Eötvös Loránd University Faculty of Pedagogy and Psychology

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SUMMARY OF DOCTORAL (PHD) DISSERTATION

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Participatory research involving individuals with intellectual disabilities: The adaptation of the Play decide method

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Theoretical background

The dissertation focuses on the involvement of the people with intellectual disabilities in the discourses, decisions and studies about their own lives. The main principle of this work is that people with disabilities should be involved in the discourse and decision-making processes about their own lives. The deliberative methods support consensus among all parties in decisions on various public policy issues. These decisions need to involve stakeholders, individuals who are concerned about certain topics, experts, decision-makers, researchers, etc. In order to make reasonable and well-grounded decisions, it is crucial to have a thorough knowledge and understanding of the subject (Price, Neijens, 2007). This requires the development of knowledge-based background materials. Play decide is a deliberative method for creating such background materials in a structured manner. We used this framework in our research on topics related to the lives of people with intellectual disabilities. The adaptation of the methodology was carried out using participatory research involving stakeholders.

The theoretical framework of the dissertation is given by disability studies. This is an interdisciplinary framework (Nagy, Könczei and Hernádi, 2009) in which the emphasis is on the scientific practice of relying on the experiences of people with disabilities (Barnes, 2009). It is connected to disability movements and is part of critical social sciences (Snyder, 2005). The protagonist of disability studies is the person living with disabilities. Even its research practice is characterized by the participation of the persons concerned. There are different levels of involvement of individuals with disabilities in research. While participatory research involves both disabled people as researchers and non-disabled academic investigators, emancipatory research is conducted by people with disabilities only (Marton and Könczei, 2009). These two types of investigation are called inclusive research. Apart from their involvement of individuals with disabilities, their goal is to be useful, accessible to all, and to break down traditional hierarchical systems (Barnes, 2009). Other participatory and action research methods and paradigms, as well as their development, history, and key features are further discussed in the dissertation. In all of these paradigms, there is a significant role of self-advocacy and independent decision making by representatives of marginalized or oppressed groups. In the theoretical part of the dissertation, I discuss the question of power in traditional and in inclusive research. As it has been recognized in the literature, conventional research preserves and often strengthens existing power relations. The subjects of traditional research often become vulnerable because the researchers survey them about their lives and interpret the results in accordance with their own interpretation and goals. Inequality also stems from one-sidedness, as the researcher asks the questions and the subject responds to them: the life of the subject is an open book for the researcher, but the subjects do not get to know the researcher (Oliver, 1992).

The purpose of this research

The present study focused on three target areas based on the specific goals and outcomes.
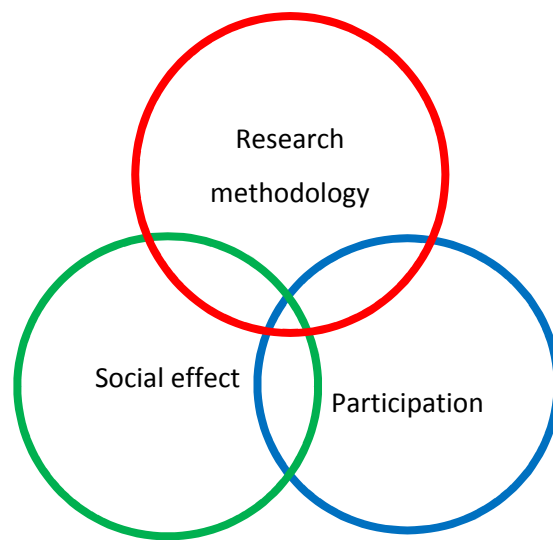
Figure 1: Main areas of interest

1. In our country, the involvement of people with intellectual disabilities in participatory research is new. With our results, I would like to contribute to the scarce literature and facilitate further research involving people with intellectual disabilities. I would like to offer a methodological "toolkit" for those researchers who take a similar initiative. I will do so by providing a systematic summary of the literature and by analyzing concrete experiences from the present research project. My aim is to show specific circumstances under which one may carry out successful participatory research with persons with intellectual disabilities.

2. The aim of this inclusive research is to eliminate the gap between the subjects and the researcher, between science and practice and between professionals and clients through empowerment. During this research, our goal was to create a balanced relationship among the persons involved in the study (whether academic researchers, professionals or persons with intellectual disabilities). A further aim was to ensure that all people involved in this research benefit from their participation. These benefits were manifested at a personal level, in improvement of certain cognitive and linguistic skills, as well as through empowerment.

3. Our final goal was to adapt the Play decide method by developing and producing interactive DVDs for individuals with intellectual disabilities. Thanks to its audiovisual form, this method can be a useful resource of self-advocacy for people with intellectual disabilities. It may help them to understand important issues that affect their lives. The development of the auxiliary material was done with the participation of persons with intellectual disabilities using an easily understandable language, in an easy-to-read format. The auxiliary material generates discourse among the researchers and helps people with intellectual disabilities to create their own opinion about important topics concerning their lives, including taboo subjects, such as love and sexuality.

Taken together, the overall aim of our research was to provide tools and outcomes that support the participants of this research, as well as other people with intellectual disabilities and the practitioners working with these individuals. Finally, it was our intention to further advancescientific research involving people with intellectual disabilities by providing them with methodological suggestions.

Research questions

We organized our research questions according to the purpose and the expected results of the research.

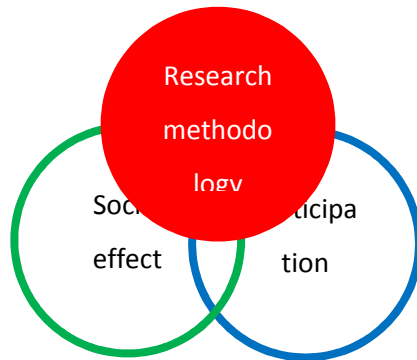## 1. Questions related to the methodology of participatory research

Figure 2: An illustration of the research questions, highlighting "Research Methodology"

1. What methods and methodological elements support the participation of people with intellectual disabilities in participatory research?

2. What kind of power relationships are apparent among the participants and how do these relations change during the research process?

3. What features related to the intellectual disability affect the research process?

4. What methodological solutions do we find for the features above?

5. What kind of decision-making mechanisms can be observed during the research?

6. How does the participants' disability manifest in the research and what do they think about the concept of disability and about their own disability?

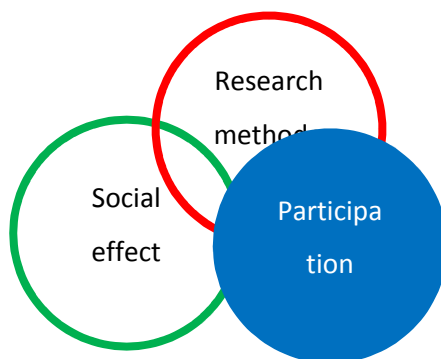## 2. Questions related to the changes that emerged in the participants

Figure 3: An illustration of research issues: highlighting "Participation"

1. How does the cognitive and linguistic level of participants with intellectual disabilities change during the research process?

2. What is the motivation of the participants in partaking in the research project?

3. In what specific cases may we observe the empowerment of the participants during the study?

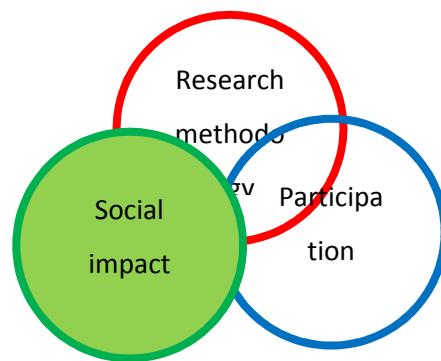### 3. Questions related to social impact

Figure 4: An illustration of research questions: highlighting the "Social Impact"

1. How can the Play Decide method be adapted for people with intellectual disabilities?

2. How do participants contribute to the completion of the DVDs?

3. What kind of social awareness-raising effects can be experienced in the present participatory research?

Methodology

This research study was conducted from May 2011 to May 2013. During these two years, we had meetings in four different locations, altogether eighteen times.

When choosing the participants, I relied on my personal and professional acquaintances. A good relationship among the participants is particularly important for the success of participatory research.

Selection Criteria:

- Prior relationship between the research leader and the research associates

- Personal interest in the topic

- Commitment to participation in research

- Age between 20 and 30 years

- Living in a family

- Equal gender distribution

- Working or studying in institutions for people living with disabilities, or being a special education student.

Eight people participated in the research project as researchers. This includes me as the primary investigator, the research assistant (co-facilitator), and six persons with intellectual disabilities. However, during the two years period, there were 5 permanent participants in the study; 3 females and 2 males, all between the ages of 20 to 30 years. Two of the people with intellectual disabilities were women (their age at the beginning of the research project was 20 and 26 years, both were diagnosed with Down Syndrome) and one man (22 years old at the beginning of the research project; he did not have a specific diagnosis, but had a moderate degree of intellectual disability). They all lived with their families, in or around Budapest. At the time of the study, one of them went to school, two of them attended special centers.

Applied methods

Participatory research with persons with intellectual impairment is characterized by the application of multiple methods in a flexible manner (Nind, 2008, Walmsley and Johnson, 2003). Our participatory research was primarily based on the qualitative methodology, but we used both qualitative and quantitative methods for data collection and data analysis. In the dissertation, I distinguish between the methods used with the active participation of people with intellectual disabilities and those that were used to collect data about the participants.
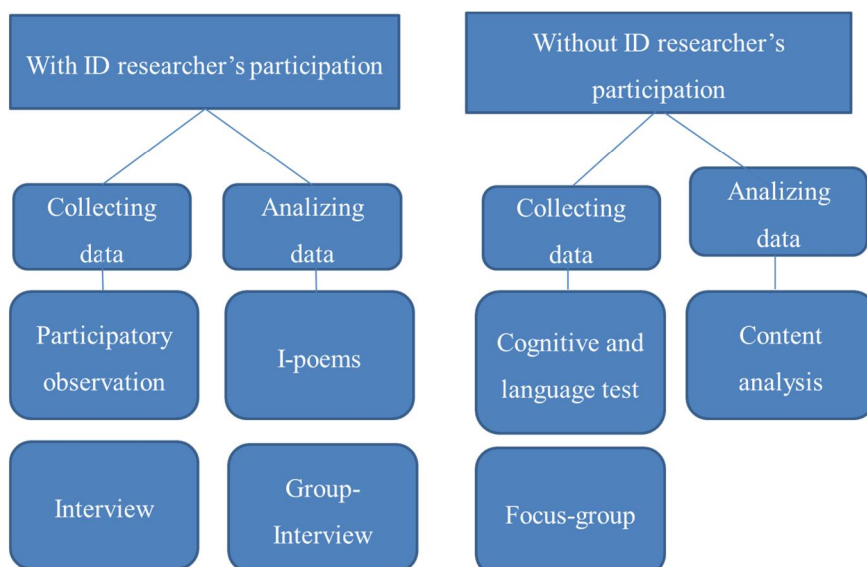

Figure 5: Illustration of the methods used in participatory research

Data collection methods involving participants living with intellectual disabilities as researchers:

Participatory observation:

To collect general impressions of participants. To observe the features of the intellectual disability and its impact on participants' involvement in research. To collect and document methods and tools supporting the participation of people with intellectual disabilities.

Participatory Interview:

Each participant with intellectual disability made an interview with one of their tutors on the topic of leisure time in connection with their own activities. Each participant was supported by students of the ELTE-Barczi Gusztáv Faculty of Special Education. Individuals with intellectual disability –interviewers- and special education students worked together in pairs.

Data collection methods that have been realized without the participation of people with intellectual disabilities:

Cognitive and linguistic examination:

With my supervisor, Klara Marton we compiled a protocol to test the cognitive and linguistic performance of the participants at the beginning and at the end of the study. Procedures included the examination of speech fluency, vocabulary, decision making mechanisms and problem-solving skills, memory recall, response consistency, and participants' persistence during testing.

Focus group:

The focus groups involving the persons with intellectual disability gave us an opportunity to better understand their views, knowledge, and information on specific topics. Besides the concrete answers, the commentaries, gestures, and group dynamics also included important information. Using the focus group method, we learned about group processes, interactions, and group conventions while discussing certain topics.

Data analysis methods with the participation of researchers with intellectual disabilities:

I-poems method:

At the completion of the research project, we administered "I-poems" (Edwards, Weller, 2012), a method that allows people with intellectual disabilities to contribute to the data analysis phase of the research. The essence of the method is that the research leader (in some cases together with the participants) gathers first person singular sentences. These personalized manifestations are then grouped either in a more general way (participants' manifestations by theme) or by each participant individually to create a poem together. These poems reflect the participants' views about the research process and about their role in it.

Group Interview:

The final evaluation of the research was conducted with the participants living with intellectual disabilities in a group interview at the last joint meeting. We were curious about the general opinion of the participants, their criticism of the research project, their motivation

for participation and about the most memorable moments for them. Participants responded to the evaluation questions successively.

Data analysis methods that have been realized without the participation of people with intellectual disabilities:

Content analysis:

We made recordings at the research meetings, which were transcribed following the end of the research project. I conducted a content analysis on the transcripts in accordance with the research questions. During the content analysis, I systematically examined the transcripts using the Atlas.ti software. The software provides both qualitative and quantitative measures. If you are encoding the text, you can retrieve text details from the code categories and paste them next to each other. This feature enables the researcher to observe relevant phenomena, analyze the similarities and differences across texts, and to examine the structures and patterns. These are objective data that may complement or contradict the researcher's subjective observations (Vicsek, 2006).

Results

Similarly to the objectives and research questions, the results are also discussed within this trilateral structure. I discuss each result according to the research questions.

1. Results related to research methodology

Methods, methodological elements

Within this section I examined which methods and methodological elements may facilitate the participation of people with intellectual disabilities in research. I grouped the methods depending on whether they involved the active participation of people with intellectual disabilities or not.

Methods for collecting data by research participants living with intellectual disabilities:

- *Participatory observation*

Participatory observations were more helpful for the research participants in finding the runaway rules and for getting to know each other better. The participants were taking notes in their diaries. The diary entries gave us insight into the thought processes of the individuals with intellectual disabilities. This method allowed us to observe that participants did not always understand the theoretical contents of the research sessions and that note taking was a difficult process for them. But journal entries also showed that the participants were serious about participating in the research, and that they considered the

research as something serious but often incomprehensible to them. However, the entries showed that they were thinking about the themes at home and outside the research sessions. For example, they collected contents to the theme of leisure time on their own. The participant's observation method naturally allowed everyone to participate in the conversations and helped me to observe how participants living with intellectual disabilities behaved in the research situation. The observation and the notes showed the same: participants living with intellectual disabilities were motivated to participate, but not so much because of the content (which they often didn't even understand), but because of the activity itself (see later: Participants' motivation to participate in research).

- Participatory interview

Participants living with intellectual disabilities conducted structured interviews with the support of peer university students with a person who was involved in their free time activities (e.g., teacher, mentor, tutor, etc.). Interviews were recorded on videos that were finally analyzed with all participants. We aimed to observe how people living with intellectual disabilities conduct interviews and how the non-disabled interviewees behave in such a situation; how power relations are reflected in such a reversed situation. Overall, we could not make any general conclusion about the way people with intellectual disabilities behaved as interviewers because each participant behaved differently in this situation. Based on the observations, we may conclude that the interviews were largely determined by the interviewers' personality and by their relationship with the interviewee. Each participant needed direct support either during the preparation phase or during the interview. The attitude of the interviewee (non-disabled people) was mostly determined by their general attitude towards people with disabilities, their personality and their relationship with the interviewer. Interviewing is therefore a research method which needs careful preparation and appropriate support for motivated people living with intellectual disabilities. Using it multiple times, people with intellectual disabilities may become more confident in interviewing others, which will help them to make more successful interviews.

Methods for data analysis, involving people with intellectual disabilities as researchers

- I-poem method

This method has been used to give participants a tool for data analysis by recalling the earlier events of the present research. It was also important for the participants to be able to place themselves in the research process and to see their role in it. The purpose of this method was also to create tangible memories, to remind participants of the research that they have participated in. We found that participants were motivated by such emotional and memory-related facrtors (see motivation of participants for participation). They were proud that their words were recited, kept, noted and considered as to be important.

- Group interview

At the last meeting of this research project, we conducted a group interview, in which the participants evaluated the study and reported on their experiences. In the group interview, participants living with intellectual disabilities could clearly grasp the essence of the biggest difficulty of this study: the problem of understanding each other. Accurate feedback was given by the participants of the role of the research manager and assistant, according to which

the assistant supports the participants, while the leader is planning, organizing the study and is the "smart" one. The group interview showed that the participants did not influence each other, rather inspired each other to formulate honest opinions and experiences.

Data collection methods used without the involvement of researchers living with intellectual disabilities

- Cognitive and linguistic examination

The results of this part are outlined in Section 2 of the Results

- Focus Group

Based on our experience, for the application of the method people with intellectual disabilities need a more informal, friendly atmosphere, where they know and understand each other. This encourages the participants to promote greater self-expression and facilitate easier understanding of each other. Voice recordings of conversations is even more important with participants living with intellectual disabilities than in typical cases because it is often difficult to understand what the participants are saying. There are a number of benefits of the focus group method, such as its consistent structure which also helped participants to, understand the specific roles and the group dynamics. It was a disadvantage of this method that I was "assigned" a prominent role as the moderator (and research leader) by explicitly directing the conversation. In many cases I determined who would talk about what. This role assignment is in many respects contradicting the principles of our research, namely that all people involved in the study can shape the research process equally. Despite this characteristic of our team work, equality was achieved by showing mutual respect toward each other as human beings. In some cases, it is useful to apply the focus group method with people with intellectual disabilities, when we are interested in the participants' views, knowledge, experiences, and roles in the group. In our research, we were able to use the method to find out how much participants living with intellectual disabilities know about certain topics and how they think about these themes as we were developing the interactive DVDs for other people with intellectual disabilities.

Data analysis, without the involvement of researchers living with intellectual disabilities

- Content Analysis

I worked on the transcriptions of the audio recordings from the research meetings with Atlas.ti software. I created code categories of the details of the conversations corresponding to our research questions. I report the results of the content analysis in the following subsections.

Methodological tools

In the dissertation, I summarized those methodological tools that enabled people living with intellectual disabilities to actively participate in the present research project and that resulted in successful cooperation between the research leader and the other participants. These were pictures, reminders, the presence of co-facilitators, overviews of the research process, explanations, and other verbal clarifications. Based on these outcomes, I would like to offer a

methodological "toolkit" for researchers conducting participative research involving people living with intellectual disabilities in the future.

Power relations

As part of evaluating the research methods, I examined the power relations among all people involved in this research and how they evolved during the research process. One of the main principles of participatory research is the equal partnership among all participants. We made an attempt to keep this principle in mind during the entire research project, through both using explicit verbal manifestations and the application of an inclusive behavior, as well as by involving participants living with intellectual disabilities in decisions related to the study. Here I list the way in which they were manifested in our research.

- Explicit vocabulary

- Implicitly, with behavior, topic, honesty, vocabulary

- By reciprocity: participants living with intellectual disability could ask questions from the research leader, even personal, private questions

- Sharing technical background information about the research (even private)

- By acknowledging my weaknesses in certain situations as a research leader

- With respect to boundaries: everyone could talk about anything as long as it was comfortable for him or her (and I have often reminded the participants of this)

During the entire study, one could observe a certain level of hierarchy among the researchers, which was due, in part, to the intellectual disability of our participants. Most frequently because of my role as "teacher. Based on our experience, balancing power relations is very difficult because everyone is accustomed to the scheme that people living with intellectual disabilities are "inferior" compared to their peers with no disability. I tried to express my desire for equality in various ways; using a specific statement and exhibiting a certain attitude, but the individuals with intellectual disability themselves kept reinforcing my "superiority". The following attitudes and tools helped us to establish equality: friendly attitude among participants, honest emotional manifestations towards one another, respect for each other's boundaries, and most of all reciprocity, so that everyone could ask any questions from anyone else in the group. Participation in the decision-making process also aimed at balancing power positions.

Characteristics arising from intellectual disabilities

I collected the features that may be related to the participants' intellectual disability and were observable during the study. I also collected methodological solutions that may help future researchers conducting studies of similar nature.

- Hierarchical world

We have found that almost every decision requires a reference person for the participants living with intellectual disabilities. It is very difficult to make a methodological suggestion in this regard, because we did not want to "stir up" the participants against their parents or relatives, but we tried to make them aware that they themselves would be able to act independently and decide in situations that they do not usually have this possibility. We

emphasized that it's important to be aware of issues that affect their lives. The hierarchical world motifs appeared even in the jointly-produced Play Decide-based interactive DVDs that were discussed critically during the discussions.

- Being easily influenced

It may be a consequence of the hierarchical world described above that participants living with intellectual disabilities are accustomed to - being generally ruled by others. It can also be a result of the desire to conform: when I asked a clarification question, participants often thought that I did not like their answer. Another reason for being easily influenced might be related to the lack of confidence, because of their fears that they did not understand the question correctly and that is why I ask them to clarify their thought.. A solution can be if we consistently ensure participants that this is not the case. Once they make a decision (or at least a decision is made with their participation and consent), we may ensure them that they can't give a wrong answer, and if they do not understand something, there is nothing wrong with it.

- Difficulty with understanding each other

Many times, it happened that the participants living with intellectual disabilities, the research assistant and the research leader did not understand each other. Many inadequate answers and situations emerged when the response of the participants living with intellectual disabilities was not related to the question discussed. The reason may be because we have often talked about unfamiliar topics and in a manner (openly and with the attitude of equality) that was not familiar to the people living with intellectual disabilities. A solution might be for participants to talk openly about their life, their issues at home or in other settings. There were also cases when the subject's abstractness or metacognitive nature caused the difficulties of understanding.

Therefore, intellectual disabilities may be associated with difficulties in participating in research. These issues can be partially dealt with by setting realistic expectations (no more or less than what the participants are capable of), with individual attention, open communication, with thorough knowledge of the participants, research practice, well preparedness (about topic, the participants, and especially the research itself), with gradual progress (when the elements of the research are built on each other) with many repetitions, but most importantly with respect.

Decision-making mechanisms in the research

I have tried to involve participants living with intellectual disabilities in as many decision-making situations as possible during this research. However, there were some decisions - technical and material in nature - that had to be made without their involvement. The following four categories represent the decision-making situations we experienced during this research:

1. I made the decision without the other participants; in situations where important practical or objective considerations had to be made. For example, when selecting the technical experts who created the DVDs, I had to consider the individuals' expertise and our financial resources.

2. Democratic decision-making: We jointly made the decision considering our sessions. For example, we determined together the length and the frequency of our meetings.

3. Own decisions of participants living with intellectual disabilities: On several occasions, I have entrusted the decision to participants living with intellectual disabilities. For example, they selected the gender and the name of the characters on the DVDs. Although the participants may not have been able to explain their choices, they made a solid decision on their own.

4. Persuasion: It also happened that for some reason (usually professional or practical) I did not agree with the decision of the participants, so I tried to convince them about another position. For example, the participants wanted to choose a non-disabled character for the DVD, but since the material was about people with intellectual disabilities, I thought it was professionally important that people living with intellectual disabilities appear in some situations.

Thus, four levels of involvement of participants living with intellectual disabilities in research decisions were distinguished. According to the principles of participative research, the optimal case is no. 2, when the participants reach a consensus in a democratic way. Everyone is learning the most in that way, and everyone is equally involved. During this research, we sought to make decisions of that kind.

Issue of disability

The disability theme would not have come up in our discussions if I did not force it. The participants did not consider themselves as disabled some participants felt offended by being called disabled and they considered it as a stigma. According to the participants, disability is a negative term that reflects a concept created by the society, and should be forgotten. They associated disability with aggressive people, with a pathological curve of the spine and with different emotions. Participants with intellectual disability did not consider themselves disabled, they considered themselves as being "different", as everybody else is different.

2. Results that are useful to participants living with intellectual disabilities

Changes in cognitive and linguistic levels of participants living with intellectual disabilities during the research

The cognitive and linguistic test protocol was administered during the first and the last occasion of the study. Based on the sound recording outcomes, results indicate a clear change in each participant. We investigated speech fluency, vocabulary, decision-making mechanisms, memory recall, response consistency, and problem-solving ability of participants living with intellectual disabilities.

All participants clearly spoke more at the second time, gave more relevant answers, could recall more words, made decisions more confidently, and recalled memories easier. It was only the problem-solving task where we did not observe any change over time.

Participants exhibited strong emotional motivation throughout the study, although during the content analysis I also found examples of task-oriented motivations.

The main emotional motives were:

- The sympathy towards me, as the research leader

- A friendly atmosphere

- Meals and drinks consumed during the meetings

- Possibility of sharing thoughts and feelings with a contemporary group

Task oriented motivation factors:

- Curiosity

- Intent to perform a meaningful activity

3. Social Impact, specific product: An adapted version of the Play Decide method for people living with intellectual disabilities

Play Decide is a deliberative method for disseminating knowledge and creating discourse on subjects that divide the society. The discussions are held between people who have different points of view (stakeholders or people who are interested in certain topics) on a specific subject. Its form is similar to an informative board game, during which long and complicated descriptions have to be read and understood. One of our goals in this study was to develop an adaptation of the Play Decide method in which we would present the topics using pictures, sound effects and easy-to-understand texts. The most suitable form for this was to create interactive DVDs. The DVDs have the same structure as the original board games, with the following changes. We created interactive DVDs on three themes according to the Play Decide method: decision making, leisure time, love.

In the following table, we are showing the differences and similarities between the jointly developed interactive audio-visual DVDs and the original Play Decide method:

	Play Decide	**Interactive DVDs**
Form	Paper based	DVD
Type of information	Complicated texts to read	Audiovisual stimuli, pictures and easy to understand oral texts
1st part	Written introduction	Introduction via a film: pictures and easy to understand oral texts
2nd part	Story cards: written cards	Opinions: told by actors
3rd part	Information cards: written cards	Information: by clicking on a picture the information can

		be heard
4th part	Issue cards: written cards	Questions: by clicking on a picture the question can be heard.
5th part	Decision: witten text, 4 different policy positions	Decision: 4 different versions of the same situation on short videos

1. Table: Differences and similarities between the interactive audio-visual DVDs and the original Play decide method

Contribution of participants living with intellectual disabilities in the completion of the DVDs:
- Selection of themes

- Participants' knowledge and attitude towards themes

- Use of a simplified vocabulary, rephrasing sentences to increase comprehension

- Selecting pictures related to texts

- Identifying the names and gender of the characters on the DVDs, and deciding whether they are living with disability or not

- Acting or recommending someone else as an actor

The list above shows the cases in which it was possible and necessary to involve people living with intellectual disabilities in the study. In general, involving people who are concerned about certain themes, can help us to better understand their interests and knowledge in order to develop professional materials together with them. According to our experience, people living with intellectual disabilities are pleased to appear in professional materials and are proud of their contribution[1]. With the above examples, we want to point out that people living with intellectual disabilities can be involved in research and may inspire other researchers to work with them together.

Social effects of the research
We experienced multiple levels of impact of this research on both the participants and their families. The implications for the participants are discussed above. This research also had an impact on the parents of the participants living with intellectual disabilities; they started treating their sons and daughters more as adults. The study had an impact on professionals who were interested in using the interactive DVDs in their work with people living with intellectual disabilities. It has an impact on the people living with intellectual disabilities who are using the interactive DVDs and who talk about the issues affecting their lives. In addition to immediate effects, this research has long-term effects as well. For example, partly because of the results of this research, a person with intellectual disability was hired as a lecturer in an institute of higher education. This study also has a number of theoretical implications as a result of its critical point of view and principles.

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[1] However, it is very important to note that this is only part of the joint work, which in itself can not be called participatory work, as it involves the multi-month, year-old acquaintance, participation in a complex research process.

Summary

The dissertation is focused on three main areas. One is the methodology in which we wanted to summarize the experiences gained from our participative research. In addition to inspiring future research, we can provide a methodological "toolkit" for researchers who involve people living with intellectual disabilities in their research. In this research, we focused on the power relationships between the participants and made every effort to create equal status for each participant. We explored different methods to decrease the hierarchy within the group. Furtrher, the aim of his research was to promote empowerment and the self-advocacy of people living with intellectual disabilities. Finally, interactive DVDs were created using a deliberative method, called Play Decide, with people living with intellectual disabilities for people living with intellectual disabilities to facilitate their social participation.

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Conference publications and conference presentations

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