



RESEARCH METHODS FOR QUESTIONING PEOPLE WITH INTELLECTUAL DISABILITIES. Rapid Review Protocol and Overview of Results.

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ABSTRACT

Introduction

People with intellectual disabilities are often an unattainable and overlooked population in research. Due to different challenges, such as low literacy, this target group is often excluded by researchers.

Methods and analysis

The aim of this rapid review is to present an overview of the current discussion of research methods on existing survey problems in people with intellectual disabilities.

Results

The data is charted in tables and give a brief report about challenges and research methods questioning people with intellectual disabilities.

Ethics and dissemination

Ethics approval is not required. Findings will be disseminated through professional networks, conference presentations and publication in a scientific journal.

Keywords: people with intellectual disabilities, research methods

TABLE OF CONTENTS

1. Introduction	
2. Objectives	1
3. Method	1
3.1 Rapid Reviews	1
3.2 Development of the search strategy	2
3.3 Eligibility criteria	2
3.4 Information sources	2
3.5 Search terms	3
3.6 Screening procedure	3
3.7 Data charting and synthesis	3
4. Overview of Results	4
4.1 Selection of sources	4
4.2 Specific challenges questioning PWID?	4
4.3 Research methods	6
5. Ethics and Dissemination	17
6. Strength and Limitations	17
7. Implications	17
8. References	18
8.1 References of the chapters Introduction and Method	18
8.2 References of included articles in alphabetical order	18

1. INTRODUCTION

Low literacy means that a person can only read and write up to the level of simple sentences at best and that coherent (even short) texts are challenging (Grotlüschen et al. 2019). According to the American Association of Intellectual and Developmental Disabilities (AAID 2024), intellectual impairment is acquired during adolescence, which distinguishes it from other diseases or syndromes (e.g. dementia, acquired brain damage) and is measured using an IQ test (IQ below 75). It is characterized by significant limitations in intellectual functioning and adaptive (social) behaviour that affect activities of daily living. Thus, people with intellectual disabilities (PWID) can be described as a population group with low literacy. Overall, there is a lack of suitable survey instruments to meet the needs of PWID (Rathmann et al. 2019). As early as 2013, the Federal Ministry of Labour and Social Affairs (BMAS) stated that PWID are not adequately reached in representative surveys due to the challenges mentioned above. PWID are often an unattainable and overlooked population in research. Due to different challenges, such as low literacy, this target group is often excluded by researchers. In order to clarify the known current state of research methods in a short time, a rapid review is carried out.

2. OBJECTIVES

The aim of this review is to present an overview of specific challenges questioning PWID and to present the current state of research questioning PWID taken into account the specific challenges. The general challenges in questioning PWID and the status quo are outlined in a brief report. Therefore, the overarching research questions for this review are:

1. What specific challenges can be identified questioning PWID?
2. What is the current state of research methods questioning PWID?

3. METHOD

3.1 Rapid Reviews

“Rapid reviews are a form of knowledge synthesis in which components of the systematic review process are simplified or omitted to produce information in a timely manner” (Tricco et al. 2015, p. 2). Adjustments in rapid reviews compared to systematic reviews are usually:

- Limiting the number of databases searched
- Limiting the search itself by date, language, geographical area, or study design
- Search only for other systematic reviews
- Use a layered searching approach, identifying existing systematic reviews and then updating them with a summary of more recent eligible primary studies and
- Adjustments to the needs of the research (King et al, 2022).

The documentation of the complete search strategy is orientated on the PRISMA standards (Preferred Reporting Items for Systemic Reviews and Meta-Analyses) (Page et al., 2020).

3.2 Development of the search strategy

To realize a quick overview, a search strategy that is as specific as possible was tailored to a narrow question. The focus was on research methods that took the needs of PWID into account. English search terms were tested in Medline via Pubmed and Cinahl. German search terms were tested in Psyndex in early March 2024. The development of the search strategy was conducted by one researcher (DB).

3.3 Eligibility criteria

The following eligibility criteria are formulated:

Table 1: Eligibility criteria

	Inclusion	Exclusion
Population	Adults with intellectual disabilities	People with intellectual disabilities are not addressed or are under 18 years of age
Concept	Research methods	Studies that merely describe the barriers in their own research are excluded, as these do not provide any information on the current status of discussion.
Context	Any context, e.g. outpatient care or inpatient care	None
Other	<ul style="list-style-type: none">• Period from 2014 to 2024 (10 years)• Language German or English• All relevant studies, regardless of their design and quality, including dissertations, editorial articles, overviews and systematic reviews	<ul style="list-style-type: none">• Before 2014 (older than 10 years)• Not written in German or English• Abstracts for conferences or poster,• Full Text is not available

3.4 Information sources

The search was performed across nine databases to retrieve a wide range of potentially relevant articles and to take an interdisciplinary approach. All searches were conducted in the middle of March 2024. The following databases were searched with English search terms:

1. Medline via PubMed
2. CINAHL via EBSCOHost
3. Eric
4. Web of Science
5. LIVIVO - The Search Portal for Life Sciences
6. Wiley Online Library
7. PsycInfo via EBSCOHost

The following databases were searched with German search terms:

8. Psyndex
9. Fachportal Pädagogik /FIS Bildung

3.5 Search terms

The search terms are shown in Table 2 (English) and Table 3 (German). They are only relevant if they appear in the title or abstract. Search terms are adapted to the requirements of the database.

Table 2: English search terms

Target group	Topic
Intellectual* disab* OR learning disab* OR developmental disab*	quantitative research OR quantitative evaluation OR qualitative research OR qualitative evaluation

Table 3: German search terms

Target group	Topic
geistige behind* OR Intellektuelle Behind* OR intellektuelle beeinträcht* OR menschen mit lernschwierigkeit*	Qualitative Forschung OR Quantitative Forschung

3.6 Screening procedure

The review was conducted in Rayyan, a web-based systematic review platform. All articles obtained from the database searches were imported. The platform was used to detect and remove duplicates. After that, all titles and abstracts are screened according to the eligibility criteria. Articles that appeared suitable were ordered as full texts and checked again for suitability. The screening procedure was conducted by one researcher (DB).

3.7 Data charting and synthesis

Data were mapped with the following categories:

- Qualitative or Quantitative research methods
- Type of publication (was categorized in the charting process)
- Focus of the publication
- Main results / Reasons for inclusion
- Sample
- Authors
- Years of publication
- Title
- Country
- Journal
- Language

4. OVERVIEW OF RESULTS

4.1 Selection of sources

The search resulted in 4,998 articles. After screening titles and abstracts, 87 articles were reviewed in full text. Finally, 36 articles were included (see Figure 1).

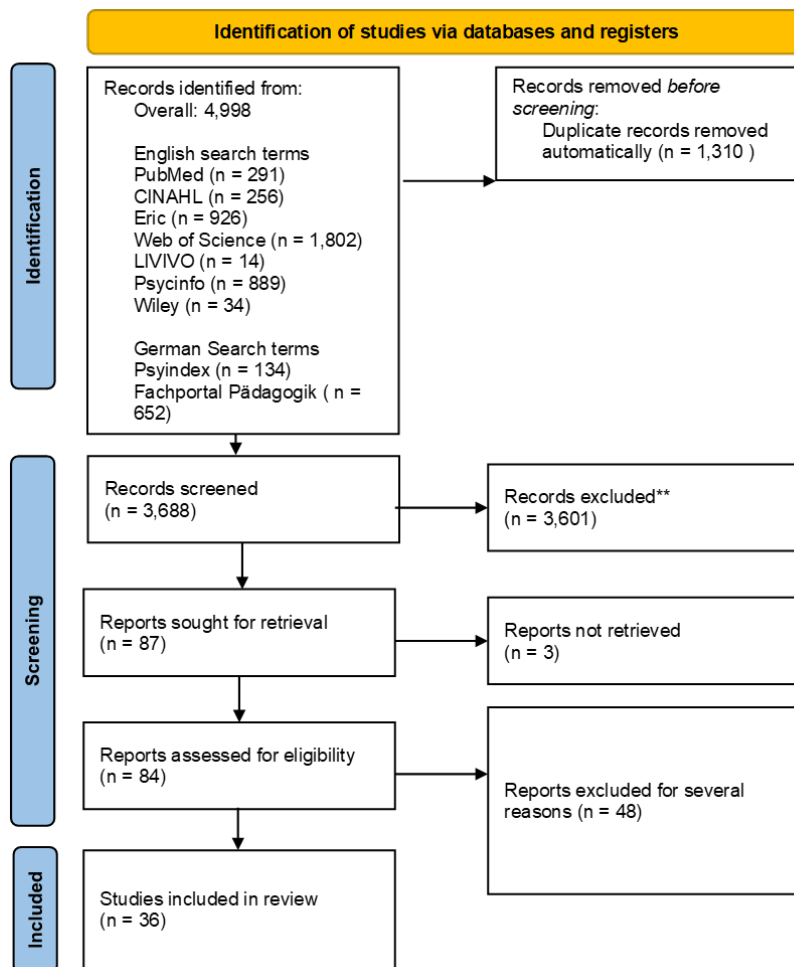


Figure 1: Flow diagram based on PRISMA 2020 (Page et al. 2021)

Exceptions: During the process, three contributions prior to the publication year 2014 came to our attention. These were considered as important and have been included. These are Clark et al. (2012), Ollerton (2012), Ottmann & Crobsie (2013). In contrast Moisl (2017), who published on methods for interviewing people with intellectual disabilities, spoke against this, as this was only a summary that was not useful for answering our research questions.

4.2 Specific challenges questioning PWID?

The first research question is: What specific challenges can be identified questioning PWID? An overview of the specific challenges is presented in Table 4. As the aim is a short report, a descriptive summary in tabular form was agreed upon as an overview of the results. The data is summarized from the included contributions and not provided with the source. More detailed results will be published elsewhere.

Table 4: Overview of specific challenges of surveying PWID

Challenges	Description
Heterogeneous skills	<ul style="list-style-type: none"> • Impairment of communication, mainly due to incomprehensibility or alternative communication • Challenges to generalize experiences, including difficulties remembering dates and times • Difficulties in formulating own points of view • Limited ability to provide information due to limited ability to adopt perspectives, reflect on norms and lack of understanding of a specific frame of reference • (Rapid) cognitive overload
Attitude and ability of the researchers	<ul style="list-style-type: none"> • Methodologically complex surveys and necessary adjustments to participants during ongoing data collection • Lack of research guidelines
Ethical issues	<ul style="list-style-type: none"> • Attention to vulnerability • Ethical tensions related to the power imbalance between researchers and participants • Misunderstandings about the purpose of research and (false) hopes that researchers can improve their lives
Participant recruitment	<ul style="list-style-type: none"> • Access to participants with strong involvement of 'gatekeepers' • Power relationships between research participants and professionals/supporters who act as gatekeepers (often very protective and want to avoid all risks) • Identification of participants relevant to the research question, taking into account participants' abilities (excluding often persons with lower cognitive abilities) • Number of participants (to achieve meaningful results)
Clarification of research projects (at the beginning of the data collection)	<ul style="list-style-type: none"> • Informed and genuinely understood consent • Consent to participate in research based on a desire to please the researcher and the experience of not having their opinion recognized
Preparation and realization	<ul style="list-style-type: none"> • Selection of the appropriate method (e.g. interview guide) and adaptations, as normative ideas of communication competence (understanding, agreement and expressiveness) are inappropriate • Selection of a suitable place to conduct the interview • Form of the exchange (building trust is crucial) • Socially desirable answers, sometimes to a high degree
Data evaluation	<ul style="list-style-type: none"> • Accessible design of the research results for participants

4.3 Research methods

The second research question is: What is the current state of research methods questioning PWID? Included articles were categorized inductively. The categories are shown in Table 5.

Table 5: Category Overview

Research Approach	n	Categories
Qualitative (n=32)	9	Authors reflected experience and methods of own research
	6	Overviews about methods like literature reviews and general descriptions
	14	Developmental or adaptations of used research methods
	1	Focus on visual support
	2	Description of Online studies
Quantitative (n=4)	4	Description of development of or conducting questionnaire surveys

As the aim is a short report, a descriptive summary in tabular form was agreed upon as an overview of the results. A result overview is sorted by the categories of Table 4 and shown in tables 6 -11. More detailed results will be published elsewhere.

A mandatory notice:

- The aim was to visualize the founded results rapidly. Therefore, the statements are mostly copied directly from the articles to be rapid, these are mostly direct quotations.
- German Language is translated into English. The original title of publications can be viewed in the references.
- The results are very heterogeneous, and so is the description of them.

Table 6: Authors reflected experience and methods of own research Part I

Authors, year and language	Title	Aim	Main results / Reasons for inclusion	Sample	Country	Journal
Ollerton (2012) English	IPAR, an inclusive disability research methodology with accessible analytical tools	Describing Inclusive Participatory Action Research (IPAR) as a practical alternative methodology with which to inform disability research design, and to illustrate some accessible analytical tools. It is not discussed how each of these methods was used. It concerns IPAR and its creative visual evaluation process.	Inclusive methodologies and accessible research tools can provide access to new forms of knowing. The creative methods used included: 1) role-play to teach research ethics, 2) photography to develop pictorial texts for institutional ethnographic examination, 3) metaphor to assist people in articulating meaning within their photographs, 4) poetry to analyse and make meaning from data, 5) photo-voice as a data collection, analysis and dissemination tool and 6) colour-coding using patchwork as a means of evaluating the inclusivity of the IPAR process.	Not mentioned	Australia	International Practice Developmental Journal
Tozer et al. (2014) English	'My brother likes meeting new people, but don't ask him any direct questions': involving adults with autism plus learning disability in a qualitative research project	Describing experiences of facilitating the involvement of people with autism and a learning disability, the methods used and understandings gained, with the aim of encouraging practitioners and researchers to do likewise.	Lesson learned and discussion about planning to meet, learning from the involvement of sibling with autism, limitations of involvement, implications for practice and research.	21 adult siblings	UK	British Journal of Learning Disabilities
Beall & Williams (2014) English	Using Qualitative Methods in Research with People Who Have Intellectual Disabilities	Examining the frequency of qualitative studies published in three major intellectual disability journals over a decade and based on that, critical reflections.	Lesson learned and reflections from the literature - main categories: Identifying participants relevant to the research question, abilities of participants, quality of data, interviews, how many participants, analysis.	Not mentioned	UK	Journal of Applied Research in Intellectual Disabilities
Sigstad (2014) English	Characteristic interviews, different strategies: Methodological challenges in qualitative interviewing among respondents with mild intellectual disabilities	Specific challenges were discussed in general to elucidate researchers.	Lesson learned and discussion about informed consent, challenges associated with communication, planning and adaptation of the research interview in accordance with informants' own terms.	Not mentioned	Norway	Journal of Intellectual Disabilities
Kidney & McDonald (2014) English	A toolkit for accessible and respectful engagement in research	Developing a qualitative study toolkit emphasizing accessibility, flexibility, variety, and responsiveness.	Toolkit has information on: finding people to be in a study, people making decisions about being in a study, where and how to interview people, taking breaks during interviews, and giving people something to thank them for being in a study.	Not mentioned	USA	Disability & Society

Table 6: Authors reflected experience and methods of own research IPart II

Authors, year and language	Title	Aim	Main results / Reasons for inclusion	Sample	Country	Journal
Wilkenfeld (2015) English	"Being Heard": Qualitative Research Conundrums With Individuals With Developmental Disabilities	Examine qualitative research dilemmas encountered with participants who have communication, physical and cognitive impairments.	Three overarching conundrums emerged over the course of the study, which consisted of recruitment-related issues, communication conundrums and role-shifting confusion.	20 people with intellectual or developmental disabilities	USA	Research on Social Work Practice
Rose et al. (2018) English	Is it possible to use interpretive phenomenological analysis in research with people who have intellectual disabilities?	This article examines the appropriateness of using interpretive phenomenological analysis (IPA) in research with people who have intellectual disabilities, focussing on quality.	<p>IPA can be an appropriate methodology to use in research with people with intellectual disabilities. IPA researchers are encouraged to:</p> <ul style="list-style-type: none"> • Provide more information about data collection methods, • to be more creative in their approach to data collection, • to develop more detailed and interpretive analyses, • to present analyses which engage with longer sequences of data, • and to provide more transparency about their sampling strategies and the characteristics of their samples. 	Not mentioned	UK	Journal of Applied Research in Intellectual Disabilities
Sigstad & Garrels (2018) English	Facilitating qualitative research interviews for respondents with intellectual disability	Discussing several communication techniques from counselling practice	Share lessons learned directly from participants and from the literature regarding best practices in interviews – main categories: planning interviews, location and exchange, conducting interviews, analyses and reporting.	Not mentioned	Norway	European Journal of Special Needs Education
Versegby et al. (2020) English	Key considerations when interviewing individuals with expressive language difficulties	Recommendations are made for collecting, analysing, and reporting data from participants who are quiet or have expressive language difficulties	Drawing on experience of the research project 'Friendly Housemates' gleaned from interviews conducted for the study and earlier research, recommendations are made for collecting, analyzing, and reporting data from participants who are quiet or have expressive language difficulties.	Not mentioned	Canada	Qualitative Research

Table 7: Overview / Reviews Part I

Authors, year and language	Title	Aim	Main results / Reasons for inclusion	Sample	Country	Journal
Ottmann & Crobsie (2013) English	Mixed method approaches in open-ended, qualitative, exploratory research involving people with intellectual disabilities: A comparative methods study.	This study sought to identify and compare a mix of methods that would adequately represent the views of a group of people with an intellectual disability and provide insight into what is important in their lives.	A number of conclusions can be drawn from this study. Different methodologies generate different insights. Whereas more "formal" methods, such as semi-structured interviews produce a number of issues that appear to be more complex, "informal" methods bring to light a number of no less important issues that are more concrete and related to everyday life. When asking carers to respond on behalf of a person, it might be important to distinguish between complex and everyday issues bearing in mind the short-term, medium-term, and long-term implications. Questionnaires represent a poor choice of method for both carers/family members and principal participants. Focus groups can be very difficult to organize and are likely to produce uneven outcomes. Semi-structured interviews, proxy responses, Photovoice, and ethnographic observation generate a far better representation. However, the data presented in this study clearly suggests that a mix of methods may be required to capture the opinions and aspirations of people with intellectual disability. For researchers and practitioners, this raises the question as to which mix of methods to employ.	Not mentioned	Australia	Journal of Intellectual Disabilities
Keeley (2015) German	Qualitative research with people with intellectual disabilities. Necessity and methodological possibilities for collecting subjective views with special consideration of the needs of people with intellectual disabilities	Qualitative research methods are reflected with regard to the special needs of people with intellectual disabilities.	Use of proxy interviews, everyday observations, participant observation and video analysis are discussed. Finally, projects based on the use of different methods are presented.	Not mentioned	Germany	Zeitschrift für Heilpädagogik

Table 7: Overview / Reviews Part II

Authors, year and language	Title	Aim	Main results / Reasons for inclusion	Sample	Country	Journal
Haas et al (2015) German	Qualitative research methods in inclusive contexts.	The starting point of this article is the question how qualitative research, which takes seriously what is given in personal experience, can be implemented in inclusive contexts. Based on the critical question of how and whether research can capture the complexity of the world, a qualitative research methodological approach is presented that focuses on research as an intersubjective space of experience.	The article presents a combination of qualitative research methods that are oriented towards an intersubjective and bodily-sensual interest in knowledge and thereby outline an entire research process.	Not mentioned	Germany	Book chapter: Inklusion im interdisziplinären Diskurs. Band 1. Eine Herausforderung für Schule und Hochschule, Seite 145 - 168
Katzenbach (Editor) (2016) German	Qualitative research methods in special education	Handbook about qualitative research methods in special education	Comprehensive overview of access, data collection and data analysis.	Not mentioned	Germany	Book
Diaz (2022) English	Qualitative methodological approaches involving participants with intellectual disabilities: Scoping review of literature exploring death and dying	Scoping review of methods used mainly to provide an overview of qualitative data collection methods used in research involving participants with intellectual disabilities to explore death and dying.	Overview and recommendations about methods used: participant observation, nominal group technique, distress protocols. Studies demonstrate a flexible approach, future research must adequately report study characteristics to ensure transparency and reliability.	Not mentioned	Switzerland	Journal of Policy and Practice in Intellectual Disabilities
Moramana et al. (2023) German	Ethical reflection during a research process involving persons with intellectual disabilities	Ethical reflections	Overview of ethical tensions in research with people with intellectual disabilities.	Not mentioned	Switzerland	Vierteiljahresschrift für Heilpädagogik und ihre Nachbargebiete

Table 8: Describing, developing or testing new research methods Part I

Authors, year and language	Title	Aim	Main results / Reasons for inclusion	Sample	Country	Journal
Clarke et al. (2012) English	How Effective is the Cognitive Interview When Used with Adults with Intellectual Disabilities Specifically with Conversation Recall?	The cognitive interview (CI) has been shown to increase correct memory recall of a diverse range of participant types without an increase in the number of incorrect or confabulated details. However, it has rarely been examined for use with adults with intellectual disability.	The findings suggest that the CI can enable adults with intellectual disability to provide a fuller picture of an experienced event. Implications of this research are discussed.	21 people with intellectual disabilities	UK	Journal of Applied Research in Intellectual Disabilities
Caldwell (2014) English	Dyadic interviewing: a technique valuing interdependence in interviews with individuals with intellectual disabilities	Dyadic interview technique has been adapted to address some of the difficulties that present when conducting interviews with individuals with intellectual disabilities.	Dyadic interviewing shows great promise for improving the participation of PWID in research, mitigating some of the difficulties that arise during fieldwork and providing researchers with a structure that can improve the quality of their research and facilitate communication with participants and intermediaries while conducting research.	Not mentioned	USA	Qualitative Research
Overmars-Marx et al. (2016) English	Photovoice in research involving people with intellectual disabilities: A guided photovoice approach as an alternative	The "guided photovoice" approach was tested with people with intellectual disabilities. The outcomes of the approach were evaluated.	A more standardized, guided photovoice approach is a helpful addition to the various options for using photovoice; it is important to decide which approach best fits the needs and capabilities of the participant.	14 people with intellectual disabilities	Netherlands	Journal of Applied Research in Intellectual Disabilities
Hollomotz (2018) English	Successful interviews with people with intellectual disability	This article considers the successes and flaws in interviewing techniques.	A responsive approach to each participant's particular communication style, combined with avoidance of inaccessible question formats, are key ingredients of a successful interview.	29 participants	UK	Qualitative Research
Corby et al. (2018) English	Meeting the challenge of interpretation: Hearing the voices of people with intellectual and developmental disability through I-Poems	Explaining how the Listening Guide was applied as an additional step in the analysis during a study which used hermeneutic interviews with people with intellectual disability as the sole method of data collection. An argument is made for the systematic application of the guide with a focus on using I-Poems.	It is concluded that this method of drawing attention to the participants' own voices provides a unique basis for interpreting interviews.	Not mentioned	Ireland & UK	Journal of Intellectual Disabilities

Table 8: Describing, developing or testing new research methods Part II

Authors, year and language	Title	Aim	Main results / Reasons for inclusion	Sample	Country	Journal
Geukes & Latteck (2018) German	Kruse's integrative basic method as a qualitative-reconstructive method for interviews using the example of people with intellectual disabilities	Kruse (2014) developed an integrative basic procedure as an analysis method that enables the constructive evaluation of interview material from people with intellectual disabilities. It includes proven analytical steps from grounded theory methodology and analyzes the specific data material of people with intellectual disabilities on a linguistic-communicative level.	The analysis procedure is discussed against the background of various target group-specific features.	Not mentioned	Germany	Journal für qualitative Forschung in Pflege- und Gesundheitswissenschaften
Kaley et al. (2019) English	More Than Words: The Use of Video in Ethnographic Research With People With Intellectual Disabilities	Share the methodological insights gained from a visual ethnographic study that sought to explore the experiences of people with intellectual disabilities.	Set out an innovative way of doing ethnographic research with people with intellectual disabilities. For the authors, the added value of video method lies with its potential to elicit the experiences of people who may prefer to see alternative forms of communication to the spoken or written word. This is because video values non-verbal forms of expression and offers people the opportunity to communicate their experiences by moving their bodies, as well as by using their words.	13 participants	UK	Qualitative Health Research
Bains & Turnbull (2020) English	Conducting theory-based qualitative interviews with adults with intellectual disabilities and their carers: Adaptations to facilitate participation	Adapted a behaviour change theory-based research approach.	A community-based, staged recruitment process and iterative approach to data collection and analysis supported successful participation amongst adults with intellectual disabilities in behaviour-change theory-based interview research. Methodological adaptations enabled richer data collection amongst adults with mild-moderate intellectual disabilities and carers.	12 adults with mild to moderate intellectual disabilities, 12 staff and family carer	UK	Journal of Applied Research in Intellectual Disabilities
Stölting & Hasseler (2020) German	First Results of an explorative study about the provision of health and nursing care for people with intellectual disabilities: A target group-specific interview guide	Developing a target-group-specific interview guide.	Presenting development and conducting of a target-group-specific open guideline interview for people with intellectual disabilities and discussing it in the context of life dimensions.	23 people with intellectual disabilities	Germany	Pflege & Gesellschaft

Table 8: Describing, developing or testing new research methods Part III

Authors, year and language	Title	Aim	Main results / Reasons for inclusion	Sample	Country	Journal
Dee-Price et al. (2021) English	Every voice counts: exploring communication accessible research methods	Herein the purpose of the study was to develop and test new methods of data collection that would improve access to research participation for people with augmentative and alternative communication.	The study provides an illustration of how sociology (and potentially other fields of inquiry) might shape research methods to collect and understand the insights of participants with Complex Communication (Access) Needs (CCAN). In this instance, it was achieved by combining ideas, experimental adaptation and testing of alternative research methods to augmentative and alternative communication, coupled with the guidance and advice from people with CCAN. The study also reinforces the view that not only is it possible to accommodate the research contribution of people with CCAN, but that it is ethically and fundamentally appropriate to pursue access to research participation for every human being. The study findings challenge several gaps in methods, ethical guidelines, research or policy standards which prevent the 'voices' of people with CCAN.	10 adults with augmentative and alternative communication	Australia / USA	Disability & Society
van der Weele & Bedewold (2021) English	Shadowing as a qualitative research method for intellectual disability research: Opportunities and challenges	Describes Shadowing as an alternative method to respond to ethical and methodological challenges.	Shadowing is a promising method for intellectual disabilities, benefits are an accessible and flexible method, unique insight, giving people a voice, breaking traditional researcher and participant role.	Not mentioned, two research projects	Netherlands	Journal of Intellectual & Developmental Disability
Mc Farland et al. (2022) English	Adaptive interviewing for the inclusion of people with intellectual disability in qualitative research	Presents an adaptive interviewing approach from a participatory action research project	Describing adaptive interviewing approach incorporating multiple methods: (1.) responsive communication techniques; (2.) the inclusion and support of family carers; (3.) visual tools; (4.) walking interview	5 people ageing with intellectual disabilities	Australia	Journal of Applied Research in Intellectual Disabilities
Nind et al. (2022) English	Focus group method: Doing research inclusively and supporting social inclusion	The chapter shows how focus groups can be political or playful as a means of co-production. This will be illustrated using data from studies involving people with intellectual disabilities, where mutual support among those in dialogue is evident. The authors argue that the experience of taking part in focus groups enhances the social inclusion of those involved.	Creating vibrant interactive spaces in which best use can be made of participants' potential not just to contribute but to learn from each other's contributions and come to know themselves and their own situation a little better. Focus groups can create these spaces, especially when the researcher is alert to their inclusive and transformative potential and open to the idea of hybrids of focus groups and other methods.	Not mentioned	UK	Handbook of social inclusion: Research and practices in health and social sciences. pp. 1041-1061

Table 8: Describing, developing or testing new research methods Part IV

Authors, year and language	Title	Aim	Main results / Reasons for inclusion	Sample	Country	Journal
Scheffers et al. (2024) English	Photographic visualization of stories: documenting the experiences of people with intellectual disabilities with guided photovoice	Guided photovoice is used. Through thematic analyses, the experiences of people with intellectual disabilities regarding photovoice are discussed.	In sum, current results provide new insights into the experiences of people with intellectual disabilities participating in a guided photovoice procedure. These findings also support the need for future research regarding guided photovoice in people with intellectual disabilities. An individual tailor-made approach has been emphasized in the current research. In the future, it would be interesting to evaluate the findings of guided photovoice in a small group compared to the individual approach.	14 people with intellectual disabilities	Netherlands	Journal of Intellectual Disabilities

Table 9: Visual Support

Authors, year and language	Title	Aim	Main results / Reasons for inclusion	Sample	Country	Journal
Stewart et al. (2018) English	Evaluating service users' experiences using Talking Mats®	Discusses the use of Talking Mats in comparison to a validated questionnaire with two data surveys. – Talking Mats provide a symbol-based, structured framework to supporting people's communication.	The literature suggests that people with intellectual and developing disabilities find it difficult to criticise services and that Talking Mats can help people express dissatisfaction. In this study, they were able to use Talking Mats to express dissatisfaction, supported by verbal responses.	8 people with moderate to severe learning disability (2 had an additional diagnosis of autism)	UK	Tizard Learning Disability Review

Table 10: Online Research

Authors, year and language	Title	Aim	Main results / Reasons for inclusion	Sample	Country	Journal
Bergström (2023) English	Mixed method approaches in open-ended, qualitative, exploratory research involving people with intellectual disabilities: A comparative methods study	Based on memos from a qualitative study, this article focuses on identified gaps related to the challenges of informed consent, access to Internet arenas and using stimulus materials. Opportunities, in terms of flexibility and relationships, are discussed and problematized.	The discussion shows that researchers may need to move out of their comfort zone and try nonconventional methods of data collection. It is important to be creative and innovative but also to look after the rights and interests of participants. Furthermore, take a non-directive approach and assume young people with intellectual disability to be experts on their own lives. Finally, the power imbalance between a researcher and participant should be considered and the researcher should ask him-/herself which perspective he/she wishes to present or 'whose side are we on?'	17 young people with intellectual disabilities	Sweden	Journal of Intellectual Disabilities
Baillie et al. (2023) English	A call to action for more disability-inclusive health policy and systems research	Online Focus Group	Their reflections add to the growing body of evidence indicating that online qualitative methods can be effective in engaging underrepresented groups and are essential to ensuring their input into health policy and systems research.	Not mentioned	Australia	BMJ Global Health

Table 11: Quantitative Research

Authors, year and language	Title	Aim	Main results / Reasons for inclusion	Sample	Country	Journal
Malam et al. (2014) English	Challenges in the first ever national survey of people with intellectual disabilities	The population of adults with intellectual disabilities has been largely neglected in survey research, as the significant impairments in communication and understanding that are common among this population were considered too great a barrier to their participation in large-scale surveys, this article considers how to overcome the problems facing this group.	Overview of barriers and how to overcome them: 1) The challenge of putting together an inclusive research team, 2) The challenge of designing an inclusive sample, 3) The challenge of designing an inclusive data collection approach, and 4) The challenge of building on this success.	2,974 interviews	UK	Book chapter in Hard-to-survey populations. pp. 347-367
Russell et al. (2018) English	The feasibility of using the EQ-5D-3L with adults with mild to moderate learning disabilities within a randomized control trial: a qualitative evaluation	A qualitative evaluation of the use of the EQ-5D-3L in a feasibility randomised control trial with participants who had a mild to moderate learning disability and type 2 diabetes.	Further research is required to develop and evaluate a version of the EQ-5D appropriate for this population in trial research. It is unrealistic to expect that adjustments to the wording alone will deliver an appropriate measure: supporter or researcher involvement will almost always be required. This requirement needs to be factored into the development and administration guidelines of any new version of the EQ-5D for adults with a learning disability.	77 participants with mild to moderate learning disabilities	UK	Pilot Feasibility Studies
Bakker-van Gijssel (2019) English	Constructing a health assessment questionnaire for people with intellectual disabilities: A cognitive interview study	Developing a health assessment questionnaire using the cognitive interview technique to improve comprehensibility. The utility of this approach to questionnaire development involving PWID is assessed.	363 identified problems led to 316 changes. Most problems (102) concerned the comprehension of the question, followed by problems in the "missing answer categories" and "inaccurate instruction" sections.	14 participants	Netherland	Journal of Applied Research in Intellectual Disabilities
Rathmann et al. (2022) English	Health consciousness and health literacy among people with disabilities. First results of a questionnaire in easy language in facilities for people with disabilities	Health consciousness and health literacy were recorded using a questionnaire in easy language. Uni- and bivariate analyses were used for data analyses.	Developing questionnaires in easy language and conducting the data collection via fact-to-face-interviews are described. The use of the questionnaires is considered valid.	351 people with intellectual disabilities	Germany	Prävention und Gesundheitsförderung

5. ETHICS AND DISSEMINATION

This work analyses existing research studies, and therefore involves no individuals nor unpublished secondary data. As such, approval from an ethics committee is not required. Findings of the rapid review will be disseminated through professional networks, conference presentations and publication in a scientific journal.

6. STRENGTH AND LIMITATIONS

The implementation was approached pragmatically, which is appropriate for a rapid review (King et al. 2022). There are several limitations to mention. Overall, the inclusion of articles can be considered subjective due to that fact that only one author conducted the review. For example, the exceptions mentioned in Chapter 4.1: The inclusion of contributions despite actual exclusion criteria and rejection despite inclusion criteria. This seemed to make sense and it can be assumed that the informative value of the review is not diminished by the exceptions. In this rapid review, only a small selection of search terms were used, narrowed down to the search in title and/or abstract. An expansion with terms such as interviews, focus groups, questionnaires, etc., would have resulted in more hits. However, the search strategy test found that the articles often focus on the apply of usual research methods for data collection and identify challenges without a specific discussion adapting or developing research methods in relation to the challenges before data collection. The aim of this review is to present an overview of specific challenges questioning PWID and to present the current state of research questioning PWID taken into account the specific challenges. It is highly assumed that the hits could have been increased, but the benefit of the larger hit selection would not have been given for this rapid review. We are convinced that the accuracy and scope of the hits are sufficient to answer the research questions. Moreover, articles may have been overlooked due to the restriction of the last ten years. This can be seen from the exceptions mentioned in section 4.1. Since the surveys have only gained momentum in recent years and we want to show the current state of research, the limitation seems to be appropriate. As an overview characteristics of included articles are presented in tables. The relevant data were charted that relate to the review questions and the aim of the review. Nevertheless, a synthesis of results is not given due to time constraints. This should be undertaken in the course of further work on this topic. In general, the objective of providing a brief report has been achieved.

7. IMPLICATIONS

The aim of this review is to present an overview of the current discussion of qualitative and quantitative research methods on existing survey problems in PWID. It can be assumed that researchers who wish to conduct research on people with intellectual disabilities will find a good foundation for the current state of research here.

8. REFERENCES

8.1 References of the chapters Introduction and Method

- AAID - American Association of Intellectual and Developmental Disabilities (2024). Definition of Intellectual Disability. <https://www.aaid.org/intellectual-disability/definition> (28.08.2024).
- Bailie, J., Fortune, N., Plunkett, K., Gordon, J., Gwynnyth, L. (2023). A call to action for more disability-inclusive health policy and systems research. *BMJ Global Health*, 8, e011561.
- BMAS – Bundesministerium für Arbeit und Soziales (2013). Teilhabebericht der Bundesregierung über die Lebenslagen von Menschen mit Beeinträchtigungen. https://www.bmas.de/SharedDocs/Downloads/DE/Publikationen/a125-13-teilhabebericht.pdf?__blob=publicationFile&v=2 (28.06.2024).
- Grotlüschen, A., Buddeberg, K., Dutz, G., Heilmann, L., & Stammer, C. (2019): LEO 2018 – Leben mit geringer Literalität. Hamburg, Pressebroschüre. Online unter: <https://leo.blogs.uni-hamburg.de/> (27.08.2024).
- King, V.J., Stevens, A., Nussbaumer-Streit, B. Kamel, C., & Garritty, C. (2022). Paper 2: Performing rapid reviews. *Systematic Reviews*, 11, <https://doi.org/10.1186/s13643-022-02011-5>.
- Moisl, D. (2017). Methoden zur Befragung von Menschen mit geistiger Behinderung. *Public Health Forum*, 25(4), S. 321 – 323.
- Page M J, McKenzie J E, Bossuyt P M, Boutron I, Hoffmann T C, Mulrow C D et al. (2021). The PRISMA 2020 statement: an updated guideline for reporting systematic reviews *BMJ*; 372, n71.
- Rathmann, K., Nellen, C., Brambrink, J. & Krause, C. (2019). Gesundheitsbezogene Lebensqualität von Beschäftigten in Werkstätten für Menschen mit Behinderung: soziale und behinderungsspezifische Unterschiede. *Prävention und Gesundheitsförderung*, 14(3), S. 248–255.
- Tricco, A. C., Antony, J., Zarin, W., Striffler, L., Ghassemi, M., Ivory, J., Perrier, L., Hutton, B., Moher, D., & Straus, S. E. (2015). A scoping review of rapid review methods. *BMC medicine*, 13, <https://doi.org/10.1186/s12916-015-0465-6>.

8.2 References of included articles in alphabetical order

1. Bailie, J., Fortune, N., Plunkett, K., Gordon, J., & Llewellyn, G. (2023). A call to action for more disability-inclusive health policy and systems research. *BMJ global health*, 8(3), e011561.
2. Bains, K. K., & Turnbull, T. (2022). Conducting theory-based qualitative interviews with adults with intellectual disabilities and their carers: Adaptations to facilitate participation. *Journal of Applied Research in Intellectual Disabilities*, 35(2), S. 556–568.
3. Bakker-van Gijssel, E. J., Lucassen, P. L. B. J., Olde Hartman, T. C., Assendelft, W. J. J., & van Schroyen Lantman-de Valk, H. M. J. (2020). Constructing a health assessment

- questionnaire for people with intellectual disabilities: A cognitive interview study. *Journal of applied research in intellectual disabilities*, 33(3), 345–353.
4. Beail, N., & Williams, K. (2014). Using Qualitative Methods in Research with People Who Have Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities*, 27, 85-96.
 5. Borgström, Å. (2023). Young people with intellectual disability and the internet: Challenges and opportunities in qualitative research. *Journal of Intellectual Disabilities*, 27(3), S. 598–612.
 6. Caldwell, K. (2014). Dyadic interviewing: a technique valuing interdependence in interviews with individuals with intellectual disabilities. *Qualitative Research*, 14(4), S. 488-507.
 7. Clarke, J., Prescott, K., & Milne, R. (2013). How effective is the cognitive interview when used with adults with intellectual disabilities specifically with conversation recall? *Journal of applied research in intellectual disabilities*, 26(6), S. 546–556.
 8. Corby, D., Taggart, L., & Cousins, W. (2018). Meeting the challenge of interpretation: Hearing the voices of people with intellectual and developmental disability through I-Poems. *Journal of intellectual disabilities*, 22(2), S. 197–205.
 9. Dee-Price, B.-J. M., Hallahan, L., Nelson Bryen, D., & Watson, J. M. (2021). Every voice counts: exploring communication accessible research methods. *Disability & Society*, 36(2), S. 240–264.
 10. Diaz, M. A., Bickenbach, J. E., Sabariego, C., & Bernard, R. M. (2024). Qualitative methodological approaches involving participants with intellectual disabilities: Scoping review of literature exploring death and dying. *Journal of applied research in intellectual disabilities*, 37(2), e13119.
 11. Geukes, C., & Latteck, Ä.-D. (2018). Das integrative Basisverfahren von Kruse als qualitativ-rekonstruktive Methode für Interviews am Beispiel von Menschen mit geistiger Behinderung. *Journal für Qualitative Forschung in Pflege und Gesundheitswissenschaft*, 5(2), S. 100-109.
 12. Haas, E. (2015). Qualitative Forschungsmethoden in inklusiven Kontexten. In. Bäuml-Roßnagl, M.-A., Berner, S., Bliemetsrieder, S., Molitor, M. (Eds.). *Inklusion im interdisziplinären Diskurs. Band 1. Eine Herausforderung für Schule und Hochschule.* München, Herbert Utz Verlag, 145 – 168.
 13. Hollomotz, A. (2018). Successful interviews with people with intellectual disability. *Qualitative Research*, 18(2), S. 153-170.
 14. Kaley, A., Hatton, C., & Milligan, C. (2019). More Than Words: The Use of Video in Ethnographic Research With People With Intellectual Disabilities. *Qualitative health research*, 29(7), S. 931–943.
 15. Katzenbach, D. (Eds.) (2016): *Qualitative Forschungsmethoden in der Sonderpädagogik.* Stuttgart: Verlag W. Kohlhammer.
 16. Keeley, C. (2015). Qualitative Forschung mit Menschen mit geistiger Behinderung. Notwendigkeit und methodische Möglichkeiten zur Erhebung subjektiver Sichtweisen unter besonderer Berücksichtigung der Bedürfnisse von Menschen mit geistiger Behinderung. *Zeitschrift für Heilpädagogik*, 3, 108 – 119.

17. Kidney, C. A., & McDonald, K. E. (2014). A toolkit for accessible and respectful engagement in research. *Disability & Society*, 29(7), 1013–1030.
18. Malam, S., Emerson, E., & Davies, I. (2014). Challenges in the first ever national survey of people with intellectual disabilities. In: Tourangeau, R., Edwards, B., Johnson, T. P., Wolter, K. M., & Bates N. (Hrsg). *Hard-to-Survey Populations*. Cambridge: Cambridge University Press, S. 347–367.
19. McFarland, B., Bryant, L., Wark, S., & Morales, B. T. (2024). Adaptive interviewing for the inclusion of people with intellectual disability in qualitative research. *Journal of Applied Research in Intellectual Disabilities*, 37(1), 1–10.
20. Moramana, N., Bühler, I., Zambrino, N., Büschi, E., & Calabrese, S. (2015). Ethische Reflexionen im Forschungsprozess mit Menschen mit kognitiven Beeinträchtigungen. *Vierteljahresschrift für Heilpädagogik und ihre Nachbargebiete*, 92(3), 185 – 197.
21. Nind, M., Kaley, A., & Hall, E. (2022). Focus Group Method. In: Liamputtong, P. (Hrsg.). *Handbook of Social Inclusion*. Springer, Cham, S. 1041-1061.
22. Ollerton, J. (2012). IPAR, an inclusive disability research methodology with accessible analytical tools. *International Practice Developmental Journal*, 2 (2), 1 - 20, https://www.fons.org/wp-content/uploads/2024/03/IPDJ_0202_03.pdf, accessed 15.10.2024.
23. Ottmann, G., & Crosbie, J. (2013). Mixed method approaches in open-ended, qualitative, exploratory research involving people with intellectual disabilities: a comparative methods study. *Journal of intellectual disabilities*, 17(3), 182–197.
24. Overmars-Marx, T., Thomése, F., & Moonen, X. (2018): Photovoice in research involving people with intellectual disabilities: A guided photovoice approach as an alternative. *Journal of applied research in intellectual disabilities* 31 (1), e92-e104.
25. Rathmann, K., Zelfl, L., Kleine, A., Dadaczynski, K. (2022). Gesundheitsbewusstsein und Gesundheitskompetenz von Menschen mit Behinderung. *Prävention und Gesundheitsförderung*, 17, S. 59–66.
26. Rose, J., Malik, K., Hirata, E., Roughan, H., Aston, K., & Larkin, M. (2019). Is it possible to use interpretative phenomenological analysis in research with people who have intellectual disabilities?. *Journal of applied research in intellectual disabilities*, 32(5), 1007–1017.
27. Russell, A. M., O'Dwyer, J. L., Bryant, L. D., House, A.O., Birtwistle, J. C., Meer, S., Wright-Hughes, A., Walwyn, R. E. A., Graham, E., Farrin, A. J., & Hulme C. T. (2018). The feasibility of using the EQ-5D-3L with adults with mild to moderate learning disabilities within a randomized control trial: a qualitative evaluation. *Pilot Feasibility Studies*, 4, S. 164–173.
28. Scheffers, F., Moonen, X., & van Vugt, E. (2024). Photographic visualization of stories: documenting the experiences of people with intellectual disabilities with guided photovoice. *Journal of intellectual disabilities*. doi.org/10.1177/17446295241229002.
29. Sigstad H. M. (2014). Characteristic interviews, different strategies: Methodological challenges in qualitative interviewing among respondents with mild intellectual disabilities. *Journal of intellectual disabilities*, 18(2), 188–202.

30. Sigstad, H. M. H., & Garrels, V. (2018). Facilitating qualitative research interviews for respondents with intellectual disability. *European Journal of Special Needs Education, 33*(5), 692–706.
31. Stewart, K., Bradshaw, J., & Beadle-Brown, J. (2018). Evaluating service users' experiences using Talking Mats®. *Tizard Learning Disability Review, 23*(2), 78 - 86.
32. Stölting, L., & Hasseler, M. (2020). Erste Ergebnisse einer explorativen Studie zur pflegerischen und gesundheitlichen Versorgung von Menschen mit geistigen Beeinträchtigungen. Ein zielgruppenspezifischer Interviewleitfaden. *Pflege & Gesellschaft 5*, 242-255.
33. Tozer, R., Atkin, K., & Wenham, A. (2014). 'My brother likes meeting new people, but don't ask him any direct questions': involving adults with autism plus learning disability in a qualitative research project. *British Journal of Learning Disabilities, 42* (4), 292 – 300.
34. Van der Weele, S., & Bredewold, F. (2021): Shadowing as a qualitative research method for intellectual disability research: Opportunities and challenges. *Journal of Intellectual & Developmental Disability, 46* (4), S. 340–350.
35. Versegny, J., Atack, L., & Maher, J. (2020). Key considerations when interviewing individuals with expressive language difficulties. *Qualitative Research, 20*(6), 960-970.
36. Wilkenfeld, B. F. (2015). "Being Heard": Qualitative Research Conundrums With Individuals With Developmental Disabilities. *Research on Social Work Practice, 25*(6), 702-710.