

Petz
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ICCHP

Open Access Compendium



Future Perspectives of AT, eAccessibility and eInclusion

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Editorial

This is it: The very first digital edition of the ICCHP open access compendium “Future Perspectives of AT, eAccessibility and eInclusion”. It took 17 ICCHP editions and more than 30 years to go this last step towards an additional publication to reach a 360° view on AT, Accessibility, ICT with and for people with disabilities and older adults.

The idea to collect these hidden gems and precious contributions that typically get forgotten in mere theoretically based conference proceedings was in our heads for more than 10 years now – to put together these practically oriented gems within all this theory and compile a hands on, user driven, open access and accessible compendium out of it that makes our proceedings “whole” again. AT, eAccessibility and eInclusion are user, practice and service driven domains. Progress and success are very much based on the interaction with, contribution by and participation of all stakeholder groups (e.g. users, end user organizations, service providers, policy, administration, industry, NGOs). Every voice counts in the exchange on the impact of R&D on practice and in domains in need of creative and innovative R&D and co-operation.

And this is what happened now in order to strengthen exchange and co-operation between practice and R&D as a key asset for technical and social innovation. ICCHP invited interested authors coming from diverse domains to submit outlines of concept papers, models, reports, ideas, and position papers on topics related to digital inclusion.

In this compendium, you find these “gems” out of all handed in contributions, 29 papers that were accepted as contributions that will be / are / were also part of the ICCHP presentation program 2020 and will help / helps / helped us support a creative and innovative program facilitating cross-sector interaction. Over 180 pages of knowledge, application and experience to foster innovation and enable a glimpse into user experiences and what happened to all the findings we made in these decades since the very first ICCHP. The papers are aligned to follow the structure of the 2020 ICCHP proceedings and give you a complete overview on what was presented during ICCHP 2020 – Come and get involved, lean back and enjoy the full view for this very first time!

Of course this is also an opportunity to thank: To all the people strengthening us and supporting us in this endeavor, to all authors that went this important step with us, to all colleagues from JKU Linz and Masaryk University Brno that supported us with designing, collecting and tweaking the accessibility of this format – and to ICCHPs founder Roland Wagner, who is not able to celebrate with us this new ICCHP “baby”, but would be more than happy to see it grow and succeed.



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Association ICCHP, August 2020, Linz, AT

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Aim and scope: To communicate and complete knowledge on ICT, AT and Accessibility for/with people with disabilities and older adults and connect research in these domains with the necessary practical background and user related aspects.

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The MekoS Project

Sonja Abend

Abstract

The project "People with intellectual disabilities in empirical social research" (MekoS), funded by Aktion Mensch, was carried out at the Institute for Empirical Sociology (IfeS) in Nuremberg from March to July 2017. The MekoS project pursued two main goals: The acquisition and expansion of the participating scientists' competencies in communicating with people with (intellectual) disabilities and the empowerment of people with intellectual disabilities in research. Participants of the project were scientists from IfeS and employees of the Workshop for Disabled People Noris Inklusion (WfbM), the latter being people with intellectual disabilities. In order to get to know each other and to exchange information at eye-level, the participants visited each other at their workplaces. Several trainings on the topics of disability, communication, Easy-to-read language, and care rights were carried out. During these, the participants had the opportunity to cultivate self-awareness and reflection. They could practice their newly acquired soft skills with the help of a theoretical input from lectures given by expert speakers. Some training modules were inclusive, i.e. people with and without intellectual disabilities took part. As a central and sustainable project result, a two-part brochure was produced cooperatively. It includes a standard language section aimed at academics, which conveys various aspects of participatory research and thus provides support for inclusive research projects. In a second part, it informs people with intellectual disabilities in Easy-to-read about empirical social research. Easy-to-read was also used to create papers such as the consent form, all developed by both scientists and WfbM employees. The brochure can be downloaded free of charge.

Introduction

People with intellectual disabilities are the focus of many research projects. An overview of all planned, ongoing and completed projects in Germany can be found on the REHADAT homepage.[2] Participatory approaches of research no longer regard the people whose circumstances they investigate as objects to be explored, but include them in the research process. They are regarded as actively involved co-researchers with their own point of view. The joint research of scientists together with people with intellectual disabilities [7] requires that the participants know their research partners' living and working spaces as a foundation for cooperative work. The ability to communicate successfully with each other also plays a very prominent role. The first major project goal of MekoS was to establish and train the communication ability of scientists. As part of the MekoS project, scientists were trained in Easy-to-read before first contact with the employees of WfbM. The focus lay on practicing dialogues. (The joint seminars for the scientists and the employees of the Workshop for Disabled People are presented in more detail in the section *Our Work*.) The MekoS project aimed to give young scientists the opportunity to gain experience in contact and communication with people with (intellectual) disabilities. This is relevant because for the success of surveys about people with intellectual disabilities, it is not so much their cognitive abilities that make an impact, but primarily the communicative competence of the interviewers [10]. The project and the brochure produced within serve as a basis for further participatory and inclusive research projects.

The second major project goal was to inform people with intellectual disabilities about research. It pursued approaches of empowerment and was achieved specifically for the project itself through the exchange and mutual acquaintance of the workplaces and the creation of the brochure. MekoS aimed to enable people with intellectual disabilities to make self-determined decisions about participation in subdivided stages of a research process. The brochure consists of a part in Easy-to-read, which is addressed to people with intellectual disabilities, and a part in standard language, which is addressed to

researchers. The booklet is reversibly bound. An enclosed glossary explains terms that have been identified as relevant by the employees of the Workshop for Disabled People. In the part of the booklet that is addressed to researchers, text templates as well as information on communication with people with disabilities can be found. The text templates were developed by the participating researchers and employees of the Workshop for Disabled People according to the rules for Easy-to-read of *Inclusion Europe*.^[9]

Our Work

At the beginning of the project, the scientists were coached for the interaction with people with disabilities through training units. In the first seminar they received general information about different types of disabilities and the respective communication specifics. The topics were hearing and deafness, visual impairment and blindness as well as physical disability with wheelchair use.

After the theoretical introduction, the participants could take part in an excursion to upskill self-awareness: Mundane tasks were to be completed in groups of two. One person was simulated to be blind or in a wheelchair, the second person was an accompanying. The roles were swapped after the completion of the assignment.

In a blindness simulation, participants had to withdraw money from an ATM. The first problem already occurred when they tried to find the headphone plug-in, which is necessary to enable the voice output of the machine. The still visually impaired participants were also challenged to buy a tram ticket. The groups that were travelling in wheelchairs were tasked to buy a coffee to go.

Most important was the subsequent reflection. The scientists were impressed and touched by their experiences and insights into the daily challenges of people with disabilities.

The second seminar focused on Easy-to-read language and intellectual disability. In this seminar, the legal framework for Easy-to-read, its history and the guidelines of *Inclusion Europe* were presented. The researchers were educated in Easy-to-read by developing a text which helped them introduce themselves during their first visit to the Workshop for Disabled People.

Next, the scientists visited the Workshop for Disabled People Noris Inklusion (WfbM). The MekoS project was presented to a group of employees there. These employees had been briefed by a member of the workshop's social services department about the purpose of the project and could decide voluntarily for or against participation. The workshop council was involved in the decision making process from the very beginning. After getting to know each other and introducing themselves, the workshop employees showed the scientists their workplace - a printing shop with various printing machines and everything needed to produce print media. The brochure that would be created over the course of the next few weeks would be printed using the machines of the workshop as part of the cooperation.

Due to the fact that both groups were well prepared for the other group, everyone was quickly in exchange and dialogue. Four employees of the workshop decided to continue working on the project. They were accompanied at all further appointments by a member of the social services department. This was important so that the workshop employees always had someone close at hand who they could trust in new situations and unfamiliar surroundings.

At the next meeting, the employees of the workshop for disabled people visited the Institute for Empirical Sociology. They were given a tour of all the offices, the library, the copy room and the servers, and each member of the institute's staff shortly explained their own projects. A common break had been prepared by the student assistants of the institute. Based on the assumption that breaks play an important role at congresses, the breaks and the provision of snacks were already taken into account in the project planning. It was impressive to see the commitment of the student assistants. Eating habits

and food intolerances were discussed – in non-complex language. One student assistant, for example, began to address the question of whether it was possible for people with intellectual disabilities to choose a special diet such as veganism for themselves, and how employees of a Workshop for Disabled People could implement it.

All further meetings took place in the rooms of the Institute for Empirical Sociology. That was, above all else, the wish of the WfbM employees. The common breaks after the meetings were soon attended by all the present employees of the Institute, even those not involved in the project. In this way, scientists from other areas were also able to gain experience in dealing with people with intellectual disabilities.

The German law on guardianship has many levels and is much discussed in all its complexity. Self-help for the disabled, politics or research are just some of the addressed areas. In MekoS, a lawyer, who also serves as a guardian for people with disabilities, hosted a two-part seminar on care law. The seminar was inclusive and all employees of the institute had the opportunity to participate, the information being presented with the help of case studies. Care and guardianship are part of the everyday life of the employees of the Workshop for Disabled People; thus, they were able to enrich the abstract topic with their personal contributions.

An especially controversial question came up: Should people in care be allowed to decide for themselves whether they want to participate in a research project or should the consent of the guardian be required? A legal assessment of the issue clarified that people in care should decide for themselves whether they participate in a research project as respondents or not. The lawyer present backed this by referring to the constitutionally guaranteed right to freedom of expression.

Textvorlagen

Projektbeschreibung	
Ziel einer Projektbeschreibung ist es, über alle relevanten Dinge eines Projektes zu informieren. Wichtig ist dabei, dies kurz, prägnant und verständlich zu tun. Folgende Tabelle dient der Orientierung, welche Inhalte in einer Projektbeschreibung enthalten sein sollten.	
Inhalt	Erläuterung
Wer	Name der Forschungseinrichtung Name der Mitarbeiter:innen
Barrierefrei	Nutzung/Gebrauch ohne fremde Hilfe möglich
Welches Projekt	Name des Projekts
Was	Darstellung des Forschungsvorhabens (in einem Satz)
Forschungsdesign	Vorgehen bei der Projektumsetzung, inkl. zeitlicher Umfang
Freiwilligkeit	...der Teilnahme
Anonymität	Wahrung der Anonymität
Projektansprechpartner:	Name, Telefonnummer und Mailadresse
Projektpartner	Name des/r Ansprechpartners/in

Figure 1: The matrix for the project description

Another part of the project was to decide which explanations should be written in Easy-to-read language. The workshop employees were taught about the ideal typical sequence of a research process

[11]. They were already familiar with individual steps from earlier in the MekoS project, from the tour of the institute and from the stories of the researchers in the personal conversations, which always took place in between seminars or during the breaks.

In the end, they asked for three text templates in Easy-to-read: a project description, a declaration of consent for participation and a declaration of consent for the use of photos, film and sound recordings.

All parties involved felt that the declaration of consent, which respondents have to sign before interviews, should be written in Easy-to-read. The employees of the Workshop for Disabled People repeatedly pointed out that it also would be best to keep it short. An additional explanatory document was rejected. However, it was very important to the employees that the declaration of consent could be discussed in depth with the researchers or interviewers before or during the completion of the document. This should serve to create the opportunity for the employees to ask questions because personal interaction seemed more important to them than written explanations.

Einverständniserklärung

Nachname	Vorname
Ich bin über das Ziel der Studie _____ informiert.	
Ich bin über den Ablauf der Studie X. _____ informiert.	
Ich bin damit einverstanden, dass alles, was ich bei der Befragung	
<ul style="list-style-type: none"> • sage oder • aufschreibe 	
von _____ wissenschaftlich bearbeitet werden darf.	
Alle Daten über mich werden anonymisiert.	
Und das, was ich gesagt oder aufgeschrieben habe auch.	
Anonymisiert heißt, man kann nicht mehr erkennen, welche Person was gesagt hat.	
Ich nehme freiwillig an der Studie teil. Ich weiß, dass alle Angaben nur für die Wissenschaft verwendet werden. Die Ergebnisse der Studie werden anonymisiert veröffentlicht.	
Ich weiß, dass diese Erklärung bei _____ aufbewahrt wird. Ich weiß auch, dass diese Erklärung vernichtet wird, wenn die Studie fertig ist.	
Datum, Unterschrift	

Figure 2: The declaration of consent

The document on the use of photos, film and sound recordings was designed after the special request of the WfbM employees. Declarations of consent for the use of photographs are becoming increasingly important with the ongoing debate about data protection. One participant was able to share his experiences on an event where he had signed such an especially tailored declaration. This document is designed in a way that it can serve as a template for events.

Textvorlagen

Nutzung von Foto-, Film- und Tonaufnahmen

Nachname

Vorname

Geburtsdatum

Ich bin damit einverstanden, dass _____ Foto-, Film- und Tonaufnahmen für seine Öffentlichkeits-Arbeit nutzen darf.

Die Aufnahmen dürfen gedruckt werden.
 Sie dürfen auch im Internet veröffentlicht werden.

Ich verzichte darauf, dass mein Name genannt wird.
 Ich bin jedoch damit einverstanden, wenn mein Name genannt wird.

Diese Einverständnis-Erklärung gilt ohne Beschränkung auf die

- **inhaltliche**
- **zeitliche und**
- **räumliche Nutzung.**

Sie gilt also „für alles, immer und überall“.

Ich kann diese Einverständnis-Erklärung schriftlich widerrufen.
 Das kann ich immer machen.
 Ich muss das schriftlich machen.
 Ich kann mir dabei helfen lassen.

Datum, Unterschrift

Figure 3: The document of consent for the use of photo, film and sound recordings

In the discussion about where in the brochure the developed documents should be included, it was important to the WfbM employees that the templates were placed in the standard language part which is addressed to the researchers because they are the ones who first work with the documents. Another reason for this placement was the concern that if the templates were included in the Easy-to-read section, they might be overlooked by scientists.

Some of the project funds went into the graphic design of the brochure. Responsible for that was a social work student who had experience in graphic design and in Easy-to-read language. She participated in all the meetings. From the beginning, there was a consensus that photos were not suitable. Drawings, as they are used in many Easy-to-read publications, were rejected by the employees of the Workshop for Disabled People because they evoked the association of picture books for children. Pictograms, on the other hand, were considered appropriate. It was especially important to the WfbM employees though to avoid an abundance of pictorial elements. Again and again they highlighted that the booklet was not a picture book for children, but a brochure for adults.

The WfbM graphic designer attended the last meet-up in order to create the final design. The workshop staff (supported by the social service employee) explained the brochure and the desired procedure to follow. Based on that overview, the graphic designer could develop her own layout design. Her suggestion was to dispense with any form of symbols and pictures and instead work with colorful highlights that would help the clarity of structure. This proposal was accepted and the colors were determined together. The employees of the workshop wanted to avoid too many colors in order to keep up a design that was aimed at adults. The color blue was agreed upon very quickly because it

is part of the *Inclusion Europe* logo. The second color, based on the wish of one male WmbF employee, was supposed to look "solid". Everyone agreed with grey.

When eventually the graphic designer presented the new design, it became apparent that the color-guided layout was much more popular among the workshop employees than the design that used pictograms.

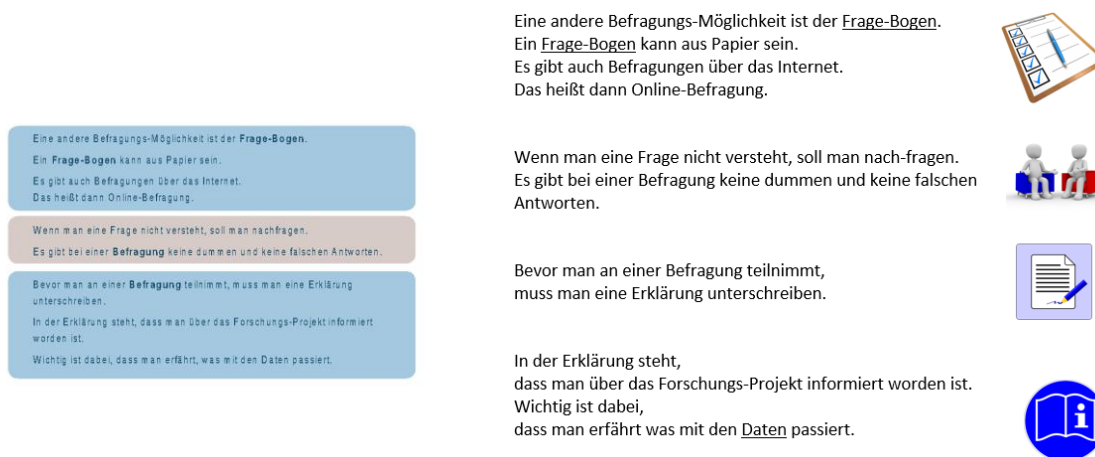


Figure 4: On the left: One page of the MekoS brochure with color highlights. On the right: The same page of the MekoS brochure with pictograms (previous design).

In a poll, all the employees of the Workshop for Disabled People voted for the layout with color highlighting and without pictograms.

Conclusions and Possible Next Steps

Research by Bock has shown that texts that include pictures are better accepted by people with functional illiteracy as well as people with intellectual disabilities. However, in Bock's study, participants initially opted for texts without images. Subsequent surveys showed that by doing without pictures, the participants wanted to express their self-image as competent readers [5].

To date, there are no empirical studies that have taken layout into account by using color highlighting. This desideratum should be closed. The question to be further explored is whether color-guided structures have a positive influence on the textual understanding of people with intellectual disabilities and at the same time maintain the self-image of the competent reader.

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