirical study design followed a two-phase approach:

PHASE 1

- 1) **Demographic Questionnaire** was distributed at this phase to gather the basic demographic data from the project participants. We collected the following: age, gender, country, declared disability, living arrangement, relationship status, working status and, frequency of attendance at day services.
- 2) **Survey 1** was administered at the beginning of the study. It served as a baseline assessment instrument to measure the participants' existing awareness and understanding of basic human rights before the project's intervention.
- 3) **Human Rights Workshop** aimed to introduce participants to the project followed by the baseline assessment **Survey 2**. This survey aimed to measure the participants' access to the existing information about basic human rights and to evaluate the accessibility of this existing information. We aimed to find out what formats help people with learning disabilities to understand information best, for example, leaflets, websites, or multimedia. We also wanted to explore how they go about finding information about human rights? Do they understand the existing information? Is the information helpful?

PHASE 2

- 1) **RIX Wiki Focus Group** was set-up in each Lithuania, Poland and Greece. RIX Wiki was being used during each focus group. The aim of the focus group was to inform learners of their basic human rights using multimedia and gauge their perceptions of what makes information accessible and their view of RIX Wiki as a tool for providing accessible information.
- 2) **Survey 3** was administered at the end of the study to measure the impact of the project on participants' knowledge and understanding of human rights.



- 3) Survey 4.** Following the delivery of the workshops and focus group survey 4 was administered to staff to capture their perceptions of participants' human rights knowledge, experiences and viewpoints on accessibility of information.

The questionnaires were constructed following the easy-to-read method so that more people with ID could easily engage in the study as it is less demanding for them.

The above process was implemented with 220 participants with ID from the partner countries and it was facilitated by 19 staff who knew and worked with the participants before the study. The data collection occurred over approximately two months between April and June 2016.

Facilitators that were involved in the administration of questionnaires and focus group discussions, besides participating in the above-mentioned training sessions, received specific guidance developed by the project 'Evaluation Protocol'. Before the questionnaires were completed, participants were introduced to the notions of the project, reassured that their confidentiality would be respected, and had explained that 'there are no right or wrong answers'. Also, facilitators had prepared visual resources that helped participants understand the questions. The bottom-up approach of the empirical study allowed participants with ID to express their needs and desires regarding their comprehension of human rights, and access to related information.

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 people with ID in Greece, Lithuania and Poland.

RESULTS

This section refers to the results from the survey assessing participant's awareness of basic human rights and the ways in which participants are accessing information about human rights. The diagrams below show in percentage and quantity how the situation looks as a whole, across Greece, Lithuania, and Poland. The title refers to the survey question, and the legend details the given answers.

Although partners had the option to administer the questionnaires using an electronic survey tool, all responses were collected on printed questionnaires. The response rate was 100%.



SESSION 1

DEMOGRAPHIC QUESTIONNAIRE

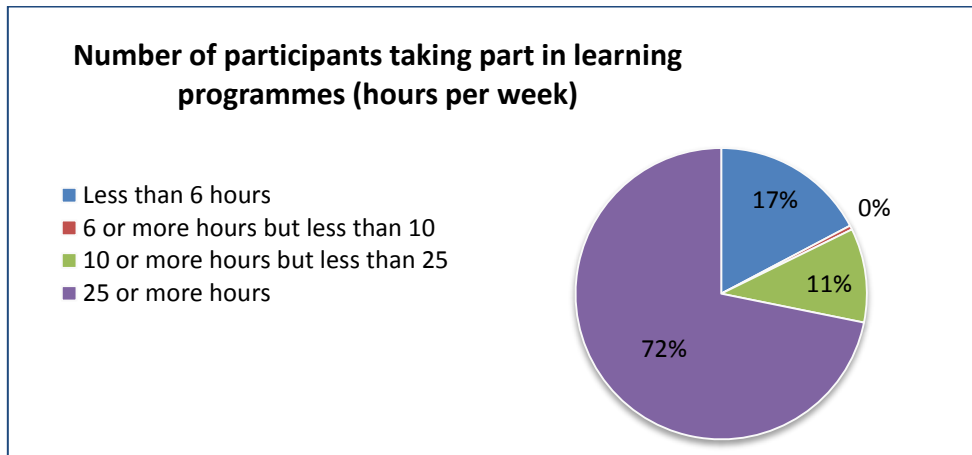


CHART 1: PARTICIPANTS LEARNING STATUS

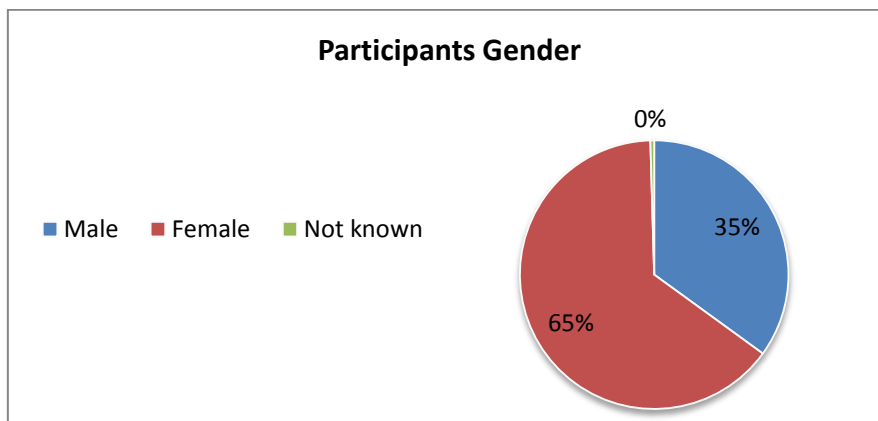


CHART 2: PARTICIPANTS GENDER

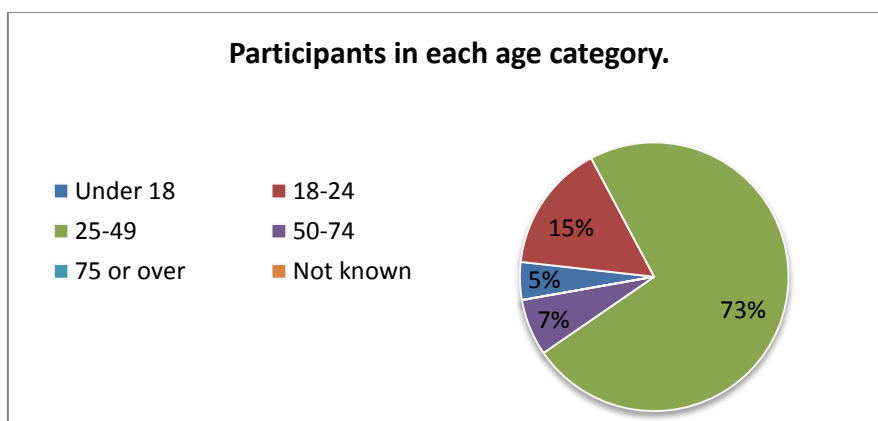


CHART 3: PARTICIPANTS AGE



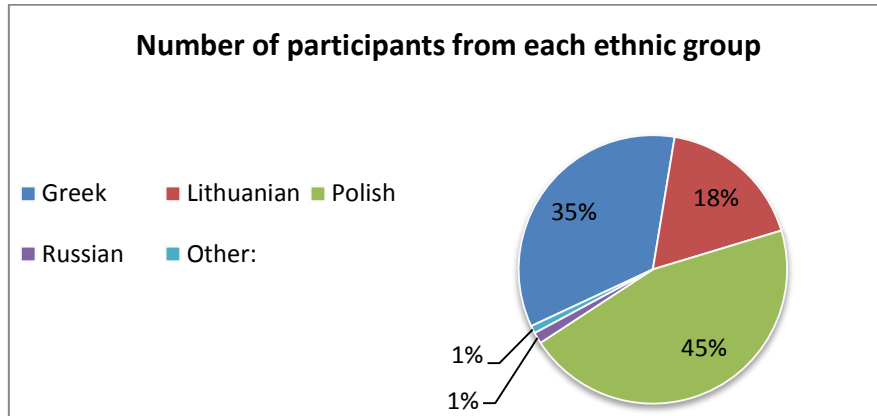


CHART 4: PARTICIPANTS ETHNICITY

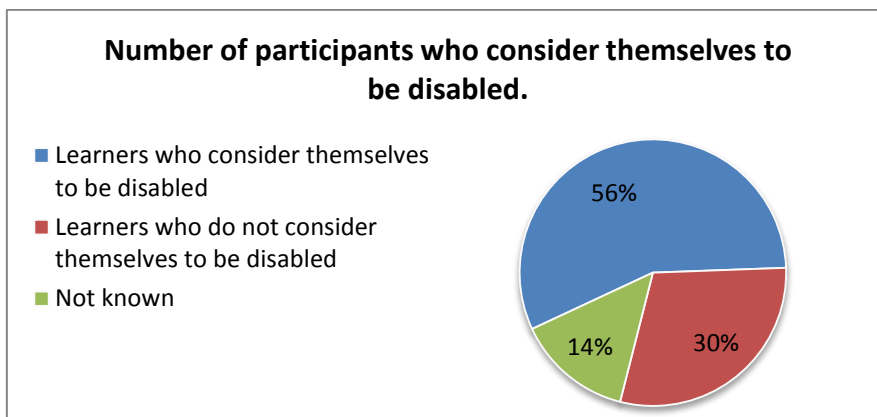


CHART 5: DISABILITY STATUS

Number of participants with the following employment statuses

	SUM	Percent
Currently in paid work – employed	1	0%
In full time education or training	84	38%
In full time day centre	130	59%
In part time day centre	1	0%
Not in education or training	2	1%
Currently in voluntary employment – not paid – part time	1	0%
Other	1	0%

TABLE 1: PARTICIPANTS EMPLOYMENT STATUS

Number of participants who intend to progress onto the following.

	SUM	Percent
Further community learning with your organisation	146	55%
Further community learning with another organisation	5	2%
An accredited course other than literacy, language or numeracy	17	6%
A literacy, language or numeracy accredited course	3	1%
Volunteering	13	5%
Paid work – employed	39	15%
Paid work – self employed	3	1%
No plans to progress on to any of the above at this time	8	3%
Not known/information not available	31	12%

TABLE 2: PARTICIPANTS INTENTION FOR FURTHER STUDY OR EMPLOYMENT



SESSION 2

SURVEY 1 - BASIC HUMAN RIGHTS

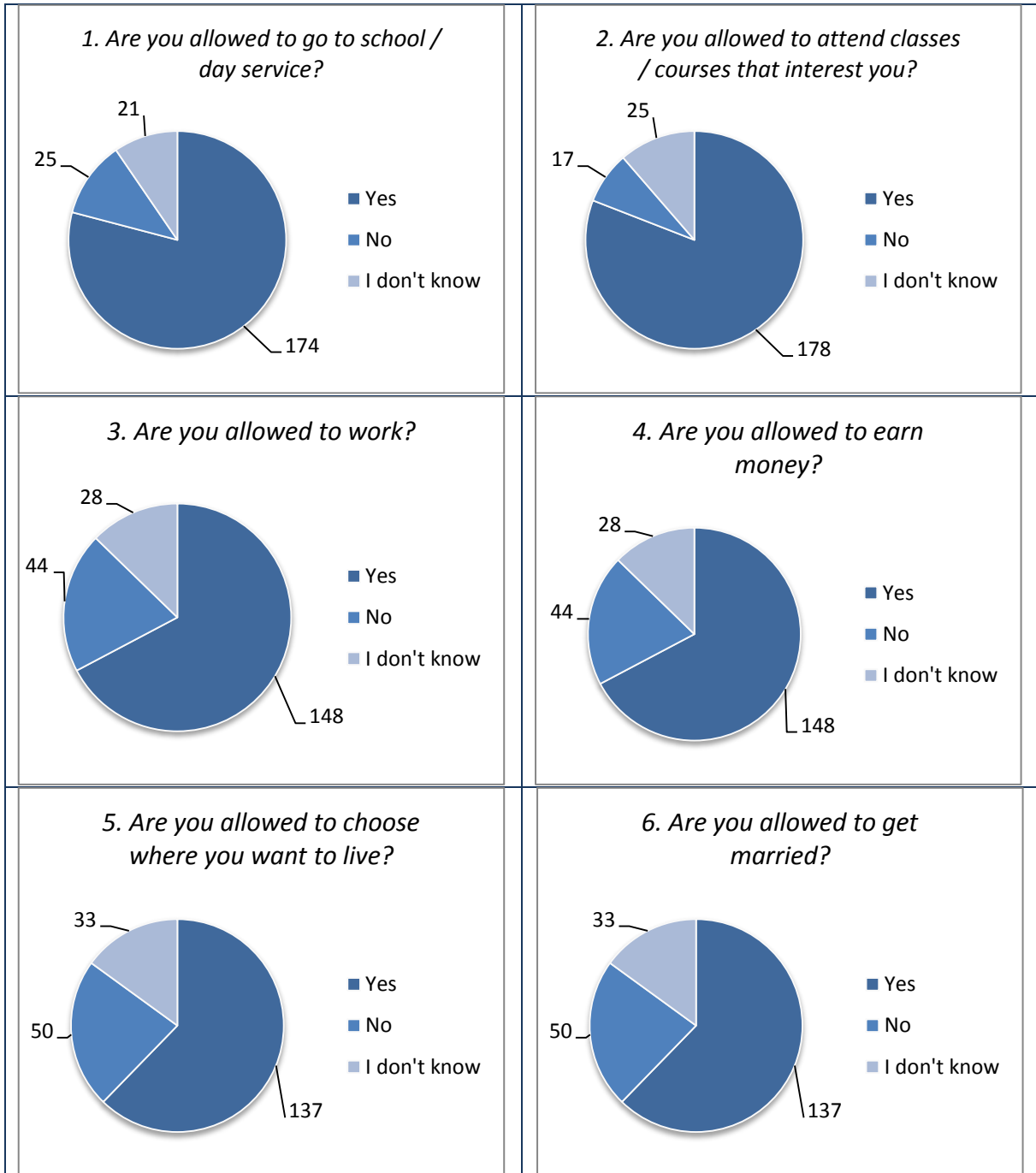


TABLE 3: BASIC HUMAN RIGHTS AWARENESS – QUESTIONS 1 - 6

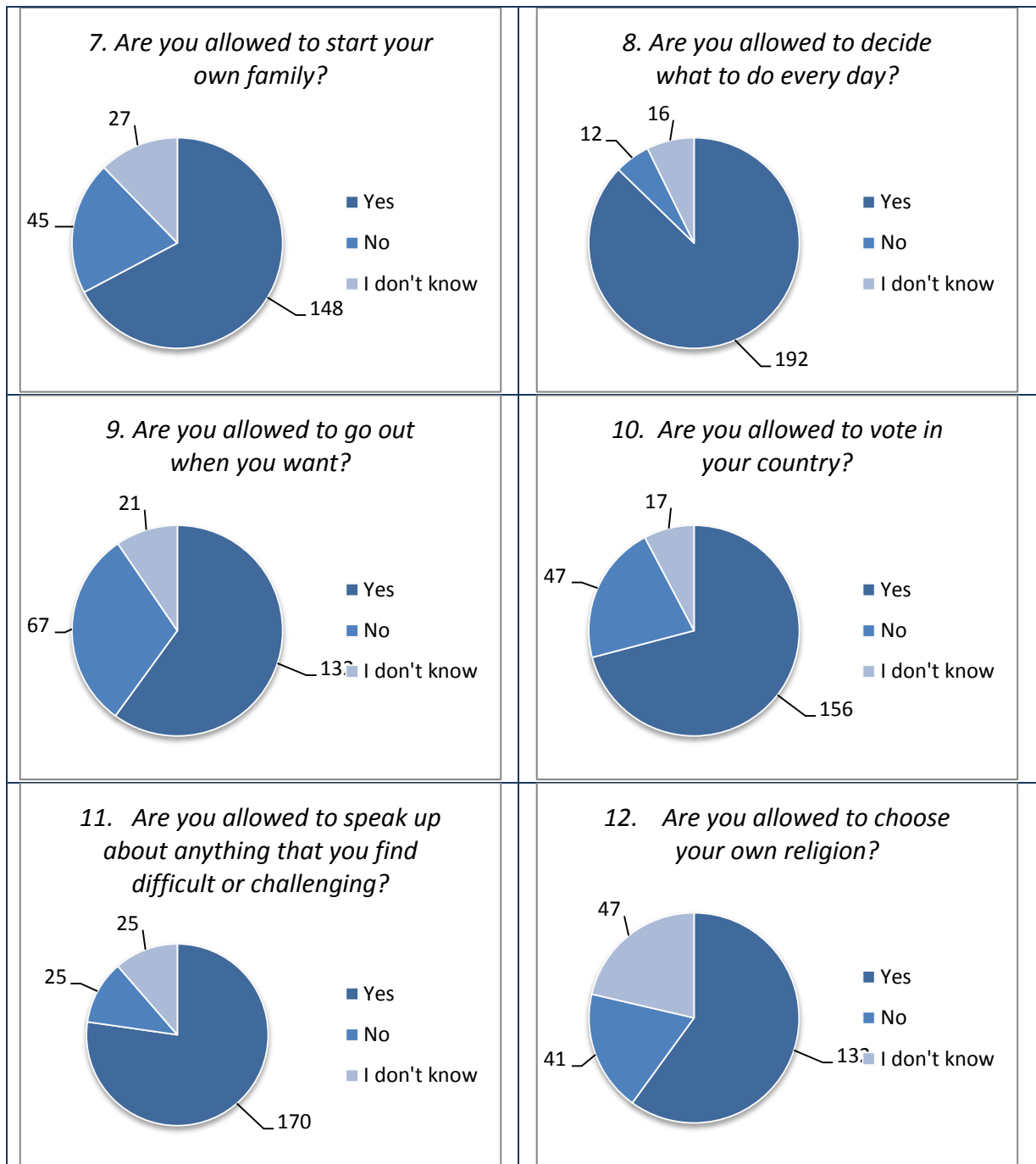


TABLE 4: BASIC HUMAN RIGHTS AWARENESS – QUESTIONS 7 - 12

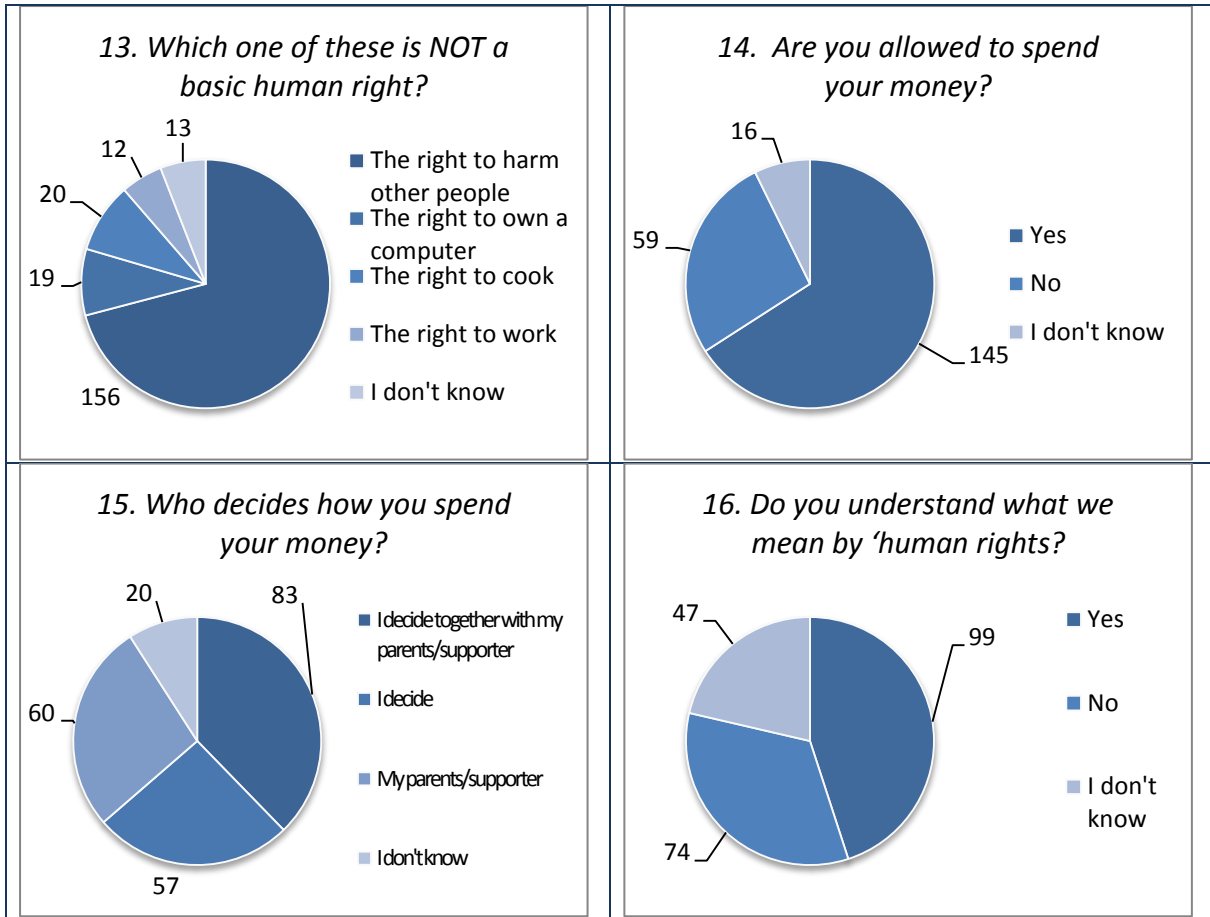


TABLE 5: BASIC HUMAN RIGHTS AWARENESS – QUESTIONS 13 - 16

SESSION 3

SURVEY 2 - MY HUMAN RIGHTS

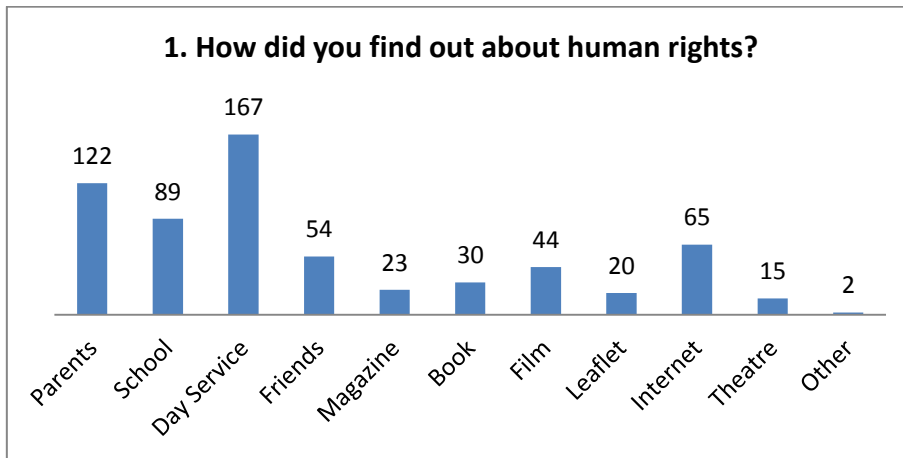


CHART 6: HOW DID YOU FIND OUT ABOUT HUMAN RIGHTS?

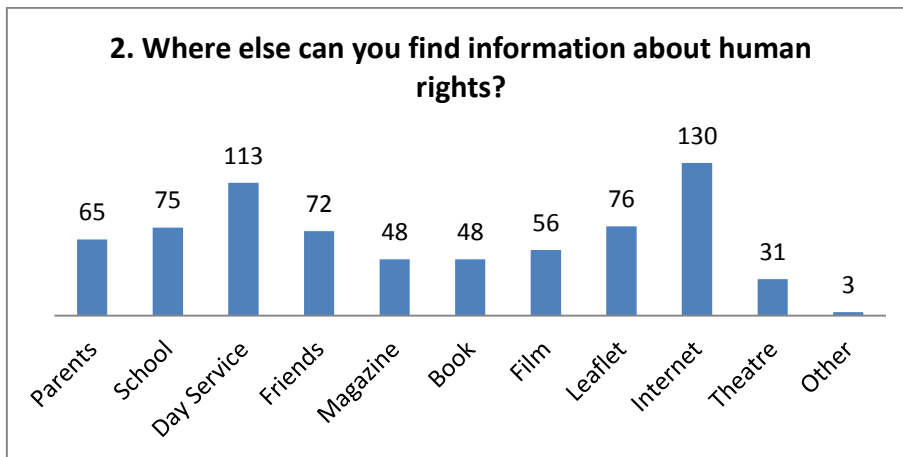


CHART 7: WHERE ELSE CAN YOU FIND OUT INFORMATION ABOUT HUMAN RIGHTS?

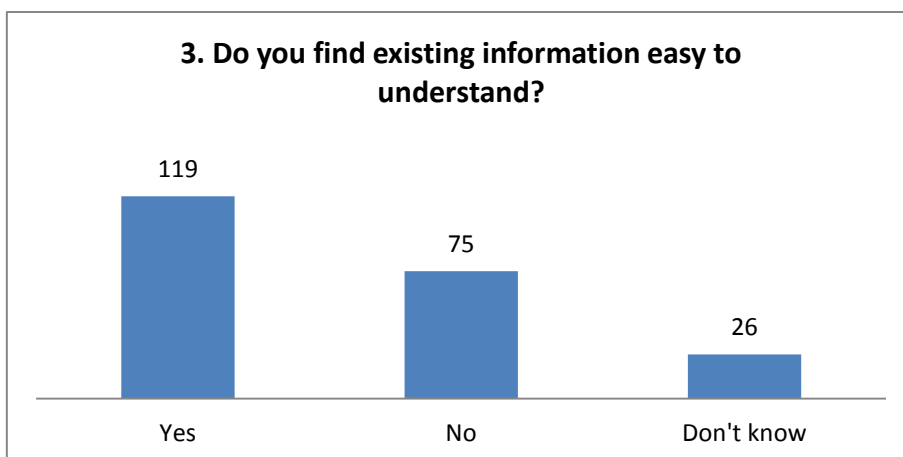


CHART 8: UNDERSTANDING OF EXISTING INFORMATION



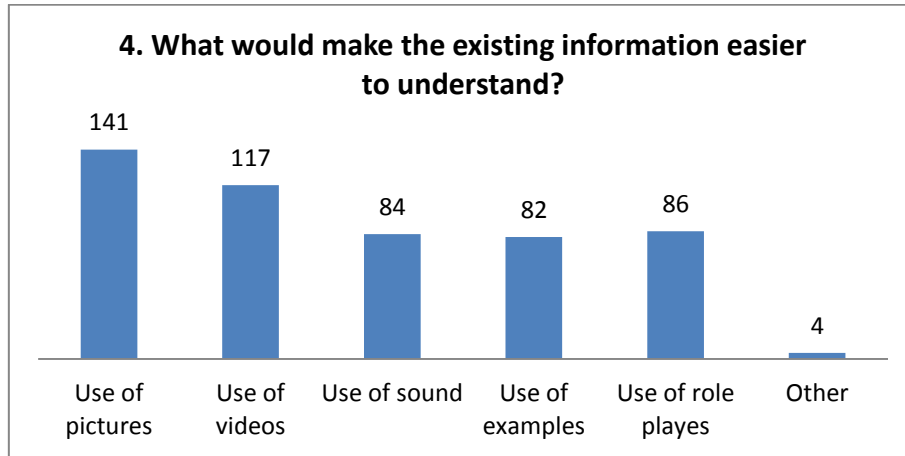


CHART 9: HOW TO MAKE INFORMATION EASIER TO UNDERSTAND?

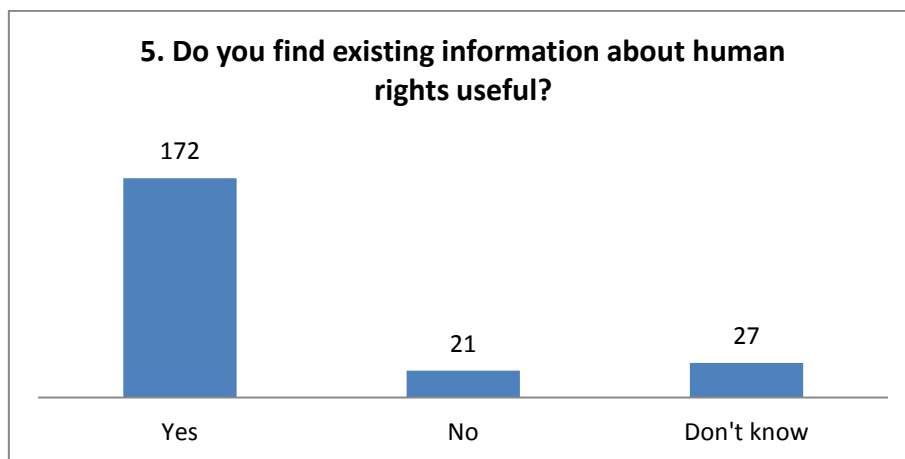


CHART 10: USEFULNESS OF INFORMATION ABOUT HUMAN RIGHTS

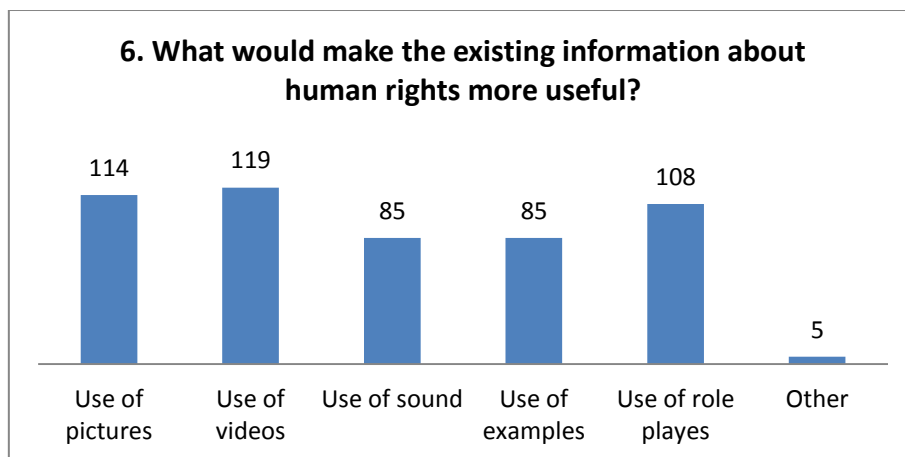


CHART 11: HOW TO IMPROVE USEFULNESS OF INFORMATION



SURVEY 3 - BASIC HUMAN RIGHTS

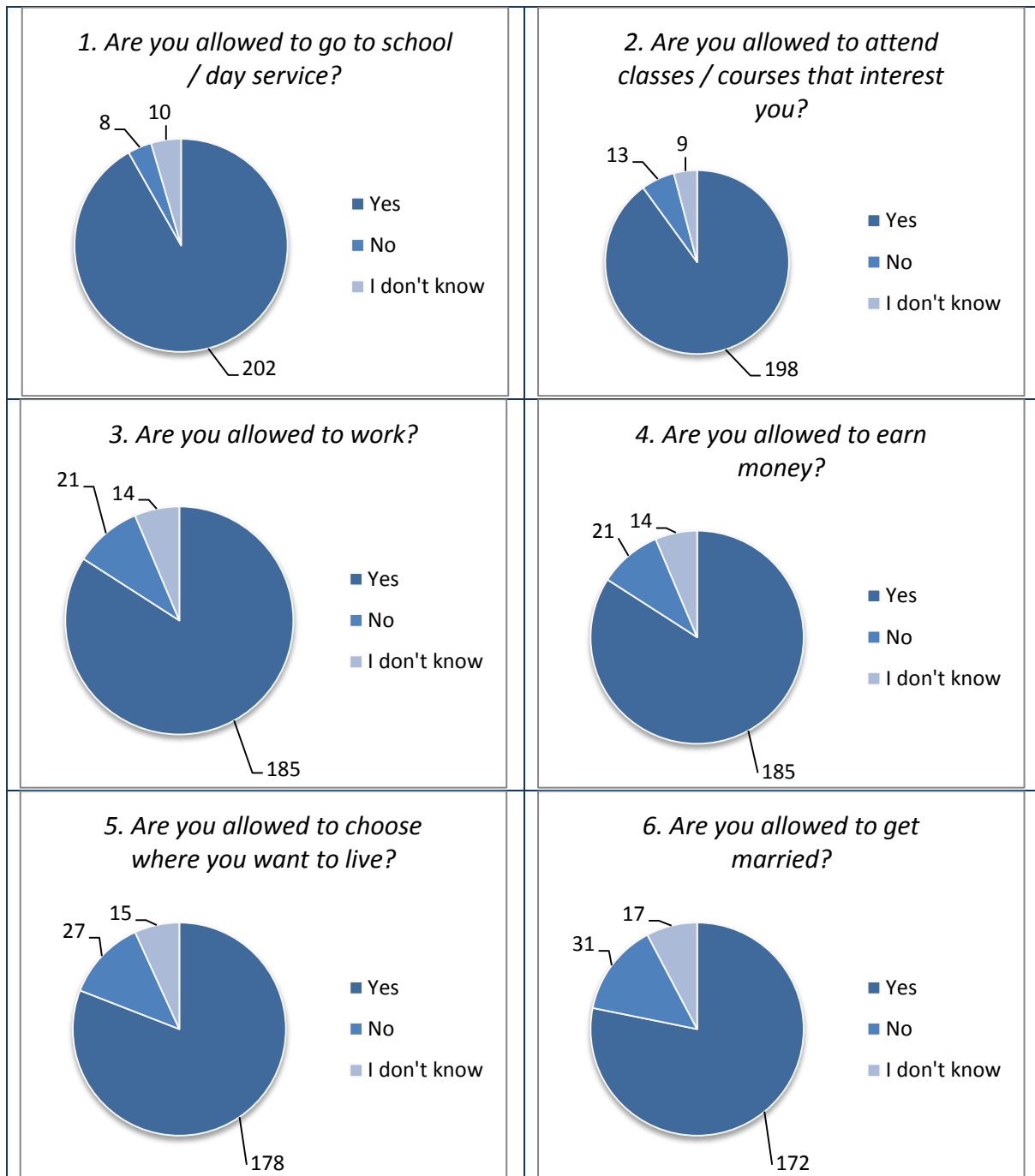


TABLE 6: UNDERSTANDING OF BASIC HUMAN RIGHTS AFTER WORKSHOPS – QUESTIONS 1 - 6

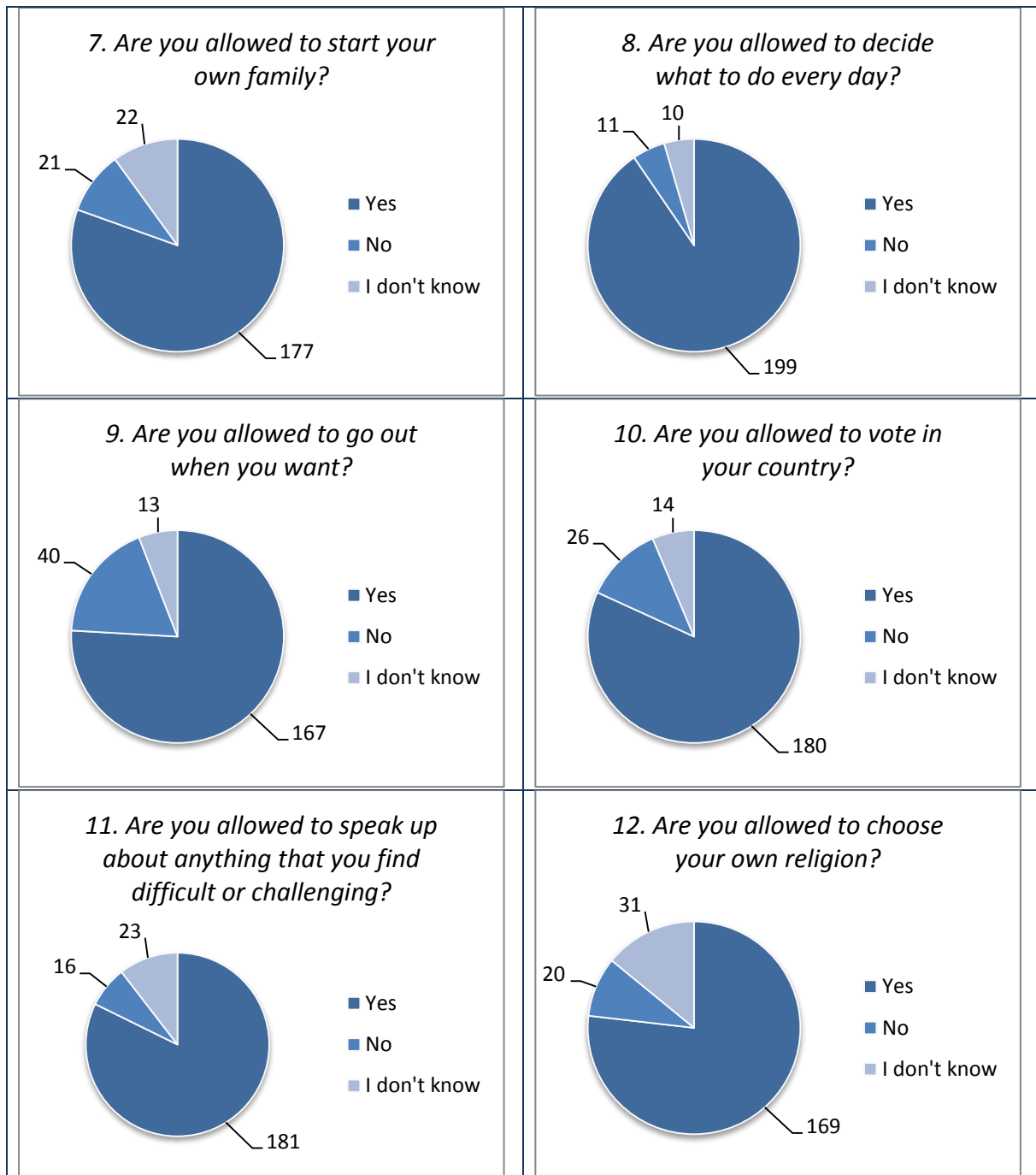


TABLE 7: UNDERSTANDING OF BASIC HUMAN RIGHTS AFTER WORKSHOPS – QUESTIONS 7 - 12

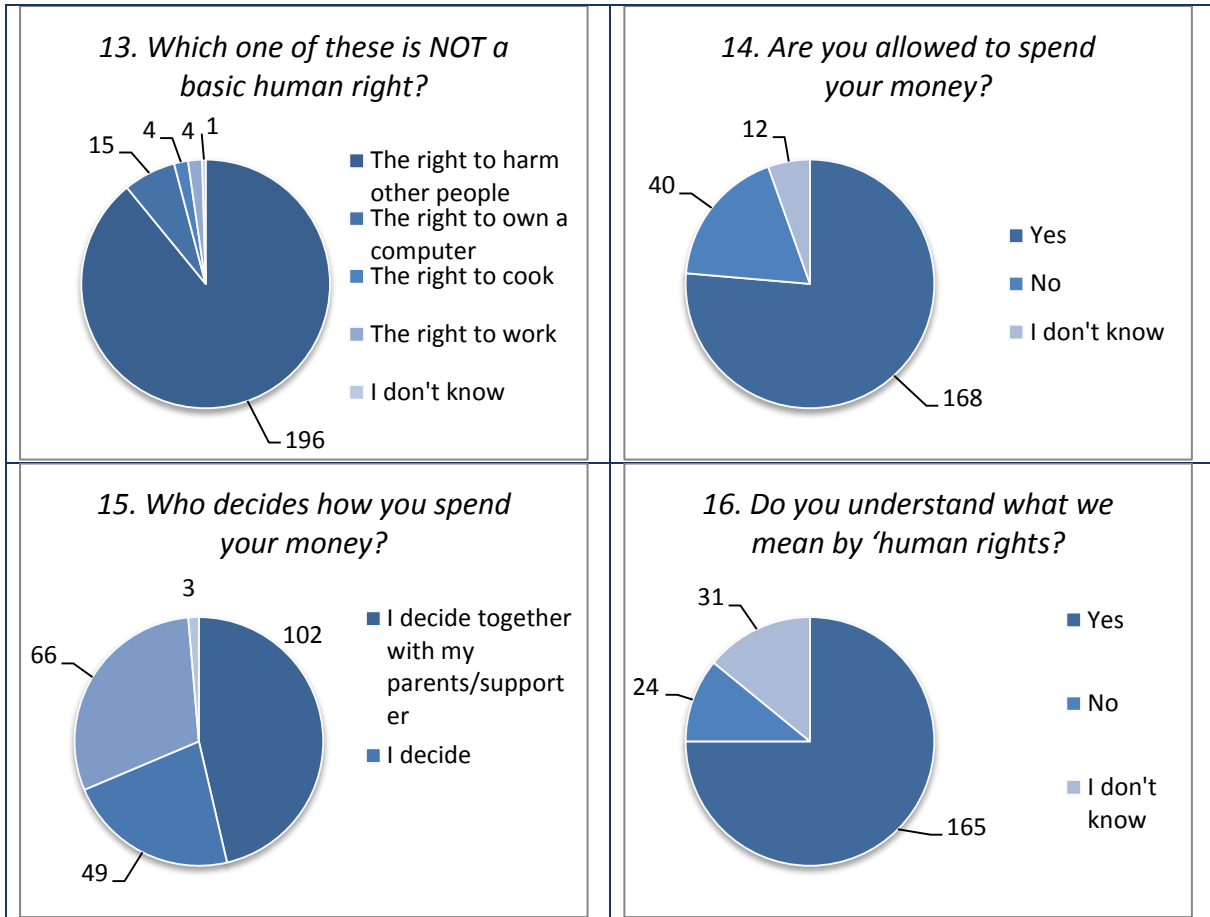


TABLE 8: UNDERSTANDING OF BASIC HUMAN RIGHTS AFTER WORKSHOPS – QUESTIONS 13 - 16

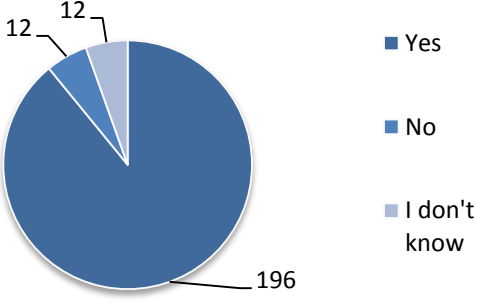
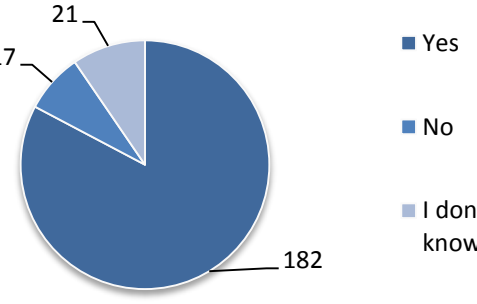
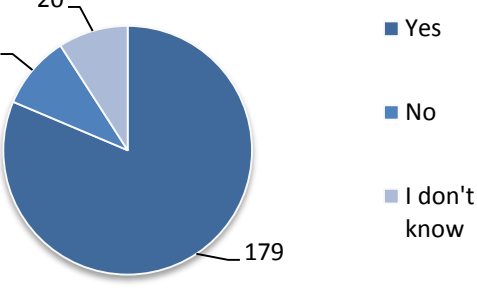
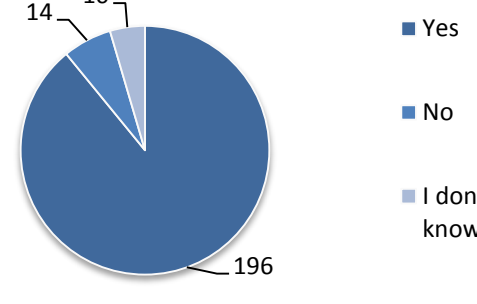
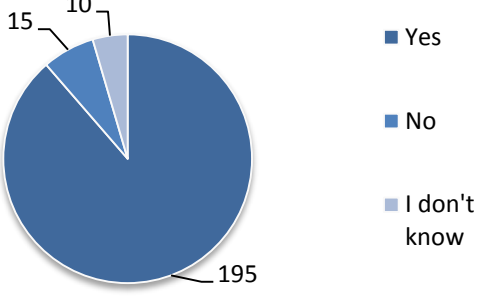
<p><i>17. Use of pictures helps me to understand information better?</i></p>  <p>■ Yes ■ No ■ I don't know</p>	<p><i>18. Use of videos helps me to understand information better?</i></p>  <p>■ Yes ■ No ■ I don't know</p>
<p><i>19. Use of sound helps me to understand information better?</i></p>  <p>■ Yes ■ No ■ I don't know</p>	<p><i>20. Use of examples helps me to understand information better?</i></p>  <p>■ Yes ■ No ■ I don't know</p>
<p><i>21. Use of role play helps me to understand information better?</i></p>  <p>■ Yes ■ No ■ I don't know</p>	

TABLE 9: WHAT AIDS UNDERSTANDING OF INFORMATION FOR PEOPLE WITH ID

RESULTS BY COUNTRY

Session 1 –Baseline Survey- Responses by country

		Yes			No			I don't know		
		PL	GR	LT	PL	GR	LT	PL	GR	LT
1	Are you allowed to go to school / day service?	78%	88%	64%	11%	10%	15%	11%	3%	21%
2	Are you allowed to attend classes / courses that interest you?	72%	95%	74%	12%	1%	10%	16%	4%	15%
3	Are you allowed to work?	54%	83%	69%	33%	5%	18%	13%	13%	13%
4	Are you allowed to earn money?	60%	98%	77%	25%	1%	13%	15%	1%	10%
5	Are you allowed to choose where you want to live?	44%	73%	87%	35%	15%	8%	21%	13%	5%
6	Are you allowed to get married?	51%	76%	62%	34%	13%	15%	15%	11%	23%
7	Are you allowed to start your own family?	56%	79%	72%	29%	13%	15%	15%	9%	13%
8	Are you allowed to decide what to do every day?	81%	94%	90%	8%	5%	0%	11%	1%	10%
9	Are you allowed to go out when you want?	64%	49%	72%	20%	49%	21%	16%	3%	8%
10	Are you allowed to vote in your country?	57%	84%	79%	29%	15%	15%	14%	1%	5%
11	Are you allowed to speak up about anything that you find difficult or challenging?	68%	90%	74%	18%	4%	10%	14%	6%	15%
12	Are you allowed to choose your own religion?	61%	59%	59%	19%	23%	10%	20%	19%	31%
13	Are you allowed to spend your money?	67%	59%	77%	22%	40%	13%	11%	1%	10%
14	Do you understand what we mean by 'human rights'?	31%	55%	59%	43%	30%	18%	26%	15%	23%
	AVERAGE	62%	79%	72%	23%	15%	13%	15%	7%	15%

TABLE 10: BASELINE SURVEY RESPONSES BY COUNTRY

15 Who decides how you spend your money?	PL	GR	LT
I decide together with my parents/supporter	27%	59%	23%
I decide	31%	18%	28%
My parents/supporter	29%	24%	31%
I don't know	13%	0%	18%

TABLE 11: SESSION 1 SURVEY RESPONSES BY COUNTRY Q15 WHO DECIDES HOW YOU SPEND YOUR MONEY?



SESSION 2 – IMPACT SURVEY - RESPONSES BY COUNTRY

		Yes			No			I don't know		
		PL	GR	LT	PL	GR	LT	PL	GR	LT
1	Are you allowed to go to school / day service?	94%	95%	79%	2%	4%	8%	4%	1%	13%
2	Are you allowed to attend classes / courses that interest you?	92%	93%	79%	3%	6%	13%	5%	1%	8%
3	Are you allowed to work?	74%	99%	79%	17%	0%	10%	9%	1%	10%
4	Are you allowed to earn money?	82%	91%	90%	12%	6%	8%	6%	3%	3%
5	Are you allowed to choose where you want to live?	65%	95%	92%	22%	4%	5%	13%	1%	3%
6	Are you allowed to get married?	77%	85%	69%	16%	11%	15%	7%	4%	15%
7	Are you allowed to start your own family?	81%	84%	74%	11%	6%	13%	8%	10%	13%
8	Are you allowed to decide what to do every day?	91%	91%	87%	4%	8%	3%	5%	1%	10%
9	Are you allowed to go out when you want?	70%	78%	87%	21%	21%	5%	9%	1%	8%
10	Are you allowed to vote in your country?	70%	94%	87%	16%	6%	13%	14%	0%	0%
11	Are you allowed to speak up about anything that you find difficult or challenging?	78%	89%	79%	10%	1%	13%	12%	10%	8%
12	Are you allowed to choose your own religion?	75%	80%	74%	6%	14%	8%	19%	6%	18%
13	Are you allowed to spend your money?	81%	73%	74%	12%	28%	13%	7%	0%	13%
14	Do you understand what we mean by 'human rights'?	69%	81%	79%	19%	4%	5%	12%	15%	15%
	AVERAGE	80%	88%	82%	11%	8%	9%	9%	4%	9%

TABLE 12: IMPACT SURVEY RESPONSES BY COUNTRY



SURVEY 4 RESULTS

Staff supporting and teaching project participants were asked before and after the project intervention to share their views on participants' knowledge and understanding of basic human rights, on the scale of 1 – 5? (1= Very Poor; 5=Excellent). Responses are noted in the table below.

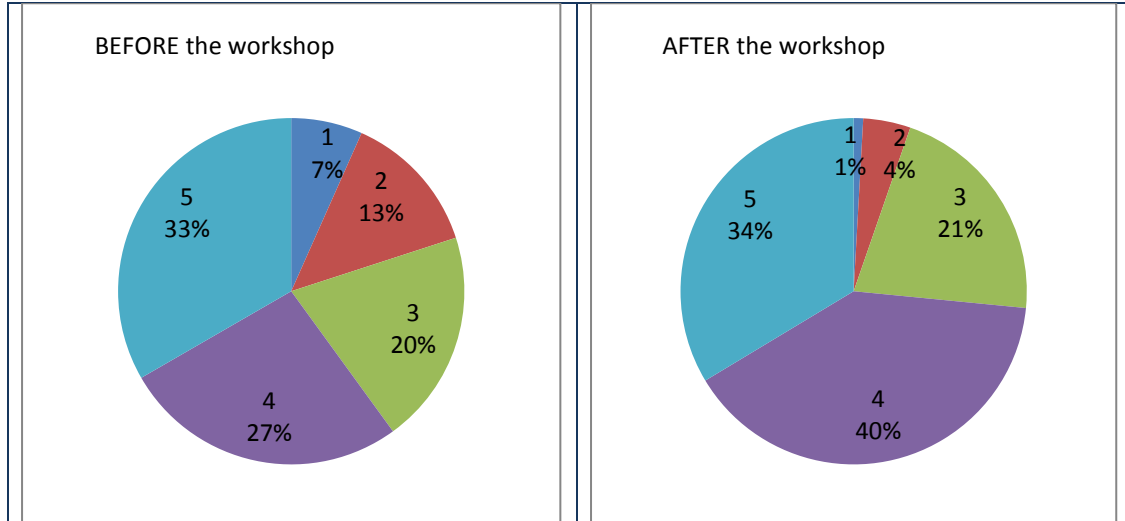


TABLE 13: STAFF' PERCEPTIONS OF THEIR BASIC HUMAN RIGHTS BEFORE AND AFTER THE STUDY.

ANALYSIS AND DISCUSSIONS

During this study 220 people in Europe were asked to complete the surveys about basic human rights and take part in workshops creating an 'easy-to-read' RIX Wiki website. The participants were people with intellectual disabilities, aged between 25 and 49.

This study found that 56% of participants considered themselves to be disabled, 16% disclosed that they wanted to make progress into work activities, and only one person was in paid employment at the time of the research.

'MY RIGHTS' AWARENESS

In the results from the first survey (Table 10), we can observe the differences in awareness of basic human rights across Greece (GR), Lithuania (LT) and, Poland (PL). The first survey, completed before the multimedia advocacy workshops, shows a big difference between the European countries. The lowest level was in Poland, where the overall knowledge and understanding of human rights was only 62%. Lithuania was better with 72%, and the best was Greece where the overall awareness and understanding of human rights achieved 79%. In Poland and Lithuania, the same percentage of people answered questions with, "I don't know", 15% of the time, but in Greece, only 7% of people were not sure of their answers. In question 15, we asked participants "Do you understand what we mean by 'human rights'?" and only 45% of people answered "Yes", with the highest level in Lithuania. This seems to suggest that a larger proportion of the project participants did not have an awareness of their human rights. This finding highlights the importance of raising awareness of basic human rights that every person has.

The survey showed interesting differences between countries that reflected the different problems people had with different spheres of their lives. For example, in Poland, only half of the participants knew that according to basic human rights, everyone can choose to decide where they want to live, whether or not they can get married or go to work. This finding is not surprising as these rights can be very difficult to exercise due to economic, social and political reasons. On one hand, families and carers might want to enable people that they support to live their lives they want but on the other hand the economic climate might not make this possible and therefore, carers choose not to raise expectations of those they care for. For participants in Greece, the most challenging question was, "Are you allowed to go out when



you want?” where less than half of the participants was aware of their right to independence (Table 10). One of the possible causes of the above result may be the fact that a large group of people with ID that took part in our study from Greece, live in full-time care homes where specific rules go on to apply. In care homes, individuals are able to talk about their problems/needs, decide what they want to do in their free time, and what education or work they want to do. However, this kind of care does have its limitations, such as not having the potential to go out without prior arrangements or agreement with carers. The situation looks different in cases where people with disabilities are living in family homes, very often with parents. In these cases, as we can see from Polish surveys, the possibility of mobility is much bigger but the decisions about education, spending money or future planning very often are made by parents who are choosing the ‘best way’ without necessarily discussing available options with their children. In Lithuania, the situation looks a little different to that in Poland and Greece, with the exception of the question “Are you allowed to decide what to do every day?” where most of the participants answered “Yes”. (Table 10, question 8)

One of the lowest percentages of positive answers we can find is under question 12 “Are you allowed to choose your own religion?” with the result of 59% in Greece and Lithuania, and 61% in Poland.

In question 15, (Table 14) we asked “Who decides how you spend your money?” which gives us very interesting feedback. It was only in Greece that everyone was aware of who is responsible for making decisions about spending their money. However, Greece also had the lowest percentage of people with complete control over their spending just where 18% of respondents answered “I decide how to spend my money”. This compares to 28% in Lithuania, and 31% in Poland who both had very similar numbers of participants who decided with their parent/supporter (23%, 27% respectively).

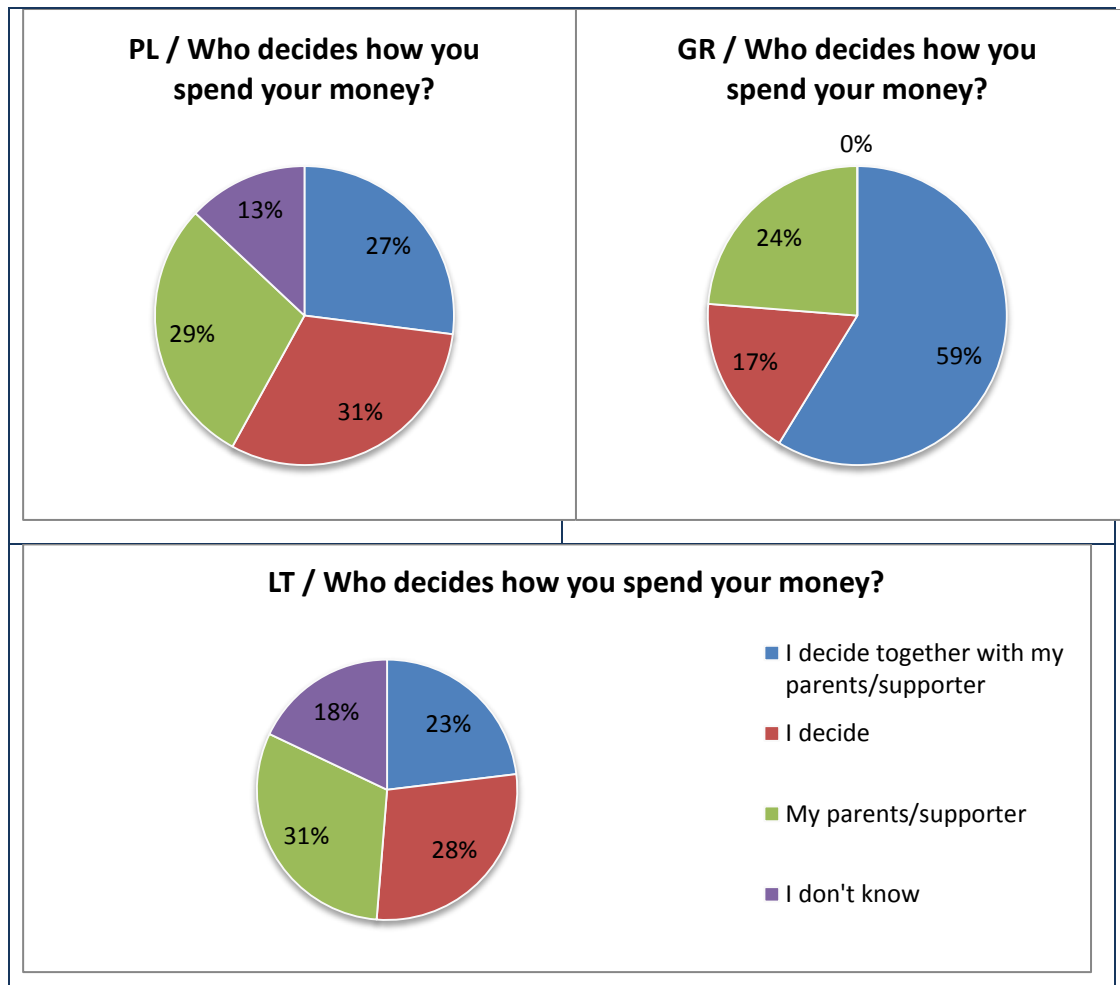


TABLE 14: COMPARISON OF RESULTS BY COUNTRY: WHO DECIDES HOW YOU SPEND YOUR MONEY?

ACCESSIBILITY OF AVAILABLE INFORMATION

Survey 2 showed that people with learning disabilities gather information about human rights mostly from day service, parents, and school (Chart 6). However, it is worth noting that our respondents were aware that there are other places to find out about human rights with 59% listing the internet as one of such places (Chart 7). 53% of our participants found the existing information about human rights accessible, about 35% of our participants did not think that the existing easy-to-read information was easy to understand and the remaining 12% were not sure. This finding supports our literature review where similar results were reported in other studies. The information about human rights was still difficult to comprehend by our participants despite the presence of images and the simplified text.

Our participants expressed multimedia as useful tools for presenting information with many respondents identifying pictures, videos, and sound as media that helps them to understand

information (Chart 9). The use of examples and role play were also listed by participant as possible ways of making information easier to understand. (Chart 9).

When looking at the usefulness of existing information of human rights, it was refreshing to note that majority of our respondents agreed that the existing information about human rights is useful (Chart 10). That results show us that this group of people not only have the right to know what are their rights but they want to know and were happy to engage in the project that helped them to raise awareness of their human rights and direct them to sources of information. 60% of respondents noted that they have access to the internet and use it to find multimedia information, however, only 29% said that they used the internet to access information about human rights. Why? Perhaps one of the reasons is that the available information is not easy-to-read for our target audience, as noted earlier.

COMPARATIVE ANALYSIS

Following the first set of surveys, every country conducted workshops with the same group of participants where they used multimedia to create a RIX Wiki website about their basic human rights. After these workshops, the first survey was then repeated to see if any progress was made in individual's knowledge and understanding. Results from this survey were very optimistic, with correct answers rising on average by 18% in Poland, 9% in Greece, and 10% in Lithuania (Table 12). The largest progress was made in question 14 where participants were asked, 'Do you understand what we mean by human rights?' The initial 'yes' response went from 31% to 69% in Poland, 55% to 81% in Greece, and finally in Lithuania positive answers went from 69% to 79%. Another positive result of this workshop was the reduction of 'I don't know' responses. In Lithuania and Poland, that level was reduced from 15% to 9%, and in Greece from 7% to 4%.

Following the Multimedia Advocacy workshop participants were also asked which forms of communication and multimedia (pictures, videos, sounds, examples, role play) helped them to understand information better. People taking part in workshops answered that all of these multimedia methods of presenting information are very helpful for understanding. It could be investigated further to understand if there is a difference between participants authoring and creating their own material, or if, alternatively, simply viewing easy-to-read, multimedia information, on a platform like the RIX Wiki, could also improve results.



CONCLUSIONS

Actions taken within Intellectual Output number 3 of the Puzzle project, gave us a glimpse into the current situation of people with ID and their awareness of their own human rights in different parts of Europe. We have also gained insight into the availability of information regarding human rights and how multimedia workshops using pictures, sound, video, RIX Wikis and other tools can help improve participants' awareness. Using surveys, we found that the quality and quantity of knowledge of human rights could depend on where the person lives. Our results suggested that Greece is where this awareness is at its highest level. This might reflect their education model that is focused on raising independence and socialising for people with disabilities through work and earning money. In Poland and Lithuania, it is likely their model is different, and this reflects in their average positive answers being lower than that of Greece. Furthermore, the surveys revealed that people with intellectual disabilities are looking for information about human rights, but very often, available documents may be easy-to-read in the simplest terms but not easy to understand by our target audience. From our own evaluation of easy-to-read documents, we found improvements could be made which could increase the quality of self-education for people with ID. We also found that workshops using multimedia tools helped participants to improve their knowledge and awareness about their rights to a significant degree. Today's growth in potential access to low cost media technologies provides additional opportunities for education and information provision. It is important to utilise the new tools and methods that emerging technologies can provide in our work with people with disabilities. The experience of the Puzzle team is that the use of multimedia approaches enhances the sharing of information about human rights with this group. Our research has shown these new approaches to have a positive impact. Combining workshop approaches that embrace a spectrum of media, multimedia and Web tools with improved application of easy-to-read communication can further increase a positive awareness of human rights within the ID community in future. This can in turn positively affect the pursuit of self-determination and independent living and so the quality of life for individuals with intellectual disabilities.

The work conducted in Puzzle has proven instrumental in the definition of the set of Recommendations and Instructions on improving access to information on human rights issues for persons with ID that appear in pp. 41-43.



RECOMMENDATIONS FOR FURTHER RESEARCH

Our small-scale research activity has shown that access to information on human rights for people with intellectual disabilities is limited (Hodgdon L. A. 1995; Fyson R. & Cromby J. 2012) It has been evidenced that there is a sizeable quantity of information that has been created about the European Convention on the Rights of Persons with Disabilities that meets the recommended standards for easy-to-read, using pictures and simple text. (Barron R. 2011) However, our research has shown that information provided in easy-to-read format is not always accessible or easy to understand for people with intellectual disabilities. There is little research that assesses the accessibility of easy-to-read information for audiences with Intellectual Disabilities (Hodgdon L. A. 1995; Fyson R. & Cromby J. 2012) and how easy such content is for individuals with ID to understand the intended information content. Our research evidenced the potential enhancement of understanding that can be achieved by using multimedia to convey the intended messages. It would seem timely to further measure the impact and effectiveness of using multimedia in order to enhance the accessibility and of information material produced to existing easy-to-read standards. A subsequent re-evaluation of existing Easy-to-Read standards and guidelines to incorporate evidence-based learning on the added impact of multimedia approaches to information development would then help to bring these standards more up-to-date. The Puzzle Project's methodology for evaluating easy-to-read materials could be applied in a wider research study to evaluate of a spectrum of easy-to-read materials with their targeted audiences.

Teachers, staff and professionals who are working with or supporting people with Intellectual Disabilities will benefit from further guidance on methods that deploy emerging digital information tools. Further research is needed to trial how these tools might be used to enhance the understanding of important information for people with various intellectual and communication difficulties.

Further research could also be conducted to continue to explore further how the 'understandability' of easy-to read information corresponds to the diversity of abilities and the spectrum of communication preferences that disabled individuals exhibit. Such a study could establish recommendations on ways to engage individuals matched to various genres of intellectual and communication impairment and seek to thus provide a spectrum of approaches that would draw on multiple media formats and production methods to meet everyone's needs.



An additional tranche of research could explore how the use of the participatory methods of information content creation that are enshrined in the 'Multimedia Advocacy' approach can enhance the accessibility of the resultant information for a wider range of individuals.

In conclusion, our research experience prompts us to propose an agenda going forwards that incorporates the opportunities that multimedia formats and production processes can bring to the Easy-to-Read standards and methods that are in place. In the process our research suggests that information will be produced in more accessible forms, reaching a wider spectrum of users and that the ways in which people with ID can be actively involved in creating such information will be extended.



Developing knowledge on human rights for people with ID: Recommendations for improving the potential for engagement, understanding and learning

A literature review and a survey conducted by the Puzzle project revealed that persons with ID in Greece, Lithuania and Poland face a number of barriers to accessing information on human rights and have limited knowledge of their rights. It was found that a person's knowledge of their human rights cannot be achieved if the person with ID:

- *Does not understand the concept of human rights*
- *Lack awareness of Rights and that information on Human Rights is available*
- *Cannot access the information*
- *Cannot understand the information*
- *Is fully dependent on support from others to access and comprehend the information available.*

The research identified a set of exemplar working approaches that provide possible solutions to tackle these principle barriers and so improve the knowledge that people with ID might gain about their rights. These working approaches are highlighted in the bullets below.

Persons with ID frequently do not understand the concept of 'Human Rights'

The concept of 'Human Rights' is abstract and complex for an individual with ID to grasp and is best understood when it is set in the context of their own lives, their personal goals, their aspirations and their dreams. 'Human Rights' tell us that it is reasonable to have aspirations for your life as a disabled person - and your community and local services should help you to achieve these rights.

- ***Start work on human rights with learners with ID by sharing each others' personal hopes and dreams for the future***
- ***Introduce the concept of Human Rights as an agreed understanding in our societies that we are all entitled to key aspirations and to the expectation of support to achieve these fundamental goals***

The majority of persons with ID are not aware of their human rights and that information is available on the subject for them

The research identified willingness across supporters and educators to engage in activities that can help people with ID to raise awareness of their basic rights. However there was less evidence of this approach within families, where a protective approach sometimes worked against the pursuit of independence by persons with ID.

- ***Provide resources for supporters to assist persons with ID to build simple understanding of their personal rights and how they can apply in their daily lives***



- ***Educators and supporters need to actively raise the awareness about the Human Rights of persons with ID with their parents and carers***

Persons with ID face a variety of problems in accessing information on basic human rights

People with ID frequently lack *sufficient literacy skills* to enable them to *actively search and find* relevant information for the understanding and pursuit of their Human Rights. They get their information mostly from through their day service and school – and to a lesser extend from their parents and carers. There is wide understanding that Information can be found through Internet, but barriers of accessibility are prevalent online as in printed documents.

- ***Access to information can be facilitated be raising knowledge and understanding of educators, supporters, parents and carers about Easy-to-Read and Easy-to-Understand information design for persons with ID***
- ***A focus on training individuals to search for Easy-to-Understand information on the Internet will also improve access to relevant sources of information for persons with ID***

Persons with ID have difficulties in understanding Information about human rights

Information should, regardless of media, be easy to read and easy to understand. Easy-to-read concepts and methods contribute greatly to this effort.

- ***Present information in a clear way:***
 - ***Make information short***
 - ***Break down information into step by step***
 - ***Use a clear structure***

Even very simple text is often too difficult to understand for persons with ID who have more complex communication needs. The combination of images with text can significantly improve the accessibility of text for this audience.

- ***Make content easy to understand by supporting text with illustrations and pictures that can anchor the intended message or extend the meaning with illustrations that tell a more detailed story.***
- ***Words combined with pictures should be:***
 - ***Easy to interpret and understand***
 - ***Specific and NOT abstract***
 - ***Clearly connected to support each other***

Where individuals do not have reading ability, alternative media formats such as sound and video clips can convey information in ways that are Easy-to-Understand for a yet wider spectrum of audiences. Presented with simple messages conveyed in multiple



media formats, they can opt for their preferred individual mode of communication. They can then benefit from the way messages are reinforced by their presentation in additional different media formats.

- Present information about Human Rights in *multiple media formats*
- Use of *multimedia* (pictures, videos, and sound and interactivity) in this way will enable the widest possible spectrum of persons with ID to comprehend information
- Use the growing range of easy to use IT tools (*Apps and desktop software*) that are available at low cost to combine different media formats (pictures & text, video & audio clips) into a simple *multimedia* communication format

Multimedia production process also provides a wider range of ways in which individuals can take part in the creation of accessible information. Persons with ID can participate in various roles as co-creators; as presenters, actors, presenters, photographers, production 'crew' etc.

- ***Actively engage persons with ID and supporters of persons with ID in the process of design and production of accessible multimedia information***
- ***Work on personal experiences that relate to individuals Human Rights that are familiar to the audience. Take into account the audiences' prior knowledge and their personal 'frames of references' as you script and create content***

The 'Multimedia Advocacy' process takes this approach a step further to position work on Human Rights around the individual aspirations and the personal life-planning of persons with ID. This approach can further facilitate understanding of information on Human Rights through their strengthened personal and emotional engagement with the subject. The *Multimedia Advocacy approach develops capability* for individuals to share their goals with others and communicate about the support that they need to pursue them.

Persons with ID are fully dependent on support from others to access and comprehend the information available.

The Multimedia Advocacy approach provides a model and a structure for support that challenges dependency and promotes *self advocacy* in its place. The supporter can use the co-creation of pictures, text, sound, video, art and performance to assist people with ID to communicate effectively their wishes, wants, ideas and preferences. Each of these activities can proactively engage persons with ID in conversations on their Human Rights in the context of what they want to happen in their own lives.

- ***Apply Multimedia Advocacy tools and guiding principles to enhance the person's capacity for self advocacy and self determination***
- ***This provides a very concrete, rather than abstract way for persons with ID to both engage and exercise their human rights***



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APPENDIX: EXAMPLES OF EASY-TO-READ RESOURCES RELATING TO HUMAN RIGHTS

Puzzle - Literature Review								
Language	Title of the article or resource	Format (Text, Video, Sound)	Available (online, leaflet, book, article)	Link	Key recommendations	Produced by and date	Easy to Read? (Yes, No)	Notes
English	A Guide to the Human Rights Act	words and pictures	online - pdf booklet	http://www.equalityhumanrights.com/sites/default/files/publication_pdf/human-rights-act-learning-disabilities.pdf		The Ministry of Justice (UK) - 2011	Yes - Change Picture Bank images are being used	This is an easy to read guide for people with learning disabilities. I find it still difficult to understand as it has lots of writing. More than one idea per picture.
English	Human Rights Materials for use by People with Learning Disabilities	Words article	online - pdf article	http://base-uk.org/sites/base-uk.org/files/[user-raw]/11-07/dh_115164.pdf	Use easy read guidance. Break down messages. Use single leaflet for single issue. Use lots of pictures. Use stories to explain rights. Use video and audio. Use role play, workshops and drama with groups. Always provide contact details.	John Northfield-2009	No	This is a literature review with lots of links to Human Rights resources produced for people with learning disabilities.
English	Health Advocacy: A vital step in attaining human rights for adults	article - words	online - pdf article	http://web.b.ebscohost.com.ezproxy.samford.edu/ehost/pdfviewer/pdfviewer?sid=72f68526-c7f4-4ef1-ae9-	Explores parent and support workers advocacy as one means to address social determinants of health rights for people with ID. Interviewed parents of children	Brolan, Boyle, Dean, Taylor Gomez,	No	



	with intellectual disability			4a736e44b7d2%40sessionmgr113&vid=11&hid=123	with ID and care workers about their understanding and past experience with advocacy. It found five consistent themes shared by both parties. Lastly it concluded that under the United Nations Convention on the Rights of Persons with Disabilities (CRPD) the government is obligated to support self-advocacy	War, Lennox, Journal of Intellectual Disability Research [Nov. 2012, Vol. 56 Issue 11, pg. 1087-1097		
English	The concept of quality of life and its role in enhancing human rights in the field of intellectual disability	article - words	Pdf online	http://web.b.ebscohost.com/ezproxy.samford.edu/ehost/pdfviewer/pdfviewer?sid=72f68526-c7f4-4ef1-ae9-4a736e44b7d2%40sessionmgr113&vid=13&hid=123	"The changed societal views of persons with disabilities are reflected in the 2006 United Nations Convention on the Rights of Persons with Disabilities . However, what is not specified in the Convention is how to operationalise and measure the Articles composing the Convention, and how to use that information to further enhance the human rights of persons with disabilities . Method The authors <u>analyse the relationships between eight core quality of life domains and the 34 Articles contained in the Convention</u> . Results There is a close relationship between the core quality of life domains and the 34 Articles contained in the Convention. Furthermore, the current status of these Articles can be evaluated through the assessment of indicators	Journal of Intellectual Disability	No	



					<p>associated with the eight core quality of life domains. Conclusions Based on the assessment of these quality of life-related outcomes, three strategies can be used to enhance the human rights of persons with intellectual disability. These three are to employ person-centred planning, publish provider profiles and implement a system of support."</p>	<p>Research [Nov. 2012, Vol. 56 Issue 11, pg. 1036-1045] Verdugo, Navas, Gomez, Schalock</p>		
English	"Human Rights and Intellectual disabilities in an era of 'choice'"	article - words	Pdf online		<p>"Efforts to uphold and promote the human rights of people with intellectual disabilities (ID) are being affected by the increasing emphasis on 'choice' in the delivery of social care services. While rights presume subjects or selves to whom they apply, there is a disconnect between the subjects presumed within human rights frameworks and the variable capacities of a heterogeneous ID population. This disconnect is amplified by choice discourses which</p>	<p>Authors: Fyson, Cromby, Journal of Intellectual Disability Research [Vol 57, Part 12, pg. 1164-1172]</p>	No	



					<p>characterise current service provision based upon neoliberal ideologies. Method Conceptual assumptions and theoretical positions associated with human rights in relation to people with ID are critically examined. Results The analysis results in an argument that current conceptualisations of personhood in relation to human rights exclude people with ID. The adverse effects of this exclusion are exacerbated within services which emphasise the permissive rights associated with a neoliberal agenda of 'choice' over protective rights. Conclusions In order to ensure that the human rights of people with ID are upheld, neoliberal emphases on choice need to be tempered and a more nuanced and inclusive notion of personhood in relation to universal human rights needs to be adopted."</p>			
Polish	KONWENCJA O PRAWACH OSÓB NIEPEŁNOSPRAWNYCH	Words and pictures	Online - pdf booklet	http://www.psouu.org.pl/sites/default/files/publikacje/konwencja-pdf.pdf		Copyright by PSOUU, Warszawa 2008	Yes	This is an easy to read guide for people with learning disabilities. It wasn't easy to find but that Organisation has



								a lot of easy to read documents
Polish	Kształcenie profesjonalistów zajmujących się edukacją ustawiczną	Words	Online - pdf booklet	http://www.psouu.org.pl/sites/default/files/publikacje/Kształcenie%20profesjonalistow%20-%20internet_0.pdf		Copyright for the Polish edition by PSOUU, 2012	No	Document describing how use easy to read format in writing texts for people with learning disabilities
Polish	NUMER 3/2012 - PFRON łatwy w czytaniu	Words	Online	http://www.pfron.org.pl/ebi/popzednie-wydania/numer-32012-pfron-latw/12,Zasadykonstruowaniatekstulatwegowczytaniu.html		eBIFRON, 2012	No	Document describing how use easy to read format in writing texts for people with learning disabilities on official website of Polish Fund for People With Disabilities
Polish	Konwencja Praw Osób Niepełnosprawnych	Words	Online - pdf booklet	http://www.unic.un.org.pl/dokumenty/Konwencja_Praw_Osob_Niepelnosprawnych.pdf		A/RES/61/106 13 December 2006	No	61/06 Convention on the Rights of Persons with Disabilities
Greek	International agreement on the rights of pwd	words, pictures/symbols sound and video (Greek sign language)	Online-word booklet	http://www.prosvasimogr/symvasi_oh/		Experts IT Integrated Solutions	Yes	This is an Easy To Read text in Greek on the Convention on Human Rights for PWD



Greek	UN Standard rules on the equalization of opportunities for persons with disabilities	words and pictures/symbols	online-word-booklet	http://www.pi-schools.gr/special_education_new/index_gr.htm		Hellenic Pedagogical Institute Department of Special Education November 2009	Yes	This booklet is about the Standard Rules of the United Nations for the Equalization of Opportunities for PWD
Greek	Law 3699/2008 and the rights of students with disabilities and special educational needs	Words and pictures/symbols	online-word booklet	http://www.pi-schools.gr/special_education_new/index_gr.htm		Hellenic Pedagogical Institute Department of Special Education and training March 2009	Yes	This is a Easy to Read booklet about a law regulating the special education and training. It is a written for the PWID
Greek	International Convention on the rights of people with disabilities and mental disabilities	Words	online-pdf	http://www.esaea.gr/legal-framework/symbasn-oh	Explanation of the importance of the UNCRPD. Summarise the articles and explains the impact it will have for PWD in Greece.	National Confederation of persons with disabilities	No	A summary of the UNCRPD in an 16 pages booklet
Greek	Country Report on Greece for the Study on Member States' Policies for Children with Disabilities							This study looks at the situation of children with disabilities in Greece to identify the gaps in the legal frameworks and its implementation, the obstacles faced by children



		Words	online-pdf	http://www.europarl.europa.eu/studies	<p>Includes the assessment of the practical implementation of the rights and legal principles in Greece. Children with disabilities in Greece face significant difficulties, many of which are related to the economic crisis. The reduced economic capacities at both State and family level prevent children from fully enjoying their right to inclusive education and the right to have access to quality health services and social care support structures. Cultural prejudices and societal perception of disability further prevent children with disabilities from becoming an integral part of society. includes a lot of useful links on the subject.</p>	<p>European Parliament, manuscript completed in June 2013. European Union, Brussels, 2013</p>	No	<p>with disabilities and best practices. This country study is part of a larger study which analyses 18 Member States. Based on a comparative analysis of the country studies, the report 'Study on Member States' Policies for Children with Disabilities' provides some recommendations for EU action to enhance the situation of children with disabilities.</p>
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Greek	Research of ActionAid Hellas on special education and training for persons with disabilities in our country	words	online-pdf	www.actionaid.gr/media/452700/ekthesi-ereunas-actionaid-teliko.pdf	<p>This is a qualitative research carried out by the researcher Pelagia Papanikolaou Candidate Dr. of Criminology University of Athens Law School, which took place in 2014. In total, 122 people responded, 84 teachers and 38 parents of children with disabilities on questions regarding information about education for persons with disabilities and access to early intervention services, involvement of parents and children in decision-making, accessibility (transport, material, human resources), the socialization of students, inclusive education in mainstream schools and teacher training.</p>	Actionaid Hellas December 2014 Pelagia I. Papanikolaou	No	<p>This research is a thorough attempt to examine whether PWIDs are aware of their right to study and be educated. The question is supposed to be answered from three different focus groups: PWIDs, their parents and people who work with them. The research also tries to examine in general the awareness of PWID's rights. The questionnaire although it was answered by numerous youth workers, it had less correspondence from the parents and the PWID themselves</p>
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Lithuanian	Convention on the Rights of Persons with Disabilities for children	words and pictures	Online pdf booklet	http://www.ndt.lt/wp-content/uploads/seni_failai/konvencija-vaikams-pataisytas-.pdf	Informative pictures, understandable for intellectually disabled people. Easy to read text written in capital letters	The Department for the Affairs of Disabled under the Ministry of Social Security and Labour	Yes	This is an easy to read guide for people with learning disabilities. I find it still difficult to understand as it has lots of writing. More than one idea per picture.
Lithuanian	Convention on the Rights of Persons with Disabilities	Words	Online	http://www.ndt.lt/wp-content/uploads/seni_failai/Neigaliuju_tesiu_konvencija.pdf	Official text	The Department for the Affairs of Disabled under the Ministry of Social Security and Labour	No	very complicated text for ID
Lithuanian	Convention on the Rights of Persons with Disabilities	PowerPoint presentation	Online	http://www.ndt.lt/wp-content/uploads/seni_failai/Neigaliuju_tesiu_konvencijos_pristatymas_pakeistas_Compatibility_Mode_.pdf	Official text	The Department for the Affairs of Disabled under the Ministry of Social Security and Labour	No	very complicated text for ID
Lithuanian	Know your rights Protection against discrimination			http://bookshop.europa.eu/lt/-inokite-savo-teises-pbDS0415271/?CatalogCate				



		Words	Online pdf booklet	goryID=EBOep2IxR4UAAAEuqdFhSE3Z	Official text	European Commission	No	very complicated text for ID
Lithuanian	Your Europe, your rights	words and pictures	Online pdf booklet	http://bookshop.europa.eu/lt/j-s-europa-j-s-teis-s-pbKM0214968/?CatalogCategoryID=EBOep2IxR4UAAAEuqdFhSE3Z	Informative pictures and official text	European Commission	No	complicated text for ID
Lithuanian	Did you know? 10 EU rights at a glance	words and pictures	Online pdf booklet	http://bookshop.europa.eu/lt/ar-inote-kad--pbNA0414127/?CatalogCategoryID=EBOep2IxR4UAAAEuqdFhSE3Z	Informative pictures and official text	European Commission, Directorate-General for Communication, Directorate-General for Justice and Consumers	No	complicated text for ID
Lithuanian	Balloon game	word, sounds and pictures	Online puzzle game	http://ec.europa.eu/0-18/balloon-game/balloon-game_lt.htm	Funny, interactive game Pixel, Urso, Kangi, Blu, Nina, Max and Bob want to guide you through your rights, but they have been captured on a desert island. Rescue them by showing that you know your rights and navigate your way to freedom.	European Commission	No	too complicated for ID
Lithuanian	Jigsaw puzzle	word, sounds and pictures	Online puzzle game	http://ec.europa.eu/0-18/balloon-game/balloon-game_lt.htm	Funny, interactive Complete the jigsaw puzzle to reveal Ana and Oli, Pixel, Urso, Kangi, Blu, Nina, Max and Bob who are here to guide you through your rights.	European Commission	No	too complicated for ID



Lithuanian	Colouring book	word, sounds and pictures	Coloring book	http://ec.europa.eu/0-18/colouring-book/colouring-book_lt.htm	Coloring book Choose your favourite colours for Ana and Oli, Pixel, Urso, Kangi, Blu, Nina, Max and Bob who are here to guide you through your rights.	European Commission	No	just for children; does not fit to young ID people
Lithuanian	Flight Game Quiz	word, sounds and pictures	Online game	http://ec.europa.eu/0-18/flight-game-quiz/flight-game-quiz_lt.htm	Funny, interactive game Navigate your plane through obstacles and collect points by answering questions about the EU and your rights.	European Commission	No	too complicated for ID
Lithuanian	Official website of the European Union		Online	http://europa.eu/index_lt.htm	Kids' Corner, Teachers' Corner, no Coner for Disabled Eu by topics - no topic Disability	European Commission	No	not adapted for ID
Lithuanian	The main rights and freedoms in the Convention		Online film	https://www.youtube.com/watch?v=VOYSV520Ra0	The Court has produced a video presenting the main rights and freedoms in the Convention. Aimed at a wide range of viewers, this video is currently available in 38 languages. The Court wishes to encourage initiatives aimed at including this video in civic education programs.		No	too complicated for ID



ANNEX I: DEMOGRAPHIC QUESTIONNAIRE

Project details

1. Please provide the following information	
<i>Participant ID (e.g. 01PL)</i>	
<i>Your email address:</i>	
<i>Project name:</i>	
<i>Country:</i>	

SECTION 1: About your learners/service users

2. Please indicate the total number of distinct (i.e. different) learners taking part in your learning programmes.	
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3. Please indicate the number of distinct learners taking part in learning programmes of the below lengths (on a weekly basis)	
<i>Less than 6 hours</i>	
<i>6 or more hours but less than 10</i>	
<i>10 or more hours but less than 25</i>	
<i>25 or more hours</i>	

4. Please indicate the number of distinct learners of each gender taking part in your learning programmes.	
<i>Male</i>	
<i>Female</i>	
<i>Not known</i>	
<i>Total of the above</i>	

5. Please indicate the number of distinct learners in each age category.	
<i>Under 18</i>	
<i>18-24</i>	
<i>25-49</i>	
<i>50-74</i>	
<i>75 or over</i>	
<i>Not known</i>	
<i>Total of the above</i>	



ANNEX II: BASIC HUMAN RIGHTS QUESTIONNAIRE (SURVEY 1)

Project details

Please provide the following information	
Participant ID (e.g. 01PL)	

Questionnaire

1. Are you allowed to go to school / day service?		
No	Yes	Don't Know
2. Are you allowed to attend classes / courses that interest you?		
No	Yes	Don't Know
3. Are you allowed to work?		
No	Yes	Don't Know
4. Are you allowed to earn money?		
No	Yes	Don't Know
5. Are you allowed to choose where you want to live?		
No	Yes	Don't Know
6. Are you allowed to get married?		
No	Yes	Don't Know
7. Are you allowed to start your own family?		
No	Yes	Don't Know
8. Are you allowed to decide what to do every day?		
No	Yes	Don't Know



9. Are you allowed to go out when you want?		
No	Yes	Don't Know
10. Are you allowed to vote in your country?		
No	Yes	Don't Know
11. Are you allowed to speak up about anything that you find difficult or challenging?		
No	Yes	Don't Know

12. Are you allowed to choose your own religion?			
No	Yes	Don't Know	
13. Which one of these is <u>NOT</u> a basic human right?			
The right to work	The right to own a computer	The right to cook	The right to harm other people
14. Are you allowed to spend your money?			
No	Yes	Don't Know	
15. Who decides how you spend your money?			
I decide	My parents / supporter	I decide together with my parents / supporter	Don't know
16. Do you understand what we mean by 'human rights'?			
No	Yes	Don't Know	



ANNEX III: MY HUMAN RIGHTS QUESTIONNAIRE (SURVEY 2)

Project details

Please provide the following information	
Participant ID (e.g. 01PL)	

Questionnaire

1. How did you find out about human rights? (Please select all that apply)			
Parents	School	Day Service	Friends
Magazine	Book	Film	Leaflet
Internet	Theatre	Other (Please Specify)	
2. Where else can you find information about human rights (Please select all that apply)			
Parents	School	Day Service	Friends
Magazine	Book	Film	Leaflet
Internet	Theatre	Other (Please Specify)	
3. Do you find existing information easy to understand?			
No	Yes	Don't Know	
4. What would make the existing information easier to understand? (Please select all that apply)			
Use of pictures	Use of videos	Use of sound	
Use of examples	Role play		
Other (please specify)			
5. Do you find existing information about human rights useful?			
	Yes	Don't Know	



No		
6. What would make the existing information about human rights more useful? (Please select all that apply)		
Use of pictures	Use of videos	Use of sound
Use of examples	Role play	
Other (please specify)		

ANNEX IV: BASIC HUMAN RIGHTS QUESTIONNAIRE (SURVEY 3)

Project details

Please provide the following information	
Participant ID (e.g. 01PL)	

Questionnaire

1. Are you allowed to go to school / day service?		
No	Yes	Don't Know
2. Are you allowed to attend classes / courses that interest you?		
No	Yes	Don't Know
3. Are you allowed to work?		
No	Yes	Don't Know
4. Are you allowed to earn money?		
No	Yes	Don't Know
5. Are you allowed to choose where you want to live?		
No	Yes	Don't Know
6. Are you allowed to get married?		
No	Yes	Don't Know
7. Are you allowed to start your own family?		
No	Yes	Don't Know
8. Are you allowed to decide what to do every day?		
No	Yes	Don't Know
9. Are you allowed to go out when you want?		



No	Yes	Don't Know
10. Are you allowed to vote in your country?		
No	Yes	Don't Know
11. Are you allowed to speak up about anything that you find difficult or challenging?		
No	Yes	Don't Know

12. Are you allowed to choose your own religion?			
No	Yes	Don't Know	
13. Which one of these is <u>NOT</u> a basic human right?			
The right to work	The right to own a computer	The right to cook	The right to harm other people
14. Are you allowed to spend your money?			
No	Yes	Don't Know	
15. Who decides how you spend your money?			
I decide	My parents / supporter	I decide together with my parents / supporter	Don't know
16. Do you understand what we mean by 'human rights'?			
No	Yes	Don't Know	
17. Use of pictures helps me to understand information better?			
No	Yes	Don't Know	

18. Use of videos helps me to understand information better?		
	Yes	Don't Know



No		
19. Use of sound helps me to understand information better?		
No	Yes	Don't Know
20. Use of examples helps me to understand information better?		
No	Yes	Don't Know
21. Use of role play helps me to understand information better?		
No	Yes	Don't Know



ANNEX V: STAFF FEEDBACK QUESTIONNAIRE (SURVEY 4)

Project details

Please provide the following information	
Participant ID (e.g. 01PL)	

Questionnaire

17. In your view what was the participants' knowledge and understanding of basic human rights article 19 <u>BEFORE</u> the workshop? (1 - Very poor, 5 - Excellent)				
1	2	3	4	5
18. In your view what was the participants' knowledge and understanding of basic human rights article 19 <u>AFTER</u> the workshop? (1 - Very poor, 5 - Excellent)				
1	2	3	4	5
19. What helped participants to gain better understanding of article 19? (1 - Not very much, 5 - A lot)				
I. Use of pictures				
1	2	3	4	5
II. Use of videos				
1	2	3	4	5
III. Use of sound				
1	2	3	4	5
IV. Use of examples				
1	2	3	4	5
V. Use of role play				
1	2	3	4	5



VI. Other (please specify)				
1	2	3	4	5
20. In your view, could the RIX Wiki be used to help create easy to read information and help people with Intellectual Disabilities to better understand information?				
No			Yes	
I. Please explain				



ANNEX VI: *EVALUATION PROTOCOL*

Evaluation overview

Every Puzzle project partner will involve learners with learning disabilities from schools, day and residential services in this evaluation.

The aim of this evaluation is:

- 1) Firstly, to find out demographic information about project participants we ask each person to complete demographic questionnaire.
- 2) Secondly, we want to find out what people with learning disabilities in your organisation or service already know about their Basic Human Rights.
- 3) Finally, to find out where people with learning disabilities from your organisation or service learn about their Basic Human Rights and if the information, that they have access to is readily available and understandable.

To meet the aims of this evaluation we propose to use the following evaluation instruments and processes:

The evaluation process

Phase 1

- 4) **Session 1 - Demographic questionnaire:** age, gender, country, declared disability, living arrangement, relationship status, working status, frequency of attending day service. Could you please ensure that you use participant ID for each person and that the same participant's ID is being used in **all** surveys.

We suggest to use number 01 – 99 followed by the country's initials eg. PL - for Polish participants, LT – for Lithuanian participants and GR for Greek participants.

Wojtek from Poland we could use - 01PL

Tommy from Greece we could use – 01GR

Lina from Lithuania we could use – 01LT

- 5) **Session 2 - Baseline assessment survey 1** aims to measure the existing awareness and understanding of Basic Human Rights. At this stage we want to find out the existing awareness and understanding of Human Rights.
- 6) **Session 3 – Human Rights Workshop** followed by the baseline assessment **Survey 2**. This survey aims to measure your access to existing information about Basic Human Rights and evaluate the accessibility of the existing information. We want to find out what formats help people with learning disabilities to understand information best e.g. leaflets, websites, multimedia etc. We want to explore how they find information about Human Rights? Do they understand it? What information is helpful?

Phase 2

- 7) **Session 4 - Rix Wiki Focus Group** - Finalise **RIX Wiki** – Article 19 and use the Wiki with your learners to educate them and evaluate RIX Wiki use as a tool for providing easy to read information.
- 8) **Survey 3** - to see the effectiveness of the use of RIX Wiki and the easy read information.
- 9) **Survey 4** - this is for staff only, following the delivery of workshops and focus groups, to capture their perceptions, experiences and viewpoints.

Please note:



All evaluation instruments are designed in English but partners are encouraged to translate each survey into their national language to maximise service users understanding.

Demographic questionnaire in particular covers questions of personal nature – please be assured that information collected as part of this evaluation will always be treated in confidence, will be anonymised and only used for the purposes of this evaluation.

All surveys can be applied electronically using tools such Kahoot for example or can be paper based. It is up to individual partner to decide what is appropriate for their learners. It is important however, that the results are captured in a spreadsheet using the provided template. If you are using Kahoot or other online survey tool the summary of results will be automatically generated. When you translating surveys please ensure that the order of questions and answers remains unchanged.

Please ensure that you save all survey results and send them in a spreadsheet to gosia@uel.ac.uk m.flint@uel.ac.uk duzewski@gmail.com

If you are using Kahoot website, the survey results will be generated automatically, in other case, you will need to collate those manually and record them in the templates provided.

DEADLINE: All results should be returned by end of May 2016.



Evaluation Procedures

Phase 1 Baseline assessment

A) Preparing for the assessment

- a. Please translate all questionnaires into your language and design them using an appropriate tool e.g. Kahoot or paper versions (whatever is more appropriate and easier for you and your participants)
- b. Please familiarise yourself with the process and questions
- c. Please prepare visual resources that you might need to use to help your participants understand the questions asked.
- d. Ensure you have enough staff to support everyone taking part in each session.

B) Session 1 – Demographic data collection

- a. Please introduce the project to your group. Please explain what the process of the evaluation and reassure your service users of the confidentiality of the information collected.
- b. Please reassure your service users that there are no right or wrong answers, we want to get as true picture as possible. Please assign a participant number for each participant e.g. 01LT, 02LT, 03 LT...etc
- c. Start the '**Demographic Questionnaire**' – allow as much time as required for the service users to complete all questions.
- d. Save the results in the form provided (Demographic_Results_Template) and name the file using the following format: Demographic_GR_Estia or Demographic_PL or Demographic_LT.
- e. Share the results with Gosia, Mark, Ulla and Wojtek.

C) Session 2 – Basic Human Rights awareness

- a. Please start this session by explaining the purpose of the evaluation and confirm that the confidentiality of all participants will be respected at all times.
- b. Please reassure your participants that there are no right or wrong answers.
- c. Start the baseline '**Survey 1 – Human Rights Basic**' – allow as much time as required for all participants to complete the survey.
- d. Save the results and call the file using the agreed format eg. Survey 1_GR etc.
- e. Share the results with Gosia, Mark, Ulla and Wojtek.

D) Session 3 – Human Rights Information - Workshop

- a. Again explain the purpose of the evaluation and confirm that the confidentiality of participants will be respected at all times.
- b. Identify a resource in your language that aims to Start with a discussion about **Basic Human Rights**

Discussion: Basic Human Rights - *What does it mean?*

Definition



“Human Rights are about how we treat each other. They are about: respect, freedom, equality, dignity and fairness. The Human Rights Act protects everyone.”

Together with the participants review the easy read version of The United Nations Convention on the Rights of People with Disabilities – in your own language. Have a look at the definition there to ensure that everyone has an understanding of what is meant by Basic Human Rights.

http://www.equalityhumanrights.com/sites/default/files/documents/publications/uncrpd_guide_easyread.pdf

- c. Start the baseline ‘**Survey 2 - My Human Rights Information**’ - allow as much time as required for the service users to complete the survey.
- d. Save the results and name the file using the agreed format e.g. Human Rights Workshop _GR_Estia.



Phase 2 RIX Wiki – Article 19 – Workshop

Link to Article 19 - <http://www.equalityhumanrights.com/private-and-public-sector-guidance/public-sector-providers/human-rights-guidance/a-guide-to-the-un-disability-convention/part-2-know-your-rights/article-19-living-independently-and-being-included-in-the-community>

1) Preparation for the Workshop

- a. Please ensure that you have access to Photosymbols or other symbol set used in your organisation/service – if you don't have access please email gosa@uel.ac.uk
- b. Please ensure that you have completed RIX Wiki about Article 19 in your own language, using easy read principles and included appropriate visual images and media content. Ensure that you apply what you have learnt in London's Easy Read training.
- c. Once Article 19 – Wiki is completed, schedule a workshop with your service users to review RIX Wiki Article 19.
- d. Go through each section of the Wiki and discuss each page with the individuals.

2) Article 19 – Wiki Workshop – 45 min or so.

Introduce the project to your service users/learners/participants.
Review the Human Rights definition again.

Open the RIX Wiki – Article 19 and go through each page with the group. Discuss with the participants what the Wiki is about:

- What do you think is happening in the picture/ video?
- What can you see?
- What does it mean?
- What does it say?
- What does it mean to you?
- As a group or in pairs please act-out what is happening on a picture/video

After the workshop please:

- 1) Apply **Survey 3 – RIX Wiki Human Rights Basic** – this survey is almost identical to survey 1 with some extra questions at the end. The purpose is for us to see if there is any change in participants' knowledge and understating of Basic Human Rights following the Wiki session and to get their views on the use of Wiki.

2) Staff/facilitators of the workshop please also complete Survey 4: Staff



Phase 3 Result – by the end of May

- a. Save the survey 3 and 4 results and name the file using the agreed format e.g. Survey 4_GR.
- b. Summarise the feedback from Wiki Workshop facilitators.
- c. After the evaluation activities please finalise your results and transfer them to the provided format and share them with gosia@uel.ac.uk, mflint@uel.ac.uk, Ulla.Bohman@mtm.se and duzewski@gmail.com

DEADLINE: 31/05/2016

Kahoot Instructions

- 1) Create account on website <https://create.kahoot.it/> following the simple steps.
- 2) Share Your Kahoot login with Wojtek - e-mail duzewski@gmail.com
- 3) Wojtek will share the project surveys with you in English
- 4) Duplicate surveys and edit them translating into your national language
- 5) After that your surveys will be ready to be used with your learners

If you find it difficult to follow the above instructions and setting up your own Kahoot accounts please contact Wojtek or Gosia and we will be happy to help you with this. Once you have an account and your surveys are in your language you are ready to start the session with your learners. Please ensure that everyone has access to a device – please note that Kahoot works across platforms.
Good Luck

DEADLINE: All results should be returned by end of May 2016.

