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Understanding Epistemic Justice through Inclusive Research about Intellectual Disability and Sexuality

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Abstract: Formal language: This paper discusses inclusive research and epistemic justice by using an example of a published study the authors conducted on intellectual disability and sexuality in supported living environments. Our study addressed taboos and pushed boundaries in content and methodology through two ways of inclusive research: (1) the second author of this paper who has an intellectual disability was a main researcher in the study; and (2) we interviewed people with intellectual disabilities about their own experiences as well as their desired solutions to obstacles they face in their supported living environments. Their input was centralized in the final research report. This method challenged the epistemic injustice of who have historically not been 'allowed' to produce knowledge in research. This paper offers historical insight into epistemic injustice as well as relational approaches from critical disability studies and non-Western understandings of disability that 'rethink' disability and that can thus promote epistemic justice in academic theory. By addressing both practice and theory in this paper, we aim to contribute to the growing body of inclusive research and to the epistemic justice of people with intellectual disabilities. **Plain language:** (1) Epistemology = thinking about knowledge, producing knowledge, sharing knowledge. (2) In history, people with intellectual disabilities have often been excluded from participating in this. This is called epistemic injustice. It is caused by the discrimination of people with intellectual disabilities (ableism). (3) Performing inclusive research with people with intellectual disabilities challenges this. It contributes to epistemic justice. Researchers and interviewees with intellectual disabilities can bring knowledge from lived experience into research. (4) Knowledge from lived experience has not always been valued in traditional research. That means we also need to think differently about 'knowledge', and about 'disability' and its 'value'. (5) Discrimination based on disability has a long history. For instance: during colonialism by European countries (starting in the 15th century), false ideas about 'poor health' and 'low intelligence' were already used to justify slavery. People with disabilities have often been locked away or even killed because they have been seen as 'less valuable'. These ways of thinking still exist. They influence our understanding of 'epistemology' because they decide whose way of thinking and way of life is valuable or not valuable. We need to change this way of thinking. (6) Some academic fields that help are critical disability studies, indigenous studies, and feminist posthumanism. These fields challenge ableist ways of thinking. They can help us understand disability as something that is not negative or less valuable, but simply part of what makes us human.

Keywords: epistemic justice; intellectual disability; sexuality; inclusive research; relationality

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1. Introduction

In this paper, we will discuss epistemic (from 'epistemology') (in)justice and -agency while using the example of a study on sexuality and intellectual disability in supported living environments. This study was performed through inclusive research over the course of eight months from 2022 to 2023 (Kelders et al. 2023). Epistemology is a branch of philosophy that looks at what it means to *know* something. It studies *knowledge*. It asks questions such as the following: what is knowledge? How do we come to know something? And what is truth? Are there objective truths in the world? And are these truths the same for every culture? Epistemic agency is "the capacity for an individual to produce, transmit, and use knowledge" (Catala et al. 2021, p. 9015). Epistemic justice is the right of people to be heard, taken seriously and contribute to knowledge production; to turn their agency into recognized action (Fricker 2007). Epistemic injustice happens when people are not heard, taken seriously, or 'allowed' to contribute to knowledge production. We will discuss the history of epistemic injustices of people with intellectual disabilities, as well as alternative epistemologies that challenge these injustices, such as critical disability studies (CDS) and non-Western understandings of disability. Additionally, limitations of our study and their underlying reasons will be explored, as well as possible practical solutions and directions for future inclusive research.

Our study on sexuality and intellectual disability pushed normative boundaries and addressed taboos both in content and methodology through inclusive research. It was in large part performed by the second author, a researcher with intellectual disability. He brought an approach and insight into the research that would otherwise have been inaccessible for neurotypical researchers without this lived experience. His contribution to the interviews was essential for making the questions accessible and in helping make some of the participants feel more at ease. Because of his lived experience with supported living environments, he was able to ask specific and practical (follow-up) questions that could not have occurred to the researcher without lived experience. He was furthermore able to build a bridge from abstract ideas to concrete experience during the interviews and during the processing of the research results. The interviews were semi-structured. Because there were specific things we needed to know, we needed to have specific questions, so it could not be completely open. We also had a particular order of questions to bring up, which was meant to start the interview as easy and comfortable as possible due to the taboo nature of the topics. However, each participant had a different way of processing questions and answering them, and had different relationships to the topics. This meant we needed to be flexible in our language use and question order. We let the interviews turn into conversations led mostly by the interviewees, only steering the questions in a certain direction if needed. Many interviewees brought up relevant topics themselves. This helped in navigating the taboo subject and it helped interviewees to feel in control. Centering the knowledge of our interviewees with intellectual disabilities during the research and in the final report pushed the boundaries of who are traditionally 'allowed' to share knowledge in research and gave some power to people who are often marginalized.

Sexuality of people with intellectual disability is often seen as taboo and as a potential cause for unsafe situations, such as vulnerability to abuse. Common stereotypes in society and media include that people with intellectual disabilities do not have a serious interest in sex and that they are 'asexual', or that they are instead (aggressive) sexual deviants (van Doorn et al. 2019). These stereotypes are not based on true lived experience. Instead, these stereotypes assume that people with intellectual disabilities have a non-normative bodymind (a body and mind that are seen as different from the 'standard'), and that the relationship people with intellectual disabilities have with their own bodymind and that of others must therefore also be non-normative (or 'abnormal'). This leads to misconceptions about the sexuality of people with intellectual disabilities. Our study aimed to counter negative narratives in dominant (mainstream) discourse (debates/conversations in society) and to decrease stigma by focusing on interviewees' positive experiences, and on the normalization of the topics. Although focusing on the positive was possible, it was also often difficult. Many experiences our interviewees shared with us came from a place of trauma, or of not being heard or taken seriously by their environments (examples of epistemic injustice). It is important to note, then, that positive representation of sexuality and intellectual disability is not limited to unequivocally positive lived experiences. It is also about understanding and representing people with intellectual disabilities as 'epistemic agents' (people who are capable of contributing to knowledge production, such as research), who carry a wealth of knowledge about themselves, their desires, and the issues they face, as well as insight into potential solutions for these issues. In other words, positive representation of people with intellectual disabilities is not about only showing positive things about someone's life. It is about showing *all* aspects of real life, and about sharing real knowledge that people with intellectual disabilities have. Taking this knowledge seriously challenges stigma, stereotypes, and epistemic injustice.

Our study started with several months of desk research into the subject of sexuality and intellectual disability. Then, interviews were held with nineteen healthcare professionals and managers and a total of nineteen adults with intellectual disabilities who live in supported living environments. The majority of the nineteen people with intellectual disabilities we interviewed were considered by themselves and/or by their healthcare professionals to have 'moderate' to 'mild' intellectual disabilities[1]. Three interviewees were considered to have a 'profound' or 'severe' intellectual disability. All interviews were carried out through verbal communication on both sides. Some interviewees preferred to have a confidant by their side during the interview, such as a healthcare professional they were close with, because of the potentially sensitive subject matter. In these cases, we sometimes, where deemed appropriate, extended our questions to these confidants as well. Sometimes a confidant would jump in on their own accord, to finish an interviewee's story if it was difficult for them to talk about, or if they lost their train of thought (see Section 3 for a discussion on both the advantages and pitfalls of this). Questions were asked about personal experiences with sexuality in the participants' supported living environment, as well as in what ways they were able to express or hindered in expressing their sexuality and their sexual rights, and in what ways their situations could, if needed or desired, be improved. Whenever confidants were present, we used the joint dyadic interviewing method. In a dyadic approach, two interviewees participate at the same time, creating an interactive interview. This method can provide a voice to people who may need assistance in talking about something (or to people who do not communicate verbally) (Caldwell 2014). Ethical approval was obtained by the medical ethics committee of Utrecht University (#22-0627). Whenever quotes by interviewees are used in this paper, including the opening quote, they have been translated from Dutch into English. Interviewees will be referred to with a number (for example 'interviewee #1′') in order to protect their anonymity.

2. Epistemic Agency and (in)Justice

Marginalized (oppressed, excluded) people with and without intellectual disabilities have been and are continuing to fight for epistemic agency and justice. Porter et al. (2022) explain that "the behaviour of epistemic actors is shaped by contextual factors and is often characterised by an unequal distribution of power and resources. These latter political and ethical concerns have clear resonance within medical sociology and disability studies, which have in common the core concerns of an individual's situated knowledge of bodies and impairment; and critiques of professional power and knowledge over those bodies" (p. 1169). What this means is that the inequality in society of power, resources and knowledge contributes to epistemic injustice. If people are not recognized as epistemic agents, they cannot contribute to knowledge production. If they cannot contribute to knowledge production, their needs will not be known and cannot be met, and they will continue to be oppressed and excluded from mainstream society. This is a vicious cycle.

The fight for the recognition of epistemic agency and justice by people with disabilities does not always include people with intellectual disabilities. This is because our (Western) common understanding of epistemology often depends on the logocentrism of propositional knowledge. Logocentrism means that the importance of 'logic' and 'rational thinking' is emphasized in knowledge production. Propositional knowledge is the logical, abstract and verbal way of knowing that something is true. It is therefore different from, for instance, practical, tacit, embodied and affective knowing. These types of knowing relate, for instance, to feeling—both emotionally and physically—and knowledge that is gained from experience—knowledge that can be expressed non-verbally. A logocentric epistemology excludes non-propositional forms of knowing. It thereby also excludes people with intellectual disabilities, for two reasons. (1): People with intellectual disabilities are often seen as not possessing logic and rationality. (2): Some people with intellectual disabilities use types of knowing that are different from logic and rationality (Catala 2020). There is also a disability hierarchy within society that shows that both disabled and non-disabled people are generally more accepting of people with physical disabilities than of people with intellectual disabilities (Tringo 1970; Thomas 2000; Dolmage 2014). This contributes further to the epistemic injustice of people with intellectual disabilities.

The dominance of propositional knowledge in our understanding of epistemology means that this type of knowing is also dominant in the knowledge production in research. Other types of knowing, such as practical, tacit, embodied and affective, are often dismissed (Catala 2020). This means that, in order for people with intellectual disabilities to be able to gain recognition as epistemic agents, steps need to be taken on a metaepistemic level first (Catala 2020). The parameters of what constitutes 'epistemology' need to shift. This means that the way in which we understand 'epistemology' itself needs to change. Including non-propositional types of knowing in the understanding of epistemology will vastly expand the pool of knowledge to draw from. It will enable research to be inclusive of people with intellectual disabilities. Performing inclusive research with people with intellectual disabilities by including their non-propositional knowledges, based on a "presumption of credibility" (Caldwell 2014, p. 495—meaning that in research, the knowledge of people with intellectual disabilities is taken seriously) can support such a parameter shift.

Epistemic injustice has long excluded people with intellectual disabilities from participating in research as equals rather than as 'objects' of study. A brief history will follow discussing the underlying reasons for epistemic injustice. It is important to look at the historical origins of the dominance of logocentric propositional knowledge in knowledge production, in order to be able to recognize and acknowledge other ways of knowing. (Critical) disability studies (CDS) has occupied itself with the deconstruction of ableism and the concept of Disability since the 1970s. Ableism "reflects a preference for species-typical normative abilities leading to the discrimination against [disabled people] as 'less able' and/or as 'impaired'". As such, it is "one of the most societally entrenched and accepted isms". It has "[h]istorically (...) been used by various social groups to justify their elevated level of rights and status in relation to other groups", including through sexism and racism (Wolbring 2008, p. 253). Ableism includes 'neuronormativity', which is the "prevalent, neurotypical set of assumptions, norms, and practices that construes neurotypicality as the sole acceptable or superior mode of cognition, and that stigmatizes attitudes, behaviors, or actions that reflect neurotypical modes of cognition as deviant or inferior" (Catala et al. 2021, p. 9016). In these definitions, we can recognize what has been discussed above. Meaning that the stereotypes about people with intellectual disabilities and sexuality and epistemic injustice are symptoms of ableism.

It is through ableism's historical path that we can trace the roots of epistemic injustice. Ableism is often positioned within CDS as closely entwined and co-constitutive with other ideologies and structures that depend on the categorization of groups based on notions of inherent physical, intellectual, and cultural superiority and inferiority. This includes colonialism, racism and patriarchy (Erevelles and Kafer 2010). What this means is that societal structures (such as politics and policies) and societal attitudes that oppress and exclude women and other marginalized genders, people with disabilities, people of color, and colonized peoples, use a 'mixture' of racism, sexism and ableism to do so. These structures are each other's building blocks. For instance: historically and presently, disability has been wrongly attributed to people in order to strip them of their humanness, and consequently of their epistemological agency and justice (Baynton 2001; Kafer 2013; Norris 2014). Ideas of 'intellectual inferiority' and 'poor health' were used in North America to justify the slavery of Black people from African countries and the oppression of women (Baynton 2001). It has also been applied to indigenous and colonized peoples to justify their oppression and the use of their lands and resources, as European (settler–)colonialists placed themselves at the top of an invented hierarchy of intellectual and cultural superiority (Norris 2014). European Enlightenment ideals about rationality, logic, individualism, universalism, independence, taxonomies, classifications and hierarchization further reinforced and contributed to these structures (Norris 2014). Ultimately, when taken to the absolute extreme, these ideologies have gone hand in hand with colonial endeavors including genocide and epistemicide, as well as the state-mandated eugenics of the late 19th and early 20th centuries (Norris 2014). Epistemicide means "the killing, silencing, annihilation, or devaluing of a knowledge system [which] happens when epistemic injustices are persistent and systematic and collectively work as a structured and systemic oppression of particular ways of knowing" (Patin et al. 2021, p. 1307).

Such ideologies can be found in (epistemic) injustices to this day. The most drastic example is that forced sterilizations of marginalized people still occur, although no longer state-mandated and on a much smaller scale in places outside the public eye, such as prisons and care facilities (Baig 2021; Bauer-Babef 2022)—examples of this in our own study follow below. Additionally, disability is still often seen through a medical model, and thus as a condition that should be prevented or cured. The medical model operates on false notions about poor quality of life (Brown et al. 2019) and positions disability as something that should not belong to the human condition (Barnes 2002). Steps that are undertaken in the medical world to prevent or cure disability are sometimes referred to as 'new eugenics', as old eugenics and "the termination of human life affected by IDD [intellectual and developmental disabilities]" in modern medicine operate on the same principle (Reinders et al. 2019, p. 100). This principle entails the idea that a life with intellectual disability is not a life worth living, which ignores "alternative views, most of all the views of persons and families directly implicated who do not consider living with intellectual disability identical with a life full of suffering" (Reinders et al. 2019, p. 99). The contemporary exclusion of people with intellectual disabilities from society, from epistemic justice, and from knowledge production, is then still linked to its complicated discriminatory history.

Enlightenment ideals are still central in knowledge production and policies: "'neutrality', 'reason', and 'rationality' are fundamental components of how 'Western' scholars and policy-makers understand 'fairness,' 'equality,' and 'justice' (. . .) and how issues of global injustice are approached in policy and practice" (Wilson 2017, p. 1081). In dominant institutions, "[k]nowledge production (. . .) involve[s] epistemic violence—the work of discourse in creating and sustaining boundaries around what is considered real and, by extension, what is unable to be seen as real (or to be seen at all)" (Hunt 2014, p. 29); think of the exclusion of non-propositional knowledge. If non-propositional knowledges are 'unable to be seen as real (or to be seen at all)', and if they are considered outside the 'boundaries around what is considered real', they can never become part of knowledge production. The exclusion of these forms of knowing means that epistemic justice is much harder to reach, which can be referred to as 'epistemic violence'.

As Judith Butler explains: "[i]t is not simply (. . .) that there is a "discourse" of dehumanization that produces [dehumanizing] effects, but rather that there is a limit to discourse that establishes the limits of human intelligibility" (Butler 2004, p. 35). In other words, discourse [debates, conversations, narratives] in dominant institutions, such as the academic world and other places of research, is limited in its ability to understand a full range of human knowing. Similarly to this notion, 'hermeneutical injustice' (Fricker 2007) refers to an 'intelligibility deficit' based in the lack of a cultural framework to interpret certain types of knowledge and experience correctly. Here, the fault of misunderstanding certain types of knowing is placed with the way society views and treats certain groups of people, rather than with the supposed 'unintelligibility' of people themselves. In other words, it is the dominant discourse, cultural frameworks and types of knowledge production that are lacking in their ability to understand beyond logocentric, propositional knowledge. For our context, this means people with intellectual disabilities who can (only) share ways of knowing that are different from logocentric propositional knowing are not lacking. Instead, the world of knowledge production lacks in understanding these types of knowing, these epistemologies. For this very reason, we framed our study on sexuality and intellectual disabilities as inadequate to accommodate the type of communication and the types of knowledge that non-verbal people with severe/profound intellectual disabilities use. Instead of contextualizing non-verbal people with intellectual disabilities as 'unable' to participate in our research, we framed this as a limitation of the study. A "methodological intelligibility deficit" (Catala 2020, p. 771), rather than a limitation of the people who could not participate.

The deliberate exclusion of what is needed to gain epistemic justice can also be referred to as 'epistemic sabotage'. Porter et al. (2022) describe epistemic sabotage in the context of the UK disability benefit system. According to them, there is a deliberate effort to "police the boundary of disability's administrative category" (p. 1183), meaning that it is a difficult process to 'prove' that you have a disability and therefore 'deserve' benefits such as (supplementary) income and specialized healthcare. This effort to treat people with a disability with distrust until they can 'prove' their disabled status contributes to a "political and popular anti-welfare consensus" (p. 1168) and thus leads to further discrimination. Disability, in such efforts, is once again categorized and placed in an individualizing medical model. Porter et al. (2022) explain that, "[f]or sociologists working at the intersections of medical sociology and disability studies, the Fundamental Principles prompt important points of reflection" (p. 1167). Among these principles is that "disability must not be individualized, meaning any methodological approach that emphasisesindividual social action (. . .) must also work analytically to make clear the role of disabling social structures" and that "all issues affecting disabled people (. . .) must genuinely involve disabled people, and must not be the preserve of a small number of non-disabled experts" (p. 1167). In other words: no political or policy decisions should ever be made without the people it concerns, in this case people with disabilities. *Nothing about us, without us*, as the famous credo goes.

As one interviewee with intellectual disability in our study explained:

> *Parliament really needs to pay attention to how people deal with disabilities, and remove the taboo from sexuality. They need to accept that not everyone just wants to share everything with their caregivers/healthcare professionals. Caregivers should live like us for a week. We need more agency. The ministry of health wants to know a lot about us, but we never see anything in return. Caregivers need to be trained better. The idea that sexuality doesn't exist among us is ridiculous.*
>
> *Tools [that are used for sex education] are often developed like 'we did it together with people with an intellectual disability and now we're done', and then it turns out it doesn't work (interviewee #2 in Kelders et al. 2023).*

In these quotes, a form of epistemic injustice and (possibly accidental) sabotage plays out. People with intellectual disabilities are 'deployed' at the start of a project, but they are not involved in the continuing, iterative development of the research or the resulting educational tools and their practical implementations. They are not involved enough in research and the development of tools for their own and their peers' actual, real-life benefit. As DS scholar Dan Goodley explains: "Disability research with participants can fall into research on participants—when the only person benefiting is the researcher and their career aspirations" (Goodley 1999, p. 43). Indeed: we have distributed the final report of our study on sexuality and intellectual disability amongst those who are interested, those who work in disability care, and our interviewees with intellectual disabilities. However, at this point in time, it is unclear whether the conclusions of our study will result in practical action that involves people with intellectual disabilities because the ball for any systemic, large-scale changes is now largely in the court of the Dutch parliament, who, six months after publication, have yet to engage with the report (note: it is possible that the delay in forming a new parliament after sudden elections plays a role in this. This does not, however, take away our concerns that the findings of our study will be low on the list of priorities for an indefinite amount of time).

3. Epistemic Justice and Relational Research

The overall underlying reasons for the injustices experienced by our interviewees (such as a lack of privacy, hindrance in starting and maintaining relationships, taboo on parenthood, and forced birth control and sterilizations) are traced back to the taboo on sexuality, and the fact that interviewees do not feel like they are always taken seriously or listened to by staff or family. One conclusion of our study was that solutions to these injustices and the issues that arise because of them could be solved by creating a less hierarchical structure within supported living environments and, simply, by listening to the residents. Creating solutions directly tackling these and other specific issues we have defined in our study are important and necessary for a direct improved quality of life for residents and staff alike, as long as these solutions are implemented, effective, and sustainable. However, several care professionals who were interviewed explained that sex education is often the first thing to be abandoned when new budget cuts hit, which has happened often during the long reign of a neoliberal political party in the Netherlands (Bertens and Palamar 2021). The decentralization of healthcare may also contribute to a lack of sustainability of new programs because of a lack of funds and differing policies in terms of implementation and effectiveness (Mulder 2019). Furthermore, our study was initiated because of a recent report on the high number of sexual abuse of residents of supported living environments (by other residents as well as staff members), while similar numbers and situations have already been known for decades (Dekker et al. 2012; Zembla 2017). As long as people with intellectual disabilities are not taken seriously, i.e., as long as epistemic injustice keeps taking place, it may be impossible to tackle the underlying structure that allows this to happen. For this reason, we not only offered practical solutions in our study to specific issues, based on input from our interviewees, but we also included a plea to the readers of the report and the governmental branch involved to be wary of the underlying root cause of these issues: ableism and its long and complex history cannot be overlooked in current systemic injustices.

Gaining epistemic justice for people with disabilities thus means tackling ableism. This means escaping the parameters of how we understand 'disability'. As discussed briefly above, ideologies about the inherent superiority or inferiority of certain subjective qualities such as intellect, logic, independence and individualism have contributed to the categorization of human beings, as well as to a 'hierarchy of preference' of certain disabilities over others. Critical disability studies (CDS) scholars offer perspectives that challenge these ideologies. For instance, the concept of 'relational autonomy' by Davy (2019) can counter societal expectations of independence. Relational autonomy "supports a view that the role of engaged others in helping the individual to live in and make sense of the world, including translating, interpreting and communicating their perspectives, is part of someone's authentic autonomy, rather than something to be feared as undermining it" (de Haas et al. 2022). Independence, for people with disabilities, "refers not to a set of skills or being able to care for one's self, as service professionals tend to define it, but rather refers to having control over making decisions that directly affect one's life" (Caldwell 2014). Eva Kittay argues that true 'independence' does not exist for anyone, and that we are all instead connected through reciprocity and intersubjectivity (Kittay 2019). Alison Kafer offers a 'relational model of disability', arguing that "[t]o eliminate disability is to eliminate the possibility of discovering alternative ways of being in the world, to foreclose the possibility of recognizing and valuing our interdependence" (Kafer 2013).

Disability as a concept as well as the word itself in reference to a condition is absent from many indigenous languages (Norris 2014). Disability as a condition in indigenous worldviews is often understood as a natural variation in the human experience, rather than an exception or 'mistake' that needs to be prevented or cured. As expressed, for instance, by a traditional Cree woman in an interview on disability: "[t]he Creator put these people [referring to people with intellectual disabilities] here for a purpose so that we will learn from them; they are our teachers. No one is considered abnormal in our culture" (Shackel 2008). An elderly Navajo singer explains: "Before the white man came, we were blind [to disabilities]. You brought us the gift of sight. I think we were happier when we couldn't see" (Connors and Donnellan 2007, p. 279). People with intellectual disabilities in cultural understandings such as these are then inherently already recognized as epistemic agents and as belonging. However, these understandings have, since colonization, been systematically erased through epistemicide (Norris 2014; de Sousa Santos 2014).

Relationality is at the core of CDS scholarship, as mentioned above. It is also at the core of many indigenous worldviews (Shawn Wilson 2008; Tynan 2021). In indigenous epistemology and ontology, knowledge is "relational, alive, emergent" (Hunt 2014). Universalisms are often seen as too static to deal with reality, which always changes (Shawn Wilson 2008; Estes and Becker 2022). Similarly, (Western) feminist theorists have encouraged researchers to understand their own positionality and situated knowledge as subjective and relational, rather than as a vehicle towards objective universal truth (often in tandem with an emphasis on intersectionality) (e.g., Sandra Harding, Donna Haraway and Patricia Hill Collins). In a relational framework, people are not valued based on their individual ability to strive towards Enlightenment ideals of independence and rationality. Instead, relationality is a way of thinking about human relationships and disability that allows space for interdependence, reciprocity and non-propositional knowledge. In addition to CDS, it can thus be useful to engage with such non-Western relational understandings of disability for the advancement of epistemic justice and the deconstruction of ableism.

4. Epistemic Justice and Future Inclusive Research

Incorporating a relational framework in research can support epistemic justice. Undertaking research non-hierarchically with researchers with intellectual disabilities is essential. Additionally, as mentioned earlier, for our study on sexuality and intellectual disability, we used the dyadic approach to include more people with intellectual disabilities who were not able to or did not want to be interviewed by themselves. The dyadic approach can be considered to be relational. However, because we also had an interviewee who expressly did not want a staff member by their side, such a construction needs to be navigated carefully. Dyadic interviewing then has two faces: on the one hand, "the suggestion of joint interviews is inherently problematic from a CDS perspective, raising concerns regarding the potential for proxy or facilitated responses to suppress the voices of people with ID [intellectual disabilities]" (Caldwell 2014, p. 489). This could result in (accidental) epistemic sabotage, if, for instance, the second person speaks for or over the person with intellectual disability while using their own subjective view of a situation to fill in the gaps incorrectly. On the other hand, the approach "recognizes the value of interconnected relationships and contextualizes in such a way that retains focus on the person with intellectual disability as the unit of analysis" (Caldwell 2014, p. 492). It could then also be particularly useful for non-verbal participants with 'severe/profound' intellectual disabilities. In this case, someone who is closely familiar with the person in question can speak for them—as they likely need to do in daily life when, for instance, advocating for them in relation to social/civil institutions. Despite the potential pitfalls of this methodology, it could still contribute to a relational understanding of disability and of epistemology and knowledge. It would have been a valuable addition to our study, which, despite being performed on an inclusive basis, still excluded non-verbal people with intellectual disabilities and their experiences. A truly relational understanding of epistemology that is inclusive of non-verbally expressed, non-propositional knowledge and/or uses the dyadic approach can contribute to a broader scope of epistemic justice.

5. Conclusions

This article has reflected upon some of the findings of our study on sexuality and intellectual disability: the taboo around this topic, and the relation of research to epistemic (in)justice. The main conclusion is that performing inclusive research can promote epistemic justice—and vice versa. Understanding the history of epistemic justice in the context of ableism and other systemic (global) structures, including colonialism and patriarchy, is important to be able to recognize it in order to recognize alternative epistemologies. This is necessary in order to dismantle the dominance of logocentrism and propositional knowledge in our understanding of epistemology and their subsequent dominance in research; as such, this approach leaves out non-propositional ways of knowing and thereby excludes people with intellectual disabilities. This means creating a shift on a metaepistemic level. Alternative epistemologies can be sourced from critical disability studies and from non-Western approaches to disability, such as relationality. Relational approaches in research, such as dyadic interviewing and non-hierarchical collaborations with people with intellectual disabilities, can contribute to epistemic justice.

Many of the findings of our study on sexuality and intellectual disability—especially when positioned in the context of this article—appear to simply try to 'prove' that people with intellectual disabilities are 'normal' people when it comes to sexuality, but also day-to-day life. Indeed, many experiences that we wrote down in the study based on the interviews are experiences, feelings and expectations that anybody, with or without intellectual disability, could have. This includes, for instance, preferences in relationships, an understanding of consent, and wishes of parenthood. This shows that people with intellectual disabilities have already suffered epistemic disablement to such an extent that their agency first needs to be proven before justice can occur. It needs to be proven first that they are able to define the problems they face in their surroundings as well as potential solutions. Writing down people's experiences and insights, accompanied by powerful quotes, helps to clarify and specify the way people with intellectual disabilities and their peers exist in society. This might otherwise be obscured to anyone who does not work in the disability field, or anyone who does not personally know anyone with an intellectual disability, since, by definition, little is often publicly known about marginalized groups. At the same time, however, our study has excluded non-verbal people with 'severe/profound' intellectual disabilities. Additionally, the fact that the people we interviewed were willing to participate in a study that was explicitly about sexuality means that they were possibly already comfortable talking about this topic to some extent. This means that the information we have uncovered may only be the tip of the iceberg. Because of these reasons, we have provided a 'further research' section in our study.

As mentioned earlier, although our study was commissioned by a government branch, it is currently unclear if its findings are on the political agenda. And, as one of our interviewees reminded us, sometimes, researchers and clients such as government branches "want to know a lot about us, but we never see anything in return" (interviewee #2 in Kelders et al. 2023). It is a well-known fact that there exists a gap between research and practice (e.g., Westerlund et al. 2019; Joyce and Cartwright 2019; Mohajerzad et al. 2021), which can be difficult for researchers and research participants to come to grips with. The good news, however, is that we have seen a large amount of people willing to participate in our study who have voiced their interests and concerns regarding its topics. Although systemic change through governing bodies is desirable, inclusive research such as this can hopefully invigorate efforts at non-government levels. During interviews with people with intellectual disabilities as well as healthcare professionals, we not only asked questions but also shared information and resources we had come across in order to exchange something for our knowledge 'extraction'. Some people with intellectual disabilities we interviewed have described the interviews as cathartic. The participation of people with intellectual disabilities in our focus group was also experienced as positive. They were happy to share their stories with each other, recognize each other's experiences, and make new connections. This is indeed at the core of the added value of doing inclusive research: because we worked directly with people whom this research concerns, it was possible to immediately give something in return rather than having to wait for new policy in the form of creating more awareness, functioning as an outlet, and opening up conversations between people. Performing inclusive research can directly and immediately positively impact the people involved, which is why it is valuable and meaningful even regardless of the implementation of its findings on a policy level. Inclusive research is a way to bridge the gap between research and practice, and it is a way to remain hopeful.

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Notes

[1] Terms that are commonly used for the categorization of intellectual disabilities are light, moderate, severe, and profound. Categorization has often been performed by measuring IQ; however, this is becoming less common as IQ is being recognized as a pseudo-science with its roots in eugenics. Instead, cultural and social factors as well as the degree and type of support needed should be considered in diagnosing an intellectual disability (Schalock et al. 2021). This means that categorization depends on socio-cultural expectations of normalcy as well as socio-cultural influences on development and support needs.

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