

Be Creative!

Literature Review on People with Intellectual Disabilities' Involvement in Media Research Studies

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Abstract. Digital media have wide-ranging potential for people with and without disabilities. The increasing interest in media usage is reflected in numerous studies worldwide. People with intellectual disabilities are excluded from research due to a number of obstacles (e.g. cognitive and linguistic abilities) in this research field. Considering the lack of research about media usage and people with intellectual disabilities, this literature review analyses the following research questions: 1) Are people with intellectual disabilities involved in current research?, 2) What research methods are used to conduct research with people with intellectual disabilities?, and 3) Which topics are researched in current studies? To answer our research questions, we conducted a literature review with 38 studies included in our sample. We found that most studies use questionnaires or interviews to research the media usage of people with intellectual disabilities. In this paper, we discuss implications to involve people with disabilities in research.

Sei kreativ!

Literatur Review zum Einbezug von Menschen mit intellektueller Beeinträchtigung in Medien-Nutzungs-Studien

Zusammenfassung. Digitale Medien haben ein weitreichendes Potenzial für Menschen mit und ohne Behinderungen. Das zunehmende Interesse an der Mediennutzung spiegelt sich in zahlreichen Studien weltweit wider. Menschen mit intellektueller Beeinträchtigung sind aufgrund einer Reihe von Hindernissen (z. B. kognitive und sprachliche Fähigkeiten) von der Forschung in diesem Bereich ausgeschlossen. In Anbetracht des Mangels an Forschung über Mediennutzung und Menschen mit intellektueller Beeinträchtigung werden in diese Literatur Review die folgenden Forschungsfragen untersucht:

1) Sind Menschen mit intellektueller Beeinträchtigung in aktuelle Forschung einbezogen? 2) Welche Forschungsmethoden werden verwendet, um Forschung mit Menschen mit intellektueller Beeinträchtigung durchzuführen? und 3) Welche Themen werden in aktuellen Studien erforscht? Zur Beantwortung der Forschungsfragen haben wurde eine Literatur Review durchgeführt und 38 Studien in die Stichprobe aufgenommen. Es stellte sich heraus, dass die meisten Studien Fragebögen oder Interviews verwenden, um die Mediennutzung von Menschen mit intellektueller Beeinträchtigung zu untersuchen. In diesem Beitrag wird diskutiert, wie Menschen mit Behinderungen in die Forschung einbezogen werden können.

1 Introduction

Our society is undergoing a media-related transformation, with digital media representing an important contribution to people's participation in public and private communication (Bosse and Hasebrink 2016; Hastall and Heitplatz 2019). Media are used as a means of communication and are integrated into the various aspects of society (e.g., everyday life, culture, social forms of action) (Krotz 2001). Digital media comprise the

“latest phase of media's contribution to modernity, but the most complex of all, a complexity illustrated by the nature of the Internet as a network of networks that connects all types of communication from one-to-one to many-to-many into a wider space of communication” (Couldry 2012, 43)

The term ‘media usage’ “assumes that people are active agents who make purposeful and rational choices” when interacting with digital media and the Internet (Harsh et al. 2012, 952). Information and communication technologies offer the possibility to communicate independently of time and location and have changed the way relationships are built and maintained (Gutiérrez and Martorell 2011).

Thus, digital media have wide-ranging potential for people on an individual level (e.g., personality development), on a group-related level (e.g., joint interaction and communication processes) and on a socio-cultural level (e.g. participation in public communication processes) (Schluchter 2012). A wide variety of people can benefit from the Internet and other digital media, as online activity and digital communication are not hindered by mobility difficulties (Miesenberger et al. 2012; Antener 2014).

The increasing interest in media usage is reflected in numerous studies, which are conducted worldwide (ARD/ZDF-Forschungskommission 2020; Medienpädagogischer Forschungsverbund Südwest 2019; Ofcom 2020; Beldhuis 2012). All of these studies are large-scale studies that mostly use quantitative research methods (e.g., questionnaires) and seemingly do not consider disability.

Despite the potential that the Internet and other digital media have for people with disabilities, there is a lack of research regarding the Internet usage by such people (Hynan, Goldbart, and Murray 2015; Dobransky and Hargittai 2016).

However, the existence of studies that actually focus on the usage of media by people with disabilities demonstrates the importance of this topic.

Caton and Chapman (2016, 135) identified potential benefits of social media usage by people with intellectual disabilities. Social media

- “increases opportunities to make and maintain relationships;
- provides another means to express a social identity, to talk about lives and experiences, and to voice opinions;
- increases self-confidence and self-esteem through learning new skills; and
- provides enjoyable activities”.

Hynan, Goldbart, and Murray (2015) stated that the vast majority of studies concerning the Internet usage of people with disabilities focus on people who can communicate verbally or rely on statements by caregivers, parents, and other proxies. The reasons for this are:

- The contents of the questionnaire are complex (Dworschak 2004)
- The independent processing and completion of questionnaires are complex (Dworschak 2004)
- The communicative competencies of the participants are not sufficient (Moisl 2017)

An additional challenge is the recruitment of participants: the so-called ‘gatekeeper problem’. If participants are acquired via gatekeepers (e.g., caregivers, teachers, parents, etc.), the decision about who will and can participate in the research is influenced by the assumptions of the gatekeepers. Participants are often excluded because gatekeepers assume that they cannot take part in the study (Rabiee, Beresford, and Sloper 2005).

Because of the still increasing importance of digital media in everyday life and the lack of research regarding the usage of digital media by people with disabilities, this review focuses on studies that have conducted research into media usage and intellectual disability. Our study focuses on media usage in the context of leisure time. This context is characterised by the voluntariness and self-determination of consuming individuals, whereas other contexts (e.g., school, employment) are characterised by rules and obligations. Our understanding of intellectual disabilities is based on the globally recognised definition by the American Association of Intellectual and Developmental Disabilities (AAIDD); therefore, an intellectual disability is understood as an impairment that originates before the age of 18. Mental and adaptive functions are affected by and influence the activities of daily living (American Association of Intellectual and Developmental Disabilities 2020).

Based on these definitions and considering the lack of research about media usage and intellectual disability, the following literature reviews and analyses the following research questions:

- How are people with intellectual disabilities involved in research?
- What research methods are used to conduct research with people with intellectual disabilities?
- Which topics are researched in the studies, and what aspects are investigated with respect to the everyday life of people with intellectual disabilities?

2 Methods and Sample

To answer the research questions above, the following ten databases were searched for data from the period of October 2019 to May 2020:

- PsycARTICLES
- Academic Search Premier
- Web of Science Core Collection
- Scopus
- Google Scholar
- BASE: Bielefeld Academic Search Engine
- Education Source
- FIS Bildung
- Medline
- ERIC

The following search terms, in both German and English, were used for every database:

- (1) 'intellectual disability' or 'learning disability' or 'learning disabilities' or 'developmental disability' AND 'media use' OR 'smartphone.'
- (2) 'augmentative and alternative communication' or 'AAC' AND 'media use' OR 'smartphone'

Considering that people with intellectual disabilities are often excluded from research on the grounds of communicative competency (Moisl 2017), we decided to complement our search terms with the acronym AAC (Augmentative and Alternative Communication); this was because a) people with intellectual disabilities may use AAC, and b) people who use AAC may also have an intellectual disability (Schröttle and Hornberg 2014).

We also included the term 'smartphone' in our research string; based on current research, we hypothesised that smartphones are also a common device among people with intellectual disabilities (Heitplatz, Bühler, and Hastall 2019; Chiner, Gómez-Puerta, and Cardona-Moltó 2017a).

In order to sort the titles, we discovered, we defined further criteria. Formal inclusion criteria included studies that were peer-reviewed and published between 2007 and 2020 and studies focusing on intellectual disabilities or related terms (i.e., developmental disabilities, learning disabilities) in combination with the use of media and smartphones. Consequently, studies focusing on only intellectual disabilities, without a link to media usage, were excluded. Due to our focus on media usage in everyday life, studies focusing on the usage of assistive technology, on interventions with a specific digital media tool, or on the testing of single features of websites were excluded from the sample. Intervention studies were excluded because they conducted research on how digital media was used to reach a particular goal rather than on how digital media is used for everyday activities. We defined 'interventions' as any kind of externally controlled, goal-oriented, and systematic influence of a person or usage (Hager and Hasselbron 2000). Certainly, the excluded studies would have provided valuable insights on how to conduct research with people with disabilities; however, in line with research on media usage by people without disabilities and with our research questions, we decided it was important to analyse studies which focused on the media usage by people with disabilities in everyday life and without a particular goal setting.

During our search (conducted via search string), we found a high number of articles across all ten databases (e.g., in Education Source: (1) 6203; (2) 5863). In order for us to be able to handle this large amount, the articles were first screened by title (see Figure 1). Only articles meeting the inclusion criteria were included in the first data set, which consisted of 142 articles. Of these articles, the abstracts were read. After this step, only empirical studies that were not intervention studies tested single features or websites, or solely focused on assistive technology were included. In total, 67 studies were read in full. The same respective inclusion and exclusion criteria were applied, resulting in 38 included articles and five accompanying reviews. Both authors carried out this screening process.

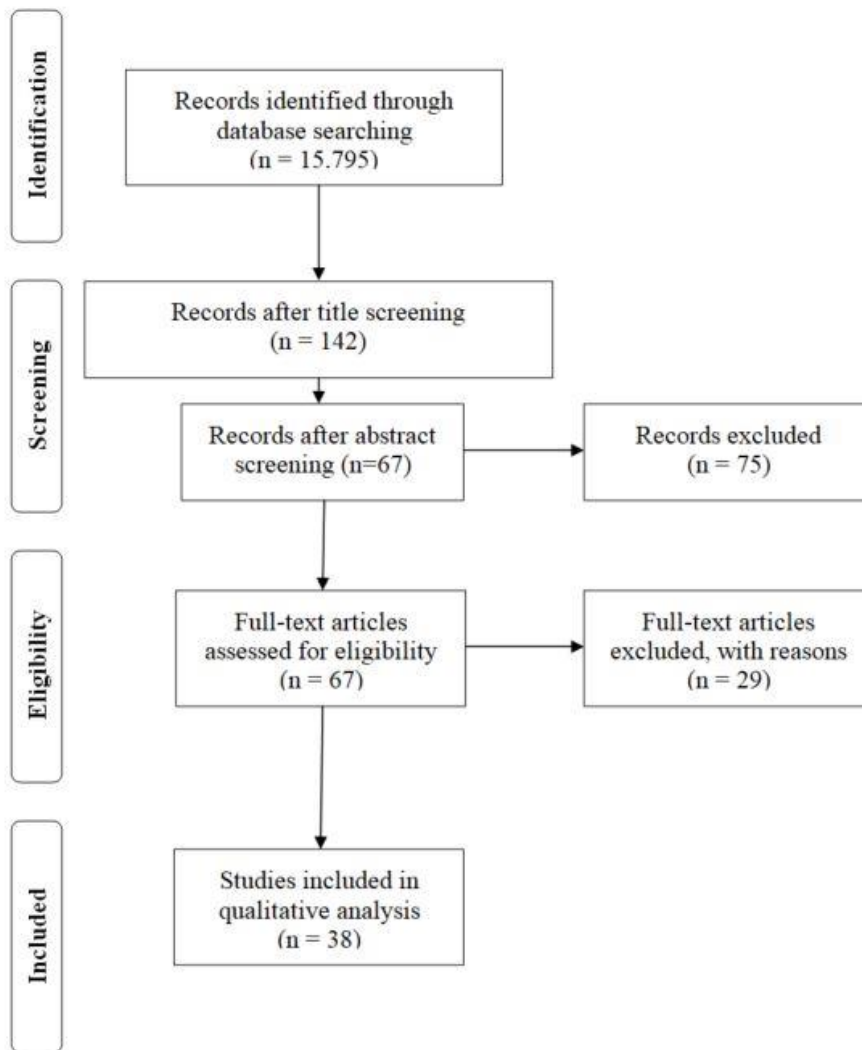


Figure 1 Flow diagram of the screening process based on the PRISMA Flow Chart (Moher et al. 2009) (own figure)

Of the included 38 studies in our sample, most studies are from the USA (n=9), Sweden (n=8), and England (n=7). Some studies are also from authors in Mexico, Italy, Spain, and Korea. We could only identify two studies that met our inclusion criteria in Germany. With regard to the studies from the USA, Sweden, and England, the variety of authors researching intellectual disabilities and media usage is remarkable, as it indicates a high level of research activity in those countries.

The analysis of the publication activity from 2007 until 2020 is also very interesting (see Figure 2).

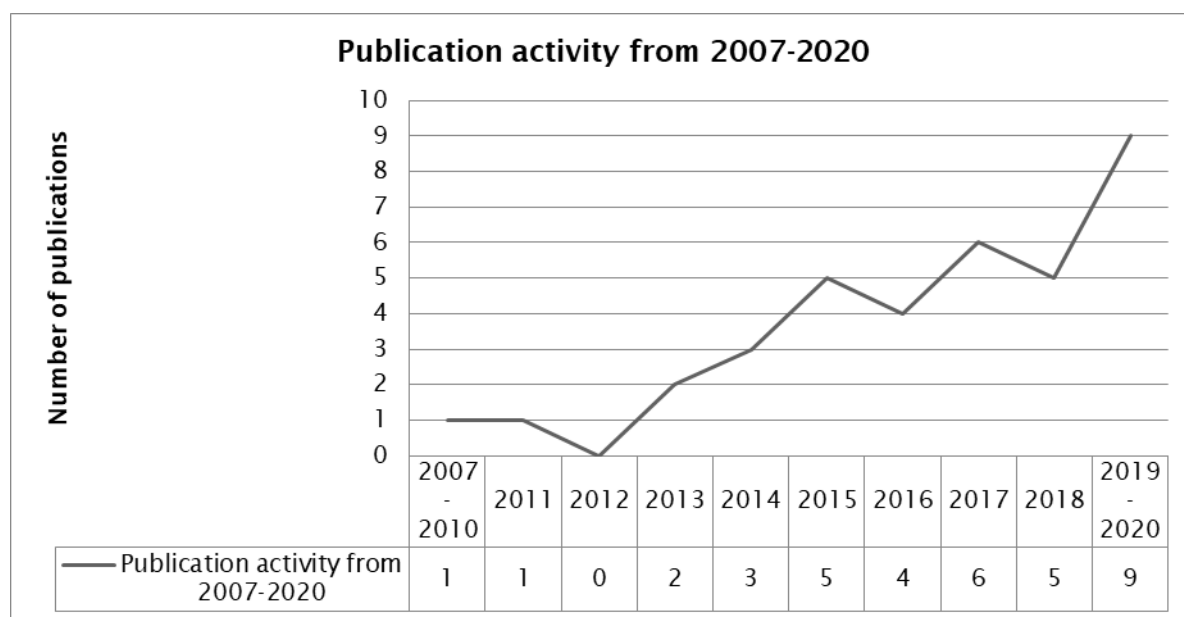


Figure 2 Publication activity from 2007 to 2020 (own figure)

As is demonstrated by the above graph, the publication of studies on Internet and media usage by people with intellectual disabilities has increased noticeably since 2015. Figure 2 clearly shows that it took about eight years for people with intellectual disabilities to become popular as a research topic. Prior to 2015, publications dealt with mobbing, cell phone and television usage, and video gaming.

To answer our research questions, we conducted a deductive-inductive content analysis (Elo et al. 2014). Following this procedure, we formed main categories and sub-categories for the analysis (see Table 1). With the help of these categories, the texts were then analyzed for clues to help answer our research questions.

Table 1 Categories of Content Analysis

Main Category	Sub Category
Participants' Involvement <i>Involvement in the research process. Are they asked for their own opinion?</i>	Self-survey Proxy-survey Multi-method-approach
Research Methods <i>Kind of research method used in the study</i>	Questionnaire Interview Focus group Observation Mixed methods
Participants' Recruitment <i>The way in which participants with disabilities have been recruited for the study</i>	Existing contacts Social facilities Self-help-organisations Internet (e.g. social media)
Disability <i>Definition of intellectual disability</i>	Children Youth Adults Definition of intellectual disability
Researched Topic	ICT in general Internet usage Social media

3 Results

The following presentation of results is based on the categories described above.

3.1 Participants with Intellectual Disabilities

The term ‘intellectual disability’, as defined above, is widely accepted in international research. Nevertheless, people with intellectual disabilities are a very heterogeneous group of people whose cognitive impairments range from mild to severe impairments. We found that not all authors use the term ‘intellectual disability’ in their studies and that some choose related or similar terms (e.g. ‘developmental disabilities’, ‘cognitive disabilities’) or concentrate on specific diseases (e.g. Down syndrome, Autism Spectrum Disorder, Williams syndrome). We found that there are three kinds of studies:

- unspecified ones;
- intellectual disability along syndromes and diseases; and
- intellectual disability along common definitions

First, we clustered studies that use the term ‘intellectual disability’ (n=7) but did not discuss in detail the limitations of the term. In these studies, it is not clear how pronounced the impairment in question is. Second, we found studies that focus on specific illnesses or syndromes, which are classified and defined according to the ICD-10 classifications, e.g. Autism Spectrum Disorder, Fragile X syndrome, Down Syndrome, and Williams Syndrome. Although these studies define intellectual disability in more detail, it is not clear how pronounced the impairment in question is or in what areas of activity difficulties occur. Third, we clustered studies that had defined in advance the criteria they required for participation in the respective studies, e.g. the presence or absence of reading, writing, or communication skills or the use of certain technologies or social media. The third cluster included studies in which intellectual disability was a prerequisite for admission to such institutions as special education schools and vocational training centres. Here, it was assumed that a specific intellectual disability had been diagnosed since this is a prerequisite for admission to such institutions. However, it is not clear in which areas of daily living deficits occur or what abilities people with intellectual disabilities have.

Additionally, we looked at the age of the participants in our sample studies. Only one study could be identified that dealt with children and intellectual disability. Mazurek and Wenstrup (2013) examined the television usage of children with autism spectrum disorder in comparison to their siblings. Eight studies in our sample focus on young people with intellectual disabilities and their media usage. However, the vast majority of the studies deal with the media usage of adults with intellectual disabilities (n=27).

3.2 Participants’ Recruitment

Due to the gatekeeper problems in this area of research, this article analyses the methods and procedures involved in recruiting participants in our sample, aiming to find out if there are any proven methods to get access to people with intellectual disabilities in their living or working institutions (see Figure 3).

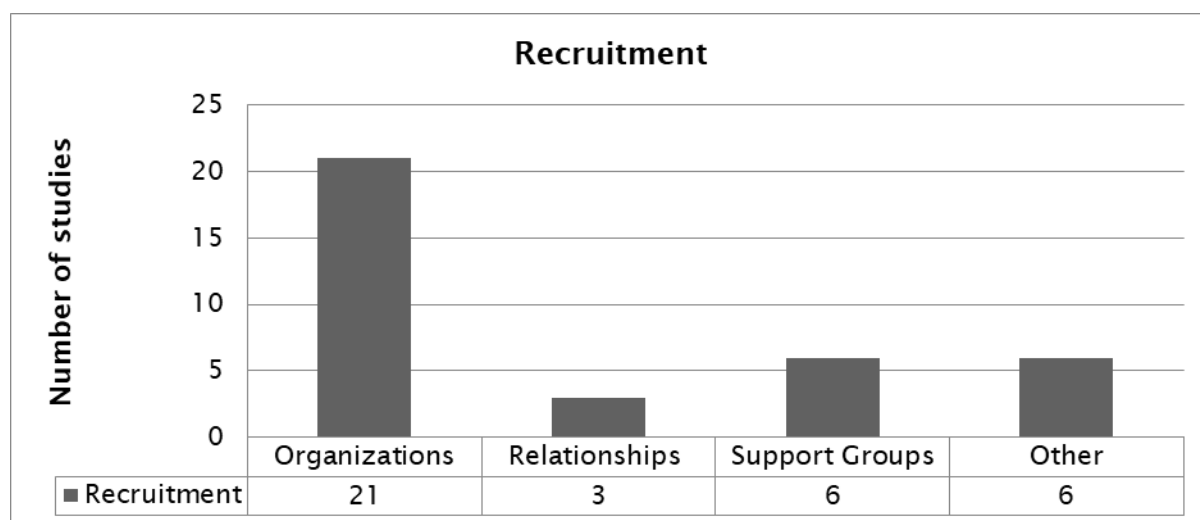


Figure 3 Recruitment methods (own figure)

Figure 3 shows that most authors recruited participants with disabilities through social organisations (i.e., institutions where people with disabilities live, work, or go to school). Jenaro et al. (2018) describe their recruiting process as follows:

“All participants were 18 years of age or older, attending educational facilities consisting of college (for participants without disabilities), and special vocational training or occupational centres for young adult people with intellectual disabilities, where having a diagnosis of intellectual disability is a requirement for being eligible to attend those educational facilities” (Jenaro et al. 2018, 261)

Another way to recruit participants was by contacting support groups for people with intellectual disabilities. Löfgren-Mårtenson (2008), for example, provided support groups with letters of intent and advertisements in order to recruit participants for their study. Three authors (Chiner, Gómez-Puerta, and Cardona-Moltó 2017b; Darragh et al. 2017; Lough and Fisher 2016) described how they used pre-existing contacts with people with intellectual disabilities because a trusting relationship had already been established gradually adding further participants through the procedure of snowball sampling. Contacting people with intellectual disabilities can also be achieved via Facebook groups or other social media platforms (Bryan and Chung 2018). Caron and Light (2015b) chose a similar approach: “The aforementioned individuals were contacted through

- a) web posting (i.e., an Internet listserv where SLPs or individuals who use AAC communicate),
- b) social media (e.g., Facebook and Twitter), and
- c) emails” (Caron and Light 2015b, 4).

The diversity of recruiting methods shows that, depending on the goal and subject of the study in question, there are a variety of ways to contact people with intellectual disabilities and motivate them to take part in the study, and a variety of opportunities to do so.

3.3 Researched Topics

In a further step, we analysed the topics of all 38 studies in our sample in order to gain an overview of currently researched topics. Figure 4 sums up the research topics that we identified.

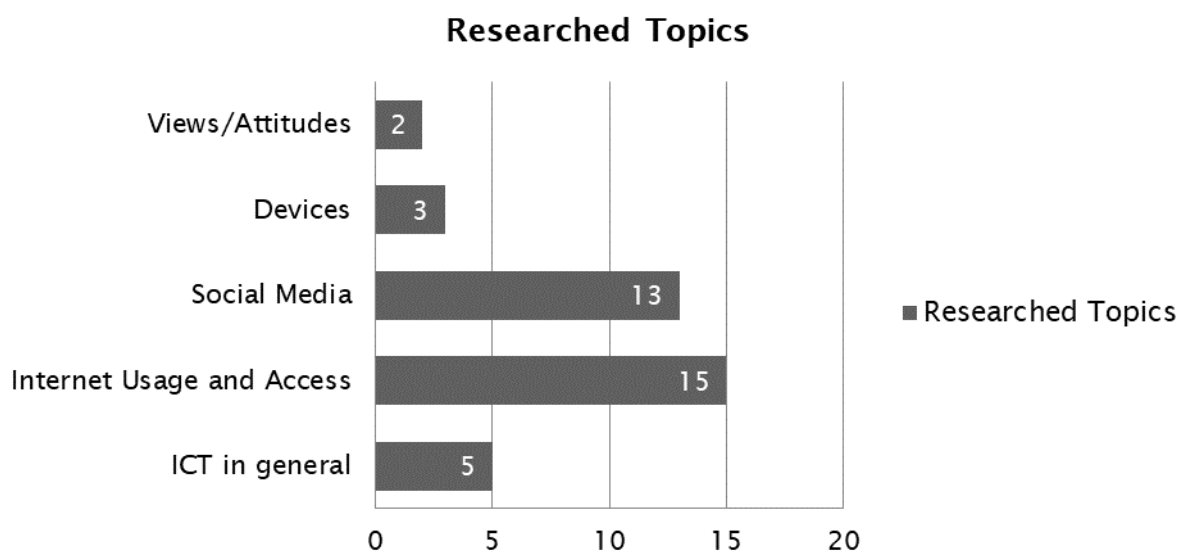


Figure 4 Researched topics (own figure)

Figure 4 shows that most of the studies in our sample analysed the social media usage of people with intellectual disabilities (n=13) or usage of and access to the Internet (n=15). The topics within this research area are diverse and range from the analysis of opportunities and risks to the frequency and intentions of usage, as well as the added value for people with intellectual disabilities. The category 'Internet usage and access' includes the studies that analyse opportunities and barriers to Internet usage and access, as well as those that analyse the risks of Internet usage, e.g., the issue of cyberbullying. The category 'ICT in general' contains studies that examine the usage of ICT by people with intellectual disabilities in different contexts. There are far fewer (n=3) studies in the sample of those that research the usage of devices (e.g. smartphone usage). The remaining category, 'views and attitudes', contains studies in which caregivers were asked about their attitudes toward the Internet or social media usage – and the attendant opportunities and risks – of people with intellectual disabilities.

3.4 Research Methods

Twenty-eight out of the 38 identified studies involved people with intellectual disabilities by asking them for their own opinions. The sample of the twenty-eight studies includes four studies in which caregivers and people with intellectual disabilities were interviewed on the same topic using different research methods (e.g., caregivers were given questionnaires and people with intellectual disabilities were interviewed). The remaining ten studies are so-called 'caregiver studies', which research the opinions of caregivers (e.g., parents, family members, professionals) regarding media usage. Figure 5 quantifies the methods used to research media usage of people with intellectual disabilities in the 38 studies of our sample. The graph shows clearly that most

of the studies are questionnaire studies (n=16). Interviews are the second most popular method (n=9). Less popular are focus group studies (n=7) and using several methods of questioning (i.e. interviews and questionnaires) (n=4). Additionally, observations were used in two studies (Näslund and Gardelli 2013; Parsons et al. 2008).

Interestingly, the focus group studies can be differentiated between ‘synchronous’ and ‘asynchronous’ focus groups. Whereas the former refers to those focus groups that “typically take place in one setting, consist of six to 10 participants plus a moderator, and take several hours” (Caron and Light 2015b, 4), asynchronous focus groups are conducted over a longer period of time, for example via platforms such as secret Facebook groups. Bryan and Chung (2018) described their procedure as follows:

“The 10-week focus group was conducted using Facebook Secret Groups. This platform was chosen for three reasons. First, participants lived in several different states and travel to one spot was not possible, so an asynchronous online focus group made communication among them possible. Second, all 8 participants were already familiar with and had a presence on Facebook. Third, Facebook Secret Groups ensured the privacy of any exchanges where asynchronous collaboration in sending and receiving ideas could occur anytime and from any place” (Bryan and Chung 2018, 80–81).

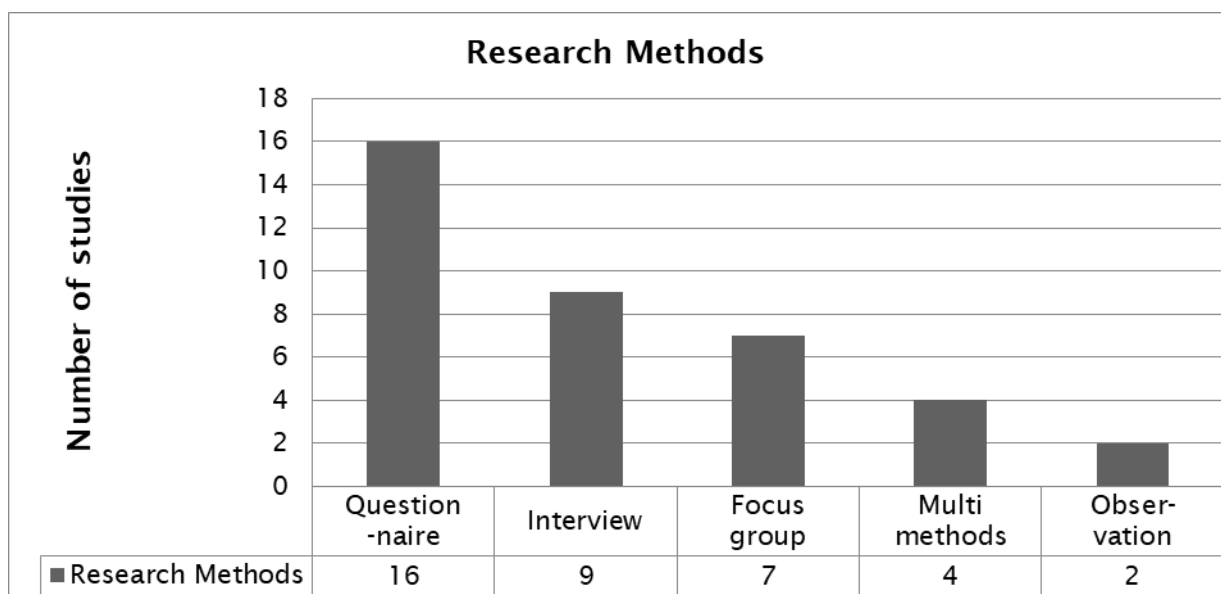


Figure 5 Analyzed research methods in our sample (own figure)

The evaluation of the research methods used by the studies in our sample shows that questionnaires, followed by interviews, are the most frequently used methods of gathering data and surveying people with intellectual disabilities.

Of the 16 studies that used questionnaires, two were caregiver studies, and two others were studies in which people with intellectual disabilities and their caregivers were questioned. Altogether, 14 studies directly asked people with intellectual disabilities for their opinions. A closer look at the analysed data of fourteen studies shows that five questionnaire studies (Alfredsson Ågren, Kjellberg, and Hemmingsson 2020; Gutiérrez and Martorell 2011; Begara Iglesias, Gómez Sánchez, and Alcedo Rodríguez 2019; A. Mendoza-González et al. 2019; Shpigelman and Gill 2014a) say that their

questionnaires are adapted to the participant's needs (e.g., using easy language) without explaining this further. The authors of the remaining nine questionnaire studies (Chiner, Gómez-Puerta, and Cardona-Moltó 2017b; Didden et al. 2009; Eghdam et al. 2016; Jenaro et al. 2018; Lough and Fisher 2016; Patrick et al. 2020; Shpigelman and Gill 2014a; Wehmeyer et al. 2012; White and Forrester-Jones 2019) do not describe any adjustments or adaptations of the questionnaire to the participants' needs in their articles. The studies in our sample that used questionnaires are often part of large-scale studies that aim to achieve wide representation (Alfredsson Ågren, Kjellberg, and Hemmingson 2019).

Figure 5 also shows that some authors – especially those of recently published studies (i.e. in the last three years) – used multi-method approaches to investigate the media usage of people with intellectual disabilities. In particular, studies which surveyed people with intellectual disabilities and their caregivers on the same topic but with different methods seem to be gaining popularity (Haage and Bosse 2017; Sallafranque-St-Louis and Normand 2017; Stiller et al. 2019; Raspa et al. 2018).

4 Discussion

Our results show that some aspects of the results regarding the inclusion in research of people with intellectual disabilities – i. e., the requirements for participation in such studies, the so-called ‘gatekeeper problems’, and methodological issues – need to be discussed. For a better overview, we structured the discussion along these topics.

4.1 Linguistic and Cognitive Abilities as Requirements

The results of our study demonstrate that having the linguistic abilities to communicate and having the cognitive abilities to understand the interview questions are often described as important preconditions to participating in a study. Sallafranque-St-Louis and Normand (2017, 4) state: “To take part in the interview, they were required to communicate well enough verbally to be understood”. In most of the major media usage studies, questionnaires or telephone interviews were used (ARD/ZDF-Forschungskommission 2020; Medienpädagogischer Forschungsverbund Südwest 2019; Initiative D21 2019; Beldhuis 2012; Ofcom 2020). This implies that the participants had certain linguistic abilities and that this procedure excludes people who cannot read or write, do not understand the questions, or have a different native language. In Germany, 6.2 million adults are not able to read or write (Deutsche Welle 2020). Haug (2008) pointed out that the German language skills of migrants in Germany are often characterised by uncertainty and that their language skills are deficient. In 2019, 26% of the German population had a ‘migration background’ (Statistisches Bundesamt 2020). These statistics make clear that it is not only people with intellectual disabilities but also other groups of people in our society who can benefit from alternative survey methods, methods that do not set language and reading skills as a prerequisite for participation.

In line with the UN Convention on the Rights of People with Disabilities and the claim ‘nothing about us without us’, multiple papers state how important it is that not only the abilities of the individual are focused on and that, accordingly, methodological challenges need to be implemented (Niediek 2016). One small-scale study

identified four factors that influence interviews with people with complex communication needs:

- a) interviewer
- b) participant
- c) environment
- d) and research instrument (e.g. a questionnaire)

The author concludes that questionnaires – including all questions, and both supplemental and supportive material – need to be designed according to the needs of the target group, and that there are other factors aside from the abilities of the interviewee (i. e. environment, motivation of the interviewee, design of the research instrument, the design of supportive and supplemental material) that need to be considered (Wilkens 2019).

4.2 Methodological Questions

Schäfers (2008) states that interviews are not the ideal way to survey every group of people due to the language requirements mentioned above. Particular problems arise when surveying people with severe disabilities who cannot articulate themselves verbally or understand questions adequately. Previous experience reports on surveys of people with intellectual disabilities recommend an upper limit of 25 questions for questionnaire studies and a time limit of 30-40 minutes for interviews (Gutiérrez and Martorell 2011). Some authors in our sample, however, say that their interviews with participants sometimes lasted longer than an hour: “[...] each interview lasted, on average, slightly over an hour” (Shpigelman 2017, 409).

A few studies in our sample chose other survey formats, such as focus groups. As Barr, McConkey, and McConaghie (2003, 579) noted:

“It has been argued that focus groups have important advantages both in the dynamics present and the outcomes that can be achieved when attempting to gain insights into views of people for whom the usage of a questionnaire would be difficult if not impossible”.

However, the dynamics of focus groups have already been shown to be helpful in overcoming existing barriers to the inclusion of people with intellectual disabilities in research (Molin, Sorbring, and Löfgren-Mårtenson 2015; Buchholz, Ferm, and Holmgren 2018; Ramsten et al. 2019). The characteristics of focus group studies allow wide-ranging adaptations to individual needs not isolated to those of people with intellectual disabilities. In addition, young children, older adults, and people who are not able to read or write are more likely to participate in a focus group than to fill out a questionnaire. Heitplatz (2021) showed that focus groups, in combination with the Talking Mats method, are an opportunity to allow even people with severe intellectual disabilities to express themselves during focus groups. Talking Mats are an “interactive resource that uses three sets of picture communication symbols – topics, options, and a visual scale [...] This can either be physical, textured mat, or digital space, for example, a tablet, smartboard, or computer screen [...]” (Talking Mats 2013). The limitations of focus groups are revealed when it comes to discussing sensitive or very personal topics that should not be shared in a group (e.g., sexual abuse, violence, etc.).

Additionally, our results show that three studies include several perspectives on a specific research topic. For example, Raspa et al. (2018) examined the media usage of adults with intellectual disabilities by interviewing both the parents of the people with intellectual disabilities and the people with intellectual disabilities themselves. Lough and Fisher (2016) used a similar approach. In these studies, the opportunities and risks of Internet usage were surveyed from the perspective of children with fragile X-Syndrome and their parents. Chiner, Gómez-Puerta, and Cardona-Moltó (2017a) interviewed the family members and formal caregivers of people with intellectual disabilities about Internet usage. The inclusion of different perspectives on a research topic is certainly helpful and is a first step towards including the opinions of people with disabilities. However, the studies found in our sample always used the same research method (i.e., questionnaires) for different groups of people. Even if the participants with intellectual disabilities had help filling out the questionnaires, it remains unclear whether the results of the questionnaires reflect their own opinion (and, if so, to what extent) or have been influenced by caregivers' opinions. In the literature, the call for participatory research methods is getting louder. 'Participatory research' is an umbrella term for collaborative approaches to the research of a specific topic. This approach "comprises a range of methodological approaches and techniques, all with the objective of handing power from the researcher to research participants [...]" (Participate 2020). A first step towards achieving this objective is considering people with intellectual disability as qualified and resourceful participants in research studies. It is the responsibility of researchers to design a research instrument that allows people with intellectual disabilities to participate and answer the questions (Wilkens 2019). However, such participative approaches require human, motivational, temporal, and financial resources. Large media usage studies (such as those mentioned in the introduction of this paper) are published annually and so usually complete their recruitment, survey, and evaluation within one year; obtaining such large and representative datasets means there is usually no time left for creative research methods, even though this should be part of the research process.

4.3 Gatekeeper Problems

As our results demonstrate, recruiting participants with intellectual disabilities through organisations or institutions where they live or work – used as a 'first step', and a 'door opener' into the research field – seems to be common practice. This results in a complex field of tension. On the one hand, many studies show that people with intellectual disabilities are seen as a vulnerable group of people who need to be protected (Chiner, Gómez-Puerta, and Cardona-Moltó 2017a; Darragh et al. 2017; Borgström, Daneback, and Molin 2019). The perceived need to protect people with intellectual disabilities can influence many areas of their lives, including their participation in research activities; if participants are acquired via gatekeepers (e.g., caregivers, teachers, parents, etc.), the decision about who will and can participate in the studies is influenced by the assumptions of the gatekeepers. Thus, Participants are often excluded because gatekeepers assume they (the participant) cannot participate in the study. Rabiee, Beresford, and Sloper (2005, 391) reported statements during the acquisition process such as "he/she is not able to participate, you will not get anything out of him/her, there is no point in asking him/her any question, I could tell you everything you would want to know."

The gatekeeper problem can only be avoided by finding ways to address the people with intellectual disabilities directly. Caron and Light (2015b) recruited their participants through three different channels:

- via posting in self-help groups online;
- via social media (e.g. Twitter and Facebook groups); and
- via email

The aim of the Caron and Light study was to find out more about behaviour when using social network sites; therefore, it was appropriate to address the participants directly via Facebook or Twitter. Shpigelman and Gill (2014a) took a similar approach in their survey of Facebook usage by people with intellectual disabilities, also posting the request of the study in different Facebook groups. This was preceded by an analysis of the groups in which these persons could be found (Shpigelman and Gill 2014b). Begara Iglesias, Gómez Sánchez, and Alcedo Rodríguez (2019) chose the offline route and distributed information in self-help groups; in a snowball effect, more and more people were found who wanted to participate in their study.

Recruiting people in this way – e.g., analysing self-help groups in the social environment or searching for Facebook groups – can take time. However, as described above, people with intellectual disabilities are still rarely asked for their opinion. Studies comparing the attitudes of caregivers and people with intellectual disabilities often find that their attitudes are divergent, and that it is worth asking people with intellectual disabilities for their own opinion (Lough and Fisher 2016; Näslund and Gardelli 2013; Raspa et al. 2018). Heitplatz (2020), for example, found that participants with intellectual disabilities showed great joy in participating in research and expressed many ideas and wishes regarding how they wanted to make their own Internet usage safer.

5 Conclusion

As in the case of many reviews, several methodological limitations must be considered when interpreting the results of our study. The review is limited to the articles found by the authors and to the quality of the available research. The high number of articles at the beginning of the screening process and the defined inclusion and exclusion criteria for both title screening and abstract screening can lead to the exclusion of articles that would have corresponded to our topic. Additionally, articles published after May 2020 are not included in this review. Furthermore, restricting the review to peer-reviewed journals in the German and English languages means that the extent of other publications (i.e., non-peer-reviewed or in another language) is unknown. It should also be noted that the review focuses only on media usage in leisure time; it would be beneficial to examine what the inclusion of people with intellectual or other disabilities looks like in other contexts. Nevertheless, on the basis of the included articles, we aimed to answer our three research questions.

(1) How are people with intellectual disabilities involved in research?

People with intellectual disabilities are involved in research in different ways. In some studies, they are interviewees or active participants (n=28). In other studies, the opinion of caregivers was surveyed. People with intellectual disabilities were mainly recruited through institutions where they work, live, or go to school. Only five studies recruited the participants via social media or self-help organisations.

(2) What research methods are used to conduct research with people with intellectual disabilities?

A variety of research methods were used to conduct research with people with intellectual disabilities, with questionnaires being the most popular method, followed by interviews. But only five studies stated that the research instrument was adapted to the participants' needs, even though different studies and articles stated that the designing the research instrument according to the needs of the target group is crucial (Wilkens 2019; Rabiee, Beresford, and Sloper 2005; Nind 2008). In most of the studies, having the linguistic and cognitive abilities to understand and answer the questions were a precondition to participating.

(3) Which topics are researched in the studies? In addition, what aspects of the everyday life of people with intellectual disabilities are investigated?

The studies researched five topics regarding the media usage of people with disabilities: views and attitudes of (mainly) caregivers, the usage of different devices, social media, Internet usage and access, and ICT in general. It is noticeable that a high number of studies not only involved the media users themselves (in this case, people with intellectual disabilities) but also the users' caregivers. This clearly shows that it is common in research studies for the data regarding the media usage of people with intellectual disabilities to be influenced by caregivers.

With regard to the high number of excluded studies from the sample, it is noteworthy that while 'only' 38 studies conducted research into the everyday usage of media by people with disabilities, 57 intervention studies on different mobile devices (e.g., different kinds of smartphones, internet applications, Google glasses) were conducted in the same period of time and published online. It seems, therefore, that the research community recognises the potential of digital media for people with intellectual disabilities, even when the research's interest lies within goal-oriented intervention instead of in the media usage in such people's everyday lives.

Conducting research into media usage is mostly done via questionnaires and interviews (ARD/ZDF-Forschungskommission 2020; Europäische Kommission and TNS Opinion & Social 2018). Also, questionnaires and interviews are mostly used in research into media usage by people with intellectual disabilities. These are research instruments which can be easily distributed, and which might more easily reach a greater number of participants. However, it might be worth considering whether questionnaires are the appropriate research instrument in this field of research in general. Questions regarding the frequency of usage are always influenced by the participant's understanding of 'media' and 'usage'. Is listening to music on YouTube while doing other things (e.g. cooking, learning) part of media usage? Moreover, is it useful to ask when and how often digital media have been used lately when it is difficult to remem-

ber? These difficulties certainly influence research, not only with people with disabilities but with all people in our society. The decision about which research instrument is used should always be guided by the research question. It is time to be creative in order to design research into media usage for everyone. This applies to the recruitment of the participants as well as to the design of (or decision to use) a particular research instrument. Once a research instrument is chosen, creativity is still needed to help decide the following:

- What adaptations are needed to reach the intended target group?
- How can I reach the target group?

As described in the discussion above, methodological questions need to be addressed in order to conduct research with a variety of target groups. If a study is designed to be adaptive and with a certain kind of flexibility, it might be possible to use such an instrument for a huge group of people that includes, for example, people without a disability, children, and people with different kinds of language problems or with different native languages. Our study shows that the decisions regarding samples and recruited participants should no longer be based on the abilities of the participants. Instead, methods need to be designed in a way that everyone can participate, even though this will certainly result in a higher expenditure of time and resources. It is part of politics to take such considerations into account when calling for proposals and research grants.

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