FACULTY OF PSYCHOLOGY
AND EDUCATIONAL SCIENCES

With my own eyes? - Re-conceptualizing visual impairment through lived experiences

Jentel Van Havermaet

Supervisor: Prof. Dr. Elisabeth De Schauwer

A dissertation submitted to Ghent University in partial
fulfilment of the requirements for the degree of
Doctor of Educational Sciences

Academic year 2025–2026

GHENT
UNIVERSITY

GHENT UNIVERSITY
FACULTY OF PSYCHOLOGY AND EDUCATIONAL SCIENCES
Department of Special Needs Education
Henri Dunantlaan 1, 9000 Ghent (Belgium)

English title:

With my own eyes? — Re-conceptualizing visual impairment through lived experiences

Titel in het Nederlands:

Met mijn eigen ogen? — Visuele beperking re-conceptualiseren door geleefde ervaringen

Jentel Van Havermaet

ORCID Jentel Van Havermaet: http://orcid.org/0000-0002-1827-2464

Supervisor: Prof. Dr. Elisabeth De Schauwer

ORCID Elisabeth De Schauwer: http://orcid.org/0000-0002-4030-8515

Academic year 2025-2026

Orthopedagogische reeks Gent, n° 74, 2025

A dissertation submitted to Ghent University in partial fulfilment of the requirements for the degree of Doctor of Educational Sciences

Guidance Committee

Dr. Elisabeth De Schauwer (supervisor)
Prof. at the Department of Special Needs Education (Ghent University)

Dr. Geert Van Hove
Prof. Em. at the Department of Special Needs Education (Ghent University)

Dr. Michel Vandenbroeck
Prof. Em. at the Department of Social Work and Social Pedagogy (Ghent University)

Dr. Bart Leroy
Prof. at the Department of Head and Skin (Ghent University)

Examination Board

Dr. Rudi Roose (chairman of the examination committee)
Prof. at the Department of Social Work and Social Pedagogy (Ghent University)

Dr. Devon Healey
Prof. at the Department of Social Justice Education (University of Toronto)

Dr. Mieke Cardol
Lector at the Rotterdam University of Applied Sciences

Dr. Toon Benoot
Postdoc researcher at the Department of Social Work and Social Pedagogy (Ghent University)

Dr. Sarah De Pauw
Prof. at the Department of Special Needs Education (Ghent University)

Dr. Elisabeth De Schauwer (non-voting member)
Prof. at the Department of Special Needs Education (Ghent University)

Reading the PHD accessibly

- The PhD is available as MS Word-file and as PDF-file.
- Headings have been used to structure the document: heading 1 announces chapters and appendices; heading 2 announces subtitles in the chapters, three subparts in Chapter 5, and four subparts in Appendices; ...
- There are nine bookmarks to provide a local content list for Chapter 1-4, three subparts in Chapter 5, Chapter 6, and Appendices.
- All text is left-aligned, except for tables of content, reference lists and sporadic larger citations that are made visually clear via indentations (style: block quote).
- This document includes no images, solely one table (in Chapter 2) and listings with bullet points only here and once in Chapter 3.

Content of the PhD

Chapter 1: Introduction

Encountering blindness: a situated starting point

A casual encounter, an everyday question—and suddenly, a deeper conversation unfolds on what it means to live with blindness. Each time I meet people, they are curious about my visual impairment. As we come to know each other, we also explore each other's lives:

> *Yes and no—it has been there since birth. I've always been partially sighted, and I later became legally blind. I use a screen reader on my computer and a voice-over on my phone. I don't have a guide dog, but I do use a white cane to move around in familiar environments. My work? I'm doing a PhD: doctoral research about how visual impairment becomes part of the lives of blind or partially sighted people and those in their networks.*

Through these conversations, I reflect on the basic information people unfamiliar with visual impairment may need. I also try to add nuance. I talk about the choices blind people, and their surroundings make, the stereotypical norms society imposes, and how lived experiences with visual impairment are rich and complex. These interactions challenge initial assumptions about disability.

People have often asked me whether I would write a guidebook for professionals, or whether I have ideas to 'solve' disability, so I have had to explain my perspective:

> *I do not see blindness as an individual issue or problem. I see it as an always-moving reality; and I'm curious about how people live with disability. I'm interested in how life takes shape. I focus on ways of 'doing' blindness, without judging them as good or bad. I don't believe that what works for one person or in one context can simply be applied to another. Recognising the value of each story is already significant, especially since such stories often go unheard or disappear.*

These dialogues are not limited to well-sighted people either. I mean that it is not only sighted people; people who see well, or good enough, to be not classified as visually impaired; who make such references. Visually impaired peers also share their experiences with blindness, and everyone brings their personal journey to the conversation. Once, I met a woman who became visually impaired in her 40s. She had always been passionate about art and photography. I disagreed with the fixed idea that she could no longer enjoy the beauty of performances. Once again, I found myself having to explain or position my own view.

These encounters raise broader questions that this PhD seeks to explore: how blindness is lived, understood, and made meaningful within everyday and social contexts. This doctoral research is grounded in the field of disability studies. The following sections outline this project's conceptual and methodological foundations and clarify its aim to reconceptualise blindness from within lived experiences.

Engaging with disability studies

This doctoral research on reconceptualising visual impairment through lived experiences is grounded in a disability studies perspective. Disability studies is an interdisciplinary field that explores disability not only as a subject of study but also as a lens through which social, political and cultural structures are critically examined (Bolt, 2012; Duckett & Pratt, 2007; Kudlick, 2018). It seeks to understand how disability acquires meaning—shaped by institutions, societal norms and people's interpretations.

Disability studies depart explicitly from dominant medical and individualistic understandings of disability (Barton & Oliver, 1997; Corker & Shakespeare, 2002; Michalko, 1998). In traditional framings, disability is seen primarily as a personal tragedy or biomedical failure. Rooted in diagnostic categorisation, clinical intervention and professional expertise, this view reduces disability to a deficit located within the body or mind. Society often perceives disability through the lens of 'a problem in need of a solution' (Titchkosky et al., 2022; Van Havermaet et al., in press). It positions disabled individuals as passive recipients of care or rehabilitation, in need of fixing; rather than as agents embedded in complex social and material contexts.

The emergence of the social model of disability in the 1970s and 1980s challenged these views. Rather than locating disability in the individual, the social model argues that society disables people with impairments (Barnes & Mercer, 1997; Whitburn & Michalko, 2019). Its focus on societal environments, institutions and norms enables a powerful shift towards political mobilisation, foregrounding issues of accessibility, discrimination and rights. It helped frame disability as a collective concern shaped by architectural barriers, inflexible systems and structural exclusion. Yet, while foundational, the social model is not without its limitations. It has been critiqued for its binary logic that separates 'impairment' from 'disability', its underdeveloped engagement with the body and affect, and its universalisation of experiences across diverse contexts. For those living with sensory differences, the social model can fail to account for the nuances of lived experiences, the emotional texture of everyday life, or the complex interplay of bodies and technologies (Bolt, 2005; Goodley, 2011; Shakespeare and Watson, 2002; Shakespeare, 2006; Titchkosky, 2011).

The field of critical disability studies emerged as a response and emphasises the relational, contextual and embodied nature of disability (Bolt, 2012, 2023; Goodley, 2013; Goodley et al., 2019; Whitburn & Michalko, 2019). It insists that scholarship is most meaningful when it remains accountable to the communities it engages with and contributes to collective processes of world-making. This commitment takes shape through the co-presence of empirical, lived and conceptual voices, a dialogical process, and research as a space for ethical responsiveness. The disability studies research group of Ghent University (where this PhD was conducted) shares many of its concerns and commitments.

Experiences of disability within this view are not only shaped by bodily or sensory differences but also by discourses, environments and systems of power (Healey, 2021; Michalko & Goodley, 2023; Titchkosky et al., 2022). Therefore, disability cannot be separated from the social and material conditions in which it emerges. As Whitburn and

Riffo-Salgado (2024) note, ‘The concept of disability is difficult to define without giving consideration to the social, material, historical, environmental and biological contexts contributing to everyday encounters’ (p. 1131). Disability studies works with disability as both a way of being (ontology) and a way of knowing (epistemology). It focuses on how disability appears and is made visible in the world in interactions, expectations, and cultural and technological systems (Healey, 2021). The field questions dominant assumptions, critiques thinking that is oriented to able-bodiedness and offers more complex ways of engaging with disability, emotionally, intellectually and politically (Bolt, 2015; Duckett & Pratt, 2007).

In this sense, it is crucial to situate the concept of ‘ableism’ within disability studies. Ableism refers to the pervasive societal belief that able-bodiedness—or normatively defined physical, sensory and cognitive functioning—is the standard against which all bodies and minds are measured. It values independence, productivity, visibility, linear time and perceptual dominance. Ableism shapes how disability is understood, discussed and regulated: as a deficit to be corrected or compensated for; rather than as a valid and valuable way of being in the world (Beckwith, 2019; Brown & Ramlackhan, 2021; Campbell, 2009; Davies, 2021; Goodley, 2016; Mingus, 2018). Instead, this PhD aligns with the invitation within disability studies to think otherwise. Disability is not only a category of difference but a potential starting point for rethinking what it means to live together in a diverse world (Michalko & Goodley, 2023). Disability studies encourages the exploration of ambiguity, contradiction and situated knowledge. As Titchkosky et al. (2022) propose, the field offers an invitation to expand our horizons, directing our attention towards underexplored aspects, or to embark on a journey of reimagining and rethinking what else can open up our ideas on disability. Disability studies invites reflection and imagination. It encourages researchers to remain open to new ways of perceiving and experiencing disability, as it emerges through living together and different kinds of encounters (Michalko, 2002; Van Havermaet et al., in press).

This PhD project takes an affirming approach informed by an existential reading of disability (Bolt, 2005, 2013). It aims for a dynamic understanding that welcomes complexity and lived variations (Goodley & Runswick-Cole, 2014). This study investigates how blind people navigate tensions between normative ideals of independence and the embodied realities of interdependence. It views access as a technical or legal standard and approaches it as an ethical and relational practice, embedded in space, time and mutual recognition.

Starting from lived experiences

One of the core principles of disability studies is its emphasis on lived experiences. Lived realities are not just illustrative but are treated as legitimate sources of insight. They help identify barriers, imagine alternatives and reshape how disability is understood in both academic and everyday settings. In this tradition, disability research values embodied knowledge alongside more conventional academic forms of knowledge (Bolt, 2023; Whitburn, 2014). Within disability studies, there is a deep entwinement between knowledge production and emancipatory praxis.

This insistence on the value of lived experiences is also ethical and political. The field has emerged in dialogue with activism, grounded in a commitment to social justice and dismantling systemic inequalities. Rather than studying disabled people as passive subjects, disability studies calls for research that is conducted 'with' rather than 'about' them (Goodley & Van Hove, 2005). This orientation rejects extractive methodologies and advocates for participatory, co-constructed forms of inquiry that affirm agency and foster inclusion. Knowledge is seen as something that should lead to transformation, not only in academic discourse, but in institutions, practices and everyday life. In this view, research becomes a tool for solidarity, unsettling and unseating ableist assumptions, and imagining more just and inclusive futures.

Positioning the perspective of lived experiences at the centre allows for more grounded, ethical and meaningful research. Disability studies reposition disabled people as experts of their own experiences (Tregaskis & Goodley, 2005). Their everyday lives, relationships and reflections provide knowledge that professional discourse often overlooks or undervalues (Bolt, 2013; Whitburn & Goodley, 2019). The focus on lived experiences challenges the dominance of clinical or outsider views. To truly grasp the complexities of lived realities, it is relevant to emphasise the importance of thinking *with* people with disabilities themselves. By engaging directly with these experiences, invaluable insights and perspectives can be gained that dismantle barriers and enable possibilities (Van Havermaet et al., in press).

Aligning with calls in disability studies to examine the existential, social and relational aspects of impairment (Healey, 2023; Omansky Gordon, 2004), this doctoral research seeks to think with (disabled) people. It engages with their narratives, interpretations and ways of making sense of the world. Similarly, blindness is not just a condition; understanding it requires attention to how it is lived, felt and shared. This PhD recognises the authority and significance of disabled people's perspectives, and those of their allies. This includes not only research participants but also experiential literature and autobiographical accounts. These diverse sources open up new understandings that might otherwise remain measured, categorised, invisible or excluded.

By starting from lived experiences, the PhD project uncovers how blindness takes shape in people's lives and how they negotiate meaning through and with it. These insights not only reconceptualise blindness but also challenge broader assumptions about normalcy, capacity and knowledge itself. This PhD project aims not to define or fix blindness but to open up space for alternative ways of being, relating and knowing. The research is not simply about representation or interpretation but solidarity, empowerment and transformation. This has led to a politicisation of research practices—a turn towards reflexivity, relationality and ethical engagement. As such, the boundaries between theory and practice are deliberately blurred.

Blind scholars as intellectual companions

Throughout this doctoral research, the work of blind scholars in disability studies has been deeply influential—both theoretically and personally. Discovering their work reveals unexpected possibilities in the academic world, and their perspectives have helped shape how blindness is approached in this research.

Rod Michalko's writing has been a foundational reference since my master's thesis. His work—such as *Blindness enters the classroom* (2001), *The mystery of the eye and the shadow of blindness* (1998), and *The difference that disability makes* (2002)—opened up ways to think differently about the presence of blindness in institutional spaces and knowledge production. Michalko's more recent collaboration with Dan Goodley, *Letters with Smokie: blindness and more-than-human relations* (2023), offers fresh perspectives on understanding blindness beyond the human subject.

Michalko's close collaboration with Tanya Titchkosky has also been highly impactful. Although not blind herself, Titchkosky critically explores how disability appears and disappears in social contexts. Her books, *The question of access: disability, space, meaning* (Titchkosky, 2011) and *DisAppearing: encounters in disability studies* (Titchkosky et al., 2022), have informed this PhD project's theoretical scope. The latter includes a powerful chapter by Devon Healey, 'Blind perception: disappearing blindness … with a twist', which examines blindness through narrative and creative engagement. Healey's book, *Dramatizing blindness: disability studies as critical creative narrative* (2021), further builds on this approach.

David Bolt's work has also been crucial to this doctoral research. He draws attention to the language used around visual impairment and how cultural narratives frame blindness. His concept of 'ocularcentrism' (also written as 'ocular-centrism')—the privileging of sight as the dominant mode of knowing—helped to critically examine how blindness is constructed in discourse. Bolt's books, *The metanarrative of blindness: a re-reading of twentieth-century anglophone writing* (2013) and *Finding blindness: international constructions and deconstructions* (2023), have been touchstones in this research.

Finally, the work of Georgina Kleege has had a lasting impact. Her writings—*Sight unseen* (1999), 'Blindness and visual culture: an eyewitness account' (2005) and 'Introduction: blindness and literature' (2009)—challenge the dominant visual metaphors surrounding blindness and offer richly personal, yet widely resonant, ways of thinking about difference.

These disability studies scholars provide theory and embody ways of seeing, knowing and narrating blindness that inform this PhD at its core. Their work legitimises new modes of understanding and formulates the invitation to think from blindness rather than merely about it. While these scholars grounded the theoretical framework, the following section turns to how this framework shaped the conceptual lens of the doctoral research.

Reconceptualising visual impairment

This PhD project does not aim to define blindness from the outside; rather, it explores how it lives and breathes within the texture of daily existence. 'To tell the story of blindness as it was revealed to me' (Michalko, 1998, p. 158) is to begin from within: from embodied, relational and affective experiences. The doctoral research engages with how blindness comes to mean what it means. It asks: How is blindness made to appear? Through what practices, narratives, relationships and environments does blindness come into being? And how might we think otherwise?

At its core, this research is not about redefining blindness through an abstract lens but about working with conceptualising—attending to how conceptions of blindness are formed, circulated and lived. In this sense, conceptualising is not a preliminary stage but a method: a continuous, situated and critical engagement with the representations and meanings of blindness. This research's first movement involves tracing how blindness is typically conceptualised—what Bolt (2013) and Healey (2021) call its dominant appearances or representations. Blindness is not a neutral descriptor but 'a theorized narrative and a narrated theory' (Whitburn & Goodley, 2019): a construction made visible through language, ideology, cultural imagery, institutional framing and interpersonal interaction. These conceptions define it and conceal its meanings and feelings (Bolt, 2013). Like all forms of disability, blindness is never experienced in isolation. It is mediated through metaphors, organised through discourses, and enacted in relational contexts. The very notion of blindness, as constructed in society, often obscures the plurality of blind life. It is produced through what Kleege (2018) calls 'sighted expectation', often denying access to other possible ways of being and knowing.

Therefore, to work with conceptualising is to attend to these layered framings: the biomedical, the tragic, the inspirational, the invisible. It also notices how people live with and through such framings—sometimes resisting them, sometimes redefining them, sometimes reshaping them entirely. It includes moments of contestation (Whitburn & Goodley, 2019), cultivation and imagination (Healey, 2023). It means acknowledging that blindness is not experienced the same way by all people, nor should it be captured by a single framework. This work resists a final or universal definition of blindness. As Whitburn and Michalko (2019) argue, because understandings of blindness emerge from diverse social and embodied positions, no singular conception can suffice. Rather, it calls for an attunement to 'conceptual shapeshifting' (Van Havermaet et al., in press)—the idea that concepts themselves must move, bend and evolve with the realities they seek to describe. Thus, reconceptualisation insists on multiplicity, not clarity; relationality, not resolution. It is not merely experienced—it is performed, acted upon, spoken of, managed and interpreted.

Reconceptualising blindness involves more than critique. It is a shift in vision that moves from the dominant to the plural. This does not simply mean replacing negative representations with positive ones but challenging the very structures that produce such binaries. As Chi Wing Lau (2019) suggests, it may involve 'cripping' normative ideas of disability, twisting them in ways that reveal their limits and open new possibilities. Reconceptualising promotes change in thinking, deconstructive recognition, proposing reconsiderations, revising images and resisting problematising formulations (Bolt, 2012, 2013; Michalko, 2002; Symeonidou, 2024).

Importantly, reconceptualising blindness is not a tidy process. It involves discomfort, contradiction and ambiguity. It includes working with the contradictions rather than resolving them (Hammer, 2019). It means inhabiting the tensions between social representation and lived reality, diagnosis and identity, visibility and invisibility. This is where reconceptualising meets lived experience. As Omansky Gordon (2004), Omansky (2011) and Michalko and Goodley (2023) show, blind people often navigate a world that insists on their lack, while asserting their own forms of presence, knowledge and agency. Therefore, reconceptualising must be both critical and imaginative—it must unravel what blindness has been made to mean, while also listening for what else it might become. In this process, acts of reconceptualisation are also acts of self-formation and resistance. Following Foucault's notion of 'technologies of the self' (in Allan, 1999), blind people do not merely absorb dominant representations; they respond to them. They retell, reframe and remake blindness on their own terms. Through counter-narratives, language reclamation and everyday relational practices, they challenge the limits imposed by normative discourses and cultivate new ways of being seen—and seeing.

Reconceptualising blindness is about opening a space for different stories to be told, different questions to be asked, and different meanings to be lived. It is about working with conceptualisation as a practice of inquiry, attention and respect. It does not seek a better definition or singular representation of blindness; it wants to understand its multiplicity (Van Havermaet et al., in press). Ultimately, this PhD project aims to develop a conceptual language that is grounded in the experiences of blind individuals and their networks. It seeks to analyse, listen and attend carefully to the textures of lived life, and to trace how blindness is co-produced through environments, relationships and meaning-making practices. To reconceptualise is to imagine otherwise. It doesn't start with the question, 'What is blindness?' but 'How is blindness lived?' and 'What might it become?'.

Contextualising blindness

Beyond rethinking what blindness means, this section asks where and with whom blindness is lived, foregrounding its emergence within shared practices. Conceptions of visual impairment are embedded in context, and reconceptualising blindness happens contextually. 'What if blindness becomes contexted?' ask Michalko and Goodley (2023). This question invites us to consider blindness not as an isolated condition, but as something that takes shape within environments, relationships and meaning-making practices. Contextualising blindness means attending to the entangled ways it is lived—with others, through others, and in connection with the world. It is giving context: thinking, feeling, connecting and walking with ideas; learning and navigating the world together; sitting with and detailing moving through the world with blindness; and sharing how (blind and sighted) people see, understand and feel blindness (Michalko & Goodley, 2023).

Blindness exists not only within the body but also within a web of connections. Families, partners, peers and caregivers—those intimately involved in the lives of blind individuals—also navigate and negotiate the implications of visual impairment. Their experiences are also part of the meaning-making process. This recognition of shared and relational experiences underscores the value of contextualised knowledge (Bolt, 2015; Tregaskis & Goodley, 2005).

As Goodley and Runswick-Cole (2014) show, disability is always relational: shaped through social, material and affective interactions. Therefore, contextualising blindness requires attention to personal narratives and the structural, historical and discursive forces that shape them (Omansky Gordon, 2004; Whitburn & Michalko, 2019). More-than-human processes that concentrate on material factors, social relations, political power, history, culture, literature and other aspects of discourse are relevant to acknowledge too (Michalko & Goodley, 2023; Omansky, 2006, 2011; Omansky Gordon, 2004; Whitburn & Michalko, 2019; Whitburn & Riffo-Salgado, 2024). Exploring such connections gives context.

This research takes seriously the insights of those within the networks of disabled persons—children, parents, teachers and allies—who often occupy a ‘privileged position’ in relation to these experiences (Salminen & Karhula, 2014). It also acknowledges the role of non-human and material actants: the white cane, the guide dog, technologies and environments that mediate how blindness is lived. In the togetherness of human and non-human or materialities, of sightedness and blindness, animals or aids also have many insights to share about their journey into blindness. These entities co-constitute experience and meaning; they participate in unfolding blindness in the world (Davies, 2021).

Such contextualisation resists simplification. It embraces complexity, contradiction and diversity. It reminds us that blindness is not a singular story, but a network of stories—fluid, situated and always in relation. Contextualising blindness is weaving together these human and non-human, individual and collective, experiential and structural strands. It is a slow, reciprocal process of attending that favours a more nuanced understanding of disability. Circling and recircling, conceptualising and reconceptualising, searching and re-searching/researching make space for contextualisation and complexity.

Discourses of blindness

Language, naming and power

Language plays a powerful role in shaping how blindness is understood. Terms such as ‘visual impairment’, ‘low vision’ and ‘partially sighted’ are commonly used in clinical and academic contexts, often reflecting an individual or medical model of disability. These terms focus on loss or dysfunction and tend to be defined by sighted professionals—ophthalmologists, educators and rehabilitation experts—who hold institutional authority to categorise and label. Such naming practices can result in linguistic objectification, locating people within diagnostic boundaries rather than lived realities (Bolt, 2005; Michalko, 1998).

While these terms are sometimes used by blind individuals themselves, often regarding access barriers or inaccessibility, they do not always reflect how people understand their own experiences (Kleege, 1999; Whitburn, 2014). Some scholars and activists emphasise alternative expressions—'blind experiences’, ‘blind perceptions’ and ‘being blind'—that draw attention to how blindness is lived, performed and situated in context (Bulk, 2021; Healey, 2021; Michalko, 1998). In this sense, terminology is not simply descriptive; it is constitutive. It shapes what blindness is allowed to mean, how it becomes visible, and who is authorised to speak about it.

The ongoing contestation of these terms reveals deeper tensions between dominant and insider perspectives. Rather than aiming for consensus, this doctoral research acknowledges words' political and affective weight and engages with terminology as a site of meaning-making and power negotiation.

Medicalization and the expert gaze

Mainstream constructions of blindness are often grounded in 'hypothetical' figures rather than lived experience. The 'blind person'—imagined by professionals and institutions—is frequently the point of reference in how blindness is defined, treated or corrected (Kleege, 2018). These models emphasise diagnosis, prognosis and rehabilitation, separating blindness from the subjectivities of those who live with it (Healey, 2022).

In this framework, visual impairment is constructed as a personal deficit that resides in the eyes and can be addressed through medical or technical intervention. Disciplines such as ophthalmology, psychology and rehabilitation shape social narratives about what blindness is, how blind people should behave, and how they should be helped. These interventions are often aimed at normalisation—supporting people to appear more sighted, more functional, more ordinary (Michalko, 1998; Omansky, 2006).

Blindness becomes a problem to manage, rather than a mode of being that carries its own meanings and ways of knowing. Such an approach risks sidelining blindness itself. As Michalko (1998) argues, the meaning of blindness is frequently 'shoved aside' to make space for acceptance and adjustment, rather than being examined as an experience in its own right.

Ocular-normativity and the dominance of sight

Many dominant conceptions are underpinned by the privileging of vision in Western culture: the deeply rooted cultural assumption that vision is the dominant and most reliable way of knowing, learning and being. Sight is treated as the most essential sense, the default for accessing and understanding the world. To see is to understand. To not see is to lack. Sightedness becomes normalised as 'neutral' and unmarked, while blindness is framed as absence or deviation (Healey, 2021; Michalko, 2002).

In the context of blindness, ableism often works hand-in-hand with ocularcentrism. This ocular-normative worldview equates visual perception with objectivity, clarity and intelligence, leaving blindness conceptually aligned with confusion, darkness, ignorance or inferiority (Bolt, 2013; Grealy & Kleege, 2007; Kleege, 1999; Michalko, 1998; Omansky, 2006). This normative logic equates seeing with knowing, and positions blindness as an epistemological threat: if one cannot see, one is assumed to know less, or not at all.

These cultural assumptions are embedded in everyday language and values. Phrases like ‘seeing is believing’ reinforce the idea that knowledge is anchored in visual perception (Healey, 2022; Michalko, 2001), thereby marginalising other sensory or relational forms of understanding. This binary creates a hierarchy that defines blindness against the backdrop of ideal vision and thus marginalises it as a deviation rather than acknowledging it as a distinct way of being. It becomes the shadow of seeing: a state associated with danger, confusion, ignorance or incapacity. Within this paradigm, blindness is not only a physiological condition, but also a conceptual problem—something that unsettles dominant ways of knowing and being in the world.

Cultural imagery and symbolic weight

Blindness also circulates in culture. Conceptions of blindness in media, literature and popular imagination are saturated with symbolism. The word ‘blind’ often carries a heavy load of negative associations tied to darkness, tragedy and fear (Bolt, 2015; Kleege, 2018). These connotations fix blindness in moralistic frames, where it symbolises misfortune, helplessness or even death.

Iconic images—such as the white cane, guide dog or dark glasses—have become cultural shorthand for blindness. While these tools offer real-world access, their symbolic use often reduces blind people to passive figures of dependence or pity. These visuals contribute to a broader ‘metanarrative’ (Bolt, 2013), a series of familiar tropes that flatten the richness of blind life. As a result, the person is frequently reduced to their perceived deficit—a process Bolt (2013) describes as ‘normate reductionism’.

What is lost in such narratives is complexity. Dominant depictions often obscure blind people’s agency, affect, creativity and expertise. Instead, blindness is framed as something that must be explained, compensated or overcome.

Terminological choices in the research

This PhD project critically engages with discourses of blindness, not by rejecting terminology altogether, but by examining how blindness becomes meaningful in specific contexts. The term ‘blindness’ is used deliberately throughout this text—not to universalise or essentialise but to explore its layered and shifting meanings.

Throughout the PhD, terminological complexity is acknowledged. Different terms are used depending on the connotations or nuances they carry. While ‘visual impairment’ is used in participant selection—since many participants self-identify with this term—the terms ‘partial sight’, ‘severe visual impairment’ and ‘blindness’ are used to concretise the nature of participants’ vision. The term ‘blind’ is employed in chapter titles and analysis. Here, blindness is understood as living with a visual impairment, encompassing a complex, contextual and interactive conception of disability. Rather than focusing on medical classifications, the research seeks to foreground the full spectrum of participants’ lived experiences.

During peer review, explicit attention was drawn to the author’s positionality—particularly regarding disability—while other intersecting aspects of identity were left largely unaddressed. Phrases such as ‘the author, who is visually impaired’ or ‘who is blind’ were considered sufficient markers of insider status. While there is some commonality between the researcher and participants (e.g. living with visual impairment), there are also significant differences in terms of the nature of the impairment—its stability, progression, or degree of sight loss. We may all be visually impaired, but each of us has distinct, personal relationships to that experience. Additional comments addressed how ‘visual issues’ were negotiated in research encounters, such as non-verbal cues, and how collaboration with sighted pedagogues validates the research within ocularcentric academic norms. Acknowledging the researcher’s environment—working alongside non-visually impaired colleagues—was framed as a way to counter ‘blindness bias’ and affirm the research’s relevance in predominantly sighted contexts.

Importantly, no two experiences of visual impairment are the same. The term ‘blind’ may evoke resistance or unease, depending on who uses it, in what context, and from which position. In this PhD, blindness is approached as relational, representational and lived. It is something that appears and disappears, is visible and invisible, knowable and unknowable. It is not simply about what is missing, but about how meaning is produced in relation to the absence or presence of sight. This approach aligns with scholars such as Michalko, Healey and Bolt, who challenge simplistic or medicalised definitions of blindness. As Kleege (1999) reminds us, ‘There’s more here than meets the eye, but what meets the eye is still what matters most’ (p. 27). By tracing the ways blindness is named, represented and interpreted, this PhD project contributes to a more nuanced understanding—one that resists reduction and affirms the complexity of blind ways of being, knowing and belonging.

Discovering patterns in crochet

This section draws on the tactile and imaginative metaphor of crochet to reflect on the evolving process of knowledge-making in this PhD project. What began as a leisurely activity during periods of intensive computer work gradually became an anchor point for thinking through the research process itself. Crochet revealed itself as more than a hobby—it became a way of conceptualising how inquiry unfolds: slowly, attentively, rhythmically, and always with the potential to rework and reimagine.

Crochet is a method of working with patterns and discovering them, sometimes by following, other times by deviating. Julia Blackburn describes, in her book *Threads* (2015), crocheting as a methodical yet creative process of patching together insights into something new, something that offers comfort, resistance, and beauty. Similarly, this research does not just aim to produce knowledge but to craft it—through practices that invite repetition, variation and responsiveness to what emerges.

Like the process of reconceptualising blindness, crochet is not linear. It involves touch, rhythm, decision-making and adjustment. It creates shape while resisting rigid form. The patterns that appear in crochet are often iterative: stitches are looped into previous ones, forming textures that grow stitch by stitch. Research shares this quality. It develops through recursive movements between interviews, texts, writing and reflection—between slip knots of intuition and tighter weaves of analysis.

Both crochet and research are serious assembling practices. They involve returning to the same material yet producing something different each time. There is comfort in the rhythm but also surprise in the pattern. In crochet, one can undo and rework, just as an analytical idea can be pulled apart and restitched. This flexibility allows both practices to respond to complexity and embrace incompleteness.

As Vandenbussche et al. (2024) describe, crochet is a material-discursive practice that can help us visualise and feel 'entangled knots' and 'intra-actions' that are not easily captured in linear explanation. In this sense, the metaphor of crochet captures something profound about working with blindness: the way meaning is not found, but formed through contact, through relation, through time.

Crochet requires tools and guidance: yarn, hooks, stitch markers and patterns. In the context of this research, these take on metaphorical significance. Yarn represents the rich, textured data—autobiographical insights, interview narratives and situational reflections—that carry existential and affective weight. Hooks become analytical tools: theoretical frameworks, conversations and questions that draw loops of meaning from the material. Stitch markers indicate tension or curiosity—key moments in the data that deserve closer attention. Patterns in crochet mirror the structure of analysis. Simple stitches like the chain or single crochet serve as foundations, while more advanced techniques—cluster stitches, front-post stitches, extended double crochets—allow for creative elaboration. Similarly, this research begins with basic engagements: interviews, preliminary analysis and autobiographical notes. Over time, the methods become more layered, drawing in intersectional, relational and material perspectives to add depth and variation.

Each analytic moment, like each row of stitches, builds on what came before. Yet the process is never rigid. Like in crochet, backtracking is not failure but part of the process. Tension can be adjusted, and sections can be reworked. The possibility of undoing allows for openness, recursiveness and iteration. It affirms the exploratory, affective and responsive nature of inquiry. As Barad (2012) and Haraway (2016) remind us, becoming-with ideas and materials requires attentiveness to emergence—what might appear, shift or twist under your fingers.

Patterns do not eliminate difference; they sustain it. In this PhD project, patterns provided rhythm and guidance but never dictated fixed pathways. Like crochet pieces, no two analytical paths unfolded exactly the same way. A similar starting point—a quote, an encounter, a tension—could unravel into something entirely new, depending on what it was looped into: 'It doesn't search for one representation of blindness but wants to understand its multiplicity' (Van Havermaet et al., in press).

Stitch by stitch, pattern by pattern, the doctoral research grew more complex and more cohesive. But the goal was never uniformity. Instead, it was to embrace variation as richness. Rather than being external to the research, personal experiences of blindness acted as recurring motifs—appearing, receding and reappearing in different contexts. Each engagement, each ‘stitch’, added texture to the pattern.

Through this metaphor, blindness is not seen as a single story, but as a layered tapestry: sometimes tight, sometimes loose, always formed in relation. Like a crocheted piece, the PhD project holds traces of what came before. Even when threads are undone, their memory lingers in the tension, in the loop, in the hand.

Unlike crochet, where the end product is sometimes known in advance, research resists closure. It follows patterns, but it also has deviations, surprises and interruptions. The moment of fastening off—when a piece is tied and completed—only comes when the fabric feels strong enough to hold. In this PhD, chapters are not endpoints but woven pieces within a larger fabric of meaning-making. Each chapter returns to themes of blindness, embodiment and relationality—not to resolve them, but to explore how they can be restitched, resisted and reimagined.

As such, discovering patterns in crochet became more than a metaphor; it became a way to inhabit and perform the conceptual work of the research. It helped shape methodological choices, grounded theoretical reflections, and affirmed that knowledge, like fabric, is always made and always re-makable.

What follows in this PhD: a chapter overview

This PhD project explores how visual impairment is lived, made meaningful, and narrated from within. It takes lived experiences as a starting point to reconceptualise blindness—not as a fixed condition, but as something relational, situated and dynamic. Visual impairment is a connecting thread across all publications, which explores how partial sightedness or blindness takes up space and meaning in everyday life. Rather than focusing on the impairment itself or the individual as an isolated subject, the research examines how blindness appears and matters in everyday life. This first chapter has set the conceptual and methodological groundwork for the empirical chapters that follow.

Across multiple empirical chapters, another context for blindness enables reconceptualisation of blindness. Each of these conceptual approaches focuses on a different domain where visual impairment appears and takes shape. The PhD project traces how blindness takes form in contexts such as parenting, educational and social participation, white cane use and academic work. Rather than aiming to define blindness, these studies create space for alternative understandings that emerge from lived experience—perspectives that exceed conventional, medicalised or binary framings.

‘Chapter 2: Unseen? A qualitative study on how mothers and fathers living with a visual impairment experience parenthood’ explores parenthood. It offers visibility to the lived, personal and multi-layered experiences of parenthood. It captures how visually impaired parents experience the upbringing of their children and how they deal with views on ‘ideal parenting’ from inside. The focus of this chapter is not their impairment but their role as parents and their parenting practices. It examines the plurality of parental experiences in daily living and explores a complex, bottom-up understanding of how parenthood and disablement are entangled.

‘Chapter 3: Living with blindness: unravelling contextualised lived experiences of James and his networks’ shifts attention to a deeper, time-bound exploration of blindness as relational identity. It unravels the contextualised and complex meaning of blindness; the multi-layered and shared lived experiences of blindness across the life span, to understand how these have evolved over time. The chapter focuses on how James, who is blind, experiences himself, how he is understood by others (family, friends and caregivers), and how he is positioned in various systems in life (upbringing, education and leisure). In particular, educational and social participation are used as entry points for exploring how blindness is experienced. Underlying this is that blind individuals and their social networks engage in ongoing negotiations and relational practices that influence how societal participation is shaped and narrated.

‘Chapter 4: A counter-narrative: the world according to the white cane’ turns, in addition to the biographical depth of Chapter 3, to the material and symbolic significance of one specific object. Public signs of blindness make the disability variously visible; they influence how blindness is conceptualised. Across multiple white cane users’ experiences, the chapter unravels the materiality of the white cane and sheds light on the functionalities, relationalities and ways of being and becoming in the world with and without a white cane. The white cane—with all its meanings—is an integral part of the assemblage of blindness and is always entangled with its user, allies and material surroundings. The white cane matters to blindness; it is an entrance for illustrating what becomes possible when someone is visually impaired.

‘Chapter 5: Positioning’ brings with ‘Why I do what I do and why I think what I think: the “so what” of my positioning’ the researcher’s own experiences and academic positioning into focus. This chapter turns the gaze inward, acknowledging that the embodied presence of visual impairment shapes the research process itself. It locates blindness within personal life and the doctorate. This chapter serves as a reflective and methodological positioning to critically engage with the role of being an insider researcher. The initial researcher positioning has evolved throughout the academic trajectory, leading to the realisation that the researcher is also a subject-in-process—whose perspective actively shapes the research and the meanings attached to blindness. These realisations signify that ‘what’ someone does and ‘how’ they do it has significance. The visual impairment of the doctoral candidate invites an ongoing balancing act between ableism and recognition, within and through connection. Specifically, the publications that are included as two intermezzos ‘Accessible participation in academic conferences if you are visually impaired’ and ‘Cripping time: temporalities in academia’ are woven into the body of this chapter.

As the concluding chapter shows, these chapters offer a layered and situated reconceptualisation of visual impairment—one that is grounded in lived experiences, interdependency and critical reflection. Rather than seeking a unifying definition of blindness, this research traces its multiple appearances—as perception, role, relation resistance—through the lived experiences of those who encounter it.

References

Allan, J. (1999). Chapter 4: Transgressive practices: Shaping the self. In J. Allan & R. Slee (Eds.), *Actively seeking inclusion: Pupils with special needs in mainstream schools*. Falmer Press.

Barton, L & Oliver, M. (1997). *Disability Studies: Past, Present and Future.* Leeds: Disability Press.

Barnes, C., & Mercer, G. (Eds.). (1997). *Doing disability research*. Leeds: The Disability Press.

Barnes, C., Mercer, G. & Shakespeare, T. (1999). *Exploring Disability. A Sociological Introduction*. Cambridge: Polity Press.

Barad, K. (2012). On touching—the inhuman that therefore I am. Differences, 23(3), 206-223. https://doi.org/10.1215/10407391-1892943

Beckwith, D. (2019). Chapter 3: Disability advocacy within the ableist environment of academia. In C. McMaster & B. Whitburn (Eds.), *Disability and the university: A disabled students' manifesto*. Peter Lang.

Blackburn, J. (2015). *Threads*. Random House.

Bolt, D. (2005). From blindness to visual impairment: Terminological typology and the social model of disability. *Disability & Society*, *20*(5), 539-552. https://doi.org/10.1080/09687590500156246

Bolt, D. (2012). Chapter 21: Social encounters, cultural representation and critical avoidance. In N. Watson (Ed.), *Routledge handbook of disability studies*. Routledge.

Bolt, D. (2013). *The metanarrative of blindness: A re-reading of twentieth-century Anglophone writing*. US: University of Michigan Press. https://doi.org/10.3998/mpub.5725818

Bolt, D. (2015). The importance of disability research. *Revista de La Facultad de Medicina*, *63*, 11-12. https://doi.org/10.15446/revfacmed.v63n3sup.52718

Bolt, D. (Ed.). (2023). *Finding blindness: International constructions and deconstructions*. Routledge.

Brown, N., & Ramlackhan, K. (2021). Exploring experiences of ableism in academia: A constructivist inquiry. *Higher Education*, *83*, 1225-1239. https://doi.org/10.1007/s10734-021-00739-y

Bulk, L. Y. (2020). *Being blind and belonging in academia* [PhD-proefschrift, University of British Columbia]. https://doi.org/10.14288/1.0395453

Campbell, F.K. (2009). *Contours of Ableism: The Production of Disability and Abledness.* Hampshire: Palgrave Macmillan.

Campbell, J., & Oliver, M. (1996). *Disability politics: Understanding our past, changing our future.* London: Routledge.

Chi Wing Lau, T. (2019). Chapter 2: Slowness, disability, and academic productivity: The need to rethink academic culture. In C. McMaster & B. Whitburn (Eds.). *Disability and the university: A disabled students' Manifesto*. Peter Lang.

Corker, M. & Shakespeare, T. (2002). Mapping the Terrain. In M. Corker & T. Shakespeare (Eds.), *Disability/postmodernity: embodying disability theory* (pp.1-17). London/New York: Continuum.

Davies, B. (2021). *Entanglement in the world's becoming and the doing of new materialist inquiry*. Routledge.

Duckett, P., & Pratt, R. (2007). The emancipation of visually impaired people in social science research practice. *British Journal of Visual Impairment*, *25*(1), 5-20. https://doi.org/10.1177/0264619607071771

Goodley, D. (2011). *Disability studies: An interdisciplinary introduction*. London: Sage Publications.

Goodley, D. (2013). Dis/entangling critical disability studies. *Disability & Society*, 28(5), 631-644. https://doi.org/10.1080/09687599.2012.717884

Goodley, D., & Runswick-Cole, K. (2014). Becoming dishuman: Thinking about the human through dis/ability. *Discourse: Studies in the Cultural Politics of Education*, *37*(1), 1-15.

Goodley, D., Lawthom, R., Liddiard K., & Runswick-Cole, K. (2019). Provocations for Critical Disability Studies. *Disability & Society*, 34(6), 972-997. https://doi.org/10.1080/09687599.2019.1566889

Goodley, D., & Van Hove, G. (Eds.). (2005). *Another disability studies reader? People with learning difficulties and a disabling world.* Leuven/Apeldoorn: Garant.

Grealy, L., & Kleege, G. (2007). Chapter 2: Tyranny of the visual. In S. B. Mintz (Ed.), *Unruly bodies: Life writing by women with disabilities*. University of North Carolina Press.

Hammer, G. (2019). *Blindness Through the Looking Glass: The Performance of Blindness, Gender, and the Sensory Body.* University of Michigan Press. https://doi.org/10.3998/mpub.9271356

Haraway, D. J. (2016). *Staying with the trouble*. Duke University Press.

Healey, D. (2021). *Dramatizing blindness: Disability studies as critical creative narrative*. Palgrave Macmillan.

Healey, D. (2022). Chapter 10: Blind perception: DisAppearing blindness … with a twist. In T. Titchkosky, E. Cagulada, & M. DeWelles (Eds.). *DisAppearing: Encounters in disability studies*. Canadian Scholars.

Healey, D. (2023). Chapter 12: Sighted-blindness-consultants and the ever-lasting station of blindness. In D. Bolt (Ed.), *Finding blindness: International constructions and deconstructions*. Routledge.

Kleege, G. (1999). *Sight unseen*. Yale University Press.

Kleege, G. (2005). Blindness and visual culture: An eyewitness account. *Journal of Visual Culture*, *4*(2), 179-190.

Kleege, G. (2009). Introduction: Blindness and literature. *Journal of Literary & Cultural Disability Studies*, *3*(2), 113-114.

Kleege, G. (2018). *More than meets the eye: What blindness brings to art*. Oxford University Press.

Kudlick, C. (2018). Chapter 6: Social history of medicine and disability history. In M. A. Rembis, C. J. Kudlick, & K. E. Nielsen (Eds.), *The Oxford handbook of disability history*. Oxford University Press.

Michalko, R. (1998). *The mystery of the eye and the shadow of blindness*. University of Toronto Press.

Michalko, R. (2001). Blindness enters the classroom. *Disability & Society*, *16*(3), 349-359. https://doi.org/10.1080/09687590120045923

Michalko, R. (2002). *The difference that disability makes*. Temple University Press.

Michalko, R., & Goodley, D., with Smokie (2023). *Letters with Smokie: Blindness and more-than-human relations*. University of Manitoba Press.

Michalko, R., & Titchkosky, T. (2020). Blindness: A cultural history of blindness. In D. T. Mitchell & S. L. Snyder (Eds.), *A cultural history of disability in the modern age* (pp. 61-78). Bloomsbury Academic.

Mingus, M. (2018). Opening keynote presentation by Mia Mingus. Disability Intersectionality Summit (DIS). https://www.youtube.com/watch?v=lm21KpsNk1s&t=37s

Omansky Gordon, B. (2004). *Researching the social construction of blindness*. University of Queensland.

Omansky, B. (2006). *Not blind enough: Living in the borderland called legal blindness*. University of Queensland.

Omansky, B. (2011). *Borderlands of blindness*. Lynne Rienner Publishers.

Salminen, A., & Karhula, M. E. (2014). Young persons with visual impairment: Challenges of participation. *Scandinavian Journal of Occupational Therapy*, *21*(4), 267-276. https://doi.org/10.3109/11038128.2014.899622

Shakespeare, T. (2006). *Disability rights and wrongs*. London/New York: Routledge.

Shakespeare, T., & Watson, N. (2002). The social model of disability: An outdated ideology? *Research in Social Science and Disability*, 2, 9-28.

Symeonidou, S. (2024). Teacher education for disability-focused anti-oppressive pedagogy: The case for reconceptualisation. *Disability & Society*, *40*(5), 1404-1424. https://doi.org/10.1080/09687599.2024.2360430

Titchkosky, T. (2011). *The question of access: Disability, space, meaning*. University of Toronto Press.

Titchkosky, T., Cagulada, E., & DeWelles, M. (2022). *DisAppearing: Encounters in disability studies*. Canadian Scholars.

Tregaskis, C., & Goodley, D. (2005). Disability research by disabled and non-disabled people: Towards a relational methodology of research production. *International Journal of Social Research Methodology*, *8*(5), 363-374.

Vandenbussche, H., Van Goidsenhoven, L., Vandekerckhove, A., & De Schauwer, E. (2024). 'The university is made for those who can climb the stairs': Dialoguing with counterstories in higher education. *Qualitative Inquiry*, 1-13. https://doi.org/10.1177/10778004241254393

Van Havermaet, J., Carette, L., & De Schauwer, E. (in press). [Review of the book *DisAppearing: Encounters in disability studies*, by T. Titchkosky, E. Cagulada, & M. DeWelles with E. Gold]. *Journal of Literary & Cultural Disability Studies*.

Whitburn, B. (2014). The indelible ink of the special stamp: An insider's research essay on imprints and erasures. *Disability & Society*, *29*(4), 624-637. https://doi.org/10.1080/09687599.2013.844097

Whitburn, B., & Goodley, D. (2019). Storying disability's potential. *International Journal of Inclusive Education*, 26(4), 415-428.

Whitburn, B., & Michalko, R. (2019). Blindness/sightedness: Disability studies and the defiance of di-vision. In N. Watson & S. Vehmaas (Eds.), *The Routledge handbook of disability studies* (pp. 219-233). Routledge.

Whitburn, B., & Riffo-Salgado, P. (2024). Negotiating access, access and belonging in a higher education institution: A postqualitative narrative. *Higher Education*, *89*, 1129-1143.

Chapter 2: Unseen? A qualitative study on how mothers and fathers living with a visual impairment experience parenthood

- INTRODUCTION
- PARENTS LIVING WITH A VISUAL IMPAIRMENT: INSIGHTS FROM PREVIOUS RESEARCH
- METHOD
- RESULTS
    - *Daily parenting practices*
    - *A parental urge to prove themselves*
    - *Relational parenting: Connections with partner and children*
- DISCUSSION AND CONCLUSION
- REFERENCES

Based on: Van Havermaet, J., De Schauwer, E., & Van Hove, G. (2021). Unseen? A qualitative study on how mothers and fathers living with a visual impairment experience parenthood. *DiGeSt Journal of Diversity and Gender* Studies, Parenthood: norms and experiences, 7(2), 68-80. http://dx.doi.org/10.21825/digest.v7i2.17565

Abstract

It is barely taken into account that a visually impaired child might one day become a parent. Research on the insider perspectives of parents on parenting with a visual impairment is scarce. This exploratory study reports on how six mothers and seven fathers living with a visual impairment experience parenthood. An individual or paired open interview, followed by qualitative content analysis, captured their multi-layered and personal lived experiences on parenting. Analysis of the collected data reveals three themes: the actual practices of daily parenting as an exploration of a personal and unique toolbox for each parent; a parental urge to prove themselves to overcome extra doubts, pressure and othering; and the relational work of parents with their partner and child(ren).

Keywords: disability studies, parenting, partial sightedness or blindness, lived experiences

Introduction

This research offers visibility to mothers and fathers living with visual impairment and their lived experiences with parenting— a group and particular mode of child-rearing generally overlooked in literature on parenting. Instead of their visual impairment as such, their position as parents and their parenting is the primary focus of this study. Consequently, this exploratory research employs a person-centred approach based on lived experiences to comprehensively make sense of the existing practices of visually impaired parenting and expand existing societal views on the subject.

The person-centred perspective is motivated by the fact that parents living with a visual impairment are unperceived or unidentified (Kilkey & Clarke, 2010; Ramaekers & Suissa, 2013; Van der Pas, 2008). The prevalence of visually impaired parents is unclear; only estimations of the number of visually impaired people in general are available (Blindenzorg Licht en Liefde, 2014; Pascolini & Mariotti, 2012; World Health Organization, 2018). While the number of parents among these visually impaired is unknown, the group is large enough to draw some attention (Peta, 2017; Soyez et al., 2009). The present research highlights the insider position of parents living with a visual impairment and elucidates experiential subjectivity in qualitative research (Ashby, 2011) — which remains largely unrecognised. The scarce to begin with, existing research often comes across as reductionist, ocular-normative and ocular-centric (Bolt, 2005, 2013). A homogenising focus on visual impairment effaces the plurality of parental lived experiences in the literature. Moreover, its instrumental approach displays differentiating, simple and problematic views on visually impaired parenting — leading Bolt (2015), Goodley and Runswick-Cole (2014) and Titchkosky and Michalko (2012) to call for a destabilization of such considerations of visually impaired parenting.

Consequently, this research brings the marginalised and silenced perspectives of parents living with a visual impairment to the forefront by reporting on their multi-layered representations (Ashby, 2011). It aims to answer the question: 'How do mothers and fathers living with a visual impairment experience parenthood in Flanders (Belgium)?' The study is based on open dialogues with six mothers and seven fathers living with a visual impairment to explore the lived experiences of visually impaired parents—as parents, and in their own words. It examines how they deal with their parenting, and explores a complex, bottom-up understanding of the personal lived experiences of visually impaired parents (Goodley & Runswick-Cole, 2014).

Parents living with a visual impairment: Insights from previous research

The existing literature about visually impaired parenting elaborates on a range of different, highly specific topics, such as transport, daily parenting practices and techniques, socio-emotional challenges, external resources and use of senses. The following overview of previous research demonstrates how these topics affect the parenthood of men and women labelled as visually disabled.

As noted by multiple sources, transport is the predominant challenge for visually impaired parents. Their mobility struggle additionally impacts the child in terms of transport limitations impacting leisure time outside the home environment (De Visscher, 2014; Molden, 2014; Vancoillie, n.d.). Throughout their life, all activities must be sufficiently anticipated and carefully planned (Rosenblum et al., 2009), and all materials or means of transport are applied and adapted to reduced mobility possibilities (Kent, 2002; Van den Abbeel & Balfoort, 2016). Concretely, visually impaired parents use strollers, baby slings and other equipment that can be utilised while moving by train, a passenger in a car/taxi and/or on foot.

Daily practices, nutrition, health and homework also feature in existing literature. For example, it is observed that breastfeeding makes blind mothers insecure (Cezario et al., 2017); notwithstanding their ability to do so autonomously (De Visscher, 2014; Vancoillie, n.d.) and it negotiates practical issues such as measuring bottle nutrition or aiming spoons.

Using a spoken scale, self-made markers and practicing is helpful, and may mediate practical challenges (Cezario et al., 2017; De Visscher, 2014; Vancoillie, n.d.; Van den Abbeel & Balfoort, 2016). Ensuring safety by preventing and resolving unsafe situations—when changing a nappy (Knighton, 2010), for example, or when giving correct medication (Vancoillie, n.d.)—ultimately become automatisms by developing personal tricks, like reading the braille on packages (Pagliuca et al., 2009; Rosenblum et al., 2009). Assisting with their child's homework can be practically challenging when books or the diary are unreadable for visually impaired parents (Rosenblum et al., 2009). Even when children present something, such as at school events, parents lack visual input, which hinders them from fully acknowledging their child's achievements and causes emotional distress (De Visscher, 2014).

In general, adults with a visual impairment experience social beliefs including judgmental, curious, worried, admiring and anxious reactions as harmful (De Visscher, 2014; Kent, 2002; Molden, 2014; Van den Abbeel & Balfoort, 2016), and societal responses tend to betray ignorance and incomprehension (Rosenblum et al., 2009). Progress and acceptance of disability, barriers in daily living, or (in)dependence of them as a parent are socially and emotionally challenging (Molden, 2014; Rosenblum et al., 2009). Popular narratives on the pursuit of parenthood generally do not consider a place for visual impairment (Kent, 2002), leading visually impaired parents to experience stigmatization — even when this is not intended (De Visscher, 2014; Kent, 2002; Van den Abbeel & Balfoort, 2016).

The external information sources of parents (Cezario et al., 2017; Pagliuca et al., 2009; Rosenblum et al., 2009) are multiple (e.g. exchanges with companions and non-disabled parents), personal and disability-specific (Kent, 2002). Like others, disabled parents receive support from their social network, such as for babysitting (Cezario et al., 2017; Pagliuca et al., 2009; Rosenblum et al., 2009), but sometimes visually impaired parents require psychological help too. Eight of the nine interviewed mothers in Molden's (2014) study would have liked the chance to have had access to some form of emotional support to assist them in their trajectory.

Visually impaired parents also attempt to compensate for sensory difficulties (Molden, 2014). Where possible, partially sighted parents use high contrast (De Visscher, 2014; Vancoillie, n.d.) and all visually impaired parents develop alternative strategies based on other senses (Cezario et al., 2017; Pagliuca et al., 2009). For instance, they touch or listen more intensively to acquire the information they need. But vision loss may nevertheless create specific child-rearing issues for visually impaired parents, because sight, out of all the five senses, is considered the most important in the function of attachment (Molden, 2014).

While valuable, existing literature continues to be dominated by a technical and top-down perspective on visually impaired parenting. The practical, socio-emotional and communicative impact of visual impairment on the parent and their parenthood provides an instrumental focus on (impairment-specific) deficits or problems and the effects on child outcomes (Kilkey & Clarke, 2010). In this research, we want to present personable meanings of parents living with a visual impairment and their parenting by focusing on their position as parents and parental experiences in daily living.

Method

This qualitative descriptive research (Snape & Spencer, 2003) used only two selection criteria: the participants must be a parent of at least one child and must be visually impaired (i.e. describe themself as partially sighted or blind). The selected participants were acquaintances of the first author, candidates of a Facebook group or selected by snowball sampling (Ritchie et al., 2003). Candidates were recruited and interviewed, with sampling coming to an end when different parental experiences were repeated.

The sample consisted of individual parents and (visually impaired) pairs (Ritchie et al., 2003). Interviews 1-6 and 9 were individual, and Interviews 7, 8 and 10 were paired. All parents had a partner at the time the interview was conducted. In total, thirteen parents—six mothers and seven fathers, living in Flanders (Belgium)—were included in the study. At the time of the interview, five parents were partially sighted (Father 2, Father 3, Father 4, Father 5 and Mother 6), five parents were severely visually impaired (Mother 1, Mother 2, Mother 3, Mother 5 and Father 6) and three parents were blind (Father 1, Mother 4 and Father 7). In three of ten families (Interview 6, 7 and 10), one or more children were visually impaired too.

Table: Information on the sample

Interview	Parent	Age	Work	Child(ren)
1	Mother 1	n/a	Part-time	Daughter (24y) Son (20y)

				Son (16y)
2	Father 1	n/a	Four-fifths	Son (8y)
3	Father 2	34y	Part-time	Daughter (8m)
4	Father 3	33y	At home	Daughter (6y) Daughter (3y)
5	Mother 2	32y	Four-fifths	Daughter (4y) Son (18m)
6	Mother 3	n/a	At home	Stepdaughter (11y) Stepdaughter (8y) Daughter (5y) Daughter (14m) Son (5m)
7	Father 4	61y	Retired	Son (39y) Son (35y)
	Mother 4	60y	Retired	
8	Father 5	35y	Fulltime	Daughter (4y)
	Mother 5	40y	At Home	
9	Father 6	57y	Fulltime	Daughter (29y) Son (28y)
10	Mother 6	n/a	Four-fifths	Daughter (9m)
	Father 7	38y	Fulltime	

Concerning data collection, the first author organised oral interviews. Only Interview 3 used computer-mediated communication (Shepherd, 2003), as preferred by the participant. At the start of each interview, the participants were asked for informed consent (Lewis, 2003). All participants agreed to audio recording of the interviews to facilitate the generation of complete and coherent transcripts. Subsequently, parental narratives were revealed through open, unstructured interviews (Baarda et al., 2013). To collect situational representations and meaning-making through a naturalistic and interpretative approach, the starting question was: 'This research is about how visually impaired parents experience parenthood; what does it mean to you?' The interviews then followed the spontaneous flow of the parents' stories. Participants pinpointed their own topics very naturally, without much researcher intervention. Additional questions were formulated organically and were therefore specific to each interview. Interviews were conducted between January and September 2018 and lasted two hours on average. With the permission of the participants, observations and interviews were transcribed in full. All interview transcripts were also validated through named member checking (Glesne, 2014).

Each transcript was carefully read through several times and subjected to qualitative content analysis. This process of analysis followed inductive and conceptual mapping procedures, as suggested by Clarke (2005) and Charmaz (2006). Upon coding the interviews, the first author identified reoccurring themes, common patterns and key points (Boeije, 2012; Zhang & Wildemuth, 2009). The themes were examined for consistent patterns and exceptions. The group of analysers discussed the most important inter-relating threads and searched for entanglements across more concrete and more abstract dimensions of experience.

The first author is young, female, Flemish and not a parent at the time of interviewing. She is also visually impaired herself, which provides a subjective insider position that constitutes a significant source of expert knowledge (Tregaskis & Goodley, 2005). She was conscious of accessible documents (e.g. informed consent or transcripts). Her existential experiences with visual impairment provided sensitive access to participants and entailed a close understanding of participants' daily lived experiences. This position made it possible to capture unwritten assumptions or subtle cues concerning visual impairment. This unique meta-perspective enriched the process and output of the research. At the same time, the first author negotiated visual issues (e.g., how participants and the first author deal with non-verbal cues) to one of the co-authors. To preserve distance from the content, she also collaborated with three sighted pedagogues to look at the data and the patterns in the analysis. During analysis, for the consistency of the themes and in writing up the results, there was a continuous dialogue and discussion with the two co-authors about interpreting the narratives.

Results

Analysis of the narratives of the six mothers and seven fathers living with a visual impairment resulted in three themes: daily practical burdens and solutions; the urge to provide 'good enough' parenting; and relational parenting concerning partnership and connection with their children.

Daily parenting practices

Concerning quotidian parenting activities, visual impairment did cause practical challenges. The interviewed parents gave multiple examples of how they manage practical burdens and their parenting with a personal, unique 'box of tricks', that accommodates and supports them in their daily living environments.

The interviewed parents discussed mobility very explicitly. They were less flexible and more dependent in relation to going out with the children; specifically, taking the children to day-care, school, the shops or the doctor. Father 2 identified not being able to drive a car as more difficult than living with a disability. Father 1 mentioned taxis and public transport as viable alternatives, but nevertheless perceived mobility as a particularly delicate point. The interviewed parents had to walk with their children, even in bad weather. It was also painful for Mother 1, Mother 2 and Mother 3 to no longer be able to drive a car by themselves and to have lost autonomous transport options because of the progressivity of their impairment. This was confrontational for the parent and their family. They needed time to accept and explore alternative options:

> *Mother 2: I think that's actually the hardest adjustment now, the fact that I can't drive the car anymore. I'm really struggling with that, still. This is also very difficult for the family; my husband now has to bring the children and me everywhere.*

Rehabilitation of the person (e.g. mobility training, help with administration and learning to use certain software) to maximally maintain their independence was considered important by Mother 1, Father 3, Mother 2, Mother 3 and Father 6. Only one of the thirteen interviewed parents reported a need for psychological support. Father 1 and Mother 2 criticised the absence and redundancy of professional support for parents and their parenting: rehabilitators never negotiated their visually impaired parenting. Moreover, Mother 3, Mother 5 and Father 7 found that the baby training course of the Brailleliga[1] was not helpful because it needed to be more practical or did not work for them.

Each interviewed parent possessed a highly personal set of tools tailored to their own general needs, including an (extendable) cane, computer software, labels or a talking scale — the uses of which extend to parenting. Additionally, they used common materials, such as a baby sling instead of a stroller (to remain handsfree) or using email instead of a school diary to address their parental responsibilities in their own way. These reasonable accommodations were important for the participants and their children because they create safety, structure and peace of mind. The interviewed parents found that an anticipatory and solution-oriented attitude is satisfying and necessary. They are creative, proactive and resourceful to plan and think 'outside the box':

> *Father 7: There will probably be other things, but you'll just have to try to find a solution most of the time, and sometimes the circumstances will just force you to. In*

> *the beginning, things seem impossible, but then you try or simply can't find anyone else and end up doing it yourself.*

The interviewed parents found a pleasant role division and smooth organizational structure in their family. They were proud when their parenting ran uncomplicatedly, without chaos or problems. Their parenting became a habit over time: the interviewed parents live their daily lives with a visual impairment, and as a parent, they were no longer constantly aware of both these characteristics. The context habituated, and the parent gained trust and fell back on recurrent experiences. Their parenting became less awkward or strange to themselves and their social network.

A parental urge to prove themselves

The interviewed parents experienced internal and external pressures about their parenting being 'good enough'. They had some extra doubts and felt scrutiny about their parenting. The definition of a parent is specific, and all of the participants doubted whether their parenting was 'good enough'. Indeed, visual impairment can result in additional concerns or pressures to become a good parent. The participants had feelings of uncertainties, questions of doubt and experienced guilt. Mother 1 questioned herself and her parenting regularly and profoundly; whether it was valuable enough to each of her children:

> *Mother 1: As a mother, you always feel like 'I love all three of my children equally, and I should do the same for all three of them', but because of that visual impairment it is different.*

The participants pointed out that parenting with a visual impairment does not occur regularly, making it exceptional and unfamiliar. The visual impairment was often wrongly understood or made an issue by others. Father 1 was asked indiscrete questions about his impairment while waiting for an underground, and a café owner did not understand why Father 4 guided Mother 4 to the toilet. These excluding and differentiating stigmas were experienced as annoying and dealing with them was difficult for the participants. Mostly, it focused more on visual impairment than parenting. The outsiders' thoughts, prejudices and opinions about parenting by mothers and fathers with a visual impairment often remained unspoken. The interviewed parents felt marginalised and excluded—not necessarily in an explicit and physical way, but more in an indirect and emotional way:

> *Father 7: I think there are a lot of people who do a double-take when you pass by with a white cane and a stroller ... You already attract attention so add a stroller and it's completely ... Not something you see every day in any case.*

Participants in Interviews 7 and 10 showed self-conscious disobedience to overcome extra doubts, practical and emotional burdens, and well-intended discouragement from family and doctors:

> *Father 7: Once, we had to go to the hospital, and they wanted to do psychological tests and more that I didn't know. Mother 6: That professor examined us. She asked questions about our capacities to raise children, whether we are responsible ... With*

> *us, she dared not, but we know others that consulted her, a blind couple ... They had to forward her letters from friends stating they would be supported. (Interview 10)*

All interviewed parents demonstrated their parenting as a personal choice, a strong belief based on personality and the right to become a parent:

> *Mother 5: If you really want children, you should just go for it. Don't think 'I am partially sighted, I can't do it', that's not true.*

However, the parental belief of being or becoming a 'good enough' parent was dominant in all participants' narratives. It was important for them to connect with role models and significant others. Knowing other people who have been through it before gave them the confidence to become an able parent. Consulting those with similar experiences was valuable to the interviewed parents for inspiration, exchanges and consultation. These (visually impaired) people were a resource to overcome parental issues. The interviewed parents were not feeling isolated and could share experiences:

> *Father 3: I ask them many questions about children and how to do certain things, public transport, walking in the dark with a stroller. There is not a lot of information available about this; everything is very personalised. But I like the contact with these people; it makes you feel like you are not alone.*

All interviewed parents also wanted to be maximally independent, for themselves and their children. Being as independent as possible was experienced as a balancing act that encouraged overcoming anxieties, uncertainties or difficult situations; reinforced their drive; facilitated achieving goals; and boosted self-esteem:

> *Mother 1: I will not sit on the couch all day. I didn't want that for my children either. I did not want later, when they remember their childhood, they say 'my mum always sat at home on the couch because she was partially sighted and she couldn't do anything'. So I did not want that. I want them to say 'my mum still does [sport], my mum plays the [instrument], and ...'*
>
> *Mother 3: That, despite my sight, I can say at the end of the day that I have managed to do it all, that I have washed them, that I have put the clothes in the bins, that my laundry is done, that they have sandwiches, that the schoolbags are okay ... I can always say, 'it's been a good day, everything's fine'. I'm proud of that.*

The interviewed parents desired to be seen as equal to non-disabled parents. They emphasised that what they do is 'normal' from their perspective and cannot be considered different, extraordinary or problematic. Mother 5 compared themself and their skills as visually impaired parents to non-disabled parents. Father 3 and Father 7 stated that there are non-disabled parents who also use a baby sling or do not have a driving license. This urge to prove themselves as equally good parents recurred throughout the interviews:

> *Father 5: Like I used to hear my mother say, 'you need to have eyes in the back of your head'. Well, my normal eyes may function less, but the eyes on my back work as well as anyone else's.*

The environment got used to the impairment over time, according to the participants. The visual impairment was no longer an ever-present topic, it did not have to be mentioned anymore, and people knew how they could interact:

> *Mother 5: The first time I went to pick her up, everyone was staring like 'hey, what's she doing here?' Yes, I still had the stroller and the white cane; but after a while, they don't even notice anymore, and you need to look twice when entering the playground. Meanwhile, they're all so used to it.*

Relational parenting: Connections with partner and children

Connections with their partner and children were characteristic of parenting for the participants. In this case, a visual impairment could increase relational and personal pressures:

> *Mother 1: In the beginning, I found that very difficult ... always have to ask. Also, [feeling like] a burden to your partner, the feeling that he always has to provide everything. I have to solve all that and do it all on my own, and then again on weekends, on Sundays, constantly asking for help for the children, for home help, for the groceries, for everything.*
>
> *Father 6: I had the advantage ... that I could still help them there for the first twelve, thirteen, fourteen years and that I could give them that security ... [Partner] has been doing a lot of work for me in the garden for the last two years, and I want to avoid that as much as possible.*

The sighted partner was expected to spend considerable time doing the shopping and activities related to children, such as transport to hobbies and school, and homework. They compensated for certain visual issues: going outside with a young child, paying attention to medical symptoms, following up on the school diary, styling the children and working. Partners, as parents, were searching for modes of cooperation that suited their personal and relational preferences and capacities. Even for the visually impaired parents, role patterns became different or changed because of the impairment. Father 1 and Father 2 were doing more homemaking to compensate for the inequality of doing child-related tasks. Mother 1 shifted her lifestyle because of her acquired visual impairment, which affects their family bond and family life. The participants often talked about the advantage of time and not needing to rush:

> *Mother 1: So I have a different relationship with my children, and automatically with my partner. Because ... he comes home from work and the food is ready. We didn't used to, we came home and 'what are we going to do tonight?' because both of us didn't have time to go shopping. Yeah, so always that rush, that's a lot less. And for him it is also more pleasant now, it all goes more smoothly at home because I have more time and because you yourself are quieter and less rushed.*

The sighted partner was also personally significant for the visually impaired parents. They help them by giving a hand outside or reflecting about the impairment: explaining it to children, prompting when people want to give something, encouraging to overcome challenges or to consider using a cane. Activities as partners were changed; for example, watching a film together became exhausting, so alternative connectedness needed to be found:

> *Mother 1: I missed that so much at first. I'm often there for fun, but then I feel so silly ... He's watching a movie and I'm like this ... If that's the news, I can still listen in, but there are certain films; I'm not with him, and I don't feel like making an effort if you don't see any of them. And then I just lay there on the couch staring at the ceiling. Ten minutes I can keep that up, and then I stand up. Then all of a sudden [partner] says, and that's why I think he's really sorry, 'what are you gonna do?' And then sometimes I say, 'all, just going to the bathroom'.*

Parenting was also experienced as being connected with their children: the interviewed mothers and fathers experienced warm relationships with their children. They used all of their senses often and in many ways while parenting. Where possible, their residual vision and contrasts were used. Interviewed parents who have/had visual perceptions appreciated participating visually at key developmental milestones for their children, such as their baby's first steps. In addition, touch, hearing and being alert with all senses were actively used in daily interactions. Communication and physical contact with their children became very valuable in a multisensorial way:

> *Mother 3: I thought to myself, from now on I have to see if I can feel it too, then I held him against me, and I could really feel him grimacing. Then I thought to myself, it's fine, if I don't see him anymore, I can still feel him laughing.*

The (progression of) impairment could provoke uncertainties and some existential or painful conversations for the participants. The interviewed parents were honest with their children when they asked questions, but these conversations could make parents feel very vulnerable. Such conversations were not singular; they recurred over and over again. However, even in these situations, the interviewed parents and their children fell back on their strong, loving relationships:

> *Mother 2: Very often, in the weeks and months after, came the questions: 'Are your eyes already better? Have you already been to the doctor? Can't the doctor help your eyes? Can't you take pills?' The logic of a child. So yes, we actually kept repeating that 'the doctor can't make the eyes better'. Because we also felt she had a right to know honestly.*

The participants experienced that the children got used to their parent or parents' visual impairment. The interviewed parents thought their children did not regard the family situation, parenthood and parent as being exceptional over time. The children did not notice it anymore:

> *Mother 1: Sometimes they even say it, like 'hey mum, at home we don't even notice it anymore', but I've never really noticed that they had a problem with it.*

Moreover, the interviewed participants reported that visual impairment might have added value to their parental interactions. First, the visual impairment resulted in an enrichment of parent-child interactions: the relationship felt more open, existential or emotional subjects were more negotiable, and the psychological and physical proximity closer. Second, visual impairment was experienced as a possible enrichment for the child. The visual impairment of their parent(s) was part of their daily life and felt normal (possibly except when they are in puberty), giving the children a more open and positive view of diversity. Despite the visual impairment, parents could still function as parents for their children; for example, in teaching them independence. Third, according to the interviewed parents, when a child lives with a visual impairment, their experiences could be an added value when dealing with the child's disability. The interviewed parents were already familiar with the impairment and could act accordingly. Other parents might lack the knowledge and experience to respond quickly. Their self-experienced accuracy felt like an added value to the development of children. Their experiential knowledge gave the interviewed parents basic confidence in their own abilities:

> *Mother 1: We are much closer, I think, than we would have been otherwise, because we say everything and speak certainly more about feelings than we would have done before (...) And yes, a hug, because you don't see their laugh or facial expression. So being more physical ... That is also different. Yes, I think we have really come closer together and how my children are now towards other people: I am really proud of them.*
>
> *Mother 6: I knew I had to immediately find someone for early intervention or something for [daughter] to stimulate her. So, in this case, it had helped a lot, to show her things closely or let her touch things that she can take in her hands.*

Discussion and Conclusion

This research has provided some valuable insights into how parents experience the upbringing of their children and their position as parents in Flemish (Belgian) society. It directly involved parents living with visual impairment as participants in qualitative research; which was exceptional and offers an alternative to the dominant disability discourse (Ashby, 2011). The study acknowledged both fathers and mothers' insider perspectives by interviewing seven fathers and six mothers. It created a broader understanding or expansive conceptualisation of visually impaired parenting (Ashby, 2011). Elucidating experiential subjectivity provided deeper insights into the insider perspectives of visually impaired parents. An exploration of the lived experiences of the visually impaired parents themselves showed that they encounter the assumed exceptionality or unfamiliarity of their parenting. It took time to prove themselves and relationships were highly significant for the parents. Opening up on these personal insights has made visually impaired parenting more visible and negotiable (Soyez et al., 2009) by giving the parents a voice (Kleege, 2005). Themes such as their parental urge to prove themselves or relationships with family members, were unobserved in theoretical frameworks, which accentuates the novelty of this research in its field. A respectful, honest and open dialogue made the individual parental experiences fully visible. Open communication allowed the expression of an authentic and complete parental perspective: it broadened the vision and revealed what was unseen.

Concerning the actual practice of daily parenting, this was experienced as the exploration of a personal, unique box of tricks. Both the interviewed parents and the existing literature (De Visscher, 2014; Kent, 2002; Molden, 2014; Rosenblum et al., 2009; Vancoillie, n.d.; Van den Abbeel & Balfoort, 2016) concurred that mobility was the most significant practical issue and emotional burden. Less agreement was found on the need for additional psychological support for the parents themselves (Molden, 2014). However, parents having their own approach involving a personal set of tools and a smooth organizational structure were dominant accommodations to daily parenting. Available studies' claims about nutrition, health, homework and information sources that involve problems and solutions (Cezario et al., 2017; De Visscher, 2014; Knighton, 2010; Pagliuca et al., 2009; Rosenblum et al., 2009; Vancoillie, n.d.; Van den Abbeel & Balfoort, 2016) were supported by the daily examples reported in the interviews. It is therefore necessary to consider the implications of these practical struggles and thresholds in the support that is available for the parents. It is crucial to safeguard all possible independence but at the same time assume a personal and adaptive approach to the specific needs and uncertainties of each parent labelled as visually disabled.

The findings explicitly questioned socio-emotional challenges (Molden, 2014; Rosenblum et al., 2009) and harmful societal responses (De Visscher, 2014; Kent, 2002; Molden, 2014, Rosenblum et al., 2009; Van den Abbeel & Balfoort, 2016). At several moments in their lives, the interviewed parents experienced added doubts, pressures, misunderstandings and othering. But, in addition to the observations made in existing literature about these issues, a powerful internal drive was dominant in all participants' narratives. Throughout the interviews, participants' parental belief of being or becoming a 'good enough' parent, their connection with role models, their motivation to be maximally independent, and their urge to prove themselves as parents were repeatedly stated. This conclusion confirms that disabled parents struggle with a poisonous normativity on ideal mothering or fathering and feel a strong urge to prove themselves as parents: they argue against their parenting's assumed inferiority or try to overcome social assumptions (Malacrida, 2009). Visually impaired parents resist idealised parenthood that threatens each of us every day, while simultaneously doing their utmost to be recognised as such and prove how brave and strong they are without needing extra support for themselves.

The last point we want to address in this conclusion is the emphasis on becoming a parent in a web of warm and supportive relationships with the partner, child(ren) and family. Connectedness with a partner and their children was a primordial experience for the parents and their daily parenting. In this case, the visual impairment and its consequences affected these relationships. In practical terms, participants depended on their partners for issues like mobility. But the significance of partners to visually impaired parents and their relationship is more all-encompassing than those practical considerations alone. Visual impairment is a personal characteristic that is facilitated or considered differently by the environment (Michalko, 2002; Soyez et al., 2009) and influences the child (in)directly. This vulnerability is difficult to experience; it is continuously ongoing and has to be negotiated with the children. However, these parents' relationships with their children were also very multisensorial (Cezario et al., 2017; De Visscher, 2014; Molden, 2014; Pagliuca et al., 2009; Vancoillie, n.d.). The interviewed parents confirmed that sight influences these interconnections and they use their residual vision and contrasts where possible. They also pointed out that they used their senses often and in many ways: touching, hearing and being alert with all senses actively in daily interactions. They doubted if their impairment discourages their relationships, but intuitively experienced attachable bindings that felt warm, open, close and negotiable. The warm and close bond—including communication and physical contact—with family members was experienced as important and made the parents proud of their strong and deep connections.

Note:

1. Brailleliga is a Belgian Foundation for the Blind with several missions: to help blind and visually impaired people through financial and material support, to support scientific research and to raise public awareness through information campaigns.

Acknowledgement

This article would not have been possible without the inspiring data collection phase with the thirteen participants: their rich narratives were the basis of the first author's master's thesis.

References

Ashby, C. E. (2011). Whose 'voice' is it anyway?: Giving voice and qualitative research involving individuals that type to communicate. *Disability Studies Quarterly*, 31(4). https://doi.org/10.18061/dsq.v31i4.1723

Baarda, B., Bakker, E., & Fischer, T. (2013). *Basisboek kwalitatief onderzoek: Handleiding voor het opzetten en uitvoeren van kwalitatief onderzoek [Basic book qualitative research: Manual for setting up and conducting qualitative research]* (3rd ed.). Noordhoff Uitgevers.

Blindenzorg Licht en Liefde. (2014). Een visuele handicap—Licht En Liefde. Blindenzorg Licht & Liefde. https://www.blindenzorglichtenliefde.be/nl/meerweten/index/7929

Boeije, H. (2012). Hoofdstuk 5: Principes van kwalitatieve analyse [Chapter 5: Principles of qualitative analysis] In *Analyseren in kwalitatief onderzoek: Denken en doen [Analysing in qualitative research: thinking and conducting]*. Boom Lemma uitgevers.

Bolt, D. (2005). From blindness to visual impairment: Terminological typology and the Social Model of Disability. *Disability & Society*, 20(5), 539-552. https://doi.org/10.1080/09687590500156246

Bolt, D. (2013). *The metanarrative of blindness: A re-reading of twentieth-century Anglophone writing*. US: University of Michigan Press. https://doi.org/10.3998/mpub.5725818

Bolt, D. (2015). The importance of disability research. *Revista de La Facultad de Medicina*, 63, 11-12. https://doi.org/10.15446/revfacmed.v63n3sup.52718

Cezario, K. G., de Oliveira, P. M. P., de Sousa, A. A. S., Carvalho, Q. C. M., dos Santos Pennafort, V. P., & dos Santos, L. A. P. F. (2017). Blind parents and nutrition of children: Experiences and care. *Revista Da Rede de Enfermagem Do Nordeste*, 17(6), 850. https://doi.org/10.15253/2175-6783.2016000600017

Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. SAGE.

Clarke, A. (2005). *Situational analysis: Grounded theory after the postmodern turn*. SAGE.

De Visscher, E. (2014). Een kwalitatief onderzoek naar hoe moeders met een visuele beperking hun ouderschap ervaren. [A qualitative research on how visually impaired mothers experience their parenting]. Universiteit Gent. http://lib.ugent.be/catalog/rug01:002165725

Glesne, C. (2014). Prestudy tasks: Doing what is good for you. In *Qualitative research for educational sciences*. Pearson Education.

Goodley, D., & Runswick-Cole, K. (2014). Becoming dishuman: Thinking about the human through dis/ability. *Discourse: Studies in the Cultural Politics of Education*, 37(1), 1-15. https://doi.org/10.1080/01596306.2014.930021

Kent, D. (2002). Beyond expectations: Being blind and becoming a mother. *Sexuality and Disability*, 20(1), 81-88. https://doi.org/10.1023/A:1015238505439

Kilkey, M., & Clarke, H. (2010). Disabled men and fathering: Opportunities and constraints. *Community, Work & Family*, 13(2), 127-146. https://doi.org/10.1080/13668800902923738

Kleege, G. (2005). Blindness and visual culture: An eyewitness account. *Journal of Visual Culture*, 4(2), 179-190. https://doi.org/10.1177/1470412905054672

Knighton, R. (2010). *C'mon Papa: Dispatches from a dad in the dark*. Knopf Canada.

Lewis, J. (2003). Design issues. In J. Ritchie & J. Lewis (Eds.), *Qualitative research practice: A guide for social science students and researchers* (pp. 47-76). SAGE.

Malacrida, C. (2009). Performing motherhood in a disablist world: Dilemmas of motherhood, femininity and disability. *International Journal of Qualitative Studies in Education*, 22(1), 99-117. https://doi.org/10.1080/095 18390802581927

Michalko, R. (2002). *The difference that disability makes*. Temple University Press.

Molden, H. (2014). A phenomenological investigation into the impact of parenthood: Giving a voice to mothers with visual impairment in the United Kingdom. *British Journal of Visual Impairment*, 32(2), 136-147. https://doi.org/10.1177/0264619613511616

Pagliuca, L. M. F., Uchoa, R. S., & Machado, M. M. T. (2009). Blind parents: Their experience in care for their children. *Revista Latino-Americana de Enfermagem*, 17(2), 271-274. https://doi.org/10.1590/s0104-11692009000200021

Pascolini, D., & Mariotti, S. (2012). Global estimates of visual impairment: 2010. World Health Organization. https://www.who.int/blindness/publications/globaldata/en/

Peta, C. (2017). Disability is not asexuality: The childbearing experiences and aspirations of women with disability in Zimbabwe. *Reproductive Health Matters*, 25(50), 10-19. https://doi.org/10.1080/09688080.2017.1331684

Ramaekers, S., & Suissa, J. (2013). Hoofdstuk 3: Goed genoeg ouderschap? [Chapter 3: Good enough parenting?] In *Goed ouderschap: Een andere blik op opvoeden [Good parenting: Another view of parenting]* (p. 1-58). Garant.

Ritchie, J., Lewis, J., & Elam, G. (2003). Designing and selecting samples. In J. Ritchie & J. Lewis (Eds.), *Qualitative research practice: A guide for social science students and researchers* (pp. 77-108). SAGE.

Rosenblum, L. P., Hong, S., & Harris, B. (2009). Experiences of parents with visual impairments who are raising children. *Journal of Visual Impairment & Blindness*, 103(2), 81-92. http://dx.doi.org/10.1177/0145482X0910300207

Shepherd, N. (2003). Interviewing online: Qualitative research in the network(ed) society. University of Queensland. https://www.researchgate.net/publication/37617070_Interviewing_Online_Qualitativ e_Research_in_the Networked_Society

Snape, D., & Spencer, L. (2003). The foundations of qualitative research. In J. Ritchie & J. Lewis (Eds.), *Qualitative research practice: A guide for social science students and researchers* (pp. 1-23). SAGE.

Soyez, V., Van Hove, G., & Vanderplasschen, W. (2009). Kinderen van ouders met een beperking [Children of disabled parents]. In M. Taal (Ed.), *Handboek kinderen en adolescenten: Problemen en risicosituaties [Handbook: Children and adolescents: Problems and risk situations]*. Bohn-Stafleu Van Loghum.

Titchkosky, T., & Michalko, R. (2012). The body as the problem of individuality: A phenomenological disability studies approach. In D. Goodley, B. Hughes, & L. Davis (Eds.), *Disability and social theory: New developments and directions* (pp. 127-142). Palgrave Macmillan.

Tregaskis, C., & Goodley, D. (2005). Disability research by disabled and non-disabled people: Towards a relational methodology of research production. *International Journal of Social Research Methodology*, 8(5), 363-374. https://doi.org/10.1080/13645570500402439

Van den Abbeel, M., & Balfoort, B. (2016). *Graag zien: Blinde mama, sterke vrouw [Like to see: Blind mother, strong woman]*. Van Halewyck.

Van der Pas, A. (2008). Het nut van ouderschapstheorie—En de valkuilen [The usefulness of parenting theory—And the pitfalls]. *The Parental Perspective*. http://www.alicevanderpas.nl/pas/downloads.html

Vancoillie, M. (n.d.). Een koffer doorheen de reis naar ouderschap, ontwikkeld voor personen met een visuele beperking [A parenting box: Developed for visually impaired people].

World Health Organization. (2018). Vision impairment and blindness. World Health Organization. https://www.who.int/news-room/fact-sheets/detail/blindness-and-visual-impairment

Zhang, Y., & Wildemuth, B. M. (2009). Qualitative analysis of content. In B. Wildemuth (Ed.), *Applications of social research methods to questions in information and library science* (pp. 308-319). Libraries Unlimited.

Chapter 3: Living with blindness: unravelling contextualised lived experiences of James and his networks

- INTRODUCTION
- LIVING WITH BLINDNESS
- METHODOLOGY
- RESULTS
  - *Decisions and processes on (inclusive) education*
  - *Connecting with others*
- DISCUSSION AND CONCLUSION
- REFERENCES

Based on: Van Havermaet, J., Van Hove, G., & De Schauwer, E. (2024). Living with blindness: unravelling contextualised lived experiences of James and his networks. *Disability & Society,* 40(5), 1158-1175. https://doi.org/10.1080/09687599.2024.2331725

Abstract

Blindness (in)directly affects all aspects of daily life and participation in society. Living with a visual impairment can be mapped in terms of the intra-actions between blindness and an individual's networks. This study conceptualised visual impairment in the context of James and his different networks across his lifespan in an attempt to understand the contextualised and complex meaning of his disability. The lived experiences of James and his networks were unravelled, and their perspectives revealed two main encounters: decisions and processes on (inclusive) education and connecting with others. James and his networks discussed how he succeeded in regular education and how he adhered to higher educational norms. The narratives highlighted the pressure to 'pass; to have a space to belong in social spheres, and to function within social networks. The concept of 'assemblage', the entangled gathering of embodiment and relationalities, was helpful in unravelling the complex and contextual conceptualisations of blindness in James' lived experiences.

Keywords: contextualisation, blindness, networks, lived experiences, assemblages

Points of interest

- This article presents a personal narrative of the experiences of James, his family, and his friends in relation to blindness.
- This study's perspective fundamentally assumes that everyone, including people with disabilities, is embedded in several networks of human and non-human elements.
- Disability is not an individual condition; rather, it is something relational and contextual. We want to understand the complexities of the participants' experiences.
- In James' networks, educational development in regular education is identified as a life goal that requires the input of everyone and everything.
- For living blindness, James and his networks also identified the relevance of being socially embedded and bonding with peers and friends.

Introduction

> *Coming to know blindness, as we have demonstrated, necessarily entails a consideration of personhood insofar as we are each part of an assemblage. (Whitburn & Michalko, 2019, p. 231)*

Disabled people are other than societal imaginings: their personal perceptions and perspectives are too often disappeared (Titchkosky et al., 2022). Disability should be contextually reconceptualised and able-bodiedness or ocularcentric beliefs must be critically explored and constantly questioned (McRuer, 2014). The predominant conceptions of disability, where the sophisticated identities of disabled people are denied and the complexities of their networks are ignored, need to be overturned (Bozalek et al., 2022; Goodley & McLaughlin, 2008). This research contextualises disability over a longer life period from internal and multiple perspectives to understand the meaning of blindness, in and through the lens of interdependency (Tregaskis & Goodley, 2005).

Rethinking blindness in terms of relationalities is about the co-constitutive interwoven, interdependent, and embodied (non-)human and (non-)material processes of knowing, becoming, and being. This relates to the interconnectivity and connections within a complex of relational compositions (Goodley & Runswick-Cole, 2014). Productive entanglements in all their multiplicity emerge from assembling intra-actions (Baker & McGuirk, 2017; Corcoran et al., 2019; Maclure, 2021; Van de Putte et al., 2017; Vandenbussche & De Schauwer, 2017). We use Barad's (2007) term intra-active here, in contrast to interaction, to signal the conceptual movement away from separate entities engaging with each other (interaction), towards the unfolding process of becoming in relation to others, where each one is capable of affecting and being affected by the other (intra-action) (De Schauwer et al., 2018). Multiple perspectives interact with one another; multiple voices and multiple lived experiences connect with each other, and they influence each other. It is a meshwork (Vandenbussche & De Schauwer, 2017) wherein everything is unique and is directly and indirectly connected; this complexity is what the current study focuses on. Everyone or everything evolves from the encounters that make up society, and blindness is also part of such intra-actions.

Disability is complicated in nature (Goodley & McLaughlin, 2008) and it re-assembles the embodiment between self and the world: conceptualisations of disability are socially driven (Rodas et al., 2012; Titchkosky, 2011) and are a public concern that mediates experience (and vice versa). An individual's experiences influence their philosophical conceptions and political responses (Goodley & Runswick-Cole, 2014). To understand the complexity of lived experiences, both macro- and micro-perspectives are needed. Non-human role players, such as societal traditions, generational ideas, and mobility aids also need to be involved (Baker & McGuirk, 2017). Disability is a collective experience that is positioned within the context of the dynamics of one's assemblages (Goodley & Runswick-Cole, 2014; Titchkosky, 2011). It is interdependently positioned and interacts with people, matter and language, which makes it a complex entanglement of experiences (Whitburn & Michalko, 2019). Contextualising, or (un)ravelling, these experiences thus involve composing, inter-weaving, weaving, or joining together perspectives (McRuer, 2014). The contextual complexities of experiences with blindness are acknowledged in the different networks in which they appear.

This study contextualises living with blindness because of its complex positioning in these entangled relationalities (Hammer, 2019; Omansky, 2006; Whitburn & Michalko, 2019). We focus on the experiences of blindness in the context of disabling social and institutional arrangements. We draw directly on everyday experiences in which the embodiment of blindness is explored to emphasise relationality and to present movements with dominant ideas of blindness (Whitburn & Michalko, 2019). We focus on personal experiences, relations, and responses, as they make visual impairment appear in a particular way by narrating the various ways blindness is lived (Titchkosky et al., 2022). We combined a theoretical framework derived from relational thinking with data drawn from in-depth interviews to examine the contextual emergence of blindness. This study dives deeply into the stories of an individual living with blindness and unravels the complexity of schooling and social connecting. By discussing their lived experiences and the differences in their perspectives, the normative order of living and responses to marginalisation and exclusion are identified. The dominant conceptions of blindness can be revised by considering how some people are conceiving and acting differently within this system. The values and consequences of desired participation and how we might approach independent living are malleable.

Living with blindness

We cannot understand blindness without considering the culture in which it exists (Bozalek et al., 2022). Professional, interdisciplinary expertise reaffirms over again the hegemony of vision and sight and privileges sightedness as an authority to speak of blindness experiences. Visuality is taken for granted, and seeing is assumed to be the dominant mode of perception. This implies a metanarrative of blindness, whereby blindness is culturally constructed as unknowing, otherness, disempowerment, ignorance, less than whole, less than human, and darkness (McLaughlin & Goodley, 2008b; Omansky, 2006; Rodas et al., 2012). The societal conception of blindness perceives it as a problem of knowledge (that seeing is knowing) and a social impairment (Michalko, 1998). The metanarratives of blindness are perpetuations of ocular-normativism, and these associate blindness with an irrational lack of understanding (Bolt, 2013). These cultural representations of otherness create social distance and marginalisation. Blindness is ontologically and epistemologically disvalued and seen as a personal tragedy, a (hopefully) curable individual pathological condition. From this perspective, a common response to sight loss is a reduction in mental health and social connectedness (Whitburn & Michalko, 2019). Societal organisations conceive of visually impaired persons that professional support is a taken-for-granted necessity (Michalko, 1998).

Everyone keys themselves to these meanings that become tropes and continue to resonate in living together, implying that visually impaired people continue to inhabit the fringes of society (Whitburn & Michalko, 2019; Worth, 2013). Problematically, blind persons often find themselves defined by those figurative/implicit usages of fantasies that bear no intrinsic relation to visual impairment (Bolt, 2013; Omansky, 2006). Dismantling these implicit assumptions requires different perceptions of support and carefulness. Experiences of blindness involve more than the diagnosed condition and the consequences of societal factors (Omansky, 2006). Visual impairment is not solely blindness or partial sightedness; multiple (non-)human agencies are involved in the life story. Examining how we interact through the presence of blindness shows the complexities of blind experiences. Michalko (1998) approaches blindness as an essential part of being, in which personhood and the condition are integrated; as something that can be lived with and that belongs in, and to, the world.

Blindness is considered as a relational social actor that moves in the world and lives in the midst of others. It has consequences for those affected and repercussions on living together in context (Michalko, 1998). Its embodied positionality emphasises interdependent relationships between people with vision impairment and others, technology, animals, and other non-human entities (Whitburn & Michalko, 2019). Blindness can be understood as a complex and contextual thing. Such relational thinking engages with the experiences of daily living, which are composed of intra-actions of matters and meanings. There are intense encounters wherein entities emerge and affect each other. The multiplicity of indebtments, affective coherence, and emergent bonding plays a role in all of these intra-actions (Davies, 2021). Blindness (in)directly influences all intra-actions and situations in daily life, in turn affecting the individual's participation in society and how they find meaning for themself and their networks. Examples of 'what it means to be blind and how to live with that condition' need to come from the 'real lives' of visually impaired persons and those who are intimately connected with them (Bolt, 2013; Michalko, 1998). They have their particular story of blindness to tell, and listening to experiential knowledge is important to critically examine and rethink the existing metanarratives.

Methodology

This qualitative study reconceptualised blindness by exploring and unravelling the entangled shared experiences in the context of James and multiple members of his social network (Iezzoni & Freedman, 2008; Salminen & Karhula, 2014). James is in his twenties, has followed regular education in both primary and secondary school, and recently graduated from higher education. He is currently working and living independently in Flanders. His mother and father also took part in this study. They are a cohabiting middle-class couple; their first language is Dutch. They had an involved family (maternal grandparents) and professional help (home counselling, occupational therapists, class support) in James' upbringing. His younger sister, a friend from secondary school, and a partially-sighted friend were also selected by James and shared their experiences.

The study was conducted from an insider perspective. The first author conducted four interviews with James and one interview with the other five participants. They are all closely related to the blindness of James, and the first author respected the particular stories. All interviews were semi-structured in-depth interviews (Baarda et al., 2013) and focused on each participant's feelings, thoughts, and meanings of living (in)directly with blindness. By interacting individually with each participant, everyone could focus on their personal situations and emphasises, which enriched the ethnographic sensitivity and variation in narratives. Retrospective accounts of their experiences (—1990-today) were obtained to illustrate their nature of life and to understand the variable, entangled, and contextually specific relations. All participants consented to the interviews being recorded and transcribed. The interviews each took —2 h and were conducted between January 2021 and May 2021. All interviews were conducted online via Microsoft Teams or Zoom.

The open-ended nature of the interviews and the depth of the questions provided information-rich data suitable for qualitative research aimed at understanding how living with a visual impairment works. Based on the ethics of Deleuze (1994), we circled with James and his networks around: 'What is it to be this? What makes the just-thisness of you, in this moment?' (Davies, 2021, p. 19). An individual's daily life experiences are the basis for the wider meaning of being human. The study focused on the interplays between James, who is blind, his familiar environments, and the sighted society in which he lives. The non-human and material context, such as the Belgian schooling policy that favours segregated, highly specialist blind education (Worth, 2013) and cane use, which is a usual trapping of blindness, was also essentially included. Thus, the participant's illustrative narratives were collected and mapped to reveal (shared) perspectives and experiences that might have otherwise remained hidden (Goodley et al., 2008a). The aim was to bring meaning to multi-layered experiences by narrating a relational biography. Two main encounters were identified in the data: decisions and processes on (inclusive) education and connecting with others.

Ethical approval for this study was obtained from the research ethics committee of Ghent University's Faculty of Psychology and Educational Sciences. This study adhered to a longer process of ongoing consent in the form of relational ethics with the participants (Goodley et al., 2008a). The research design required mutuality and reciprocity (Goodley et al., 2008b) because of the involvement of multiple participants who knew each other. Being adaptable to the complex lives of the participants, the first author spent time developing rapport with the participants and discussing privacy in relation to the study and its findings. Participants were not allowed to read the complete transcripts of the others. The quotes from each participant were checked and verified by the corresponding participant during the analysis. Moreover, the first author, who is visually impaired herself and not separate or separable from the issue (Davies, 2021), has a sustainable and longitudinal relationship with James; they have known each other since their teenage years. James and the first author of this study know each other's life histories, and this insider perspective facilitated the research. The elements of commonality between James and the first author included: they both live with a visual impairment; they have similar socio-economic classes and are similar ages; and their differences included their genders and the nature of their visual impairments (stable since birth or progressive). The first author had previously met James' mother, younger sister, and partially-sighted friend. All these existing bonds facilitated the collection of rich and in-depth data.

Results

This section focuses on how James experiences himself, how he is understood by others (family, friends, caregivers), and how he is positioned in various systems in life (upbringing, education, leisure). James acknowledged productive alliances and close family bonds with his mother, father, younger sister, and grandparents:

> *Ultimately, it is largely thanks to them that I am [where/who] I currently am. I think that they were the great stimulators, and the older you get, the more you stimulate yourself by seeing people around you doing things too. (James)*

James has two friends from secondary school as well as visually impaired friends and allies from various organisations. During his schooling in regular education, James received assistance from home counsellors, occupational therapists, and class support workers. His current life story largely paralleled his education. Below, we focus on continuums and conjunctions of effects and micro-perceptions of James' changing networks.

We unravelled his life and how his impairment intra-acts with his different networks to understand how blindness affects his lived experiences. In the interviews with James and his networks, many participants highlighted how James can do things; that he is able to do things. This is particularly evident in his education, including his higher education degree. Moreover, James' employment was incredibly important in showing what he could do. The participants particularly highlighted how they worked together to ensure that James could do, or try to do, all activities that sighted people take part in and even go above and beyond what sighted people normally do. For example, having a lot of friends is considered the norm, and they want to go higher with even more friends, though this remains a struggle and work in progress. Further, the participants talked a lot about how he can be a part of a group, how he can be involved, what support he needs, and how they invested a lot in these situations. Thus, what happens when we use (educational and social) participation as an entry for understanding blindness and not the impairment as an entry?

Decisions and processes on (inclusive) education

James' networks committed to ensuring that James received regular, high-quality education that was relevant to his future:

> *I realise, more than ever, if that choice had not been taken that I would not be where I am now. Or if I did it anyway, it would have been with many more stumbling blocks. (James)*

Different people were involved, and the various perspectives were balanced in choosing regular education for primary and secondary school. The societal prognosis for blind children was to go to segregated special education, focusing a lot on rehabilitation and self-sustainability. Experiencing this culturally violent act of division triggered resistance in his family. James' networks perceived that special education would be disadvantageous for maximising his intellectual development. His family was convinced that segregation at a young age would deviate him from society in later life. It would give him fewer opportunities to develop his intellectual capacities, and his parents believed that the school's curriculum was too functional and not challenging:

> *It was also our wish to let James go to regular education as much as possible. We had been to [an institution] a few times and we also saw the classes and we were afraid of the basal skills classes[1] (...). We thought 'maybe he will fall behind a bit after all' and we didn't want that. That is why we have decided, both of us, for regular education. (Father)*

Even years later, the family talked about their visit to the special school. James' grandfather, a person with whom James and his parents were very connected, expressed his belief in James and his growing potential. His grandfather played a massive role in choosing regular education. The family still remembers this moment of kindness: it is considered a pivotal moment in their lives. Taking his family's inspiration for his future seriously was important for James.

> *Apparently, my grandfather once went with my mom or dad to [an institution] to look at those classes and the education, and my grandfather must have told my mom that that was not going to be for me. (James)*

James' family noticed his giftedness, potential, and eagerness to learn, which strengthened their arguments for regular education. In addition, his family members and caregivers recognised his intellect, which further supported their decision to select regular education. They followed the interests and abilities of James in favour of the trope 'not seeing is not knowing':

> *James was quite gifted; we had already seen that he was quite gifted, that he learned quickly. (...). It was also the home counsellor who urged us to do that, regular education, who had also seen how James evolved, in his playing, his demeanour and everything. (Father)*
>
> *I think my grandma and grandpa played a role in that as well (...). My grandfather said 'yes, I knew then that you were going to take it further than just [the institution. (James)*

These beliefs were powerful forces bringing the networks together. Everyone collectively transformed (in previously unpredictable ways). The (grand)parents and home counsellor, occupational therapist, and class counsellor prepared stable schooling in regular education for James:

> *That also took place in consultation with [home counselling], who helped to find a school in the area that was receptive to accepting James in their school and also framed the problems surrounding blindness in such a way that the teachers could imagine what the disability entailed. We would also have liked if James started in a school that he could continue in, unless it really wouldn't work and James would not be able to. It was not the intention that he should change schools every year. (Mother)*

Being receptive to accepting a blind student is inclusive in the face of uncertainty. This acceptance depends on the goodwill of the school, and James' networks were seeking a stable school environment for him. They felt cornered as if the burden of responsibility was on them. Everyone was intent on proving James' capacities and intelligence, in contrast to the traditional stereotype of 'the incompetent blind'. In secondary school, the family preferred a broad education that was theoretical, would prepare James for higher education, and was accessible for someone labelled as visually impaired: ‘think that somehow that is a choice that was effectively influenced, because a theoretical education simply requires fewer adjustments' (James).

To succeed in regular education, both James and his networks had high expectations of his environment and himself. The perception was that this educational pathway would provide independent living and opportunities to transcend his impairment. They supported a neoliberal pressure to succeed—the trope of living a life worth living—is working towards an autonomous adult. James' parents invested in personal support and time to teach him braille, help him study, and convert courses into accessible documents. Significant efforts, support, and reasonable accommodations were requested. His mother and father acted as professional and advocating parents. The school and [class counsellors] coached James to meet his full potential and prove his abilities. Attention was paid to sightedness, with the goal being to exceed the ability of a non-visually impaired person:

> *They expect me to do a lot of what sighted people do, they really want me to be able to be independent later and to be self-reliant somewhere. That was one thing, that I had to learn how to cut meat at home, how to make sandwiches, that was to the point of boredom, of my complaining and whining about it, that it was difficult, that it didn't work and that it had to be done. I think they are convinced that this is not a problem, and they really want me to go to work later, that's always been the thing that I'm going to work later and go to college. I think they are very progressive in that and that will probably have partly formed the basis for their choice of regular education. (James)*

After finishing secondary school, continuing on to higher education was a logical step to increase James' opportunities in later life. Since starting higher education, James liked to do things alone. His drive and educational focus were on qualifications, learning skills, growing intellectually, and becoming independent. This motivated James to accomplish mainstream higher education. The desire to succeed in life, to be a full-fledged employee, and to live alone are lofty goals to achieve, but they would also enable him to claim his independence. Achieving these goals would also prevent James from living in environments of care and being lost when his parents were no longer able to support their children:

> *I am proud of everything, because James was a very easy child, for us at home anyway, and what we asked, he always tried and it always went well, with the necessary effort but (...) he accomplished his goal, yes. It was important to us, we have always said that, that he should be independent as much as possible because one day we will no longer be there and then he can no longer count on us. That was the preparation for us, that he can be independent, that has been our biggest goal: that he can say 'Look, I don't need you anymore' (...) and that is also my greatest pride: that he says, 'I am going to work', that he can do like everyone else (...) that he has*

> *accomplished something, that he says: 'I now take care of my own, I should not depend on an institution that takes care of me, I can do it myself'. (Father)*
>
> *The help we have been able to provide to James; then if you look back at the times I have been sitting next to him, interrogated and repeated; but in the end, it paid off and we are proud of that. (...) I think we have succeeded in that. We have given them [the children] the possibilities and the opportunities that they wanted or had to have, and if they took advantage of them, this was their contribution. (Mother)*

However, this educational aspect of James' life story flowed against the limits. The emphasis on independence was very strong. This pathway also included disadvantages or unexplored processes due to additional layers that are disability specific:

> *For instance, in secondary school, I always had to work very hard to stay in [education] and to have decent grades. I'm not going to say it was too heavy, but it was close (...) in regular education. I got ADL [activities of daily living] and mobility together; I got two hours a month and with that, I had to learn to walk, take the bus, take the train, make sandwiches, actually a lot of things, and I always have that. Later, when I went to college, I experienced that as a shortcoming because such a process starts much later. (James)*

Inclusive (or integrated) education in Flanders involves the provision of a special educator with expertise on visual impairment in the regular class time for 4h a week. The aim is that the pupil assumes the standardised requirements and achieves the same targets as his non-disabled peers. Additional support—for instance, the provision of home counselling or occupational therapists, extra parental efforts, and time for learning skills, such as cane use, taking public transport, using screen reader software, or making lunch—needs to be planned outside of school hours. As a consequence of James' mainstream schooling, these additional efforts and supports that are disability specific needed to be planned outside of schooling hours. There was a contrast between a fixation on intellectual learning and wider development that put pressure on his personal time.

Connecting with others

Due to his educational pursuits, little room was left for leisure, relaxation, and meeting peers. Such relational (in)access can result in limited social interactions, romantic relationships, and acceptance by others. The exclusion of blind students can stigmatise and hinder the student's socialisation, affecting the social participation and building of friendships. For James, free time was mostly spent alone, reading books, or within the family. Although he was convinced that his thinking was ahead of his non-visually impaired peers, due to his previously experienced challenges, he had missed some developmental chances to bond with his class members.

A running thread within James' narrative was a social struggle to connect with peers. The desire to feel like he belonged was mismatched with his peers' perceived attitudes. To feel included and accepted, James emphasised the need to have relationships and be connected to and with people. He experienced difficulties. He was not able to run around in the playground like his peers. During school breaks, he often came back home so 'he was left to his own devices as little as possible' (Mother). James felt dependent on peers who seemed unaccepting of him; he felt like he was left behind and that they did not involve him: 'Some people think "he cannot do anything, he cannot do this, or he cannot do that, so I am not going to worry about it"' (Friend). He felt lonely during the end of primary school and the beginning of secondary school. He found less connection with pupils who wanted to appear popular or avoid him: 'Some people think, "he is limited, I do not want to hang out with him"' (Friend). The unwillingness of others to look past his blindness was difficult to overcome.

This context affected how James could show himself. James and his networks explored how he felt, according to their perceptions, on the edge of social life with his sighted peers. James' family members and friends were concerned for his well-being and reworked their own conceptions of blindness:

> *Since birth, his life path, if we had to go back in time, I would probably follow the same life path, only the social event remains stiff and could we change that? Yes, I would change that, but I do not know how to do it. That is not an input from yourself, but people must be open to it and that is still lacking in our society. (Father)*

In their opinions, James had been made to feel asocial by societal attitudes. James is a social person, but he has only a small number of friends. The attitudes and behaviours of others led to this. Others have imposed their reality (or image of blind people) on him by saying that he will never be able to have friendships because of his visual impairment. James and his networks experienced the tacit beliefs of others who were exaggerating his needs or assuming he also had an intellectual impairment. Thus, James was reduced to his difference, his blindness, which others associate with problems and challenges. The ocularcentric idea is that visually impaired people do not offer any value. Responding to the trope that being blind means the person is socially impaired or does not belong, James' networks discussed the societal assumptions that blind people are stupid:

> *I think it is still a social problem that people are looked at (...) from the moment you are limited, they also think 'oh, that is not going to be such a smart one' (...) that people are really surprised that someone with a disability is not always stupid. And I think that in many things, that is also a bit of the fear of young people, to think of 'he may be retarded or that he is this or that and that is why society is not ready to include people with disabilities. (Mother)*

James' mother discussed people's unjust mindsets that result in the evasive or underestimating responses of others. She highlighted that he is an able human. Through the language of 'not being stupid: she emphasised the ability of her child. In an ableist culture, this strategy might make sense to force participation or convince others of his place in social interactions. It reframes the ocularcentric idea by focusing on his unexpected or unrecognised value, intellect, or independence, which in turn strengthens ableist views on what a human needs to be and needs to do:

> *All people who know James just say, 'Wow, he is super independent: and he can do a lot more than they think. It is not that you are particularly concerned about that or*

> *anything, it is just taking him by the arm and that is basically it. But people think, I think, that it takes a lot more; out of little unknowing, I guess. (Sister)*

While James can do everything to demonstrate that he is a competent and independent member of society, being authentically recognised is something different. Succeeding in regular education and progressing to higher education still does not result in equal human treatment. James' networks argued that this demonstrates the everyday reality of what it means to be blind. They asserted that people do not first seek recognition of personhood; that disability marks the outermost limits of human existence:

> *Some people stare blindly at that, nice pun, at the disability, but then sometimes don't look further at the person themselves to really get to know that person. (Friend)*

Even later in the student dorm, his peers did not invite him to activities, such as going to the cinema and dinner, and they did not invite him to parties:

> *Sure, I would think it irresponsible to drink yourself completely drunk if you know that the other person is counting on you to bring them home. But then again, I don't think it's necessary to have less fun because of that. And in that respect, sometimes I think you have more trouble bringing the drunk students back home than taking my brother back home. (Sister)*

James' networks were aware of and responded to a dominant medical and preventive thinking, but if we look further into these situations of James not being invited or being brought home early, it could be re-interpreted as his peers taking care of him. James was searching for friendships, to be treated the same, and experienced this exclusion. Being prevented from participation could fuel his fear of loneliness. His peers, who were not interviewed, might have been attempting to protect him from dangerous situations, worrying they could not take care of him appropriately. This non-visually impaired peer group had negative effects on James. His limited number of friends was perceived as inferior. This was a confrontation with being different, which caused feelings of failure. Not all interactions with peers or groups were as challenging. In secondary school, James was paired with another pupil; they became friends, whereby talking about teachers was common. At university, it felt natural to join parties and do activities together:

> *Then you realise that these are people who do not make a problem of that and that it also comes more from them than me, constantly having to force myself into the role of begging to ensure that I get a little attention. (James)*

While the wider community might have been exclusionary, James called upon himself to create new connections within which he could valuably participate. He also developed a solid and large network of visually impaired friends and allies with whom he had (and continues to have) profound contact. He recognises that he is comfortable in social contexts when blindness is on the table. These peers connect with each other because they share similar experiences with blindness. James feels comfortable sharing things with his friends who are visually impaired; this is recognised as a characteristic of having friends (because you share things). He was able to share things about blindness, one's experiences in the world, or battles with ableism and belonging, and show how you can promote inclusion and change normative views at that moment in that context. James' visually impaired peers understood the troubles he faced in situations, such as school, the question overload from strangers, and the 'unsympathetic' manner of his peers, and this promoted a sense of belonging:

> *They are mainly people who are blind or partially-sighted themselves, by which you very often have overlapping interests and experiences. And those are experiences that you cannot share with people who are well-sighted (...). I personally think that is a much deeper contact because I sometimes have the feeling that you can go to them with more specific things that you are stuck on. They are also people of whom you have to say much less 'I have to do it like this, or that is how it works for me' (...). Sometimes it is just nice to hear that people have the same experiences and that you can even exchange experiences. (James)*

Discussion and conclusion

This research conceptualised the contextual complexities of lived experiences with blindness over a longer life period from internal and multiple perspectives to understand the meaning of blindness in and through the lens of interdependency (Michalko, 1998; Tregaskis & Goodley, 2005; Whitburn & Michalko, 2019). Listening to experiential knowledge is important to critically examine, explore, question, decompose, and rethink the existing metanarratives of blindness (Bolt, 2013; McRuer, 2014; Michalko, 1998). The blindness of James was unravelled from the perspectives of his different networks to identify how it transformed throughout his lifespan. In valuing their trajectories, James, his parents, his sister, and two friends identified moments and situations with strengths and difficulties, whereby two primary encounters were explored in James and his networks' lived experiences. How James, his family, and friends live in the midst of these tensions are discussed to gain a more in-depth understanding of blindness. They experientially and relationally narrated blindness and perceive it as a condition that still enables abilities and interests (Bolt, 2013).

In regular society, the dominant notion of normalcy is a phantasmatic idealisation that results in the marginalisation of disability (Bolt, 2013; McRuer, 2014). The normative state of being 'free from (physical) disability' and capable of participating in the workforce is considered the desired state, and this demands imitation and approximation (McLaughlin & Goodley, 2008a). This able-bodiedness pressure is impossible and incomprehensible: 'No matter how much education or rehabilitation they receive, blind people can never catch up; they can never truly achieve the ocularcentric goal of normalization' (Omansky, 2006, p. 51). Although James and his networks are attempting to shift this perspective, with James being a whole and capable person who participates in his social network, the experienced pressures are unsustainable. There is a mismatch in goals and desires in terms of educational and social development. Pressures to 'pass', to have a space to belong in social spheres, and to function within the desires and norms of connectivity were discussed. James and his family and friends described dealing with (dis) ablism, heart-breaking exclusion, and humiliation despite their great efforts to belong. He achieved education success, but this was normatively incomplete. His potential was dismissed by society. James and his networks did everything to conform to the norms, but it was not always enough. Such disparaging or ignoring of a person's distinctive characteristics (misrecognition) is an unjust form of discrimination. This includes denying the creative capacities of those with differences (Penketh, 2016). James and his networks did everything to conform to ableist norms: they were aware of societal standards, they believed in educational qualification as the dominant good (Biesta, 2015), and they desired a large group of friends, but they also suffered from excessive expectations. Consequently, James and his networks enabled themselves and responded, via multiple creative capacities, to play with the norms, strengthen themselves, and transcend the traditional nature of impairment by going their own way. They explored alternatives, solutions, and flexibility. They gave an impression of heroic progress wherein James overcame his disability (McLaughlin & Goodley, 2008a; Michalko, 1998). They sought to develop new ways of doing outside existing scripts (McLaughlin & Goodley, 2008b) through creativity.

An individualised, exclusionary, and oppressive, collective representation of disability implies that visual impairment is commonly conceptualised as a problem of knowledge or a social impairment (Bolt, 2013; Michalko, 1998; Whitburn & Michalko, 2019). The intra-actions between the blind person and his different contexts are active participants and co-draft pathways; they support, value, and help progress the blind person's life. Together, they customise living with the impairment to the person, themselves, and their lived realities. They do everything they can to help, to promote growth, to love, to connect. They also see the consequences of decisions or unexplored chances. They feel similar pain in the disabled person's barriers or sorrow. Their position influences their philosophical conceptions and political responses by virtue of their personal experiences (Goodley & Runswick-Cole, 2014). All James' family and friends reported making additional efforts to consider him and support him, and that shows a lot more complexity than the static and simplistic conceptualisations of blindness in its tragic, medical meaning of blindness. Disentangling simultaneous ambiguities in being exclusionary (regulative/avoiding) and inclusionary (enabling/accepting), everyone and everything in life are interwoven, and thus, James had to fit in with normative orientations (Bolt, 2013; McLaughlin & Goodley, 2008b). The activities of James, his (grand)parents, younger sister, and friends challenge categorisations; they think differently about disability by living together (McLaughlin & Goodley, 2008a). James and his social network are all involved in ongoing negotiations or interwoven practices regarding the scope and form of James' societal participation. James' network referred to how outsiders wrongly underestimate him based on their ocularcentric misconceptions. James goes to great effort to participate, which is underestimated or unrecognised. Wider normative orientations and (experienced) exclusionary events flow into the constitution of broader responsive, inclusionary networks (Goodley & McLaughlin, 2008). Naturalised conceptualisations of visual impairment are mobilised by embedding people and their decisions and connecting with others in their constitutions.

While thinking about blindness, in theory, and through the living narratives of James and his networks, it is highly relevant to base ourselves on entangling relationalities. In exploring the multiple layers of lived experiences, 'assemblage' can be a helpful concept to understand. It helps to grasp the multiplicity, complexity, and contingency of blindness, emerging as a relational social actor (Michalko, 1998). We revealed, interpreted, and represented multiple meanings of blindness, experienced in a relational way, and how those can be (re)composed and (re)stabilised in the context of various situations, actors, and materials. We became aware of being more attentive to material connections. Attempting to understand who, where, and what matters, as well as how they matter, we approached blindness as assemblages, intra-active gathering of elements that compose complexity. Looking at the world in this way enables us to see continuous entangling movements. Based on the idea that we, and blindness, are each part of an assemblage—of assembling intra-actions (Whitburn & Michalko, 2019)—we rethought blindness in terms of entangled relationalities. We unravelled the complex, embodied, contextual understanding of blindness (Corcoran et al., 2019; Michalko, 1998), including considerations of the culture in which it exists (Bozalek et al., 2022).

The lived experiences of James, his family, and friends gained a more in-depth contextual understanding of visual impairment. This research decentred individualist conceptions of blindness and directed attention to its contextual complexity via inductive and iterative situationally reading the lived experiences with blindness (Baker & McGuirk, 2017). Complexities of blind experiences appeared in how we intra-act through the presence of blindness and how blindness is positioned in entangled relationalities. These are dependent on a variety of intersectional differences, such as sex, age, or culture, and are variable to fluid conditions of embodiment, ambient circumstances, and social conceptions (Whitburn & Michalko, 2019). Consequently, contextually conceptualising visual impairment requires more narrations of how blindness is lived (Michalko, 1998; Titchkosky et al., 2022). What if the person, their context, and their trajectory differ? We assume the narrative could be different. Thus, future studies of individuals and samples in different contexts would be of significant value.

Note:

1. For visually impaired pupils, there are only two (segregated) special education schools in Flanders, and these are automatically boarding schools because of their location. Basal skills classes focus on basic skills needed in everyday life; for example, tying shoelaces, getting dressed, setting a table. This does not necessarily prepare pupils for higher education, paid employment, societal participation and living alone. The historical conception of children with diagnoses such as blindness is they are better serviced in these schools; they can only function in segregated circuits characterised by care. Blindness is then seen as a disability, which assumes that visually impaired people can only learn basic life skills in exclusionary educational institutions ('specialised schools for the blind') and employment is impossible or unnecessary. This is an unusual and highly consequential choice.

Acknowledgments

The authors' sincerest gratitude goes to James and the members of his networks for giving voice to their lived experiences. The content of this article was discussed at the online International Conference on Disability Studies (2022), with an awarded 10-min presentation. This study forms part of the doctorate of the first author.

References

Baarda, D. B., De Goede, M. P. M., and Teunissen, J. (2013). *Basisboek kwalitatief onderzoek. Praktische handleiding voor het opzetten en uitvoeren van kwalitatief onderzoek*. Groningen: Noordhoff Uitgevers B.V.

Baker, T., and McGuirk, P. (2017). Assemblage Thinking as Methodology: Commitments and Practices for Critical Policy Research! *Territory, Politics, Governance*, 5(4): 425-442. https://doi.org/10.1080/21622671.2016.1231631.

Barad, K. (2007). *Meeting the universe halfway: Quantum physics and the entanglement of matter and meaning*. Durham, NC: Duke University Press.

Biesta, G. J. J. (2015). Mijn idee voor onderwijs #2 Gert biesta - Onderwijspedagoog. https:// www.youtube.com/watch?v=QMqFcVoXnTI.

Bolt, D. (2013). *The Metanarrative of Blindness: A Re-Reading of Twentieth-Century Anglophone Writing*. US: University of Michigan Press. https://doi.org/10.3998/mpub.5725818

Bozalek, V., Kirby, C., Romano, G., and Romano, N. (2022). Doing Higher Education Differently—In Conversation with Neuroatypicality—Session 6—Tanya Titchkosky. https://www.youtube. com/watch?v=07l5wA7GmMl.

Corcoran, T., Claiborne, L., and Whitburn, B. (2019). Paradoxes in Inclusive Education: A Necessary Condition of Relationality? *International Journal of Inclusive Education*, 23(10): 1003-1016. https://doi.org/10.1080/13603116.2019.1625453.

Davies, B. (2021). *Entanglement in the World's Becoming and the Doing of New Materialist Inquiry*. New York: Routledge.

De Schauwer, E., Van de Putte, I., Blockmans, I. G., and Davies, B. (2018). The Intra-Active Production of Normativity and Difference! *Gender and Education*, 30(5): 607-622. https://doi.org/10.1080/09540253.2016.1259463.

Deleuze, G. (1994). Difference and repetition. Columbia University Press.

Goodley, D., and McLaughlin, J. (2008). Chapter 6: Community Practices! In *Families Raising Disabled Children Enabling Care and Social Justice*, edited by J. McLaughlin, D. Goodley, E. Clavering, and P. Fisher, 105-134. United Kingdom: Palgrave Macmillan.

Goodley, D., and Runswick-Cole, K. (2014). Becoming Dishuman: Thinking about the Human through Dis/Ability. *Discourse: Studies in the Cultural Politics of Education*, 37(1): 1-15. https://doi.org/10.1080/01596306.2014.930021.

Goodley, D., McLaughlin, J., Clavering, E., and Fisher, P. (2008a). Chapter 2: Methodology! In *Families Raising Disabled Children Enabling Care and Social Justice*, edited by J. McLaughlin, D. Goodley, E. Clavering, and P. Fisher, 21-35. United Kingdom: Palgrave Macmillan.

Goodley, D., McLaughlin, J., Clavering, E., and Fisher, P. (2008b). Chapter 3: Research Encounters! In *Families Raising Disabled Children Enabling Care and Social Justice*, edited by J. McLaughlin, D. Goodley, E. Clavering, and P. Fisher, 36-52. United Kingdom: Palgrave Macmillan.

Hammer, G. (2019). Blindness through the Looking Glass: The Performance of Blindness, Gender, and the Sensory Body. United States of America: University of Michigan Press. https://doi. org/10.3998/mpub.9271356.

Iezzoni, L. I., and Freedman, V. A. (2008). Turning the Disability Tide: The Importance of Definitions! *JAMA,* 299(3): 332-334. https://doi.org/10.1001/jama.299.3.332.

Maclure, M. (2021). Post Philosophies and the Doing of Inquiry—Session 14—Maggie MacLure. https://www.youtube.com/watch?v—qvi-3UKso8.

McLaughlin, J., and Goodley, D. (2008a). Chapter 4: Unmaking Children? In *Families Raising Disabled Children Enabling Care and Social Justice*, edited by J. McLaughlin, D. Goodley, E. Clavering, and P. Fisher, 53-77. United Kingdom: Palgrave Macmillan.

McLaughlin, J., and Goodley, D. (2008b). Chapter 9: Values of Enabling Care and Social Justice! In *Families Raising Disabled Children Enabling Care and Social Justice*, edited by J. McLaughlin, D. Goodley, E. Clavering, and R Fisher, 183-198. United Kingdom: Palgrave Macmillan.

McRuer, R. (2014). Chapter 27: Compulsory Able-Bodiedness and Queer/Disabled Existence? In *The Disability Studies Reader*, edited by L. J. Davis, 369-381. 4th ed. New York: Routledge. Michalko, R. 1998. The Mystery of the Eye and the Shadow of Blindness. Canada: University of Toronto Press.

Omansky, B. (2006). Not Blind Enough: Living in the Borderland Called Legal Blindness! PhD thesis, School of Social Work & Applied Human Sciences, the University of Queensland.

Penketh, C. (2016). Epilogue: The Space of Avoidance? In *Disability Avoidance and the Academy: Challenging Resistance*, edited by D. Bolt and C. Penketh, 188-191. New York: Routledge.

Rodas, J. M., Donaldson, E. J., and Bolt, D. (2012). Introduction: The Madwoman and the Blindman? In *The Madwoman and the Blindman. Jane Eyre, Discourse, Disability*, edited by D. Bolt, J. M. Rodas, and E. J. Donaldson, 1-11. United States of America: Ohio State University.

Salminen, A., and Karhula, M. E. (2014). Young Persons with Visual Impairment: Challenges of Participation! *Scandinavian Journal of Occupational Therapy,* 21(4): 267-276. https:// doi.org/10.3109/11038128.2014.899622.

Titchkosky, T. (2011). *The Question of Access: Disability, Space, Meaning.* Canada: University of Toronto Press.

Titchkosky, T., Cagulada, E., and DeWelles, M. (2022). *Disappearing: Encounters in Disability Studies.* Canada: Canadian Scholars.

Tregaskis, C., and Goodley, D. (2005). Disability Research by Disabled and Non-Disabled People: Towards a Relational Methodology of Research Production. *International Journal of Social Research Methodology*, 8(5): 363-374. https://doi.org/10.1080/13645570500402439.

Van de Putte, I., De Schauwer, E., Van Hove, G., and Davies, B. (2017). Rethinking Agency as an Assemblage from Change Management to Collaborative Work. *International Journal of Inclusive Education*, 22(8): 885-901. https://doi.org/10.108 0/13603116.2017.1412514.

Vandenbussche, H., and De Schauwer, E. (2017). The Pursuit of Belonging in Inclusive Education: Insider Perspectives on the Meshwork of Participation. *International Journal of Inclusive Education,* 22(9): 969-982. https://doi.org/10.1080/13603116.2017.1413686.

Vandenbussche, H., De Schauwer, E., and Van Hove, G. (2019). Diffractive Lenses Catching Stories: The Meaning of Belonging through the Voice of Adolescents. In *Participatory Methodologies to Elevate Children's Voice and Agency*, edited by I. Berson, M. Berson, and C. Gray, 275-294. United States of America: Information Age.

Whitburn, B., and Michalko, R. (2019). Blindness/Sightedness: Disability Studies and the Defiance of di-Vision! In *The Routledge Handbook of Disability Studies*, edited by N. Watson and S. Vehmaas, 219-233. New York: Routledge.

Worth, N. (2013). Making Friends and Fitting in: A Social-Relational Understanding of Disability at School! *Social & Cultural Geography*, 14(1): 103-123. https://doi.org/10.1080/ 14649365.2012.735693.

Chapter 4: A counter-narrative: the world according to the white cane

INTRODUCTION
THEORETICAL UNDERSTANDING OF THE WHITE CANE
METHODOLOGY
THE WHITE CANE' COUNTER-NARRATIVE: 'WE HAVE A COMPLICATED RELATIONSHIP'
DISCUSSION
CONCLUSION
REFERENCES

Based on: Van Havermaet, J., Daelman, S., Van Hove, G., & De Schauwer, E. (2025). A counter-narrative: the world according to the white cane. *Scandinavian Journal of Disability Research,* 27(1), 162-172. http://doi.org/10.16993/sjdr.1222

Abstract

Visual impairment often becomes noticeable to others through the visibility of a white cane. This public sign of blindness is an imperative signal that people understand, interpret and act in accordance with; however, the white cane is more than an external iconic aid. This study describes, explains and reflects on movement, assemblages, relationality, companionship, interconnectedness and learning opportunities that resonated across multiple white cane users' experiences. Biographical pieces of two visually impaired people and their close networks, literature based on authors' lived experiences and testimonies of the first author who is also visually impaired are brought together into a coherent narrative, where the white cane is the protagonist. This narrative deconstructs the omnipresent metanarrative 'all blind people always use a white cane' into a complete evocation that acknowledges the complexity of daily living that materiality and blindness entail. We use the white cane to rethink blindness and open a multisensory and multidimensional understanding.

Keywords: white cane, blindness, counter-narrative, narrative inquiry

Introduction

This study explores the meanings of a white cane, following Michalko's (1998) description that 'blindness is noticeable insofar as white canes and dog guides are' (p. 138). There is a direct association between experiencing visual impairment and 'public signs of blindness' (Michalko, 1998) that makes the disability visible (Bulk et al., 2020; Crossland, 2024; Omansky, 2006). The collective and cultural representations of blindness all entail iconic aids such as the white cane, guide dogs and dark glasses. Those public signs of blindness (re)produce 'metanarratives of blindness' (Bolt, 2013)– typical and vivid reductionist images or depictions of the disability that assign stereotypes, construct attitudes and regulate discursive practices. Everyone and everything are written into the story of a sighted, ableist world; whereby the blind person is always accompanied by a white cane. For instance, sighted people picture an old image of 'the blind man (less often woman or child) travelling town streets and country roads with a staff [or] stick' (Godin, 2021, p. 145). 'Like a lot of blind people who carry canes and employ guide dogs, public signs of blindness are not always understood, and the word still needs to be spoken' (Kleege, 1999, p. 39). There is more to the story than this stock character.

The word 'blind' means something different to nearly everyone (Crossland, 2024; Michalko & Goodley, 2023). Modern ways of discussing blindness are connected to sight, defining blindness as the absence of sight. This conceptualisation of blindness confirms, maintains and prescribes that the world is sighted; it leaves few choices for blind people other than trying to 'pass' or fit in (Michalko, 1998). However, blindness can be represented in different, experiential and affirmative ways (Godin, 2021; Kleege, 2018; Kudlick, 2009; Michalko & Titchkosky, 2020; Omansky, 2006) that encompass numerous behaviour strategies to deal with 'seeing'. We support the perspective of Kleege (1999), who states: 'I announce my blindness without apology, because, I hope, that others will revise their image of blindness when they see me' (pp. 227-228). We would like to bring into focus issues around blindness by '"viewing" the world through blindness, "seeing" its creativity, learning from its "observations", and trusting its perceptions' (Healey, 2022, p. 123). We assume that multiple forms of blindness influence how those with a disability participate in life (Healey, 2022; Whitburn & Riffo-Salgado, 2024).

In this study we invited two visually impaired people and their close networks to share what it means to experience blindness in daily life. The assemblage, of their accounts, combined with literature by authors with lived experiences of blindness and the testimonies of the first author of this publication, produces a counter-narrative. The assemblage sheds light on the functionalities, relationalities and ways of becoming in the world with and without a white cane. An assemblage is a multiplicity that acts on semiotic, material and social flows (Deleuze & Guattari, 1987). Assemblages form collectives made up of human and nonhuman beings, animate and inanimate 'things' and demonstrate how an agent always acts in collaboration (Bennet, 2010 in Davies, 2021). Therefore, assemblages are always in the process of becoming through multiple encounters and become defined 'not by what they are but by what they can do or become' (Bansel & Davies, 2014, p. 41).

The assemblage in this study unravels the materiality of the white cane and the multiple strategies for being with a white cane in the world. We specifically deconstruct the metanarrative that ‘all blind people always use a white cane’ by showing the complex interplays of various intentions, perceptions and relationalities and by de-centring the human being who is blind. We insert experiential knowledge about blindness into cultural discourse, to move, displace, ‘disturb or disrupt’ (Michalko & Goodley, 2023) stereotyped ideas about the lived, embodied and social experiences of blindness. We give blindness as a lived reality a more obvious place in cultural spaces and want to expand public knowledge about blindness and its ‘appearances’ (Titchkosky et al., 2021). We intend to take seriously the ethical imperative to challenge the stability of knowable categories, such as blindness and iconic aids, as they usually emerge within metanarratives (Bolt, 2013; Whitburn & Riffo-Salgado, 2024). In doing so, we become aware that the white cane itself, known as a functional aid, must be involved as a main character in our search for an affirmative view on visual impairment.

Theoretical understanding of the white cane

Giving a basic description, the white cane is a tall, thin, white stick that sometimes folds up. On the one side, it has a golf club-like handle and on the other, a (round) tip that glides or taps the ground (Thompson, n.d.). The white cane and the technique of sweeping the cane back and forth was first introduced as a ‘blind stick' for the many disabled people during and after the World Wars (Backman, 2024). Nowadays, the identification or mobility cane is a physical object; the shorter one is a symbolic cane and the longer one is a medical tool. As a rehabilitative non-optical aid, it is widely acknowledged for its assistance in enhancing mobility and promoting independence. The white cane has reached naturalised and iconic status as a simple and straightforward tool that enables practical functionalities for who cannot completely rely on their sight (Bulk et al., 2020; Crossland, 2024; Godin, 2021; Thompson, n.d.). It is considered a substitute for the person's blind eyes–a set of non-human guiding eyes, leading the way forward, detecting hazards ahead and sensing the texture of the surface. It actively communicates useful sensory impressions to its practised user, allowing them to feel the nature of the ground and gain an understanding of their surroundings. As Kleege (2018) explains: ‘Speaking from my experience, the cane is more of an obstacle detector than a tool to map the environment. The cane’s tip proceeds me as I move through space alerting me to objects I need to step over or around. It merely announces the presence of an obstacle, without distinguishing between a rock or a tree root.’ (p. 16) This highlights how the cane enhances safe navigation by alerting the user to immediate obstacles, even though it may not provide detailed information about the environment.

The appearance of the white cane is also informative and functional for bystanders or other people occupying the space. The white cane is an obvious label of visual impairment (Backman, 2024; Bulk et al., 2020; Crossland, 2024; Healey, 2021; Hoogsteyns & van der Horst, 2016; Michalko, 1998; Omansky, 2006). The peculiarity of the white cane is a way of dressing up blindness by silently telling the world that the person is identifiable as blind. Being equipped with a white cane, and being preceded by tapping sounds, the user usually cannot move in a particularly discrete manner. They are pointed out as having difficulties, as being different. The white cane increases visibility of the disability and prevents the individual from establishing themselves as a fully sighted person. The cane also prevents anonymity and the possibility the holder could be perceived as 'anyone else'. Thus, the white cane itself is actively interacting with the surrounding world and has the ability to affect people, places, discursive practices and its user's identity. The cane can be regarded as an independent social and cultural actor that powerfully impacts and transforms reality. Although using a visible marker of blindness may enable opportunities, this sometimes comes at a high cost. It reduces the risk of confrontation by making it obvious when someone might collide with the cane user; however, it also attracts unwanted attention. For example, Allan (1999) states it was for a young woman more comfortable to act drunk to disguise disability rather than revealing blindness, when she wanted to impress a partner at a party. A rather one-dimensional figure of the blind person is evoked: the white cane represents blindness and reduces the person to their deficit, blindness, that is 'a problem in need of a solution' (Mitchell & Snyder, 2000 in Titchkosky et al., 2022, p. xxv). It relocates others' attention to the vulnerability of the user's movements. The cane motivates people to show extra consideration. For instance, in crowded environments, it is helpful that the cane alerts bystanders and activates them to offer support to the blind person (who will presumably need help). People see the cane and step aside–often without saying anything. At the same time, the cane may also provoke users to receive unkind and disqualifying comments, leaving users feeling vulnerable (or less in control).

Consequently, the white cane is–or can be–incredibly stigmatic (Backman, 2024; Bulk et al., 2020; Godin, 2021; Hoogsteyns & van der Horst, 2016; Omansky, 2006). The white cane becomes an extension of the lack that it compensates for, it becomes the visible proof of a person's 'failure'. It quickly becomes a powerful symbol of helplessness in the eyes of many sighted people and it is perceived as a way to 'cure', remediate or repair the fact that somebody cannot use their eyes in an ableist way. This stigmatising gaze may carry shame. Backman (2024) refers to the 'negative visibility of the cane' that degrades the user to another societal status. The white cane functions to signify the user as a non-able-bodied or disabled person. Thereby, the recommended aid, paradoxically, contributes to the establishment of power orders (Davies, 2021) and the reproduction of ableism, exclusion and inclusion. For many people who live with visual impairments, it is far from a comfortably integrated extension of their body; avoidance or resistance to its use is consequently reasonable. Considering such effects of the white cane, it is no wonder that this material object, more often than the absence of vision, makes the user stand out. Some cane users' reluctant attitude towards the white cane must be understood in connection with the tool's association with widespread norms of able-bodiedness.

The simple action of taking up the white cane entails more variations, nuances and layers than the initial understanding of the white cane as a straightforward external material object. In a coordinated pair, the material object and human being are in temporary coexistence (Backman, 2024; Healey, 2021; Hoogsteyns & van der Horst, 2016): the white cane and its user become interdependent, reliant on each other. The person-with-the-object affects how we could interpret co-presentations of the person and its companion species, as an inevitable part of the body. In such assemblage thinking, the person and the white cane are united like a machine for successful movement. Both are constantly connected and interact with each other. The white cane becomes an extension of the person's body, hands, touch and contact with the world, affecting the users' muscles, sensitivity and ability to discern and interpret. The body becomes an extension of the white cane, influencing its direction and movement and regulating pressure to create tapping sounds. The person, the body, the white cane, the tapping sound, the blindness, the movement and the surface become intimately entangled in an assemblage that enables movement through, participation in and becoming in the world. It is this assemblage that defines the multiplicity of disability experience. The experiential world of blindness entangles a blind person, allies, materialities, norms, … whereby 'components in the assemblage affect each other in complex, multidirectional, and unexpected ways' (Looman, 2024, p. 28). In this article, we take a creative leap of faith to provide a fresh take on the white cane and blindness.

Methodology

We are engaging in narrative inquiry. Narrative inquiries (Clandinin, 2006; Raymond et al., 2022; Rodriguez-Dorans & Jacobs, 2020) apply relational research methodologies to study people's experiences, stories, relationalities and life. Using this method, the unique unfolding of a lived life in its particularity is highlighted. By assuming that social, cultural and historical contextualisation is inherent to all knowledge, such narrative inquiries ethically attempt to entail negotiation, respect, mutuality and openness to multiple voices. We describe, reflect, interpret, explain and communicate narrated experiences to operationalise the complexity we would like to illustrate.

Related to the omnipresent metanarratives of blindness and the white cane, we compose a counter-narrative of the white cane. Metanarratives are narratives that are so widely known they are considered natural. They function to make the world comprehensive, manageable and reasonable (Lindemann, 2017, 2020; Tarrant, 2022). Metanarratives are connected to emerging normative expectations of behaviour, roles and relationships. Consequently, they become mutually reinforcing, justifying discourses on exclusion or ableism; they are seldom perceived as right or neutral. Counter-narratives intend to disturb the oppressiveness of metanarratives and replace them with accurate ones (Lindemann, 2020). Counter-narratives explore lived experiences to challenge dominant explanations and expected social behaviour associated with stereotypical profiles (Tarrant, 2022). Counter-narratives demonstrate many possible ways of being.

We interact with multiple perspectives that resonated throughout multiple participants' experiences in a Western context. The experiences of two participants (Lucie and Alice), of many of their network figures (mother and friend of Lucie and partner and colleague of Alice), and of authors of international literature as well as podcast makers (Bulk, Godin, Healey, Kleege, Kudlick, Meesters, Michalko, Omansky and Thompson) are included. We acknowledge that the first author of this publication is a vital presence in the story. She is blind; her expertise is informed by the literature, scholarship and lived experiences (Rodriguez-Dorans & Jacobs, 2020). She has woven depth and breadth of the existing literature and her own personal connection to the data of Lucie and Alice into the production of a counter-narrative. In the omnipresence of vivid metanarratives, this counter-narrative presents a more complete evocation that acknowledges and manages the complexity of the object-body-environment assemblage under investigation.

Therefor we take the white cane as the protagonist of the counter-narrative, believing the cane is an integral part of the assemblage of blindness. This involved a process of thinking, learning and experimentation to re-conceptualise our understanding (Whitburn & Riffo-Salgado, 2024) from within the skin of the material object (Kennedy, 2006; Rodriguez-Dorans & Jacobs, 2020). We become involved in knowledge construction and become witnesses to the existence of people–and objects–whose lives are largely hidden from regular society. We want to address other, more affirmative ways of thinking about blindness.

As such, we recognise the white cane as active actant that embodies ‘thing-power’. Bennett (2010; in Davies, 2021) defines thing-power as ‘the curious ability of [apparently] inanimate things to animate, to act, to produce effects dramatic and subtle’ (p. 6). Thing-power invites us to think about where our bodies, intentions, actions begin and end (Davies, 2021). It makes visible how all of us are continuously shifting in indeterminate relations and emergent assemblages wherein things are ontologically and epistemologically present. We consist in relation to and with things and that is how meaning is created (Davies, 2021). Embodying the thing-power of the white cane, we intend to make visible how patterns of blindness emerge, diffract and co-exist.

The white cane, as protagonist with thing-power, brings stories of blindness as an assemblage. It brings nuance and complexity to its own existence and the lived experiences of blindness. The white cane refers to itself with ‘I’, or ‘we’ when it’s about the togetherness with its user (‘she’). This approach of weaving academic and creative writing together invites us to imagine different ways of moving through the world, different ways of using a white cane and different ways of understanding blindness (Titchkosky et al., 2022).

The white cane’ counter-narrative: ‘We have a complicated relationship’

Initially, she denied that her vision could not be corrected with glasses or contact lenses. Although having trouble seeing things, she still has a little bit of sight. No one sees what she sees, no one knows how hard she is working to see. And no, simulation spectacles can’t let others experience what her vision is like; these spectacles would boil her entire lived experience down to things that do not work properly. She emphasises what she can see, rather than what she can't. She often sees well enough to witness passers-by staring at her when she’s on the move. Even her partner would say she is not blind, but light is blinding her. He would often say that bright contrasting lights annoy her and make moving without a cane, guide dog or human help impossible. The technical definition for her (absence of) sight, determined according to her inability to perform visual activities, is ‘legally blind with some usable sight’. She is located on the spectrum between perfect sight and total darkness and, consequently, has a complicated relationship with blindness. She struggles with her place as someone in between.

Seeing in an instantaneous and absolute way, as a whole, at a glance, demands a lot of time and concentration. She makes this effort silently and alone, as a private and intimate act. When a person would describe to her aloud what they see, it would be, essentially, a theatrical performance, almost always a shared experience whereby that person is a mediator. Her personal sight can be artistically described as ‘photorealistic painting’ rather than high-definition photographic imaging. What she sees is a product of her brain using imagination beyond visual limitations. She learned to see by relying on sight and by negotiating internally when and when not to use her sight. Even though she can see something, touching always makes things more real. It’s a matter of re-seeing or re-vision, a matter of hand-eye coordination and negotiation with the brain, where imagination, intellect and memory collaborate. Her brain connects what her eyes (don’t) see with what her hands feel and, through me, with what I touch and sense. Through touch, I am involved in this eye-brain dialogue that she navigates in an unaccustomed, unnatural way.

She doesn’t like to talk about her visual impairment to avoid drawing attention away from her actions. So, she blocked the conversation when they–some of her friends with whom she had drinks–asked her when she was going to start using me. Oh, I didn’t introduce myself, I am the white cane. Their suggestion was difficult for her, it brought the vulnerability of making her disability appear. She experienced an element of choice in being explicitly blind or to ‘pass’ as sighted. She didn’t want to be known as ‘the blind’, she felt ‘not blind enough’ to need Orientation and Mobility training. She struggled to take me into her hands as she had spent her whole life afraid of blind people. They told her that she doesn’t have to act fully sighted for life to be valuable. This comment was going against her longstanding shame about and resistance to using me. She carries me, as a nonverbal sign that she doesn’t see as much as she seems to, although she sees more than the word ‘blind’ is generally assumed to designate.

Her partially sighted friend provokes her by saying that she must use me proudly and put herself out there. When she wants to do something, she must do it with the grace of an elegant diva. It’s her choice to use me or sit at home and wait for some well-meaning sighted person to rescue her. Damn, he had a good point and she agreed that she cannot stay home; she intends to go to the office, the pharmacy and the bakery, even when there are roadworks at the moment. You know, embodying me in an assertive and trustful way can keep a blind traveller out of danger. Her colleagues and her father believe that I am useful and necessary in public spaces. They are tempted to come and get her or take her somewhere when they ‘see’ how busy, dangerous and chaotic the road is. They cannot ignore incorrectly parked cars, potholes in the road, rubbish bins and bicycles on the sidewalk and omnipresent steps. They worry about her movements and believe her survival depends on me. Their idea is that my existence ensures her independence, confidence, assertiveness and social belonging. Indeed, I try to be her bodyguard, a radar for puddles, waste or dog poo she would like to avoid, but to be honest, I might need further innovative tricks to make our appearance graceful.

Her colleague found it better for her to use me, sometimes thinking that I am more reliable than a guide dog or the support she can offer. She experienced that her guide dog or another person does not always take every aspect of her visual impairment into account. For example, the dog runs under overhanging branches of trees she gets in her face and her colleague does not notice when she painfully turned her foot. Her colleague felt guilty because she could have seen it but she was looking ahead, not at the ground. I have a functional competence, to detect obstacles; but this does not mean that I am the only way to gain orientation and mobility. I also would not notice things in the air and companionship with me compared to with humans will differ.

Her mother frequently advises her to carry her cane and hold me closely because when others notice, they can help her; they can't help if she doesn't reveal her needs (read: problem). Her mother makes her aware that I symbolise blindness, blindness as needing help and, consequently, I actively affect others' responsibility to act. Bystanders would like to care and give support when the visual impairment is prominent. Traditionally, the ultimate idea is powerlessness and the public response is well-intended paternalism. People are indeed interacting when they see me or a guide dog and ask our user if she needs help and knows where she is. Others would like to compensate for her blindness (and the related idea of helplessness); however, she chooses not to make use of this on every occasion. She gets frustrated when others take over, taking away the opportunity to be independent and learn. She feels patronised when people intrude their help rather than offering it: she will make it work; she isn't as pathetic as they think; she can do more than they think. She believes that they do not have a realistic image of how people with visual impairments live. Moreover, she recalls her colleague holding back when she saw her with a white cane. Her colleague had never known someone blind and was anxious. Her colleague decided not to intervene. So yes, sometimes I invite people to help but no, it isn't always the case. I think of my appearance as a relational act. She must know that I can enable interactions and that she can take it as an opportunity. She can carry me strategically in favour of what conversations and encounters she might fancy.

Her mother also explains that presenting me is educational, it tells the world–in case they don't know–that not all people see in the same way so people must pay attention when she's out there. To be sure, I can indeed be of help by enabling her to walk with more confidence in unfamiliar or dark environments. When I am presented, a crowd of people can be 'parted like Moses parting the Red Sea', as Crossland (2024) explained. I alert drivers and other pedestrians of the presence of blindness. This means that the person who sees me must–again–do something (i.e., go away, take a wider berth). Additionally, my owner can educate others in dealing with visually impaired people by speaking about it, explaining what she sees and what she doesn't see, or what is (not) possible for her; she can guide other people. She also wants to prove that she belongs and can do things. For example, she wants to prove that she, as a partially sighted person, can be a good professional. Her goals and desires in life are much more central than the lack of not seeing as a master lens through which to look at her and her life.

I know I am tiring. Finding her way with me takes a lot of time, energy and concentration. She cannot see the traffic lights and thus cannot tell, at least from that signal alone, whether it is safe for her to cross. She makes use of other signals to do so. Each situation is different, so she must always be alert. Walking with me fills her mind with questions: where is the threshold, where is the step, where is that rubbish bin? She is focusing on a lot of practicalities, so she doesn't easily engage in conversations. It is mostly unintentional when she doesn't say 'hello' passing in the hallway. Each trajectory and each movement we make together is challenging. We must learn our way to the office, stores, school or psychologist. You cannot simply give us the address on a small piece of paper–we will not get there. She needs a lot more details, including GPS instructions. Is there a pedestrian tunnel or crossroads? A route doesn't just end at the front door: where is the doorbell? It is highly annoying to miss the icons and enter the doctor's consultation room instead of the waiting room. It is a never-ending process. She focuses on the area of her living space and starts a life-long learning experience.

Initially, there will always be someone with me to introduce her and inform them about the techniques for holding me while manoeuvring streets or taking stairways, interpreting the sensations I give and getting to know how to inform others. This person is trained to support her, to take an active role: carrying me, presenting me, going somewhere 'alone' and receiving a response. I cannot escape the attempt to cure and compensate for blindness in many different ways, with ocular-centrism as an irrevocable standard in our society. When she is labelled 'independent', it is because of my presence. An occupational therapist, or an orientation and mobility instructor, has the expertise to educate her. She must do exercise trajectories a few times together before she can do it alone; alone with me. Therefore, she requires someone who recognises what she actually sees. Today, her partner knows from experience what he must tell her: landmarks such as a blue door, a red-coloured house, or an entrance with parking spaces. With me, she seems to know where she is going, and she really does.

Ever since she chose to use me in particular situations, she must deal with everyone's panic in the face of ambiguity. When we are somewhere together, her disability is no longer hidden. Of course, when I am there, people understand she sees differently with her eyes. The other way around, when she doesn't use me, people have no way of knowing that she sees less or differently. I am mistakenly seen as something to grab or point with, but my holder has my ownership and (little joke) they will not see when someone does this. It is tricky for a sighted person to understand that I am a supportive tool to enlarge the field of her perception but also that, sometimes, I do nothing. She is not faking blindness when she is not constantly using me. For example, we can be escorted to the airport departure gate and at the same time she can check messages on her phone. She isn't faking blindness when she walks fluently with me, without constantly bumping into edges or obstacles. In known places, I am there for unexpected situations. I am present in visually confusing situations such as bank counters, airports, hotel lobbies and department stores, where her hesitation or questions with an obvious visual answer may prompt people to impatiently snap at her.

In the early days, she saw me as an unwanted 'thing'; she found 'that' terrible and unnecessary. But finally, she calls me 'hers'. I feel appreciated when she talks about 'my cane'. We have a personal connection. We have cultivated, and are cultivating, our relationship in intimate contexts. It is often only both of us. When there are others around, I am still latently with her. She would describe us as a romantic touch, her hand and my handle make contact at a usual meeting point. Her index finger and my smooth body are in synergy with each other. Her strongly coordinating brain is a match made in heaven with my Cupid's arrow pointer that caresses the earth. We are playing a duet. Inspired by Healey (2021), I would introduce myself by saying: I, a bejewelled sparkling cane, am the source of a rhythmic jazz-like sound (a snap slide rhythm) as my holder follows me and walks scatting overtop my sound. I am the extension of my holder's body through their hand, like a conductor's baton which makes music itself and we perform a dance together. Compositions grow in the interactions between her, me and the many surfaces of the environment. Thereby, we adore the beautiful ground on which we perform as well. From her perspective, the environment is not visible, only my tip and a pixel of the ground are in her sight. I love the ground and its variation of textures that can make many smells, voices and colours sensible.

In many situations, she finds it more convenient to leave me and manoeuvre through space using something or someone else. At home or at her office, she discovers the residential area and memorises points to be careful at and recognise, moving with the touch of her hands. The coziness of these places makes me redundant, but she chooses not to use the aids! As a teenager, for example, she wore lenses instead of dark glasses. This physically limited bright light so that she could use her sight optimally but was also psychologically important to hide her impairment. She puts me in her backpack whenever she considers me 'unnecessary', as an umbrella during sunshine, because I effectively eliminate the use of one arm. Then she walks closely to her partner, holds his arm or commands the guide dog to follow him. Friends pick her up when she leaves home, without me. She relies on her mother or her sister to take her somewhere. Walking together with someone, she isn't (always) aware of her location or the presence of buses, guided lines, rubber and studded tiles. Walking with me in these places, she could better localise herself and move independently but she does not take me at all or put me away as soon as she doesn't need me.

She leaves me behind, puts me away, and would rather be without me; I could guess she is ashamed because that's not what companions do to each other. By (carelessly) sidelining me, she seems to be unaware of my added value but perhaps she has a wider repertoire of options to explore. She is used to being guided, to waiting for others to accompany her. It is as easy as intertwining arms and being gone. It is joyful to go with the flow and express confidence in someone else. It is easier to engage in conversations. Moreover, she argues that I would hinder their walking together, that she would want to feel with the cane and slow them down. She wants to be part of the group, an activity or public life.

The assistive presence of a guide dog or acquaintance can provide comfort as her attention is not needed to focus, with massive effort, ongoing with the flow. However, since she has used a guide dog, the assistance of her partner has also become redundant. Imagine–both of us hanging on the coat rack. She dares more with her dog than with me. She feels less alone with an animal than a non-human object. 'That's someone with a dog' sounds better than 'that's a blind with a stick'. She thinks that a dog is associated more with independence, although I also enable her to move on her own. When people comment, 'That's a helping dog who assists that person' or 'With that cane, that person feels where she is walking', she is happy. She smiles in the direction of the comment because the focus is turned on how she participates in the world rather than on what she is not able to do.

Most of the time, we relate positively to each other. She is really convinced of my use. She prefers others to know she is visually impaired rather than thinking something else. It is visible, it is on the table, and it is not the proverbial elephant in the room. She now wants to try everything with me first, living on the edge. After intense practice, we now do everything together and that is her freedom. She spontaneously meets friends, folds me up and it doesn’t matter when we go home. She takes trips to meet and be with other people. That is another way of interacting and connecting. She doesn't run with the group anymore and for us it's good. She experiences the mix of walking with other people, getting acquainted with a guide dog and doing the same things alone with me. Solely, my presence is not sufficient, she also needs her seeing brain and a shoulder to lean on. She is never alone, and she is always more in a togetherness, connected in respectful love with each other. The strength of interdependency is something I thankfully learned from being with her in blindness.

Discussion

Based on the counter-narrative with the white cane as the protagonist, we could state that the white cane is more than an obstacle-detecting aid, more than an extension of someone’s body or the lack that it compensates for, and more than a symbolising and stigmatising materiality to cure, compensate or rehabilitate the inability to see (Allan, 1999; Backman, 2024; Bulk et al., 2020; Crossland, 2024; Godin, 2021; Healey, 2021; Kleege, 2018; Kudlick, 2009; Michalko, 1998; Omansky, 2006; Thompson, n.d.). A white cane is a recognizable public sign of blindness, but it is not always used or not used with the same motivation. Being blind but having sight, (not) using a white cane, (not) having a guide dog, (not) wearing dark glasses or utilising them differently ‘disturbs or disrupts’ the supposedly ‘normal’ order of things (Michalko & Goodley, 2023).

Entering the thing-power of the white cane makes visible the ‘swarm of vitalities at play’ (Bennet, 2010, p. 32 in Davies, 2021) in everyday interactions with blindness. This holds the promise for people to break open normative metanarratives of blindness and start responding to the liveliness of the world where blindness belongs in. We deconstructed the metanarrative ‘all blind people always use a white cane’. Not ‘all’ people use a cane, not ‘all blind’ people, not ‘only blind’ people and not ‘always’. There are many interpretations of what blindness is, how it is experienced, and how it changes over time depending on the situation. We need to be careful of monolithic understandings of blindness–it cannot be taken for granted that we all understand the same things when we see a person with a white cane. Stated vice versa, not using a white cane does not mean that the person is not blind; for some, it is just not the way. Depending on the situation, circumstances, goals and co-creation with the material and the non-material world, other presentations of ways of moving through the world become opportune and valid. The white cane is not ‘always’ the protagonist. It is part of a repertoire and the person has a lot of alternatives for being in and navigating through the world and these can change over time.

There remains more to tell, more in the sense of Michalko (Titchkosky et al., 2021) when he said, ’Disability is always more–it provokes us to reconsider the meaning of disability. We are committed to revealing the “more”’ (p. xxix). The white cane needs to be understood as a process wherein multiple ambiguities and dynamics flow over time and interfere with each other. There is more to tell: it is a relationship that grows and changes, a relationship not only between the white cane and the person who uses it but also with the ground, the world around them, other people and what is asked of them. The white cane–with all its meanings–is an integral part of an assemblage called blindness and is always entangled with its user, allies and the material environment. Moments of stumbling and clumsiness when practicing happen but, at the same time, using the white cane manifests independent moveability. It is not the only way to achieve movement: it is a cumulation of and the guide dog and the cane and the colleague and… always in other circumstances and for other reasons.

The user’s perception of the cane also changes over time: from a functional object that affects resistance to something relational that affects affirmation of blindness. The linguistic way of addressing the cane shifts, from ‘that unwanted, unnecessary thing’ to a personal-possessive pronoun. It is an extension of the person’s finger, and it gives access to information on the ground, including obstacles and textures. It opens up sensory knowledge that is not always available or noticeable to every able-bodied person. Initially, the white cane represents non-human materiality that is hierarchically excluded in comparison with humans and animals (Michalko & Goodley, 2023); however, it is valued over time. The competitive atmosphere disappears and the cane is appreciated for its enabling creativity. The interdependency of the person and the white cane provides elements of choice, freedom and spontaneity that are experienced as an intimate performance. The aid becomes a flexible companion. The static connotations open up to rhythmic movements.

Conclusion

When we give up our epistemological domination of the white cane–when we take distance of what we think we know about it, when we stop to try to make the white cane fit our metanarratives–that is when we encounter the power of the white cane to affect and be affected in multiplicity (Bennet, 2010 in Davies, 2021). That is when we experience what assemblages can do and become (Bansel & Davies, 2014).

The white cane accompanies the person and their blindness; it enables a movement into experiences of blindness. The white cane matters to blindness. It is an entrance for illustrating what becomes possible when someone is visually impaired, in contrast with the stereotypical idea of blindness as a lack. We cannot get stuck on a simplistic representation of blindness that understands the white cane as a quick and easy way of symbolising a visual impairment. The narrative details show relational and affective entanglements, between the blind person, the materiality of the white cane, and societal interactions (Whitburn & Riffo-Salgado, 2024). The narrative shows the complexity and entanglements of interactions, perceptions and interpretations and makes us understand that there is always more to tell.

The white cane, with its numerous underlying resonances that appear in this narrative, is an example of how a person with a visual impairment is invited to move differently through the world and invites others to move along with them. The white cane in its multiplicity, de-centres the human being and provides a new context for blindness that surpasses any conventional understanding of what blindness might mean. By unpacking blindness, we find a lot more than the absence of sight, dependence and the need for support. We find movement, assemblages, relationality, companionship, interconnectedness and learning opportunities for all people involved. The person, their blindness and their white cane will guide the way. Let's take the risk of following along, listening and stumbling on obstacles once in a while.

Ethics and consent statement:

Ethical approval for this study was obtained from the research ethics committees of Ghent University's Faculty of Psychology and Educational Sciences, and of the Ghent' University Hospital (BC-10661). Informed consent was obtained from the participants, and this study adhered to a longer process of ongoing consent in the form of relational ethics as well.

Acknowledgements

The authors' sincerest gratitude goes to Lucie and Alice, and the members of their networks, for giving voice to their lived experiences. The first analysis of these conversations was presented at the Annual Conference of Interdisciplinary, Intersectional, and International Disability Studies (2023).

References

Allan, J. (1999). *Actively Seeking Inclusion: Pupils with Special Needs in Mainstream Schools*. London: Falmer Press.

Backman, M. (2024). The White Cane: An Ethnographic Account on the Widespread Ambivalence Amongst Visually Impaired Towards an Iconic Aid. *Scandinavian Journal of Disability Research*, 26(1): 82-94. https://doi. org/10.16993/sjdr.1024

Bansel, P., & Davies, B. (2014). Assembling Oscar, Assembling South Africa, Assembling Affects. *Emotion, Space and Society*, 13, 40-45. https://doi.org/10.1016/j.emospa.2014.04.002

Bolt, D. (2013). *The metanarrative of blindness: a re-reading of twentieth-century anglophone writing*. US: University of Michigan Press. https://doi.org/10.3998/mpub.5725818

Bulk, L., Smith, A., Nimmon, L., & Jarus, T. (2020). A closer look at opportunities for blind adults: Impacts of stigmatization and ocularcentrism. *British Journal of Visual Impairment*, 38(3): 270-283. https://doi.org/10.1177/0264619620911424

Clandinin, J. D. (2006). Narrative Inquiry: A Methodology for Studying Lived Experience. *Research Studies in Music Education*, 27(1): 44-54. https://doi.org/10.1177/1321103X060270010301

Crossland, M. (2024). *Vision impairment: science, art and lived experience*. London: UCL Press.

Davies, B. (2021). *Entanglement in the world's becoming and the doing of new materialist inquiry*. London: Routledge.

Deleuze, G., & Guattari, F. (1987). *A Thousand Plateaus*, New York: Continuum.

Godin, L. M. (2021). *There Plant Eyes. A personal and cultural history of blindness*. New York: Pantheon Books.

Healey, D. (2021). *Dramatizing blindness: disability studies as critical creative narrative*. New York: Palgrave Macmillan.

Healey, D. (2022). Chapter 10: Blind Perception: DisAppearing Blindness ... with a Twist. In *DisAppearing: Encounters in Disability Studies*, edited by Tanya Titchkosky, Elaine Cagulada, & Madeleine Dewelles, 123-134, Ontario: Canadian Scholars.

Hoogsteyns, M., & van der Horst, H. (2016). Voorbij verbergen of vieren: Een studie naar het bewerken van het uiterlijk van hulpmiddelen door gebruikers. In *Disability Studies in de Lage Landen* by Geert Van Hove, Alice Schippers, Mieke Cardol, & Elisabeth De Schauwer, 111-128, Antwerpen: Garant.

Hull, J. (2017). *Notes on blindness: a journey through the dark*. Great Britain: Profile books LTD.

Kennedy, A. L. (2006). Small in a way that a bullet is small. Speech at Edge Hill University, May 2006.

Kleege, G. (1999). *Sight Unseen*. London: Yale University Press.

Kleege, G. (2018). *More than meets the eye. What blindness brings to art*. New York: Oxford University Press.

Kudlick, C. (2005). The Blind Man's Harley: White Canes and Gender Identity in America. *Journal of Women in Culture and Society*, 30(2): 1589-1606. https://doi.org/10.1086/423351

Kudlick, C. (2009). Black Bike, White Cane: Nonstandard Deviations of a Special Self [A revised version of a plenary talk]. *Society for Disability Studies*, Tucson, Arizona.

Lesage, F. (2024). Karl Meesters (Zondag 28/04/2024). https://www.vrt.be/vrtmax/podcasts/radio-1/t/touche/

Lindemann, H. (2020). Counter the counterstory. Narrative approaches to narratives. *Journal of Ethics and Social Philosophy*, 17(3), doi: 10.26556/jesp.v17i3.1172

Lindemann, H. (2017). In the matter of stories. *Perspectives in biology and medicine,* 60(1), 93-102. http://dx.doi.org/10.1353/pbm.2017.0021

Looman, N. (2024). Queer late/r life sex: women and non-binary people's unruly stories. Ghent University. Faculty of Arts and Philosophy, Ghent, Belgium.

Michalko, R. (1998). *The mystery of the eye and the shadow of blindness*. US: University of Toronto Press.

Michalko, R., & Goodley, D. (2023). *Letters with Smokie. Blindness and more-than-human relations*. Canada: University of Manitoba Press.

Michalko, R., & Titchkosky, T. (2020). Blindness: a cultural history of blindness. In *A Cultural History of Disability in the Modern Age* by David T. Mitchell & Sharon L. Snyder, 61-78, Bloomsbury Academic.

Omansky, B. (2006). *Not blind enough: living in the borderland called legal blindness*. University of Queensland.

Raymond, H., Clandinin, J. D., Kubota, H., & Caine, V. (2022). Bumping Places of Social Inclusion: A Narrative Inquiry into the Experiences of Refugee Families Who Have a Child Who Is Living with a Disability. *Equity & Excellence in Education*. https://doi.org/10.1080/10665684.2022.2076781

Rodriguez-Dorans, E., & Jacobs, P. (2020). Making narrative portraits: a methodological approach to analysing qualitative data. *International Journal of Social Research Methodology,* 23(6): 611-623. https://doi.org/10.1080/13645579.2020.1719609

Tarrant, A. (2022). Independent living as a counter-narrative. *The International Journal of Disability and Social Justice*, 2(1), 48-73. Doi: 10.2307/48676196

Thompson, J. (n.d.). Telling Stories Visually: Meet Legally Blind Filmmaker and YouTube Creator Juan Alcazar. https://blindabilities.com/?p=6510

Titchkosky, T., Cagulada, E., & DeWelles, M. (2022). *DisAppearing: Encounters in Disability Studies*. Toronto: Canadian Scholars.

Whitburn, B., & Riffo-Salgado, P. (2024). Negotiating access, access and belonging in a higher education institution: A postqualitative narrative. *Higher Education,* 88(4). http://dx.doi.org/10.1007/s10734-024-01263-5

Chapter 5: Positioning

Why I do what I do and why I think what I think: the "so what" of my positioning

Introduction

Throughout this PhD project, the question of my own positioning kept resurfacing. Although commonly addressed at the beginning of a doctoral project, this chapter is located before the concluding discussion because it remains a complex and ongoing concern. What is too private to share? What feels too obvious to state? How do I determine what matters for myself and as a researcher? My time abroad at Southampton University sparked deeper existential reflections on what it truly means to position myself and my work in a broader research horizon.

With this chapter, the running thread of positioning becomes an integral part of the PhD as it effectively colours everything. The chapter entails five parts. It starts by explaining what it means to position oneself in disability research: what positioning is, why it is important (the 'so what') and how it is concretised in this PhD project. Then, it traces my personal background and research trajectory: my experience with (medical views on) visual impairment and how the doctorate came into being and gradually took shape. Consequently, it details the significance of living and researching from the inside, with reflections on insider research, resonances with participants, and repetitive lived experiences of ableism and disablism, inclusion and exclusion. The chapter explores also the knowledge that matters to my research trajectory: ethics, literature and scholarly belonging in connection with blind scholars in disability studies. I move back and forth towards positioning myself, working with insights that emerged throughout each research process.

Positioning oneself in disability research

As a researcher, it is relevant to position oneself in the research. Positionality refers to a researcher's worldview and the stance they adopt in relation to the subject of their research, including its social and political dimensions (Holmes, 2020). It is the lens through which choices are made throughout the research process—what is examined, how it is interpreted and why it matters. Reflexivity is essential: it demands awareness and a critical attitude towards the social positions inherited, as well as the values and assumptions that have taken shape through life experiences (Furlong & Marsh, 2010; Holmes, 2020).

Positioning is recursively and iteratively stitching symbols and identifying marks into the collar of your shirt that reveal who you are and why you think and act the way you do. This metaphor is inspired by the tradition among fisherwomen who knitted unique patterns into the sweaters of their loved ones. These rings, anchors and zigzags carried personal and collective meanings, often used to identify bodies washed ashore. They signified family lineage, hope, protection and connection to a way of life (Blackburn, 2015).

I take up the responsibility of making my positioning explicit. This includes disclosing the personal and contextual circumstances that shape my insights, my theoretical orientation, my relation to disability, and the perspectives that guide my interpretation of the data. I integrate personal reflections with scholarly analysis and am as transparent as possible about how my experiences and assumptions have influenced my methodological and conceptual choices throughout this work. I cannot be a writer who writes on a blank page; the page is already 'covered with preexisting, preestablished clichés that it is first necessary to erase, to clean, to flatten, even to shred' (Deleuze & Guattari, 1994, p. 204). Thus, explaining how I have made choices and set priorities is relevant (Vandecasteele et al., 2021). Relating positioning to the metaphor of crochet, it shows the threads throughout the PhD and the knots I am triggered to unravel.

By positioning myself clearly within the research, I set the remarkable context, notice the points I keep returning to, and acknowledge my significant privileges as a researcher. By doing so, I hope to offer the reader a sense of how this work has taken shape, not only in terms of what I studied, but also how and why. Making this positioning visible supports a deeper understanding of the knowledge that is produced. It reveals the pathways, questions and tensions that matter to me, and opens the work to be read not just as an external account, but from within the researcher's position.

This exploration of positioning clarifies how my presence, experiences and assumptions shaped every aspect of the research process. By explicitly locating myself, I acknowledge that the researcher is always situated and critical reflexivity is a methodological strength.

Positioning in a personal research trajectory

My position in this research is shaped by a personal history that threads throughout the doctoral journey. My personal and academic paths are deeply intertwined.

Growing up with a progressive visual impairment meant that I encountered disability from a young age. Even before I could name it, my eyesight shaped my world. Medical interventions, check-ups and rehabilitation appointments became routine. These experiences were not only medical or practical, they were existential. Surgeries interrupted the flow of everyday life, forcing me to confront how disability is treated, understood and framed dominantly from a medical and individual perspective. It affected my being and shifted my mindset. At school, I was sometimes exempted from activities like sports because of the risk of further sight loss. However, these exclusions pushed me to focus on personal development and long-term goals. I learned to be proactively prepared—not only with a 'Plan A', but with multiple backup plans. I learned to turn restrictions into strategies and alternative possibilities.

I also come from a family that values hard work and perseverance. My parents work full-time and devote their leisure hours to hands-on tasks—gardening, renovating homes and making things grow. My two brothers both completed university degrees, and my grandfather held a PhD in bioengineering. My family's ethos of nurturing talent recognises potential, validation and opportunity. In that environment, excelling is the norm. I am encouraged—implicitly and explicitly—to push limits, aim high and fully develop my potential. It strengthened my perfectionism, too. I actively engage in making a difference, creating meaning, having impact and doing something useful, and I recognise the privilege of being part of a family that continuously pushes boundaries—both mine and those of the systems around us. For research, this leads to my fascination for unravelling the powerful interactions between a disabled person and their embedded networks.

When faced with barriers, I became persistent and resourceful. My family and I chose regular education over special education and followed my older brother's footsteps into academically oriented schools. Experience trained me to keep moving, be creative in finding alternatives, and prove that obstacles could be navigated with a lot of flexibility, but determined manoeuvring and negotiating. Such a drive inspires me to discover how others make their way in different lives and contexts.

In my educational trajectory, I consistently made decisions that reflected this mindset. I explored many directions for higher education but kept 'something with visual impairment' as a backup, assuming I already had some familiarity. Ironically, when I did pursue a Master's in Special Needs Education and disability studies, I was left with unanswered questions and a hunger for deeper understanding. This gap became the seed for this PhD as I am always intrigued by glimpses to learn new, more, slower and deeper. My curiosity for complexity has always drawn me to the deeper layers of how people function in various contexts and how they respond, adapt, resist and make meaning of their daily lives. It takes students five years of training to further unpack the taught knowledge on visual impairment—which focuses mainly on diagnosis, the ability to perceive contrast and detail, and the challenges associated with it—into their professional activities. This directly links with how disability studies affirmatively approaches lived experiences. There is much more than just vision and a problem to solve. This complexity makes me curious, and it laid bare a PhD trajectory to deeply understand visual impairment from a disability studies perspective.

My goal from the beginning was to add something to the existing knowledge, and this entrance is remarkable to my positioning. When writing about parenting or inclusion in education, I did not focus on the most obvious or practical angles, like nappies or support technologies. I was drawn to the more complex emotional or relational dimensions: the urge to prove oneself, the subtleties of belonging, or the hidden emotional labour of asking for help. I attempt to be inventive by focusing on difficult issues, delving into depth and complexity, rather than obvious visual inabilities. These were not the easiest entry points, but they were the ones I kept returning to in my thinking. What may seem peripheral or subtle often contains the richest material, and I have learned to trust that instinct.

As my disability affects how much energy I have, how I can organise my time and what I can realistically pursue, I often find myself negotiating limits. Administrative burdens, arranging support and the continual advocacy required to secure accessibility—all of these need to be done before I could even begin the 'actual' academic work. Additionally, despite my ambition, surgery and subsequent recovery during the second month of my PhD disrupted the research plan. I found myself writing about that experience—not because it was in the original plan, but because it demanded attention—before I could re-focus on the doctoral research. I often felt frustrated by how much time and energy was lost to planning, commuting or solving seemingly small issues like computer glitches or arranging software. These challenges were compounded by the emotional labour of always needing to ask for help and being dependent on others for what are often perceived as mundane tasks. Also, social moments within the department brought a mix of feelings: an outsider or impostor, an advocate for accessibility, wanting to participate, having to modify the rules, and naming what I needed. I invested in conversations about work environments that minimise distraction and advocated for structural changes where possible. I carefully monitored my working hours, protected weekends and found that I was most productive during summer months, when the usual flow of the department slowed down. Eventually, I obtained a formal one-year extension for my PhD—a necessary adjustment, although far from sufficient in addressing all the barriers I faced. Pursuing a PhD cannot be taken for granted, especially while living with a disability, and this still entails ongoing negotiation.

These experiences made me more conscious of the complex internal and external barriers shaping academic life. But they also illuminated moments of connection and care: when things clicked, when access was not just permitted but actively supported. I only delegated tasks when they made sense, using disability employment funding to hire students and employees to help with presentations, bibliography work or conference logistics. A personal assistant accompanied me to Southampton, where her help with daily routines made it possible for me to focus fully on my research stay. These enabling moments gave me energy, even as they highlighted how often the default structures fall short.

Over time, I developed as a speaker and scholar. Although initially hesitant, I eventually gave numerous presentations and consistently appreciated the experience. I prepared carefully so that I could deliver attendance confidently. I also joined an international panel, at night due to time zone differences, participated in an Erasmus+ project in Bulgaria and co-taught courses during a period abroad in Southampton. These opportunities allowed me to develop my academic voice and practise saying ‘Yes’ to things just outside my comfort zone. Within this, a pattern emerged. When an opportunity appeared and I sensed even a flicker of challenge or potential, I usually accepted—sometimes impulsively, often with doubt, but rarely with regret. I needed time to imagine what it would require, and I often believed the event might fall through anyway. I embody the Dutch saying, ‘first see and then believe’. But time and again, experience taught me that I could rise to the occasion. Whether presenting in English, staying abroad or contributing to an academic panel, I discovered I could do more than I initially thought—especially when supported by those who believed in me. Reflecting on my personal and academic background revealed how deeply my research questions emerged from lived tensions and resilience. This section affirmed that scholarly curiosity is never neutral. It is rooted in biography, privilege and challenge, and these roots deserve to be named.

Positioning towards insider research and lived resonance

Lived experiences always fascinated me—not in the abstract, but in their grounded, relational and embodied forms. I am drawn to how people navigate their lives in response to particular circumstances, relationships and environments. I assume that how other people navigate their lives relates to circumstances and interactions, in a way that you cannot just copy and paste the words or solutions of another. Narratives of disability repertoires cannot simply be translated. They are situated and singular because persons, their contexts and their trajectories differ. What interests me is not just what people say, but how their stories unfold and how they move through tensions, contradictions or uncertainty. A lot of realities and life paths are possible and inspirational and, consequently, worth exploring. Everyone charts their own course, and I find value in the unpredictability of that variation. I am especially attentive to the diverse ways people with visual impairments live their lives.

Theoretical perspectives helped me articulate why this diversity matters. People respond to their own blindness in uniquely personal ways, and no single narrative can capture or define that diversity (Bolt, 2023; Bolt & Penketh, 2016). Each person's account holds epistemic value—not as a representation of a group, but as a situated agentic contribution to how we understand disability (Bolt, 2013; Rojas, 2021). As Vandecasteele et al. (2021) describe, encounters can become moments of mutual impact, where both parties affect and are affected in real time. Throughout this PhD project, I encountered participants and scholars whose experiences resonated deeply with mine. These were not distant interviews or objective data points but moments of recognition and living conversations.

As I reflected on my own life alongside the participants' experiences, I felt a strong ethical responsibility not to impose normative expectations or idealised outcomes. I urge that we not judge anyone because I never want to impose pressure on people. The habitus of ablism and its canonical affordances cause the shrinkage of the environment and its space for action for disabled people, which already pushes them to the extremities of the possible (Dokumaci, 2023). There are already more than enough fixed projections and assumptions at play—ideas about what a 'successful' disabled person should be or do. I never wanted to add to that pressure. I became increasingly aware of how deeply ableism is embedded in our daily lives, institutions and the small details that often go unnoticed. These patterns were familiar to me—too familiar. While I acknowledge their impact, I also feel fatigued by their repetition. I did not want to focus solely on the catalogue of barriers, nor produce yet another list of structural problems and individual frustrations. Instead, I was drawn to what happens after the obstacle—how people resist, adapt, find workarounds, or simply carry on. This is what Dokumaci (2023) calls 'activist affordances', the improvisations, imaginations, innovations, experimentations or creations of more liveable and accessible worlds. I was interested in what moves people and creates space for agency, connection and meaning, even in contexts where change is slow or absent.

This is where the 'with my own eyes?' in the dissertation title gains its layered meaning. In Dutch, the expression 'seeing with my own eyes' suggests first-hand confirmation, but it also reflects an ocularcentric worldview by explicitly relating to the eyes (Bolt, 2013).

The question mark complicates that assumption, pointing to the need for exploring different ways of knowing. My own disability shaped access in practical ways. Participants often assumed a basic level of shared understanding when they heard I was visually impaired. This opened conversations. The label became a bridge, softening the perceived distance between researcher and participant. My presence often evoked recognition rather than scrutiny, and this relational proximity allowed for a different kind of dialogue—more candid, less guarded. The primary entry point into the doctoral research is lived experiences—both those of participants and scholars, and my own. I continuously engage with participants, theory and my own lived experiences. Consequently, I search for a connection via research between my own experiences and the personal experiences that the data entail.

The PhD shaped my understanding of conducting research within a community, or better to say: plural communities, I am already part of. As a blind researcher working with others with visual impairments, I occupy what is often called an ‘insider' position (Bulk, 2021; Omansky, 2006) as we share blindness. This insider role is more complex and multifaceted. It means I am a community member of ‘the blind', but also a researcher of the disability studies research group and, at times, a co-witness of how professionals approach blindness. Hayano (1979; as cited in Bulk, 2021) refers to it as researching ‘one's own people' from the inside. This is a triple positioning: professional, participant and scholar. As Bulk (2021) argues, insider research reshapes every part of the process—the questions we ask, the methods we use, the meanings we create. Throughout the PhD, this insider position attains meaning and embodiment. I moved from a descriptive way of writing—faithfully representing participant voices—to a more critical and reflective mode of analysis. I struggled to go beyond quoting or summarising what was said early on. I valued every story as truth. Initially, I approached writing with caution: closely following what participants said and representing their voices faithfully, sometimes too literally. I struggled to move beyond transcription, hesitant to add interpretation out of fear of misrepresenting someone's story. I assumed that my role was to present different perspectives without prioritising one over the other. I found it difficult to take a stance or to interpret more deeply. My writing was dense, cautious and compact. Over time, I learned to unpack more, reflect more explicitly, and embrace my own analytical voice. The abstractness becomes vividity, and being inside is necessary to allow this shift. I became more attuned to moments when I instinctively set aside material that did not feel right, not as a mistake or omission, but as a sign of emerging discernment. I began to see that avoiding interpretation was not neutrality. It was an erasure of my own thinking. Through feedback and continuous writing, I learned to move beyond ‘what was said' and ask why it mattered, how it connected, and what it disrupted or revealed. For example, I initially stayed close to the participants' accounts when writing about parenting. But through further reflection, I began to see recurring themes—like the pressure to prove oneself or the tension between independence and care—that cut across stories and echoed with my own experiences (although I am not a parent myself). These became entry points to conduct research in a different way.

Over time, I found myself more willing to draw from my own experiences, more confident in naming how my perspective mattered. I became aware that considering my lived experiences does not divert attention from the things I wanted to focus on. I recognised that certain stories stood out to me because they echoed parts of my own life. For instance, I felt aligned with James because we were in similar stages of life when we spoke. In writing about the white cane, I saw traces of my own experiences (with a white cane) woven into the narratives of Lucie and Alice. Topics like schooling, mobility and institutional expectations all resonated because they were not only academic; they were personal. These moments are not simply anecdotes but part of ongoing negotiations between lived experiences and research insights. This shift from passively documenting what was said to actively theorising what mattered marked a pivotal change in how I saw myself as a scholar. I was no longer merely reporting; I was engaging in the creation of knowledge. I learned to make deliberate choices—to let go of what did not resonate and to follow the threads that did. These decisions were not arbitrary; they reflected a growing sense of intellectual agency. Often, I did not know exactly where I was headed, but I trusted the rhythm of conversations and allowed myself to be moved by certain moments—those subtle, embodied impressions that defy easy articulation yet leave a lasting trace (Vandecasteele et al., 2021). My insider position shifted my writing from cautious documentation to critical analysing and active theorising. Embracing my own lived experiences shaped how I interpreted others' stories and claimed my place as a contributor to epistemic change within disability studies.

Positioning regarding knowledge that matters

Throughout the doctoral research, I have been driven by a desire to do work that matters—work that makes a difference, resonates with others, and generates meaning beyond academic occupation. For me, research is like crochet: not simply something to keep busy with, it is a serious form of engagement. To let research matter to those involved, including the researcher, I do not aim to produce prescriptive archives with generic guidelines on managing visual impairment. I am not interested in giving fixed advice to persons labelled as disabled, parents or professionals. I want to explore repertoires of how people engage with one another in the presence of disability—how they experience, relate and coexist in ways beyond technical responses to impairment (Dokumaci, 2023). My aim is not to simplify complexity into solutions, but to attend to the texture of interaction and the everyday negotiations that shape people's lives.

I see this as an ethical commitment. The choices we make as researchers matter. How we relate to participants, represent them and carry their stories are acts of ethical engagement. Following Barad (2007) and Haraway (2008), I believe that ethics is not a matter of abstract codes, but of relational response-ability—a willingness to be affected, respond and remain accountable. I tried to treat lived experiences not as data to be extracted or compared, but as human accounts to be deeply encountered, interpreted and situated with care. Applied to the research, I assume that learning from participants, authors and myself matters. I can justify that I always focused on the ethical matters of those lived experiences. I approached the narratives of participants and multiple networks relationally. I did not want to put them against each other, so each participant and I thought together about what matters in their story, and how I could interpret them and recognise them fully in their dignity. This is highly relevant when approaching participants as embedded in various networks and interviewing multiple people with different perspectives in the same network.

I had to reflect on the specificity of the literature in the case of the PhD that touches on how the world understands and conceptualises blindness, mostly founded on lived experiences. When a colleague prepared the dissertation for her PhD, she relevantly asked about the prominence and the scientific validity of blind scholars in my research. We established that I predominantly read literature by authors who are visually impaired themselves or live closely with them. This is a significant observation because following the guidance of blind scholars was highly meaningful in the positioning of the PhD. From the beginning, I was drawn to the work of blind scholars and authors who wrote from their own lived experiences. The commitment to ethically engage with lived experiences also informs how I approached this literature. Their work was both academically rigorous and experientially grounded. It spoke to me in ways that theory alone could not. These authors showed me how disability can be written, reimagined and shared without being reduced to deficit, lack or personal tragedy. In my PhD, I wanted to see how things happen and the ups and downs it took people to do that. As I told a participating friend of Lucie, I aimed to understand the contextual conditions that make certain trajectories possible. How things work out that way in that context is incredibly complex, and you can never say exactly 'it's like this'. I am aware of prognoses that professionals can make for someone's visual abilities, but I personally had to learn to move on with—or despite—what could happen, and that life is not liveable if this constantly takes a dominant stance. I also recognise that rehabilitation helps. I learned to use software or braille too, but I am critical about how existential this is for someone's being. I also experienced a contrast between the practical resources noticed in literature, how parents negotiated their experiences relating to an urge to prove their parenting, and their relational approach. I took these conclusions as contributing, and this directed my search for further depth. I sought literature that offered possibilities. I looked for what maximised chances for participation and belonging, what reduced experiences of discrimination and exclusion, and what challenged fixed, normative expectations. I was not searching for answers, but for resonances—for language that allowed me to explore what it means to live a 'good' life with disability. These preferences shaped the conceptual framework of this PhD and were further deepened through a reading group with colleagues, where we unpacked key texts in disability studies authored by scholars who closely relate to blindness.

This orientation also shaped how I experienced academic life as a researcher with a visual impairment. I experienced a shrinkage of my world because of (the negative progression) of my blindness (Dokumaci, 2023). My visual abilities declined during my university studies, and screen magnification gradually gave way to reliance on screen reading. Doing a PhD in that context was not just a matter of intellectual labour but a form of navigating, adapting and resisting institutional norms. I learned to approach academia as a space that is often unintentionally inaccessible, and I began to view my workplace not just as a research setting, but as an object of study itself. I actualised particular affordances, possible behaviors or actions. Writing about (in)accessibility at conferences, cripping PhD-time and handling ableist distractions was fundamentally shaped by my lived academic experiences—and constitutes knowledge that matters.

I wanted to meet researchers who live with visual impairment, who are doing qualitative research in the domain of disability studies on the issue of visual impairment. It is very helpful to connect with peers and learn from micro-communities of fellows. To collect inspiration and experiential knowledge, I sought role models who could give examples of good practices or guidance for navigating the challenges. Dialoguing with these experiential experts resulted in learning to make my experiential knowledge more explicit and scientific (by including the content of those exchanges in publications and my way of handling). I actively sought out peers who shared similar experiences—disabled researchers working in disability studies on issues of visual impairment. These connections helped me transform experiential insights into scholarly contributions.

One such connection was Leendert Van de Merbel. After reading his Dutch-language article on qualitative research methods, I reached out. We exchanged tips on reading academic texts, managing large datasets and navigating conferences. Our collaboration resulted in a co-authored article, 'Accessible participation in academic conferences if you are visually impaired' (see intermezzo 1). That piece challenged the normativity of visual presentation formats at conferences and called for institutional flexibility to allow different styles of academic engagement. What I previously called struggles, hindrances, challenges, obstacles, barriers, borders, confrontations or exclusion; what Dokumaci (2023) calls 'shrinkage'; transformed into enabling (physical, digital, relational, ethical, cultural) accessible participation. Boundary conditions (like mobility and transparency), intensive preparation by the disabled individual and their entourage, connecting with colleagues (which refers to belonging and networking) and making scientific contributions (by asking relevant questions and critically presenting) emerged as meaningful themes. In my own presentations, I developed workarounds that combined visual and auditory access. Especially for talks in English, I pre-recorded the spoken part and followed up with live Q&A. Although I felt freer to improvise when I could present in Dutch, I used screen readers to support citation display and paid attention to how I could connect with audiences using my body and voice. I emphasised autonomy, not as isolation but as the ability to prepare, choose and present in ways that worked for me. But we also argued that inclusion is never an individual task. Accessibility must be negotiated collectively—before, during and after academic events—and responsibility must be shared by all involved. As Titchkosky (2011) reminds us, disability invites us to think differently about participation, not only for disabled individuals but for everyone.

Another meaningful encounter was with Ben Whitburn. After seeing a video of one of his presentations, I reached out via email, and a rich dialogue followed. We continued the ongoing exploration about functioning and belonging in academia while being visually impaired. That exchange eventually led to two important contributions. First, I was invited to write a chapter for the second edition of *Disability and the University: A Disabled Students' Manifesto*. Writing that chapter helped me concretise my positioning, and the reviewers radically pulled me out of my comfort zone. In that piece, titled 'Cripping time: temporalities in academia' (see intermezzo 2), I explored how academic timelines often reflect pressures to be fast, efficient and always productive. My contribution challenged that logic by reflecting on my own experience of managing fatigue, concentration limits and temporal constraints due to disability. I argued for a more flexible, humane academic temporality that values thinking, resting, pausing and resisting the push for constant acceleration. In reflecting on my academic journey, I acknowledged the personal adaptations I had to make and the frustration that arose from my reduced capacity to focus on actual research due to time-consuming access-related tasks. Yet, I also emphasised the vital role of collaboration—support from colleagues, assistants and institutional allies—which made participation possible. These lived experiences revealed the broader contours of blind scholarship as something far richer than merely studying blindness, and affirmed that I, like every disabled scholar, belong in academia. However, the persistent inaccessibility of time-related resources and institutional structures raises critical questions. My experiences challenged able-bodied norms and introduced the embodiment of temporary or fluctuating capacities into academic discourse. At the core, the issue is collective: we must recalibrate the weight of intensifiers in academic workloads to respect the additional labour some scholars carry and remove unnecessary barriers. Each act of resisting or struggling with dominant temporalities becomes a small but meaningful rupture—an ‘activist affordance’ (Dokumaci, 2023) or an opening that questions institutional expectations and invites change. Reimagining academic time is not a solitary task but a shared pedagogical act that can cultivate awareness and accountability across the academic community. The exchanges with Ben and the writing of this chapter gave birth to a responsible attitude of engaging with doing university differently. Second, I spent a research stay at Southampton University, where my conversations with Ben evolved and are evolving into papers. The content of this positioning chapter took shape throughout this period abroad. A publication about distractions is evolving into a co-authored text. That collaboration, which grew slowly and carefully over time, mirrored the ethos of my work: attentive, situated, dialogical. We did not rush to conclusions—we stitched together thoughts, experiences and questions until something new began to take shape. Such collaborations enrich my positioning and add scientific value.

This section crystallised my ethical commitment to situated, relational and responsive research. By prioritising experiential knowledge and drawing on work by blind scholars, I reoriented my scholarly voice towards forms of knowledge that emerge from entanglement rather than distance.

Positioning as a lived method

By doing the PhD, I learned I cannot position myself at some remove from the research or reflect on it from outside. I cannot act if I were not there or outside the research. I thought I was—or should be—a researcher who explores and represents visual impairment by interviewing people with lived experiences. My lived experiences were not prior. I had to stand back from the material being researched, assessing it and judging it from a distant vantage point because practices of knowing and being are mutually implicated (Barad, 2007), and researchers are an integral part of their research (Vandecasteele et al., 2021). I cannot be separated from the topic under investigation. I tried to keep myself out of it, but five years later, I can see that my experiences are all over the place in every chapter and everything I do.

Positioning myself within this research is not a single act. It is a process of becoming and acknowledging how I am present. I lived through it. I recognise that my own body, experiences and perspectives are part of the research. They are part of the research questions, part of the analysis, part of what makes the work meaningful. Thus, positioning is not only about declaring where I stand; it is about tracing how I was moved, how I move, and how those movements shape what I have come to know and value. It is about accepting the entanglement of subject and method, biography and scholarship. It is about responding—ethically, critically and creatively—to the lives and stories that are shared with me, and to the life I bring with me into this research. It is a massive push to further explore the researcher's subjective positioning in the research. I have to explain why I chose the methods and express my personality in it. I learned to articulate my own analytical voice because I let go of material that felt unrecognisable or unsatisfying, signalling a growing confidence in my analytical judgment:

> *Without really knowing where I was going, I followed the rhythm of my conversations … and allowed myself to be touched by moments. Moments that I could sense in my body. Moments that were rather difficult to capture in words, but which were strongly present and drove creation. (Vandecasteele et al., 2021, p. 497)*

Looking back, positioning myself within this research was not a preliminary act, but a crocheted becoming. I learned that I could not observe from a distance or detach my biography from the questions I asked. My positioning was not just about reflexivity—it became a lived method, one that never closes. It made visible how entanglements of body, context and perspective shape knowledge. Through this process, I redefined what it means to 'know from the inside'. As a contribution to disability studies, this chapter proposes that researcher positionality is not an appendix or disclaimer, but a fertile site of inquiry, resistance and methodological depth. My journey shows how disabled scholarship includes the scholar's body, pace, limits and desires, challenging dominant norms of neutrality, productivity and abstraction. This form of positioning opens space for complexity and ambiguity and insists that lived experience is not only data but a vital force in meaning-making. In the context of this PhD, this chapter is the thread running through the whole. It explains the 'so what' of why I do what I do and think the way I think. It connects content to context, and inquiry to identity. It makes the PhD not just a study about visual impairment, but a scholarly practice that is shaped by and contributes to lived disability experiences. By making this visible, I hope to invite others—readers, scholars and allies—to not only read what I wrote, but to see how and why it comes to matter.

References

Barad, K. (2007). *Meeting the universe halfway: Quantum physics and the entanglement of matter and meaning*. Duke University Press.

Blackburn, J. (2015). *Threads*. Random House.

Bolt, D. (2013). Chapter 1: Community, controversy, and compromise: The terminology of visual impairment. In *The metanarrative of blindness: A re-reading of twentieth-century Anglophone writing*. US: University of Michigan Press. https://doi.org/10.3998/mpub.5725818

Bolt, D. (Ed.). (2023). *Finding blindness: International constructions and deconstructions*. Routledge.

Bolt, D., & Penketh, C. (Eds.). (2016). *Disability, avoidance and the academy: Challenging resistance*. Routledge.

Bulk, L. Y. (2021). Being blind and belonging in academia [Doctoral thesis, University of British Columbia]. https://doi.library.ubc.ca/10.14288/1.0395453

Deleuze, G., & Guattari, F. (1994). *What is Philosophy?* Columbia University Press.

Dokumaci, A. (2023). *Activist affordances: How disabled people improvise more habitable worlds*. Duke University Press.

Furlong, P., & Marsh, D. (2010). A Skin Not a Sweater: Ontology and Epistemology in Political Science. In D. M. A. G. S. (Ed.), *Theory and Methods in Political Science (3rd ed)* (3rd ed., Vol. 3, pp. 184-211). Palgrave Macmillan. https://doi.org/10.1007/978-0-230-36664-0_10

Haraway, D. J. (2008). *When Species Meet*. University of Minnesota Press.

Holmes, A. G. D. (2020). Researcher Positionality - A Consideration of Its Influence and Place in Qualitative Research - A New Researcher Guide. *Shanlax International Journal Of Education*, *8*(4), 1–10. https://doi.org/10.34293/education.v8i4.3232

Omansky, B. F. (2006). Not blind enough: Living in the borderland called legal blindness [Doctoral thesis, University of Queensland]. https://espace.library.uq.edu.au/view/UQ:158179

Rojas, L. I. (2021). On conversation and authorship: Legal frameworks for collaborative methodologies. *International Journal of Qualitative Methods*, *20*. https://doi.org/10.1177/1609406921993289

Titchkosky, T. (2011). *The question of access: Disability, space, meaning*. University of Toronto Press.

Vandecasteele, M., De Schauwer, E., Blockmans, I., & Van Hove, G. (2021). Re-touch: Re-stitching fissures through affect in families with a family member who is labeled as disabled. *Art Research International*, *6*(2), 478–504.

Intermezzo 1: Accessible participation in academic conferences if you are visually impaired

INTRODUCTION
ACCESSIBLE PARTICIPATION – THEORETICAL FRAMEWORK
METHODS
RESULTS
  Boundary conditions
  Intensive preparation
  Connecting with colleagues
  Doing scientific contributions
DISCUSSION AND CONCLUSIONS
REFERENCES

Based on: Van Havermaet, J., van de Merbel, L., Van Hove, G., & De Schauwer, E. (2023). Accessible participation in academic conferences if you are visually impaired. *Journal of Disability Studies in Education*, 3(2), 148–165. https://doi.org/10.1163/25888803-bja10020

Abstract

Participating in academic events of knowledge exchange is primordial for researchers. The experiential experiences of people with visual impairments with accessibility differences in such scientific practices are reflected. The theoretical concept of 'accessible participation' is linked with the exchange of lived experiences of the first two authors—both PhD researchers who are visually impaired—who take part in academic conferences in the domain of disability studies. Boundary conditions, intensive preparation, connecting with colleagues and making scientific contributions are analysed as accessibility issues that are necessary to enable participation in an academic context.

Keywords: visual impairment, participation, accessibility, academic conferences

Introduction

Academic conferences are a crucial and essential part of doing qualitative and quantitative research, which is always about knowledge exchange in multiple—often visual—ways (Budge et al., 2016). The experiences of attending academic conferences often require significant navigation and negotiation of space for academics with a disability who can develop a non-stereotypical work style (Brown et al., 2018). What about the experiences with and obstacles in the accessibility of scientific practices and participating in academic conferences of disabled academics? This article positions itself in the context of disability and higher education by presenting the lived actuality of visually impaired academics who participate in academic conferences.

Contextual information is necessary for the telling of our experiences. The first two authors are both junior researchers in and engaged with conferences in the domain of disability studies. The first author participated in the EPATH conference 2019 (as audience), Academia Ophthalmologica Belgica (2019) with an e-poster, the online PhD sessions of the faculty's research day (2021) with a five-slide pitch; the online International Conference on disability studies (2022) with an awarded 10-minute presentation; and shared the content of this text at a webinar on travelling and networking with confidence at the American Foundation of the Blind (2022). The second author took part in three academic conferences: the international disability studies conference in 2013 (as audience), the same conference in 2017 with a presentation, and a conference of the European Agency for Equal Human Rights in Vienna in 2015 (as a participant in discussions). The first two authors are sharing their experiences and reflections of being visually impaired participants and speakers at academic conferences.

We reveal our presence, our way of being and our different ways of doing, and we make our participation perceivable, meaningful and sensible. We explicate our experiences with (in)accessibility challenges and justify all mailers of inclusion. We explore workarounds with inaccessible structures of university life and uncover ways we believe barriers may be overturned. Questions arise during the interactional scenes of access struggles in an educational workplace environment and giving reasons for access improvements.

We would like to bring accessible participation to the consciousness of universities by arguing for a more inclusive version of academic conferences. The aim is to provide a constructive contribution to the accessibility of academic conferences. We change how our participation is seen and how we are—or can be—treated. We seek to explore the potential of disability to unsettle and challenge exclusionary practices.

Accessible participation – theoretical framework

The concept of 'participation' occurs in a range of contexts and encompasses more than may first appear. It is extensively conceptualised in-depth as a multi-layered and relational process of becoming, as having access to and engaging with activities

(McCormack & Collins, 2012; Vandenbussche & De Schauwer, 2017). Participation is about who participates, how and in what ways (Jager-Vreugdenhil, 2011). An ideal picture of such participation, of circumstances that allow everyone to take part fully, is assumed 'inclusion' (Vosters et al., 2013). Being included—enhancing participants' access to social and educational opportunities—is a commitment required from everyone (Whitburn, 2014). An inclusive academic atmosphere facilitates everyone's involvement and invites people with disabilities to take part. Consequently, the theme and underlying principles of academic conferences need to enlarge and maximise participation. To provide participation to and belonging in academic conferences, relational accessibility is of high relevance and priority.

Participatory involvement closely connects to the concept of accessibility (Vandenbussche & De Schauwer, 2017). Accessibility is an active interpretation, a highly relational move, and an embodied perception of how places and people are made meaningful. It is a human attitude to perceive, talk and act (Titchkosky, 2011) as the opportunity to express personal needs and how these can be met This understanding of accessibility could imply that:

> *Being open, and being vulnerable to being affected by the other, is how we accomplish our humanity; it is how the communities of which we are part, create and re-create themselves. We are not separate from the encounters that make up the community but, rather, emergent with them. (Davies, 2014, p. 10)*

It is understandable as an orientation towards—or wondering about—who and how participative positionality can be found in social spaces (Titchkosky, 2011). Disability then poses the question of access for whom, or embodiment, and what (Titchkosky, 2008). Such interpretation of accessibility includes incorporating several, entangled layers of physical, relational, cultural, intellectual, technical, structural, financial and social accommodations that are necessary conditions to enabling participation (Schoeters, 2021). Putting attention on accessibility is important because of its fundamental condition for participation and belonging in an academic setting.

Accessible participation is experiencing occupational justice, 'having fair opportunities to do, be, belong, and become in accord with their potential... having the resources and opportunity for engagement' (Bulk, 2020b, p. 2). Such scholarship is about the intra-actions between the participants and their contexts (Titchkosky, 2011). Accessible participation is a basal existence for everyone, even people with (visual) impairments. It is about experiencing inclusion and engaging in meaningful (academic) occupations, based on both physical and technical, and material and social resources (Bulk, 2020a). Although assistive technologies can provide bridges to inaccessible physical and digital environments (Whitburn & Thomas, 2021), physical barriers prevent the participation of some people (Titchkosky, 2008) and physical inclusion does not necessarily result in social integration for visually impaired people (Whitburn, 2014). In a visual-orientated world, physical access could include lighting design to accommodate the lighting levels (Beckwith, 2019), and digital access to textbooks, documents, course material or presentations are often a barrier (McCall, 2019). It is about experiencing the implementation of facilitating support mechanisms and arrangements to have agency and seamless access (Whitburn, 2014). Thinking in line with Tregaskis and Goodley

(2005), disabled people must reveal too much to have equal participation. Also in academic settings, equal participation is needed to fulfil a collective accessibility approach instead of a thoroughly individualised matter of disability access issues (Titchkosky, 2011). Accessible participation is a collective ethical responsibility: (non-)human supports mutually affect the constitution of inclusion for disabled people (Whitburn & Thomas, 2021).

Methods

This article is not solely 'research on' or 'research with' visually impaired people; it is research by two researchers who are visually impaired themselves. The first two authors took their workplaces as their analysis setting (Titchkosky, 2011). We turn the analytical lens on ourselves as an axis from which to examine our participation in academic life and experiences as a person with visual impairment. No visual impairment is the same and therefore is revealing. We offer a subjective account of impairment in social discourse that challenges others' notions about our lived realities (Tregaskis & Goodley, 2005). Our lived experiences must be heard to better interpret exclusion (Whitburn, 2014), which concerns educational and social inclusion more broadly. Such participatory research methods involve insider perspectives, which is fundamental to privileging ontological experiences and reflections (Tregaskis & Goodley, 2005). Based on our positionality, we make our experiential knowledge more explicit and, in this way, scientific. From our insider perspectives by means of descriptions, we present our personal life experiences and/or research results on the issue of accessible participation in conferences and making a valuable contribution to scientific knowledge (Budge et al., 2016). Learning on account of different methods or types of engagement is facilitated when disability experiences are truly appreciated (Bolt, 2017). It is scientifically relevant to incorporate our experiences because of an epistemological problem of avoiding disability in the academy (Bolt & Penketh, 2016). We seek to transform this space of negation by recognising what is produced in this act of avoidance (by exploring and demonstrating ways in which we experience participation at conferences) with an aim to transform the nature of such encounters or relationships. We recognise the opportunities afforded by engaging with bodily difference; we recognise the creative capacities of such bodies, and we question the cultural rules about what we should be or how we should 'do' conferences. We set up a dialogue that could support conference organisers and all participants. These practical ideas and advice on how to make academia and its conferences more accessible are needed to do academia differently and feel recognised as researchers (Brown et al., 2018).

This article originated from informal exchanges between the first two authors. We are both junior PhD researchers who live with a visual impairment. We are both doing qualitative research in the domain of disability studies on the issue of visual impairment and have already taken part in some academic conferences. Doing research and academic conferences as a visually impaired researcher provides some confrontations, whereby it is very helpful to learn from fellows. We exchanged our impairment effects by sending emails to each other and having some telephone conversations, and the key to developing this connection was sharing experiences, challenges and solutions

(Tregaskis & Goodley, 2005). Dialoguing helped frame our experiences, reflections and understanding, which subsequently created scientific knowledge. We searched for commonalities in experiences via dialogues with each other, focusing on our engagements in academic conferences. We asked ourselves and each other critical questions to reflect on our positions as visually impaired researchers and our personal ways of taking part in academic conferences. In this way, we enacted a micro-community of practice (Law & Wenger, 1991) to learn from each other and educate conference organisers. Writing down what was collected in these negotiations felt like the next logical step. We brought a preliminary investigation of our individual experiences. First, we formally ordered our experiences binarily (being the audience and being the speaker at conferences), but we shifted the text into topics related to the accessibility of and participation in conferences. We surrounded ourselves with colleagues who did not have disabilities. Negotiations with the third and fourth authors structured the text and supported further thoughts on accessible participation. All the experiences were carefully discussed several times and subjected to qualitative content analysis. This process of analysis followed inductive and conceptual mapping procedures, as suggested by Clarke (2005) and Charmaz (2006). The first two authors identified reoccurring themes, common patterns and key points (Zhang &Wildemuth, 2009) concerning accessible participation. The themes were examined for consistent patterns and exceptions by all researchers, and the inter-relationships between themes were discussed. Our discussions about combining a scientific and experiential positionality, or our moving back and forth between multiple ideas, shaped our understanding. The next section, which details an exchange of experiences, shows how boundary conditions, intensive preparation, connecting with colleagues and making scientific contributions emerged as meaningful for the first two authors in our academic trajectory as visually impaired PhD researchers. This analysis is written in a dialogical way to overview the personally experienced themes.

Results

The four parts of this section overview a dialogical exchange of experiences with accessible participation in conferences. Mobility, finding our way, and the organisational transparency of conferences are conditional accessibility issues of high significance. Arranging ourselves down to the last detail is also necessary. Preparing ourselves to a great extent in advance embodies primordially fixing support to enable ourselves to participate. Belonging at conferences includes networking, meeting others and targeting interesting speakers, which is challenging due to visual impairment. Taking part in conferences as an audience member who asks relevant questions or as a researcher who presents their study results is the fourth topic of accessible participation.

Boundary conditions

A consequence of being visually impaired is the challenged ability to navigate spontaneously. Physical access is experienced as more than going somewhere. Practical and informational support is appreciated and provides embedding in the event.

Paying attention to multiple boundary conditions then enables participants to belong as an audience and speakers.

Leendert: During the second international Disability Studies conference in 2013, the theme was The Art of Belonging', which 'not only reflects on aspirations to encourage high levels of participation of people with disabilities, but also the centrality of this concept when engaging disabled people in research' (Budge et al., 2016). To make this happen, there was the so-called buddy project: participants who needed it could make use of a buddy, someone who walked along and read texts, and indicated a convenient place in the room to sit down. In 2013, I was able to be myself in a very natural way.

Jentel: In addition to this good practice, I experienced the value of a pre-determined assistant during the EPATH conference in 2019 and Academia Ophthalmologica Belgica in 2019. The supportive and amicable relationship provides a complementary match (Budge et al., 2016), whereby the assistant is a trustable and safe point. You can share your personal interests in advance, and they can take these preferences into account. Moreover, this acquaintance can assist during wider travelling (hotel, transport) when the conference consists of multiple days. However, it does not substitute for a community of attentive colleagues, a network of friends who take you into the ambience. You need more than good support to belong.

Leendert: In connection with making plans—for instance, for transport or to be able to go to the right room—it is important that the information is clear in advance and at the moment you are involved in the conference; for example, the times, the address, where you are expected in the building, etc. This information is conditional to functioning naturally during the events.

Jentel: For visually impaired people, it is difficult to navigate unfamiliar spaces: this practical need should be acknowledged. Some locations are easy to find by car but are inaccessible with public transport. The ability to acknowledge your need to be guided to or from the event location encourages me to set up a transport plan in advance. In that case, a structured overview of sessions, speakers, rooms and additional services due to special needs on a webpage or in a (digital) conference book is very helpful. At online conferences, it is also helpful to explore the tools in advance so that short keys are well known previously.

Leendert: Sometimes presentations may be plenary sessions designed for all attendees, and then there are breakout sections designed for smaller groups. In such a case, I often need help to find the right room. During meetings it is useful to know how a room is set up, so you do not end up in an odd place or where the guide dog must stand up in front of passers-by.

Jentel: I personally prefer a place at the exterior of the room, close to the doors/ walls, because of various motivations. I feel safer there than being in the crowd, the overload of whispering sounds is less dominant, and most times the wall outlets to charge your computer with braille, screen magnifier or screen reader software to take notes are over there too.

Leendert: It is also helpful to receive presentations in advance so I can read the content or follow the slides. I appreciate it when these presentations are well *structured because sometimes I miss the link between the speech and the visuals. I also like when relevant texts or images are read out during the meeting.*

Jentel: For the audience, having access to the content is a boundary condition, and it is an exercise for speakers to provide this. When I present research data, I also try to make the presentation accessible. For instance, I visually show citations of qualitative research on the slides and let the audiences also listen to a pre-recorded voice that reads them out loud.

Lessons that can be learned by academic conference organisers are offering assistance, clearness, comfort and attentiveness. This flexibility and creativity allow accessible participation by focusing on basal issues that otherwise would dominate the person's functioning.

Intensive preparation

Drawing our attention to other dimensions of our participation, such as the use of assistive technology or thoughts on receiving support, prompted us to speak about other aspects of our participation that impacted our experiences. For us, accessible participation is also linked to intensive preparation. The opportunity to develop and follow our own way of acting, which we answer with accessibility to our individual challenges, makes participation possible.

Jentel: An alternative to ordinary visual presentations is to make a presentation and record your speech in advance. Then you show a kind of movie and are present to answer questions. This feels less qualitative or professional but has equal preparation intensity In this case, the accommodation of the room is conditional to making the sound heard.
Transcending this, I am aware of the visual support for the audience of a (poster) presentation, but I am individually unable to provide an aesthetic presentation myself. Mostly, I prepare the content in a text document, and someone else puts in the colours and contrasts. This collaborative way of working is very intensive and involves much communication to transfer my ideas into attractive slides. The development of such collaborative approaches facilitates deeper access and is an important learning experience that further enriches the process.

Leendert: Well-sighted speakers can have a look or sign elements on the screen to guide the audience or catch up in their minds during the speech. Visually impaired people are not able to do this. When I am confused or diverted in my structure, I am lost.
Often, I purely tell my story without visuals. So verbally structuring the content is highly relevant. For instance, I introduce my points, I detail them, and I summarise them at the end. Intensive preparation is again key in that case.

Jentel: Yes, improvising or adjusting to time changes is more difficult.

Leendert: Some blind speakers use keywords in braille, but also in that case you must read fast. The challenge is also to find effective, short words, and I experience this exercise more intensively than well-sighted colleagues who need to do this.

Jentel: Indeed, and in my experience, I often memorise my keywords at best and find that I do not need them during the presentation. However, it is helpful to have them so you can review yourself or go over the content in a break. In my view, it is not a problem to involve your audience to check the flow of the visuals and the presentation.

The conversations on intensive preparation also made evident the need to foresee all circumstances to enable these actions. Respecting particular struggles and the temporal or collaborative differences of workarounds is an openness that recognises additional efforts.

Connecting with colleagues

We are all subjects constituted in or as our relations. Disability brings relational encounters to the world: through getting to know one another, we all get to know a little more about disability. Thus, being blind in a sighted environment can teach us about interdependency in expected interactions. Whitburn and Michalko (2019) emphasise that interdependent relationships between visually impaired people and other (non-)human entities facilitate everyday tasks such as inclusion, mobility and travel. Consequently, relational accessibility is embodied in conversations about participation and belonging in academic conferences. These events are fundamentally built on exchanges, so finding connectivity is highly relevant. We focused on the interactional access struggles within this educational environment by exploring our initiatives to strengthen personality and communication.

Leendert: At the start of a meeting where interaction will take place, it is useful to get an impression of who is present and where everyone is sitting. I need a guide to get around, but I also have limited orientation of my physical surroundings, which impacts negatively on my social skills.

Jentel: When speakers mention their names, I try to memorise who is who. This is impossible when one person introduces all speakers because then you hear vague descriptions of people and cannot link the correct name to the relevant speaker.

Leendert: I seek to prove the meaningfulness of my social existence or legitimise my appearance or participation. To be taken seriously as a researcher with a visual impairment, it is important to be and feel included in a mutual exchange of knowledge. This involves being included in informal talks and networking situations during breaks without people who are shy to speak directly. We want to share knowledge at the intellectual level of conferences, where we are not only recognised as interested clients but as researchers. I am searching for equality in situations in which I have felt stigmatised. Using a cane is in place to facilitate my inclusion, but it sometimes inhibits my approachability because of outsiders' assumptions that blindness is accompanied by deficiency so they do not have the need to talk to me (Michalko & Titchkosky, 2018).

Jentel: I cannot target helpers or make quick eye contact to connect with interesting people. And how do you do that to recognise other conference attendees?

Leendert: I have no idea what many fellow researchers look like, so I can't let someone else look out for them. I often recognise them by their voices, provided I've heard them before. And sometimes you catch names, and then you prick up your ears to determine which voice belongs to them.

Jentel: During breaks, it is nice when someone invites you to join a walk so that you can get a drink or network with other conference participants.

Leendert: Or you can go to the toilet or walk the guide dog. At the end of the meeting, it is also nice to get assistance to the exit and/or the taxi.

Jentel: It is fine when someone describes the room. First, to experience the ability to move spontaneously on the stage or with the microphone and be sure not to stand in the middle of the screen. Also, to know where I can locate the audience to involve them by (socially modified) eye contact. This emphasis on facial expressions and body language is ocular-centric and exclusionary for visually impaired people (Bolt, 2017; Whitburn & Michalko, 2019).

Leendert: Yes, I would like to know who is taking part and if there are acquaintances to whom I will apply my story. Otherwise, it seems far away when someone I know is asking a question out of nowhere. Anyway, vast groups are difficult to measure their alertness; small groups are easier for managing interaction.

Jentel: We also learned some tricks to involve the audience. For instance, moving your head seems as though you have acknowledged everyone, making gesticulations or using your body to support the story, portray or emphasise words with your hands. ... It is kind of acting like a well-sighted speaker, passing the normative format of what is expected. I am aware of doing visual things that are commonly expected.

Leendert: Yes, but this is a tricky balance too. When you are acting natural, others forget your impairment over time. When they raise their hand to add something or gesticulate when posing a question, this is still unavailable to us.

Organisers of academic conferences and all attendees can initiate accessible participation relationally by addressing the visually impaired person. Connecting with each other to give descriptions can be a starting point for further exchanges of knowledge.

Doing scientific contributions

Sharing scientific knowledge is an important goal while participating in academic conferences. In common with their colleagues, visually impaired academics desire to make scientific contributions. This can be at the level of making their experiential knowledge explicit by illustrating methodological confusions and solutions.

Jentel: At international conferences, the primary language is often different to the native language of the participants and speakers. Assistance with language translation is helpful but might be confusing when it interferes with audio descriptions of presentations. Whispering to describe, translate language or translate the meaning of visual content is not always possible when there is much noise in the (meeting) room. Even taking notes during the presentations is an extra element that makes the *multitasking experience challenging. All my senses are over-active during conferences.*

Leendert: Maybe due to the circumstances, I must show relatively much of what I can't do, while normally, in daily life, I can do a lot. Therefore, the first impressions I give other participants are not the impressions of someone who is doing well. In daily life, I know where I can find everything I need, for example. That's also why I find conferences challenging with all their intensities.

Jentel: My fear of bumbling during Q & A sessions is recognisable. The volunteers in charge of roving/handing microphones to the audience members are ready to help, to hold the microphone close enough to our mouth. But this moving of objects, things coming close to your face, not knowing when you can speak, feels stressful. For me, it is more comfortable to speak out loud for myself, whereby the speaker guarantees sound quality by repeating all comments or questions.

Leendert: And do you have a wish?

Jentel: On this issue, it is highly significant that there is openness to experiment with presentation styles. I value acting autonomously: making individual choices about my own style of presenting enables me to take part independently. We have experiences with our impairment and the common ways of presenting. Relative to time, background and experience, some presenting styles are less useful. When conference organisers are flexible, this helps massively. The goal of each researcher is to valorise their knowledge, and the way they do this is subordinate. We need the independence to prepare intensively and choose the way of saying that best fits the message of our presentation. An effective technique is ultimately what works for everyone.

The conversations showed how visually impaired academics participate in academic conferences. Recognising such expressions and showing admissibility to add small nuances in doing academia differently can increase its accessibility.

Discussion and conclusions

This article focused on the experiences and participation outcomes of the first two authors in academic conferences in a university context. Participating in academic conferences is inextricable from doing research, but the presence and participation of disability in these events are related to a host of procedures rather than peoples' rights and desires (Titchkosky, 2010). The first two authors dialogued their experiences with and obstacles in the accessibility of scientific practices and participation in these events as PhD researchers with a visual impairment. They examined the architecture and cultures of academic conferences. The overt and covert barriers to access and presence, participation and success in education were a basis for collecting inspiration and knowledge.

The impression was that academic conferences are organised with sighted audiences and speakers in mind. The cultural, structural, material and relational barriers that possibly prevent equitable participation were challenged (Whitburn & Michalko, 2019). On the issues of boundary conditions, intensive preparation, connecting with colleagues and making scientific contributions, it was made explicit what happens invisibly or differently to provide seamless access (Whitburn, 2014). Noticing this could be an eye-opener; the accessibility of and participation in events could be made conscious. It can give answers to others who have questions about the accessible participation of disabled people in academic conferences. But explaining what individuals do to improve their participation—or how they unsettle and challenge exclusionary practices—is not the whole story. Using more assistive technologies can be an alternative to improve physical participation (Whitburn & Thomas, 2021). Suggestions are available for doing things differently (by arguing for clearness in advance, for instance). However, academic conferences are fundamentally relational events, whereby empathy and responsibility are expected from everyone to take part and find their way. Collectively shared engagements in setting up inclusion is primordial: accessible participation must be negotiated at each moment with who is related and based on needs of the people that attend. It is not one size fits all and there can be conflicts in the accessibility that we need to address together. We are all in the same event, but not one and the same, when it comes to our needs. Responsibility for primary participation does not lie with the first two authors but with all those involved in the academic activities. Relational negotiation is highly relevant in this case to dialogue about accessible participation in advance, during and after academic conferences. Moving systems of participation can be a shared responsibility to fulfil the collective ethical responsibility to provide accessible participation (Titchkosky, 2011; Whitburn & Thomas, 2021).

The dialoguing provided a constructive contribution to making participation in academic conferences accessible by bringing it to consciousness. Sharing what often happens invisibly or remains unseen, has an added value. The intention was to make explicit the first two authors' participation in academic conferences, and their unaware ways of doing this, to learn for themselves and to educate organisers of conferences. The dialogue created more insight into what is experienced. Such dialogic exchange of experiences formed a starting point for further learning and feeling embedded, not being alone in searching for accessible participation. It remained in the relational interplay and not the responsibility of one or the other, the gathering is where accessibility emerges. Accessible participation can function as a source of opportunities to connect with everyone who engages in academic conferences. The desire is to stimulate inclusive thinking that incorporates accessible participation for everyone (Titchkosky, 2011). The process of searching together is maybe even more important than a totally accessible conference. Disability is in the centre of this disturbance, it helps to continue the search, rather than accepting the status quo. This might be a starting point for further facilitating accessible participation. There will not be social inclusion all at once, but every step towards social inclusion makes participation easier. It might be an activity of working collaboratively together.

References

Beckwith, D. (2019). Chapter 3: Disability advocacy within the ableist environment of academia. In C. McMaster & B. Whitburn (Eds.), *Disability and the university: A disabled students' manifesto*. Peter Lang.

Bolt, D. (2017). Enabling the classroom and the curriculum: Higher education, literary studies and disability. *Journal of Further and Higher Education*, 41(4), 556-565. http://dx.doi.org/10.1080/0309877X.2015.1135888

Bolt, D., & Penketh, C. (Eds.). (2016). *Disability, avoidance and the academy challenging resistance*. Routledge.

Brown, N., Thompson, P., & Leigh, J. S. (2018). Making academia more accessible. *Journal of Perspectives in Applied Academic Practice*, 6(2), 82-90. https://doi.org/10.14297/jpaap.v6i2.348.

Budge, F., Kool, J., Van Hove, G., & Miranda, B. (2016). More than a 'Nice Day Out'—How to encourage the meaningful participation of people with learning difficulties in disability conferences. *Journal of Educational Research*, 4(3), 27-34.

Bulk, L. Y. (2020a). Being blind and belonging in academia. University of British Columbia. https://doi.library.ubc.caboa4288/1.0395453.

Bulk, L. Y. (2020b). Occupational rights, choice and variety: A critical occupational analysis of British Columbia's Framework for Accessibility Legislation. *Journal of Occupational Science*, 29(4), 577-585. https://doi.orghoa080/14427591.2020.1805639.

Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. SAGE.

Clarke, A. (2005). *Situational analysis: Grounded theory after the postmodern turn*. SAGE.

Davies, B. (2014). *Listening to children: Being and becoming*. Routledge.

Jager-Vreugdenhil, M. (2011). Spraakverwarring over participatie. *Journal of Social Intervention: Theory and Practice*, 20(1), 76-99.

Lave, J., & Wenger, E. (1991). Situated learning: Legitimate peripheral participation. Cambridge University Press.

McCall, K. (2019). Chapter 17: Identifying and eliminating digital barriers. In C. McMaster & B. Whitburn (eds.), *Disability and the university: A disabled students' manifesto*. Peter Lang.

McCormack, C. & Collins, B. (2012). The affirmative model of disability: A means to include disability orientation in occupational therapy? *British Journal of Occupational Therapy*, 75(3)456-158. https://doi.org/10.4276/030802212,10.33=9571909.

Michalko, R., & Titchkosky, T. (2018). Traveling blind. *Disability Studies Quarterly*, 38(3). https://doi.org/10.18061/dsq.v38i3.

Schoeters, L. (2021). HiLives bijeenkomst—Onze Nieuwe Toekomst [HiLives meeting—Our New Future], presentation 24 November.

Titchkosky, T. (2008). 'To pee or not to pee?' Ordinary talk about extraordinary exclusions in a university environment. *Canadian Journal of Sociology*, 33(1). https://doi. org/10.29173/cjsi526.

Titchkosky, T. (2010). The not-yet-time of disability in the bureaucratization of university life. *Disability Studies Quarterly*, 30(3/4). https://dsq-sds.org/article/view /1295/1331.

Titchkosky, T. (2011). *The question of access: Disability, space, meaning*. University of Toronto Press.

Tregaskis, C., & Goodley, D. (2005). Disability research by disabled and non-disabled people: Towards a relational methodology of research production. *International Journal of Social Research Methodology*, 8(5), 363-374. https://doi .orgho.1080 /13645570500402439.

Vandenbussche, H., & De Schauwer, E. (2017). The pursuit of belonging in inclusive education—Insider perspectives on the meshwork of participation. *International Journal of Inclusive Education*, 22(9), 969-982. https://doLorg/10.1080/13603116.201 7.1413686.

Vosters, N., Petrina, R., & Heemskerk, I. (2013). *Inclusief Werken aan zorg en welzijn voor iedereen*. [*Inclusive. Working on care and well-being for everyone.*] Coutinho.

Whitburn, B. (2014). Accessibility and autonomy preconditions to 'our' inclusion: A grounded theory study of the experiences of secondary students with vision impairment. *Journal of Research in Special Educational Needs*, 14(1), 3-15. https://doi.orglioam/1471-3802.12014.

Whitburn, B., & Michalko, R. (2019). Blindness/sightedness: Disability studies and the defiance of di-vision. In N. Watson & S. Vehmaas (Eds.), *The Routledge handbook of disability studies* (pp. 219-233). Routledge.

Whitburn, B., & Thomas, M. K. E. (2021). A right to be included: The best and worst of times for learners with disabilities. *Scandinavian Journal of Disability Research*, 23(1)404-113. https://dotorg/10.16993/sjdr.772.

Zhang, Y., & Wildemuth, B. M. (2009). Qualitative analysis of content In B. Wildemuth (Ed.), *Applications of social research methods to questions in information and library science* (pp. 308-319). Libraries Unlimited.

Intermezzo 2: Cripping time: temporalities in academia

INTRODUCTION: TEMPORAL EXPECTATIONS
DISABILITY AS AN INTENSIFIER
PREPARATION AND CONCENTRATION
ACCESSIBILITY OF THE WORK ENVIRONMENT
RECOMMENDATIONS FOR INSTITUTIONAL IMPROVEMENT
REFERENCES

Based on: Van Havermaet, J. (2025). Chapter 2: Cripping time: Temporalities in academia. In C. McMaster & B. Whitburn (Eds.), *Disability and the university: A disabled student’s manifesto* (pp. 11-18). Peter Lang.

Introduction: temporal expectations

In undertaking academic learning and research, everyone combines different rhythms of time. We exist in all modes of times that ripple out all at once, through which we must search for ways to accomplish our goals and academic demands. Current organisational policies, study and work conditions in the higher education sector significantly impact the mental health of university students (Levecque et al., 2017). We can experience constant strain due to the time and energy consuming practices that keep pushing us into an unhealthy work-life style. The meaning of 'full participation' is assumed as a complex entanglement of intensities, dimensions, timeframes, and speeds (Vandenbussche & De Schauwer, 2017). Ableism and excellence are idealised and valued highly. Being included means paradoxically complying with temporal progression and engagement (Whitburn & Thomas, 2021). It is relevant to all (PHD) students that we can look critically to these neoliberal framing of time in universities.

A possible danger of this meaning of time is that universities pose disabling contexts for (doctoral) students, with little room for difference (Brown, 2021). Yet, in a hyper-productive environment, our experiences with being short-in-time can be intensified by the demands of life. For example, time is differentially measurable for people with disabilities. Normative time frames need to be approached flexible than, and this flow can be unsustainable in the longer term: strategies over a protracted period create time bombs as the additional efforts are not endless. Basing on my own experiences as a (doctoral) student who is vision impaired, I will show how I encountered temporal barriers. In describing examples of how I am differentially temporal, I try to crip time in academia. Like Alison Kafer (2013) states:

> *Crip time is flex time not just expanded but exploded; it requires re-imagining our notions of what can and should happen in time, or recognizing how expectations of 'how long things take' are based on very particular minds and bodies. Rather than bend disabled bodies and minds to meet the clock, crip time bends the clock to meet disabled bodies and minds. (p. 44)*

At the same time, we can also encounter other notions of time in academia, specifically, those found in the disciplines of disability studies and (post)qualitative research inquiries. Understanding this time is formed through the interrelatedness of taking time, occurring in time, and time through reflection and depth (Chi Wing Lau, 2019; Titchkosky, 2010). It is about finding a slower form of scholarly being, a different type of productivity. Relationally being in it together whereby time is doing something in the process. It is finding ‘more time to think, to digest, and even to misunderstand each other in building a dialogue between the natural sciences and humanities’ (Bozalek, 2017, p. 45). It is standing still, or seeing slowly, that reveals what might otherwise be quick to overlook (Ulmer, 2016). Reciprocity and slowness are of high importance to make space for contextualisation and complexity. By circling and re-circling, conceptualising and re-conceptualising, searching and re-searching/researching; the strict temporal procedures that pose limitations and ableism can be disturbed and overruled, in favour of a human, collective, circular sense of time.

This chapter is about struggling with time, experiencing academic time pressures, needing more time to do things or using time differently when you live with a disability. Placing my experiences as a doctoral student directly in the field of vision, is setting the time to watch the synchronising of different temporalities. I incorporate a complexity of multiple contradictory rhythms and workings of time where several speeds continually crisscross. I take time to fulfil necessary engagements. I search for other modes of time, providing small cracks, or cripping time. Students with disabilities have the power to time travel, creating new rhythms of time and attuning their inner clock to the system.

Disability as an intensifier

Disability and time are inextricably linked with each other. Living with a disability can be experienced as a time-intensive process and implies the complexity of juggling additional time-consuming activities. Dominant temporal regimes and schedules that encourage particular rhythms, paces and work scales, do not align with disability (Chi Wing Lau, 2019). In the bureaucratic structures and framing of time by universities, disability is taken for granted in a problematic and avoidable way. As a result, the academic journey of disabled students is frequently affected: additional efforts and extra workload shrink our time. We are structurally subjected to pressures; we must overcompensate for our disability in these temporal regimes, and we must acknowledge these efforts. Yet, the clock does not slow down because we need more time.

Living with a vision impairment creates particular challenges comprising additional roles (Jammaers & Williams, 2021). For instance, I must find time to undertake hospital appointments and rehabilitation sessions. Medical (eye care) consultations, mobility lessons and those for activities of daily living, and disability-specific follow-up conversations also take place during working hours and at locations outside the office, which all involve additional time. Exploring the environment, housing ‘alone’, building and sustaining (new) social networks, and organising shopping of daily living are other activities related to living away from a familiar home and near a university. On the one hand, I need to perform necessary and conditional time-consuming actions because of my impairment (Bulk, 2020). On the other hand, my tempo is personally experienced slower or not compatible with my impression of the expected rhythm of fellows (Brown, 2021; Whitburn & Thomas, 2021). I must do more in less time which provides pressures, and the complex balancing act of self-care and (over)compensation takes up much of my time.

Perpetuating ableism in academia and intern pushing thoughts conflict with my need to slow down, being forced to choose slowness over speed and rethinking daily life, due to the impairment of fostering a long-term, healthy, sustainable, balanced, and meaningful way of being. The amount of work is not adapted to what can get done in the productive hours. It feels more like a balancing act between utilising pre-identified adjustments and still failing to comply with the normative timeframes of academic culture of speed. This, quite simply, needs to change. Students with disabilities can explore their time, incorporating all intensities. Rethinking normativity, independence, and autonomy in how we are using time is helpful not only for students with disabilities, but for all people involved at university. Students with disabilities can help to put this on the table.

Preparation and concentration

Undertaking a similar level of intellectual engagement and fulfilling tasks equal to colleagues often requires greater time investment on my part. In relation to undertaking readings and writing a thesis or assessment work, certain actions require additional time, concentration, and collaboration. For example, I must invest longer periods of time reading relevant literature using a screen reader. Developing artisan skills and collaborating with support is also necessary in the analysis stage of a study, due to the inability/inaccessibility of relevant software. External assistance is invariably needed to support referencing and formatting, and other visual support is needed to lay out presentations. In these cases, I must first prepare the content, after which to negotiate with my personal assistant until we reach an acceptable result, which is accessible to me and visually attractive for audience. Schematising substantial amounts of data also demands extra temporal engagement. All of this not only asks for intense additional efforts; it also leads to physical and emotional exhaustion.

It is not difficult to understand how the above can impact on my concentration levels, and those of other students with disabilities. Working harder, for longer hours, is challenging. To craft a balance for myself, I attempt to control the length of days by working part-time at a daily average of six hours. But my study/employment circumstances often demand more work hours, forcing me to adjust to the needs of the educational/research program. While it may be possible on an individual basis to discuss progress and build in flexibility with supervisors, this is not always possible nor aligned with the structured milestones and ultimate expectations of an academic program. Customising the trajectory is difficult because essential tasks are often neither adjustable nor redistributable. The institutional and governmental rights and underlying laws need to become negotiable in favour of inspirational and differential practices.

Disability also demands extra time for daily living. Functioning in an able-bodied study/work environment involves the need for pre-planning and it can require additional energy. For example, customising things with braille labels or memorising workarounds of the microwave and coffee machine. Help from others (or in other words, their time) still stays necessary. Additional external audits, communication with IT managers, drawing an alliance with another impaired person of the university, the installation of extra software, … have all been necessary to enable functioning. I even find myself needing to ‘educate’ the cleaning team, asking if they could return the dustbins to the same place every time they clean, and not to place chairs on the tables with the legs upwards. This is a form of self-advocacy, which is yet another demand on personal time. The design of the institution can be a constraint. Even flexible workplaces and open offices can be unworkable due to the sensory overstimulation and constant variability of the environment. Finding your way around such an environment can present ongoing hindrances.

Collaborating with a diverse group of colleagues is already potentially fraught. With a disability, this can be magnified and requires an attentive attitude and the time for negotiation. For vision impaired people, for example, it is difficult to recognise others, or pick-up on non-verbal communication in group conversations; a lot of (in)formal exchanges and photos might be missed. It feels awkward to have social conversations not knowing who you are speaking to or participating in meetings when you do not know who is there. Compensating in such events often needs extra efforts. I sometimes miss on the 'fun' moments, taking recuperation time due to fatigue because of impairment effects, which fellows or the university administration are unaware is happening. The functioning of everyone must be collectively supported, which requires a rethinking of how we 'do' time together.

Accessibility of the work environment

Persons with a disability can request reasonable adjustments in the level of organisation, content, proportions, circumstances, and conditions of their engagement. However, this aspect of the support system is often individualised and time consuming to navigate. In the university, I need to learn how the 'reasonable adjustments' system works and spent many hours following up on almost every aspect. The onus falls on the student—I am expected to take responsibility for my support needs in the process. While this appears logical, it is often experienced as an inefficiency. A student with a disability cannot start making arrangements to enable disability-specific support before their first day, for reasons that in some cases it may not be clear what sort of support they might need. As a result, the starting period of administrative formalities is time-consuming, and delays are almost always inevitable. At my institution, it was impossible to officially employ a personal assistant for a project application writing process, and it took more than six months until she could begin to provide me the necessary support.

Accessibility standards are now included in many areas of higher education institutions (Titchkosky, 2010). But accessibility requirements are implicated in our temporal capacity to study, which can challenge and shrink our time to focus on actual work. For the student with a vision impairment, for example, printed textbooks or course materials need to be scanned by hand or obtained electronically, which requires external help and additional time. Existing digital documents are not always automatically readable, and these need to be remediated or retrofitted to provide accessibility. The internet, digital classrooms (or Learning Management Systems), and library platforms with publications are often not designed with universal design principles. Searching or reading information online is, as a result, an overwhelming and excessively time-consuming task. Paradoxically, I ask my personal assistant to explore the literature and to send accessible versions of resources, instead of learning to work around or deal differently with these challenges. While it is time-consuming to communicate with someone else, it is more efficient than struggling repeatedly on my own with time bearing down. It would be time saving if accessible access to all materials existed for everyone.

Mobility is also often taxing on time for disabled people. People who are vision impaired, for example, are highly dependent on public transport or taxis. But walking and using public transport to reach the campus is a highly concentrated exercise. Safety and fluidity of moving might be challenged because of route changes or road works. An occupational therapist trained me to use a cane, and to be attentive to landmarks. Orientation and mobility sessions are intensive, and each route requires repetition. Familiar routes become a habit but moving for me is never an opportunity to relax. I am constantly forward planning: ‘Next traffic Island is the bus stop; pay attention to the cyclists on your left; two meters after the traffic sign is the pedestrian crossing.’ Locational crafting by using the ability of telework can cut down the hours needed to reach the department. Searching or understanding visual prompts or applying GPS guidance takes more time and the safety of the roads cannot be estimated. To collect research data at participants' homes, or attending conferences, is additionally challenging because of physical issues. The schedule of the university does not typically account for these temporal engagements in its temporal design.

Recommendations for institutional improvement

I belong in academia, as does every disabled person. But the inaccessibility of time related resources and facilities raises important questions. My experiences in academia as a vision impaired person challenge the stereotype of disability in able-bodied culture and includes the embodiment of temporarily corporeal difference in the conversation. My experiences are not particularly unique in academia. Time weighs on all of us. Institutions need to re-structure academic temporality in traditional paths: reclaiming time for learning and doing research, being able to prioritise reading, thinking, and writing about the topic (Chi Wing Lau, 2019). Temporal differentiation (Whitburn & Thomas, 2021) could enable people to balance their jobs, additional tasks, and personal time engagements. This is not solely of high significance or relevance for disabled people, but for everyone who experiences time pressures in their work as a (doctoral) student, often in combination with personal and family live. The issue, for everyone, is to scale the value of the intensifier(s) in the workload in a healthier way that respects the extra efforts and takes away unnecessary barriers.

The current flow of academic time is a barrier to inclusion. Academic institutions can slow things down. Developing knowledge cannot be a linear path and cannot follow the traditional rhythms of the clock. This chapter calls for a de-escalation and slowing of the pace and volume of academic production and performativity, not only for disabled students, but for all scholars. It challenges the institution to de-prioritise speed, efficiency, acceleration, output, and standardised timelines in academic work.

We need to talk about time, and how the institutional concept of time continues to confront students with a disability with disablement and ableism in this very privileged environment. Students who live with disabilities should be able to work at their own pace. Each expression of struggling with or fighting the academic temporalities are meaningful small cracks that questions or moves the institutional system and its attitudes.

Such a rethinking of academic time is a collective action. Sharing experiences of contradictory temporalities makes everyone aware of what happens or needs to happen, as a meaningfully form of education. An individual fighting the system does not work. This asks for slow learning together; it asks for coalitions. We need to try alternatives, grow our small cracks upwards, as well as disrupt and resist the existing model of institutional time. We need to imagine different ways of being and becoming in time: cripping time, by exploring creative and flexible temporalities.

References

Bozalek, V. (2017). Slow scholarship in writing retreats: A diffractive methodology for response-able pedagogies. *South African Journal of Higher Education*, 3/(2), 40-57. http://dx.doi.org/10.20853/31-2-1344

Brown, N. (Ed.) (2021). *Lived experiences of ableism in academia. Strategies for inclusion in higher education.* Policy Press.

Bulk, L. Y. (2020). Being blind and belonging in academia [Doctoral dissertation]. University of British Columbia. https://doi.library.ubc.ca/10.14288/1.0395453

Chi Wing Lau, T. (2019). Slowness, disability, and academic productivity: The need to rethink academic culture. In C. McMaster & B. Whitburn (Eds.), *Disability and the university: A disabled students' manifesto* (pp. 11-19). Peter Lang.

Jammaers, E., & Williams, J. (2021). Care for the self, overcompensation and bodily crafting: The work-life balance of disabled people. *Gender, Work & Organization*, 28(1), 119-137. https://doi.org/10.1111/gwao.12531

Kafer, A. (2013). *Feminist queer crip.* Bloomington: Indiana University Press.

Levecque, K., Anseel, F., De Beuckelaer, A., Van der Heyden, J., & Gisle, L. (2017). Work organization and mental health problems in PhD students. *Research Policy*, 46(4), 868-879. https://doi.org/10.1016/j.respol.2017.02.008

Titchkosky, T. (2010). The not-yet time of disability in the bureaucratization of university life. *Disability Studies Quarterly*, 30(3/4). http://www.dsq-sds.org/article/view/1295/1331

Ulmer, J. B. (2016). Writing slow ontology. *Qualitative Inquiry*. https://doi.org/10.1177/107780041 6643994

Vandenbussche, H., & De Schauwer, E. (2017). The pursuit of belonging in inclusive education—insider perspectives on the meshwork of participation. *International Journal of inclusive Education*, 22(9), 969-982. https://doi.org/10.1080/13603116.2017.1413686

Whitburn, B., & Thomas, M. K. E. (2021). A right to be included: The best and worst of times for learners with disabilities. *Scandinavian Journal of Disability Research*, 23(1), 104-113. https:// doi.org/10.16993/sjdr.772

Chapter 6: Discussion and conclusions

INTRODUCTION
RECONCEPTUALISATIONS OF BLINDNESS
    As many-ness
    As different sensorial ways of doing
    As a way of being in the world
    As learned social roles, in cohabitation with a dominant sighted culture
    As a teacher
    As something to love
    As relational understanding
OMNIPRESENCE OF OCULAR-NORMATIVISM
    Confrontations with ableism and ocularcentrism
    Urge to prove oneself as independent and valuable
(DIS)APPEARING ACCESS
    Rethinking access: from infrastructural fix to contextualised process
    Mobility and transport as a cornerstone for accessibility
    Support and interpersonal access
    Friction and access as political practices
DOING RESEARCH: SITUATED KNOWLEDGE AND CRITICAL COMMITMENTS
    Disability studies: researching at the intersections
    Being the insider: researching with disability
REVEALING ‘THE MORE’: OPEN-ENDED UNDERSTANDINGS BEYOND NORMATIVITY
REFERENCES

Introduction

This discussion chapter revisits the foundational commitments laid out in the introduction (Chapter 1): to take lived experiences seriously as both a point of departure and a generative site for building knowledge. Drawing on disability studies, this PhD resists deficit-based, ocular-normative conceptions of blindness by foregrounding personal narratives, relational entanglements and material-discursive complexities. The insights presented here do not seek to define blindness over again but instead want to deepen its conceptualisation through themes that emerged across the empirical chapters and theoretical dialogues.

Building on the groundwork of earlier chapters—which explored blindness through the lenses of parenting, education, social participation, materiality and scholarly positionality—this discussion chapter gathers, synthesises and extends those insights. It brings into focus an assemblage-informed understanding of blindness, while simultaneously confronting the omnipresence of ableism and ocularcentrism that shape everyday experiences. The chapter foregrounds the tensions, negotiations and possibilities that arise in the lived realities of blind people and their networks, while reflecting critically on the methodological, epistemological and political commitments of doing research with disability rather than simply 'on' or 'about' it.

Rather than arriving at closure, this discussion opens up the complexity of daily living. It invites readers to think with the multiplicity, fluidity and relationality of blindness and consider how identity, worth and access are co-constituted in and through human and non-human encounters. The following pages trace how blindness is not a singular state, but an evolving constellation of meanings, practices and entanglements. In doing so, this chapter makes the case for reconceptualising blindness not as lack, but as lived difference—rich with epistemic potential and critical insights. By making urges to prove oneself as independent and valuable in response to confrontations with ableism and ocularcentrism, and by rethinking access as relational and creative activist affordances, the PhD closes with the invitation to reveal 'the more'.

Reconceptualisations of blindness

This PhD draws on the commitment of disability studies to rethink disability from lived experiences and to resist dominant medical and deficit-based framings of disability. Rather than accepting a tragic or deficit-oriented view, blindness is explored as an identity marker that holds meaning beyond its contrast with sight. It repositions blindness from a fixed biomedical condition into something that appears and becomes meaningful through its contextual, material and relational entanglements (Titchkosky et al., 2022; Van Havermaet et al., in press). This discussion chapter builds further on the conceptual groundwork in the introduction (Chapter 1), emphasising the significance of narratives that enrich our understanding of blindness as a complex, embodied and socially situated phenomenon. By engaging directly with these experiences, this doctoral research offers a counterpoint to external and professional (ocular-normative) projections that often reduce blindness to absence, loss or lack, while contributing to rethinking access and participation.

Blindness has long been framed through dominant definitions of sighted professionals (Bolt, 2013; Michalko, 1998). This doctoral research challenges reductive portrayals by focusing on how blind people perceive and interpret their experiences (Healey, 2022; Whitburn, 2014a, 2014b; Whitburn & Goodley, 2019). Participants and scholars emphasise complexity, agency and richness of perception that resists singular definitions. They argue that a blind experience is far more complex and has more nuances than simplistic descriptions suggest (Omansky Gordon, 2004). They take ‘blindness as a thing in itself, as an experience and an embodiment that does not have to steal its terms and borrow its existence through the process of metaphorization’ (Davis, 2012, p. X). Their reclaiming of the gaze focuses on what it means to be blind and how to live with that condition (Bulk, 2021; Hammer, 2018; Kleege, 2018). This PhD builds on those perspectives to highlight how blindness is lived as perception, not distortion, and how the meanings attributed to blindness differ profoundly from external assumptions. Exploring lived experiences reveals how blindness appears and disappears in different life domains and circumstances. In accordance with experiencing blindness, other conceptions of blindness have been developed, often ‘thinking with’ other blind scholars.

As many-ness

Blindness cannot be reduced to a static condition or a single story. Bolt (2023) and Titchkosky et al. (2022) tolerate a world with many stories to tell, full of sights. Many blindnesses, a diversity of blindnesses or a range of blind experiences, meanings and feelings are possible (Kleege, 2018; Rodas, 2009; Titchkosky & Michalko, 2025). Each story reveals blindness as fluid, multifaceted and dynamic. Each person who lives with visual impairment brings forward unique and evolving narratives, shaped by personal history, contexts and interactions. This ‘many-ness’ of blindness (Healey, 2017, 2021, 2023; Michalko, 1998, 2002) reflects a broader diversity in how disability is understood, expressed and embodied. It disrupts the idea of a singular or normative disability experience, emphasising instead that blindness can take many forms—each with its own logic, emotion and rhythm.

As different sensorial ways of doing

Blindness gives rise to alternative sensorial strategies for navigating and engaging with the world. Seeing becomes a bodily, relational and cognitive process that extends beyond the eyes. There are more ways to look, more vantage points, more viewing conditions (Kleege, 1999). Blind people use touch, hearing, smell, memory and imagination in coordinated ways that challenge normative ideas of what ‘looking’ entails. These adaptations are not lesser but different—and often deeply creative and embodied. They reconfigure movement, communication and presence in everyday life. Blindness as seeing differently is a beautiful, powerful and graceful possibility of a perception quite distinct from what is commonly understood as coming along with sight (Healey, 2021). Rather than compensating for sight, these practices reshape what perception can mean (Grealy & Kleege, 1965; Michalko, 2002; Michalko & Titchkosky, 2020; Omansky, 2006). In this way, blindness becomes a form of doing; of inventing ways to engage with the world that are sensorially rich and experientially full (Kleege, 2018; Michalko, 1998, 2002, 2010).

As a way of being in the world

Blindness is not merely a sensory difference, but an embodied perspective that contributes to how one understands, relates and exists. It positions blindness as a meaningful way of being in the world (Michalko, 1998, 2002, 2009; Whitburn & Riffo-Salgado, 2024). It locates blindness as part of the world in a distinct and dynamic way. Blindness is an alternate way of being in and knowing the world; an embodied ontology and epistemology, a permanent companion to every facet of the embodied and lived experience (Healey, 2021, 2022; Omansky, 2006). It is tied to identity, memory, social connections and existential reflections. Blindness is not something to be overcome, but something that is lived with and through, offering insights into how life can be experienced differently and deeply.

As learned social roles, in cohabitation with a dominant sighted culture

Blindness does not arise in isolation, but within a network of social, cultural, generational and historical influences (Healey, 2023; Michalko, 1998, 2010; Titchkosky et al., 2019). This public matter is shaped by how societies define ability, assign roles and impose expectations. Blindness is learned (Scott, 1969; Whitburn & Michalko, 2019), in the sense that people adapt to social scripts and relational norms about what it means to be blind. These roles are formed in cohabitation with dominant sighted culture and are often mediated by language, representation and institutional structures:

> Given the diversity of the cultural stations … the blindness to which they lead differs from time to time, place to place, and person to person. We find blindness in different ways and learn about it from good, bad, or in different cultural stations. (Bolt, 2023, p. 4)

As such, blindness is a socially constructed experience that intersects with power, normativity and belonging (Bolt, 2023; Davis, 2012; Grealy & Kleege, 1965; Hammer, 2019; Kleege, 1999; Rodas, 2009).

As a teacher

Blindness can potentially teach (Michalko, 1998, 2009; Michalko & Titchkosky, 2020). It brings awareness and reveals hidden assumptions about perception, normalcy and knowledge. Living with blindness offers critical reflections on how we understand ability, difference and human variation. Blindness provokes thoughts about self, others and the world. It is an occasion for personal and societal learning, not because it needs to be explained, but because it illuminates new possibilities of knowing (Devos, 2018; Hammer, 2019). Healey (2021) argues that the specific character of blindness teaches all of us, disability studies, sighted people and blind people, that the perceptions of blindness may reveal a new understanding of the world: this ‘is more than meets the eye and it is this more that needs to be explored’ (p. 18). Approaching blindness as a teacher is also methodologically relevant, as it validates lived experiences as an epistemic resource.

As something to love

Taking disability as worthy, valid and valuable ways of being and becoming in the world is challenged by (socially learned) roles. Affirmative perspectives teach to view disability as a positive difference that can be celebrated and enrich life. Affirmative conceptions of blindness are perspectives that invite us to imagine, look and dream; to take disability as something positive. Rather than being a source of shame or limitation, blindness can also be appreciated and even loved. Blindness enriches life, opens new perspectives and fosters unexpected connections. This research affirms the idea that disability is not inherently negative, and grounds this epistemically valuable perspective also on more-than-human new materialist ideas. Blind scholars spoke of moments when blindness brought joy, meaning and shared experience or growing in togetherness (Bolt, 2017, 2023; Michalko, 1998). The book, *Letters with Smokie: blindness and more-than-human relations* (Michalko & Goodley, 2023), opens up a novel way of approaching blindness and gives the reader a peek into the joy and togetherness that also can come with it. Herein, guide dog Smokie strikingly remarked:

> Blindness gave me a chance to do shit I never would have done, and I wanted to show Rod [Michalko] that it would do the same for him ... it can be a shitload of fun.... Blindness meant more to me than just working and experiencing stuff and it meant more to Rod than just shit.... I want him to love his blindness. But I settled for him liking it, at least as a start. (Michalko & Goodley, 2023, p. 113)

It is relevant to notice that this affirmative perception of blindness is not universal or omnipresent. For instance, frictions caused by ocular-normativity or inaccessibility challenge how affirmative blindness is experienced. Rather than positioning blindness as something to be resisted, processes of embracing it as an integral part of oneself are described. This affirmation is not naive; it coexists with difficulty and frustration. But it also insists that blindness can be a source of pride, connection, creativity and emotional depth.

These conceptualisations of blindness (as many-ness, doings, beings, roles, teacher and love) emerged through crocheting with theory and experience. Throughout this PhD, these understandings became clearer, more grounded and more connected. Multiple readings of the literature accessed in this PhD made various conceptions appear. Each conceptualisation of blindness finds echoes in the participants' lived experiences, even when these experiences are subtle or obscured in daily life. While these conceptualisations open new understandings of blindness, they also produce tensions: fluidity exists alongside societal scripting, affirmation alongside resistance. The PhD has aimed to bring these ways of knowing into appearance, to honour their complexity and invite others to see blindness reconceptualised. Although the theoretical frameworks offer valuable ways to reimagine blindness, the empirical chapters of this PhD add nuance, tension and complexity to these conceptualisations. This discussion chapter adds one more understanding to the rich repertoire of blindness conceptions that became central in this PhD trajectory.

As relational understanding

Life unfolds through complex interdependencies (whereby everyone depends on each other). Ongoing exchanges, embedded relationships and entangled interactions shape it. This section deepens the relational understanding of blindness, as initially introduced in Chapter 1. Disability theorists have emphasised that 'one cannot be disabled alone' (Titchkosky, 2011, p. 5), confirming that disability emerges and is sustained through relational encounters. This approach extends blindness as personal difference to a collective or intersubjective matter (Michalko, 1998, 2002). Within this perspective, blindness is co-shaped in and through relational living. Throughout this PhD, the term 'relational' has been enriched, expanded and redefined, offering a nuanced lens to reconceptualise blindness.

As Whitburn and Michalko (2019) note, coming to know blindness necessarily involves recognising our shared participation in its co-creation. Others are central to how disability manifests itself in conversation and experience. This doctoral research investigates how relational interactions influence decision-making and everyday practices. The research traces the transformations in choices and opportunities that unfold in life. Participants' stories reflect shared trajectories and interwoven contexts and underscore how personal goals often require the contributions of others, both human and non-human. As everyone collectively transforms in previously unpredictable ways, great efforts of productive alliances and close links are acknowledged.

When approached relationally, blindness becomes co-constituted by people, places, materialities, discourses and histories. Partners, family members, friends, teachers, professionals and peers all contribute to how blindness is experienced in various domains such as parenting, education, mobility and work. The presence of a guide dog, assistive tools like the white cane, institutional structures and cultural environments also play significant roles. These human and non-human actors affect how blind people relate to the world, negotiate belonging and shape identity. In this light, relationality is dynamic and productive; it opens new pathways of knowing, becoming and belonging.

Across the PhD, blind perceptions within lived experiences were explored in various life domains. These form the empirical foundation for a deeper conceptualisation of relational blindness. Chapter 2 elaborates on how visually impaired parents give shape to relational parenthood. Social, formal and informal networks are crucial support for interdependent parenting. Chapter 3 illustrates how education, social participation and identity are entangled in intra-acting assemblages: blindness interacts with all these domains and who relates to the togetherness. In Chapter 4, materials and social expectations appear as actors in telling a story of blindness in an embodied way that appears and disappears shame and pride. From my insider position (see Chapter 5), these dynamics are both observed and experienced, allowing relationality itself to become a site of knowledge. These empirical chapters contextualise how blindness is lived, which underpins a conception of relational blindness. Thus, relationality is theorised as interpersonal togetherness and manoeuvring within multilayered connections. There is a co-creation of blindness in situated and affecting symbiosis. While these relational dynamics emerge clearly in lived experiences, they also resonate with and are deepened by theoretical concepts from new materialist approaches in disability studies.

Relationality in this research extends beyond interpersonal bonds. Blindness is also shaped through interactions with material and discursive elements: traditions, technologies, norms and social scripts. It refers to distributed networks of coexistence (Corcoran et al., 2019; Davies, 2021)—what is emerging within continuous entangled gathering of elements that compose movements, multiplicity, complexity and contingency. Barad (2007) calls this 'intra-action'. The usual notion of interaction assumes that separate, fixed, individual agencies precede their interaction, whereas intra-action signals the connectivity of engaging entities that are becoming within relation to others in the multiplicity of meshwork. New materialism highlights the agency of both human and non-human entities in co-producing meaning (Whitburn & Michalko, 2019; Whitburn & Riffo-Salgado, 2024). This approach contributes to a broader conceptualisation of relationality, as it is not neutral; intra-actions influence how blindness is enacted and understood. They actively participate in (re)shaping perceptions of blindness, identity, capacity and independence. They are emotional, temporal and affective interdependent companionships that sustain through mutual reliance and ongoing negotiation.

The concept of 'assemblage'—understood as both a process and a product of combining heterogeneous elements—offers a helpful frame (Vandenbussche & De Schauwer, 2017; Vandenbussche et al., 2019). In assemblages, people and objects coexist, co-create and co-act. Thinking through relational assemblages expands how blindness can be conceptualised. Blindness is not simply lived in relation—it is a relational phenomenon, embedded within and co-created by broader entanglements. Becoming-with becomes a way to reconceptualise blindness: as a situated phenomenon that exists in networks of social and material co-participation; not contained in the individual, but stretched and shared across interactions with the world, with culture, with others. Blindness is entangled with people, environments, cultural ideas, sightedness, animals and technologies—each providing an entry point to different versions of blindness. To explore how complex blindness is, or can be, thinking with assemblages helps to unpack all intertwinements.

As Van Havermaet et al. (in press) argue, disability is entangled with more than we can see. There is always more to tell, more to perceive, and more to become aware of. Relational approaches acknowledge friction, multiplicity and the ongoing emergence of meaning. This perspective aligns with diffractive methodologies that view knowledge as emergent through entangled processes of knowing-in-being (Bansel & Davies, 2014; Mazzei, 2014; Taguchi, 2012).

The unpacking of relationally informed conceptualisations of blindness is a key contribution of the PhD to the theoretical framework laid out in the introduction (Chapter 1). This relational lens destabilises the notion of blindness as a fixed attribute or deficit and instead foregrounds its emergence through mutual shaping within social and material worlds. This shift from individualism to relationality is central to reimagining both the lived experiences of blindness and the academic frameworks used to study it. In doing so, they offer new ways of understanding and living with blindness—

as a deeply co-created, richly entangled existence. The reconceptualisations align with this PhD's broader critique of ocular-normativity, and they challenge conventional ideas about (in)accessibility.

Omnipresence of ocular-normativism

Despite this shift towards blindness as lived, situated and perceptual difference, ableist structures continue to demand assimilation and conformity to ocular-normative expectations. This reveals a tension between affirming alternative ways of knowing, becoming and belonging, and the institutional requirement to adapt to dominant norms. Chapter 1 introduced the concept of ocular-normativity theoretically. Chapters 2 to 4 discussed participants' experiences with ableism and ocularcentrism, and Chapter 5 elaborated on my own experiences with ableism in academia. This discussion chapter covers concrete experiences of ableism, with examples of everyday exclusion, and how these are manoeuvred. It entangles theoretical insights, personal reflections and empirical findings.

Confrontations with ableism and ocularcentrism

All of us are part of an ableist society. Ableist beliefs surface again and again. Disabled people are repeatedly confronted with discrimination, exclusion and ableism. The individual problem exists as a dominant and constructed reading of disability that fits the dominant ableist ideas and structures in society (Dokumaci, 2023; Vandenbussche et al., 2024).

It is impossible to ignore the presence of ableism. Ableism appears in each chapter of the PhD. The conversations with all the participants, all the readings of the literature and my experiences in academia continually put ableism on the table. Stories of being underestimated, set aside, overlooked, ignored, not recognised or written off are shared. There are attacking statements that are recurrent in all the lived experiences: 'People don't expect that you can be a good parent', 'People don't expect that you can be a valuable friend or partner', 'People don't think that you are able to work', 'People don't think you know where you are when you appear with a white cane'. People (and also blind people themselves) doubt that blind people can be good parents, loyal friends, competent workers or autonomous adults. There are a lot of things on the distractive list, things that are not happening or not possible, and things that relate to disability. Internal and external doubts, concerns and pressures about blind people and their belonging are frequently expressed. These are obstacles, challenges, inaccessibilities and exclusions that people who are labelled as blind must deal with daily.

What sighted people do is considered the norm, so ableist forces are dominantly translated into ocularcentric assumptions (Bolt, 2013). Official dominant stories of blindness are held vivid, such as 'seeing is knowing and ability'. We all know these conceptions too well. As illustrated in Chapter 2, parenting and disability seem incompatible in ableist times, whereby children are supposed to see and care for their disabled parent. Parenting is also associated with utopian independence as the norm for ‘good enough’ parenting, creating a taboo around asking for help. Parents who live with visual impairment face doubts about (and also doubt) their competences, and they undergo ongoing prejudice, stigmatisation, discrimination and normative violence from the assumption that people who live with visual impairment are incompetent as parents.

In Chapter 3, James and his network members express experienced societal assumptions. The impressions that ‘he is limited, he cannot do this and cannot do that, he cannot do anything’ as an image of blind people—‘the incompetent blind’—were shared. That he does not offer any value, does not belong, is socially and intellectually impaired, is stupid and will never be able to have friendships because of his blindness is echoing. Outsiders exaggerated his needs or supposed stupidity. Not seeing is associated very heavily with not knowing, believing that visually impaired people do not offer any value. The societal prognosis for blind children was to go to segregated education settings, focusing a lot on rehabilitation and self-sustainability. They are calling unjust mindsets disabling and resulting in evasive or underestimating responses of others. The educational contexts emphasise ‘passing to the sighted norms, passing the normative format of what is visually expected’ (Michalko, 1998), rather than recognising and learning to affirm difference. The participants described a quiet but telling act of exclusion, of James being invited to eat fries with classmates but sent home before they went out drinking and dancing. Participation and connection are not expected from him and, at the same time, if he wants to be included, he must raise the norms.

The conversations with Lucie and Alice and members of their networks (which were fundamental for writing Chapter 4) present irrevocable standards too. Disability seems to legitimise ‘normate reductionism’ (Bolt, 2013). Even when people fit ableist ideas, they are not recognised. Alice referred in the interviews to a conversation about her husband, whereby a woman interrupted her in amazement that she works and is also married. Alice did not dare to add that she has a son as well. Lucie also expressed situations when bus drivers or outsiders are impressed by her attendance in public life; although she has made endless efforts to pass, she is still outstanding.

Non-verbal interaction is highly valued. This emphasis on facial expressions and body language is ocularcentric and exclusionary for visually impaired people. One way to work around this, as discussed in Chapter 5, is being forced to provide (socially modified) eye contact and practising some tricks to involve others. For instance, moving your head seems as though you have acknowledged someone. It is being forced to act as a well-sighted person (someone who sees good enough to be not classified as visually impaired), act as if blind people belong in the world of the normal (Michalko, 2002).

Similarly, ocularcentric expressions are frequently used. ‘Unseen’ and ‘insights’ sound attractive; however, these are ocularcentric terms that refer to seeing and knowing (Healey, 2022). Also, reviewers of Van Havermaet et al. (in press) were forcefully supportive of finding other, less ocularcentric words. This text, and the other chapters, want to refer (somewhat contradictorily) to what is dis/appeared (Titchkosky et al., 2022): bringing to consciousness and making explicit what happens invisibly or differently. Ocular-normativity evokes pressure, and the research explores, unravels, counter-narrates and crips to reconceptualise.

The exceptionality or unfamiliarity of someone's blindness causes annoyingly wrong understandings, excluding and differentiating stigmas and indirect/unspoken marginalising prejudices. It is possible for recommendations around societal normativity to be formulated so that professionals can further critically question dominant discourses or hone the resilience of disabled people to withstand disproportionate participation pressures. This can be taken as an objective for caring practices, but taking blind perceptions into account makes something else appear.

This doctoral research puts attention somewhere other than these omnipresent ocular-normative examples. There is something more than these issues (Titchkosky et al., 2022). Although recognising the challenges and their severity, this PhD is interested in how to deal with these circumstances. What is—or can be—the repertoire to move on? What is more than the list of barriers? What are the efficient ways of working around blockages? What exceeds the stereotype of vision as distorted or impaired function? How can structures shift into being rethought? How can people overcome demotivating encounters or provide proof of their existence? All participants inventively search for ways of manoeuvring around ableism. All the chapters make evident how blindness is differently conceptualisable.

Urge to prove oneself as independent and valuable

There is a lot of effort to solve, fix, ignore and work around those ocularcentric issues and continuously connect with people to arrange everyday life. Blind people constantly pass ableist norms, as they (must) compensate for blindness. The dismissive or hurtful comments confirm the inner feeling of having to prove oneself competent and valuable. Narratives are about success or privilege, transcendence, qualification, autonomy and increasing opportunities; all lofty goals to achieve. There is a lot of pressure to prove someone's worth. People desire to function autonomously. They bring their networks together, overcompensate for stigmas and internalise societal norms.

This massive urge to prove oneself is highly recurrent throughout the chapters. Participants repeatedly stated a powerful drive in all their narratives. Blind people are forced (and also force themselves) to strive for a phantasmatic idealisation of independence and a life worth living. The omnipresent urge to prove worth can consequently be divided into two dimensions: first, independence, referring to performative, practical and social functioning within normative expectations (associated with independent parenting, employment and travel); and second, someone's value, related to existence and recognition (of identity, self-esteem, emotions and resistance). Both dimensions strengthen and/or compete with each other.

The societal belief that a 'good parent' should be fully self-reliant is adopted by many parents living with visual impairment, which makes them impose extra high demands on themselves. As shown in Chapter 2, parents strive to demonstrate that they are affirmed in their capacity to raise children and that they are maximally independent for themselves, their children and their families. They find creative solutions or ask for practical support from their network. The participants attach great importance and experience high pressure to do everything themselves and function as independently as possible as parents. This illustrates the tension between asking for help and accepting support, even when it would make their lives easier. In Chapter 3, James and his family also trust his cognitive abilities and potential to strive for inclusive and higher education, be a fully-fledged employee, live alone and become as independent as possible in life. They highlight how James can do things; that he is able to do things, referring to his schooling and later employment. They emphasise how he succeeds in regular education and adheres to higher educational norms. They highlight how they withstand the pressure to pass, to have a space to belong in social spheres and function within social networks. As an assemblage, they actively construct participation and convince others of James's place in diverse domains in society. The fundamental conversations in Chapter 4 also witness the urge to prove independence. Lucie explains her way to living alone, having employment and taking public transport for leisure time. Alice also emphasises that she is highly willing to work, to parent and to move on her own. It seems like a desire to compensate for what is not possible and to reach societal norms of performing a successful life. The white cane's perspective also urges to prove its user's independence; its presence counters (potential) dependency and breaks open the metanarrative of the white cane as the solution for the lack of seeing. These strong resistances are also recurrent in my personal life: going to academia, setting up a household and navigating inaccessibility.

The empirical material reveals a fundamental tension between the desire for autonomy and the necessity of interdependence. Participants emphasise their ability to function independently, yet also rely on social networks, assistive tools and environmental accommodations. This is not a contradiction, but rather an embodied negotiation. In this context, independence is not the absence of help but the capacity to direct one's life within and through supportive structures. Thus, relational autonomy becomes a more accurate frame—one that recognises mutuality without surrendering agency. Blind people not only grow in solving the problems that disability causes but also learn to counteract ableist assumptions and ocularcentric ideas about independence. Overcoming challenges continuously goes hand-in-hand with justifying actions to emphasise independence. Although often framed as empowerment, this striving paradoxically reinforces the very norms it seeks to resist. They are reinforced by blind people themselves, externally imposed by societal expectations, and extrinsically fuelled by regular negative comments from others. It stems from their personal beliefs and the internalisation of surrounding ableist norms, so the wider society has a significant impact on people living with a visual impairment. While the drive for independence reflects a desire to meet external expectations of functionality, participants' narratives also reveal a deeper striving: the need to affirm their own worth, dignity and capacity for care. This brings the realm of doing towards the realm of being.

Parents defend their right to become parents, their parenting being 'good enough', and their status being equal to non-disabled parents (see Chapter 2). They strongly encourage themselves, thinking 'what the others say, that's not true, I'll show that I can do it'. The mindset is 'go for it, get the confidence to become an able parent'. They express self-conscious disobedience towards ocularcentric statements. They recurrently emphasise that what they do is 'normal' from their perspective and cannot be considered different, extraordinary or problematic. They argue against assumptions of inferiority and are doing their utmost to be recognised. Experiencing culturally violent acts of division and symbolic or discursive forms of exclusion also triggered resistance in James and his family (see Chapter 3). Concerned about his well-being, they respond to medical/preventive thinking tropes. They emphasise his cognitive abilities and recognise his giftedness and eagerness to learn. They focus on his unexpected or unrecognised qualities and potential. They underline and stretch the longing for belonging for James and his networks. As stated in Chapter 4, occasionally hiding the impairment by wearing lenses instead of dark glasses or taking an arm instead of using a cane can be a strategy to be recognised as ‘normal’. Lucie and Alice believe and show their dignity that they are more valuable than outsiders think at first sight. They urge for belonging and an everyday image of how people with visual impairments live: disability as a daily practice instead of a problem to solve. What individuals do to improve their participation urges them to prove their right to be there and the value of their presence in the world. The intermezzo publications included in Chapter 5 undo the avoidance of disability in academia, as these processes self-recognise the efforts to assert belonging. The act of expressing experiences challenges the stereotype of disability in able-bodied culture and includes the embodiment of temporarily corporeal difference in the conversation. Legitimising a personal way of working proves someone’s worth, contribution and participation in all possible regulated work and study settings and domains.

The lived experiences of insiders, blind people and their entourage, contributes to more liveable world-making. It’s relevant to take them as learned experts, as their repertoires are inspirational for other visually impaired people and a society that really wants to move towards inclusion. Blind people and everyone and everything entangled in their assemblages discuss and rework their own conceptions of blindness. The urge to prove that life is worthwhile is a way of reconceptualising. This was committed as a work in progress, one of imitation and approximation that continuously requests a lot of investment from the person labelled as visually impaired and their allies. They felt cornered, as if the burden of responsibility was on them. Together, they customise living with blindness to the person, themselves and their lived (also material) realities. They do everything they can to help, to promote growth, to connect, to love. This conclusion confirms that disabled people struggle with (or resist) a poisonous normativity on ideal being and feel a strong and brave urge to prove themselves as valuable, and it feels necessary to do this in our current society. When people give less attention to trying to fit static and ableist connotations, or the urge to prove themselves, it becomes more possible to experience what assemblages can do and become.

Confrontations with the omnipresence of ocular-normativity give birth to multiple moments of resisting assumptions and asserting capability. However, the urge to prove, although framed as agency, also reflects the deep internalisation of ocular-normative ideals, where success is measured against non-disabled standards. Passing, presenting oneself as successful and normal, comes with a ‘cost of normativity’ (Hamraie, 2017; Price, 2024). The internal push is not optional; it is a force to survive within ableism. The strategic concealment of impairment also illustrates the ongoing negotiation between the desire for social inclusion and the cost of visibility of a visual impairment. Different efforts to be perceived as normal and ways of strategic passing are explored, which show how blind people navigate the ability to be noticed and accepted. While individual resilience is often celebrated, it obscures the deeper issue: disabled people are proving their worth in environments not designed with them in mind. This research reveals the paradox that striving to belong often requires inhabiting the very norms that exclude. We need to be very critical towards the structural causes that underpin this urge to prove themselves, whereby persons with a visual impairment are not solely responsible.

While ocular-normativity sets the stage for how disabled people are judged and measured, its effects are not confined to the symbolic. They reverberate materially. These spatial and temporal barriers bring into view the fluctuating presence of access itself.

(Dis)Appearing access

To reconceptualise blindness, it is necessary to reconceptualise access too, because conceptions of accessibility affect conceptualisations of blindness. Infrastructural access and reasonable adjustments dominantly appear but are paradoxically underpinned by ableist ideas that are situationally handled. Mobility and transport issues are framed as cornerstones for accessibility, but there is more to tell about problematised movements in the world with blindness. Technical-functional accessibility is expanded to include relational, affective and political ways of understanding accessibility in its fullest potential.

Access is crucial and happens variously, so it is relevant to situate accessibility in context and argue for structural changes. Societies are still responsible for solving ongoing hindrances or, constructively formulated, improving accessibility. Rather, physical forms of access require alignment with the law. Mobility and transport are conditional and practical accessibility issues that require infrastructural interventions, but also humility and respect for how blind people navigate the world. Social belonging requires assemblages to move together. By doing so, accessibility becomes related to identity, lived negotiation and performance rather than presence.

Rethinking access: from infrastructural fix to contextualised process

Access is often conceptualised as a technical or logistical matter within dominant discourses, current policy frameworks and institutional practices. They refer to widened doors, speech software, adapted seating or braille labels. Simultaneously, accessibility is treated as something that can be ‘solved’, completed and checked off. This view of a universal fix that ensures access for ‘everyone’ is grounded in a functional understanding of access as an objectively measurable feature, often tied to formal standards, regulations or legally defined accommodations (Hamraie, 2017; Titchkosky, 2011).

Access tends to be framed as ‘common sense’, a neutral and self-evident characteristic of good design. Yet this presumed neutrality has been critically questioned in the field of disability studies. For instance, Price (2024) and Whitburn and Riffo-Salgado (2024) critique the notion of reasonable adjustments. While these are undeniably necessary, their underlying premise reinforces the belief that there is a normative template (Hamraie, 2017), whereby the underlying assumption looks at disability as individual, measurable, manageable, and something to be resolved or removed. In doing so, such approaches tend to reduce access to a form of assimilation, seeking to normalise or even let the presence of disability disappear (Mingus, 2011; Titchkosky, 2011). Within this logic, access is framed as a limited resource, an expense weighed against feasibility, and often something for which there is never quite enough budget.

This PhD does not deny the need for technical and logistical ways of looking at accessibility, as almost all participants talked about the need for infrastructural accessibility. It interrogates the presumed neutrality and exposes the assumptions underpinning access practices. Participants in this doctoral research describe access as the ability to physically enter a space or make use of a service, but participants also speak of access as the experience of being welcomed, of being invited to take part, of living on your own, of moving with and through the world. Consequently, this PhD foregrounds access as a relational, situated and ongoing process of negotiation, attunement and friction. Access here is not an add-on to normative environments—it is emergent in relation to people, places and shifting expectations (Hamraie, 2017; Mingus, 2011; Titchkosky, 2011; Whitburn & Riffo-Salgado, 2024). The empirical chapters in this doctoral research unpack moments of highly situational, contextual access, physically and relationally. It is about rethinking access by exploring and appreciating various ways that make things possible and give space for belonging to emerge.

Mobility and transport as a cornerstone for accessibility

Access is obviously associated with mobility and transport. Navigating is a predominantly challenged ability for blind people and a conditional accessibility issue of high significance. Transport and mobility emerged throughout the PhD as particularly delicate and impactful on all domains of life in every life period. A commonly named problem of access is specifically moving with and through the world. How blind people move comfortably in known places like home and public environments is a big part of blind experiences that explicitly affect life.

Navigating unfamiliar environments is often experienced as difficult and time-consuming for blind people. The practical and emotional effort required to move through public spaces is exhausting. There are not only logistical challenges, but also emotional burdens tied to independence, autonomy and spontaneity. For example, for visually impaired parents, mobility restrictions profoundly affect family life, and the transport limitations interfere with their children’s opportunities, especially during early childhood when parental mobility directly shapes the child’s world. In general, participants consistently report that mobility challenges influence their broader social participation, which is related to being able to access work, relationships, hobbies and caregiving roles. This requires constant anticipation and adaptation. Every activity, even seemingly simple ones, must be mapped out, negotiated or accompanied. Thus, while adaptations are visible in some public environments, the sense of access remains unstable, both materially and affectively.

Planning becomes a core strategy: decisions about where to live, where children attend school, which jobs to pursue, and which leisure activities to undertake are all made with accessibility and inaccessibility in mind. Walking, cycling, relying on others and using public transport—where feasible—are central affordances to daily logistics. However, navigating public infrastructure remains precarious. While some improvements in the public realm are acknowledged, participants report inconsistent support systems. Although widely used, public transport is not consistently reliable, accessible or emotionally neutral. Taxis and organised transport services are sometimes necessary but limit flexibility and affordability. Some destinations remain inaccessible unless one drives, which is often not an option. Relying on sighted friends or family members is common, but also reinforces dependence and reduces spontaneity. Safe and independent travel is not always possible. Participants are expected to be travellers in a world built for sight, yet judged for relying on others. This double bind—where dependence is necessary but socially penalised—adds emotional weight to every journey.

Rehabilitation of the person (e.g. mobility training) was considered important for and by blind people. Each participant possessed a highly personal set of tools tailored to their general needs, including an (extendable) cane or a guide dog, for example. Intensive training activities of daily living, mobility and orientation often take place together, in addition to general parenting, schooling and work. To walk, take the bus, take the train, explore the environment, and so much more must be explicitly learned. It is an exhaustive process of ongoing personal growth, but it also deals with the connotations of the aids: they facilitate mobility and inhibit approachability, too. As illustrated in Chapter 4, one external iconic aid or straightforward material object relates to mobility and blindness: the white cane. The white cane represents a rather one-dimensional cure, remedy or repair of ableist conceptions of blindness as helplessness; it is widely acknowledged for its assistance in enhancing obstacle detection and safe navigation. The omnipresent sighted metanarrative is that blind people must always be accompanied by a white cane.

The institutional promises of access are rights and adaptations on paper that are often not being fulfilled in practice. What appears accessible on paper may remain out of reach in practice. This reveals a structural contradiction: access is promised as a right but performed as a burden. The dominant technical, instrumental or practical perspective on transport and mobility, as an impairment-specific deficit or problem, and the taken-for-granted solution of public transport services and white cane use, would once again formulate its recommendation. Compulsory legislation around permanent structural exclusions that visually impaired people experience may finally come. In addition, reconceptualisations of blindness add other perspectives and approaches to access. Blind perceptions reconceptualise the meaning of movement, and vice versa. Access is more than physically going somewhere. Mobility does not simply depend on infrastructure; it also depends on time, effort and anticipation. Multiple alternatives to the problem of transport and mobility are explored, many ‘solutions’ are combined and all the senses are overactive to respond to issues of inaccessibility. Rather than being unable, afunctional (because of blindness), the mobility of a blind person can be reconceptualised as an intensive skill/competence. We can learn a lot from taking seriously the everyday tricks and specific lifehacks to move in the world that blind people discover by experience.

Support and interpersonal access

Professional support is a taken-for-granted necessity to provide access, as traditional understandings of blindness as an individual, personal matter are worthy of professional/academic investigations (Michalko, 1998, 2002, 2010; Michalko & Titchkosky, 2020). A commonly named solution for the practical problems of access is professional support. Authority and expertise are located in 'educated experiences' of people who have professionally learned skills to (re)solve the problem of disability.

The lived experiences of blind people reveal many examples of support, such as mobility training, help with administration and learning to use certain software. Professionals who rehabilitate blind people to maximally maintain their independence are acknowledged. Nevertheless, disability-specific training is not always helpful, and the absence and redundancy of professional support are also sometimes critically noticed. And, in contrast with the assumption that visually impaired individuals require access to emotional help, not everyone reports a need for professional psychological support. Moreover, remarkably more experiences about life with blindness were shared that did not involve the efforts of professionals. For example, not everyone feels 'blind enough' to need professional orientation and mobility training. There are endless actions that make a liveable life possible. Rather than focusing on a professional perspective, participants mainly refer to the actual personal practices of daily living and urge to prove their worth.

In Chapter 2, this doctoral research confirms that the professional network of visually impaired parents consists of family care or family support services, a social worker, transport services, medical staff, the children's day care centre or school, and occasionally mainstream specialised parenting support workers for instrumental, administrative, mobility, medical and pedagogical support. As explored in Chapter 3, during James's schooling in regular education, he received assistance from home counsellors, occupational therapists and class support workers. Professional attention was paid to sightedness (via learning skills, such as taking public transport, using screen reader software, or making lunch). Related to white cane use, as elaborated on in Chapter 4, an occupational therapist or an orientation and mobility instructor is professionally trained to educate the user. They inform about the techniques for holding the cane while manoeuvring streets or taking stairways, interpreting the sensations the white cane gives, exercising trajectories and getting to know how to introduce others to disability. As discussed in Chapter 5, instead of learning to work around or deal differently with (digital) inaccessibility challenges as a blind person, professionals are asked to provide accessible resources. For example, the masterpiece of Georgina Kleege, *Sight unseen* (1999), was bought on paper and digitalised because it could not be found anywhere accessible and is at the same time too important not to include in this PhD. The blind person invariably needs and depends on (visual) support of personal assistants and external assistance. Indeed, professionals are also engaged with requiring procedures to get tools or support.

However, traditional conceptions of support are possible to rethink because the participants also express the manifest impact or strong commitment of their informal social network and society. Also (grand)parents, partners and close family and friends manifestly invest in the personal growth of the participant, as they act as professional and advocational allies without being educated to engage with disability. Unravelling contextualised lived experiences with blindness shows that a lot more happens outside the professional scope. The story of blindness is a lot more complex than the part that professionals claim. The PhD does acknowledge the existence of professional experiences as participants witnessed when and how professionals intervened, but these perspectives are de-centred while revealing a more contextualised approach to access. How can professionals be part of and work together with blind assemblages in a creative investigative way, and try to identify how life can be carried and aligned in a co-creative way?

When the professional perspective is foregrounded, parenting is called not 'good enough' and in need of solving techniques. Consultants want to empower network relationships and remediate strength development, and white cane use is assumed to provide independence. And yes, this makes sense, but it does not make other parts of the story appear. The PhD does not want to concur who is right or wrong if things are problematic; it wants to make visible what is also on the table and often remains invisible. Through lived experiences, the person, their contexts and daily practices were centred. This doctoral research does not seek to undermine professionalism or judge experts; it advocates for putting their contribution in perspective. A contextual conceptualisation of blindness and access incorporates professionals as one part of the assemblages and makes entanglements with other (non-)human intra-actions appear. Lived experiences entail unique inventions of possibilities that are contributory to accessible living together.

Access emerges in assemblages. It flows from physical adjustments into relational alignment. Tools and material support are extended to professional support and human interventions. Access is about fluent intra-actions between material and human, formal and informal. This is more than a one-size-fits-all solution. It is about recognising and valuing the searching process that occurs while moving together. The PhD argues for a contextualised approach to access, situated and aligned. A complex interplay of interactive moments with mutual effort can create another version of access. Whitburn and Riffo-Salgado (2024) state that access is shown to function effectively only when embedded in affective and institutional relationships that do not erase difference but actively learn to move with it. Access becomes an ethical practice: not a checklist, but a way of being with others, listening closely and acting attentively. Mia Mingus (2011, 2017) deepens the reframing around access by proposing the concept of 'access intimacy'—a felt sense of recognition, ease and connection around access needs that emerges through trust, responsiveness and mutual care.

Friction and access as political practices

Access is not solely about seamless adjustment or integration into existing systems. It is not a linear path toward inclusion or the endpoint of inclusion. Access is about fundamentally challenging the normative assumptions that underpin living together

(Hamraie, 2017; Mingus, 2011; Price, 2024; Titchkosky, 2011). It is a site of ongoing negotiation, resistance and creativity, whereby frictions emerge precisely where norms are confronted.

The concept of the non-compliant user offers a powerful frame to understand how blind individuals navigate and actively reshape the environments around them (Hamraie, 2017; Price, 2024; Titchkosky, 2011). Blind people develop small, creative practices of resistance to enable access. These ‘activist affordances’ (Dokumaci, 2023) are forms of activism, systemic critique and redesigning of what accessibility means. In a crip theoretical perspective (Goodley & Runswick-Cole, 2014), they crip access, protest access, actively collaborate and create movements in examining ableist privileges. Access becomes performative, inventive and affectively charged via various repertoires. In these moments of access, the assemblages of blind people refuse to disappear, refuse to adjust, refuse to fully adapt, and instead engage in tactical interventions that question the status quo. Blind parents show themselves in the public domain with an extendable white cane in one hand and a stroller in the other, defying scowling looks. James’s parents have taught him braille to enable access to educational development. Support is negotiated in the moment. Lucie reroutes walks through safer but less accessible streets to escape being trapped at home by roadworks. Transport routes are creatively reimagined. Alice improvises interactions about blindness at the office because of the companionship of her guide dog. Social interactions are navigated with embodied skills and communicative adaptations. All participants reappropriate assistive devices, such as the white cane, not merely as tools of rehabilitation but as symbols of identity, self-awareness and autonomous presence in the world. Participants in this doctoral research demonstrate how access is often improvised rather than guaranteed. These political practices expose access as a messy, affective and at times exhausting process of making space, of insisting on one’s presence in contexts that were never designed with affirming difference in mind.

While participants express pride and agency in their lived experiences, these are continually interrupted by societal ableism and structural exclusions that remain difficult to undo. The notion of ‘relational access’ thereby raises a new question: how sustainable is access when it depends on individual negotiations, rather than systemic guarantees?

Such reconceptualisations of blindness and access challenge normative thinking, and experiment with different rhythms of being and becoming. In that sense, access can be understood as a political act—an insistence on visibility, participation and belonging in environments that systematically obscure, ignore or standardise difference. The presence of friction is not a failure of accessibility, but a signal that norms are being pushed, challenged or bent. These micro-resistances offer glimpses of alternative futures: not where disabled people are simply accommodated, but where the conditions of participation themselves are reimagined. Rather than aspiring to ‘universal’ access as a neutral good, the narratives in this doctoral research suggest a shift toward crip access: relational, contested, non-linear and unfinished. This invites a broader rethinking—not only of physical environments or service provision, but of how institutions, communities and systems conceptualise human variation. In that sense, access is never just about ramps, apps or formats—it is about reconfiguring the world to have more ways of being, becoming and belonging. This relocates responsibility from the individual to the structural and relational contexts in which life emerges. At the same time, this challenges the idea of inclusion as assimilation into pre-existing norms and instead invites a deeper questioning of the structures themselves. In this way, accessibility can be understood not only as a technical concern, but also as a deeply cultural and political issue—and as such, it becomes a central lens for rethinking what it means to live with blindness in the contemporary world. The learned expertise of blind assemblages is inspirational to manoeuvre inaccessibility differently.

Doing research: situated knowledge and critical commitments

This section reflects on the process of doing research not only about disability but also through disability, as lived, embodied and politically situated. It focuses on how ways of living life add (scientific) value to what is known and how these ways can be appreciated. It brings together two interrelated dimensions: first, the methodological and ethical implications of engaging in research within the engaged, conceptual commitments of disability studies; and second, the experience of conducting research as a blind scholar within academic structures not designed for disabled bodies or minds. These perspectives are not merely parallel but entangled: the epistemological lens of disability studies shapes how disability is studied, just as the lived experience of disability reshapes how research is done. Together, they offer insights into how knowledge is produced, what counts as legitimate participation, and how both can be reimagined. When putting this into practice, research that is based on lived experiences enables everyone to reveal more than they already know and invites further craving and exploration of more lived experiences.

Disability studies: researching at the intersections

In this discussion, it is also relevant to focus on doing research from a disability studies perspective, which is critical, norm-adaptive and intersectional. By approaching a disability studies perspective in this research, it interrogates where dominant frameworks risk reproducing Western or individualised epistemologies of impairment. Positioning research within disability studies entails more than a theoretical affiliation. It involves a sustained effort to challenge normativity, to engage with embodied knowledge, and to remain accountable to the political and relational foundations of the field. This doctoral research contributes to common public perceptions about blindness and disability studies by conducting this inquiry into reconceptualising visual impairment through lived experiences. Based on critical self-evaluation, this research should highlight that applying this disability studies discourse was also challenging concerning intersectionality.

Following Omansky Gordon and Rosenblum (2001), Titchkosky et al. (2022) and Van Havermaet et al. (in press), intersectionality is, or should be, a running thread through everything research does. The significant presence of intersectionality serves as a starting point for understanding diversity and elaborating on other disciplines. It is highly relevant to focus on intersections in relation to disability: the complexity of how disability as a central organising logic intersects with race, ethnicity, sex, sexuality, class, gender, age and socio-economic status. Disability is not a static 'fact' of the body; it is performed like other intersections, deeply impacting processes of inclusion and exclusion in all life domains. It is relevant to engage with all the tensions and complementarities that occur. A consequential inclusive aspiration is that 'intersectional understanding of disability means investing in disability communities that experience the most extreme forms of marginalization' (Goodley, 2024, p. 10).

This PhD acknowledges attention for intersectionality. Universal categorisation and theorisation are assumed implausible, as the limitations imposed by impaired vision are dependent on a variety of intersectional and embodied differences (Whitburn & Michalko, 2019). Disability emerges where blindness and sightedness (ophthalmology, rehabilitation and special education) cohabit (Healey, 2023), and where being blind intersects with blind perception (Healey, 2022). Blindness is something found at the intersection of diverse journeys and stages: cultural locations, social structures, and related identities that come together, creating certain experiences of (and understanding of) blindness that are aware of privileges at play (named ableism and ocularcentrism). The intersection of power imbalances: disability involves interrelationships between the subjective embodied experience of blindness and the physical, institutional, and social environments (Bulk, 2021). This doctoral research fully grasps these intersectional complexities that assemblages of blindness entail, but despite efforts, intersectionality that relates to other forms of division or minority is less present in the participant group of this research.

The ethical tensions between inclusive sampling and the instrumentalisation of difference were palpable throughout recruitment. The recruitment of disabled participants is understood as inviting people to participate in research activities of the PhD and actively inviting a wide representation of disability into the research (Goodley, 2024). This raised questions about what kinds of diversity are sought, and at what cost. Labelling the participants as (extra)ordinary or fixating on intersectionality specifics was neither ethically comfortable nor feasible. Including people because of their 'intersectional distinctiveness' risks turning difference into spectacle. Each participant who was willing to participate was welcomed into conversations. The sample that grounded Chapter 2 involves approximately equal numbers of mothers and fathers, while research about parenting often is dominated by female participants. Also, the sample included in Chapters 3 and 4 is almost gender balanced. Although characteristics that relate to race, socio-economic status, sexual orientation or religion were not registered, these participants come across as mainstream. Excluding people would have been unfair, but it would also have been inhuman if the research primarily included participants because of their outlying intersections. Expressed with the utmost caution, when it comes to visual impairment and possible cultural privilege, the study attempted to cover a wide range of participants, but it fell short: rich intersectionality was not found. Supposedly mainstream voices revealed wonderful insights into systems and transgressions, and making those appear in research is an essential privilege. However, we have always been aware of contextual differences in narratives and have been willing to make a variety of stories appear. For example, the assemblage of James showed massive striving towards ableism, ocular-normativity and accessible belonging in a seemingly privileged context, which triggered us to have conversations with 'limited' contexts. But even with the help of a gate-keeping ophthalmologist with a rich patient base, it remained challenging to meet blind people with other intersections present in their lives. Despite the deliberate collaboration with those with a proven track record of working with diverse people (Goodley, 2024), their extended list of patients or clients could not provide access, and participants with varied intersectional characteristics were not sufficiently reached.

Being the insider: researching with disability

A unique running thread throughout the PhD is doing research with a disability, because such research is steeped in examples and experiences of how blindness affects and is affected by doing research. It is highly relevant to embody, situate and navigate doing research as a researcher who lives with blindness, as this unfolds in various contributions. Inspired by Omansky (2006), uniqueness relates to this doctoral research and the scientific world as a whole.

Researchers who live with visual impairment themselves, or are closely entangled with people labelled as blind, and have blindness as their research perspective, are at the centre of theorising disability. Such a promotion of disability studies scholarship urges a cultural reconceptualisation of disability; it reformulates how disability is understood and does justice to other disability epistemes (Goodley, 2024). Blind scholarship strongly connects theoretical insights with lived experiences, with blind life and disability as (academic) practice (Symeonidou, 2024). In this context, blind scholarship is about overcoming barriers and generating insights that emerge precisely through a non-sighted epistemology. This positioning has scientifically added value, as this perception brings other entrances, interpretations, questions or concepts to the forefront. In addition to the expert gaze of sighted people, blind perceptions uniquely enrich how blindness can be (re)conceptualised.

This PhD is contributory because it builds on research on blindness from the inside. The research manifestly encompasses scientific literature about lived experiences with blindness within the field of disability studies. The work of these scholars is deeply processed throughout the PhD. Careful efforts have been made to identify who is relevant for this research and which of their works are authoritative. As a blind disability studies researcher, my scholarship experimented with doing academia differently, and I introduced a different wind into standard ways of working in academia. Visually schematising an overview of insights is challenging, which requires alternative creativity. Key texts are unpacked in multiple meetings with colleagues from the disability studies research group. This was not a collective systematic literature review, but a scientifically valuable method that allowed discussions, contrasts and connections. What is recognisable or obvious to me, as a blind person, is made negotiable. Although some people are not labelled as blind, everyone is connected with blindness. The reading groups confront sighted people with traditional and innovative understandings of blindness. Parallels and paradoxes, both within sources and narratives, are expressed more strongly. This crocheting process allowed for mapping a bigger picture, the state of the art of this PhD. These personalised ways of doing research open up a fascinating ontological-methodological debate that is an immense opportunity for working with scholars in doing PhD research. As a blind disability studies researcher, I have been able to contribute to perceptions about blindness in academic environments. By elaborating on personal experiences with blindness within academic practices, my blind scholarship also contributes to how doing academia can be reconceptualised and legitimised. It is scientifically relevant to bring accessible participation to the consciousness of universities. I vividly experienced barriers to navigate workplaces, ableist temporalities, ocular-normativity, pressures for independence and procedural absurdities to arrange reasonable adjustments in case of accessibility, specifically in the context of (doctoral) research. As illustrated in intermezzo 1 and intermezzo 2, I have undertaken various affordances that echo earlier reflections on access normativity and the urge to prove one's worth in ocularcentric environments. I have unsettled and challenged exclusionary practices and took the lead to change how my participation is seen and how I am—or can be—treated. I argued for a more inclusive version of university life. The onus for setting up all these actions fell primarily on the blind researcher, which reinforces dis-ableism. These efforts and those of everyone else who was (unintentionally) involved were brought into educational dialogue. These embodied and invaluable insights enable us to unlock possibilities for participation and dismantle barriers encountered in everyday situations. Incorporating all intensities, and continuously questioning, moving or at times fighting, was consuming but conditional to prove my belonging in academia and to do this research. Translating the personal disability-specific struggles into the ability to respond provided meaningful 'small cracks' in the system, or at least situated and temporal alternatives to move on. We attempted to no end to urge to prove worth and to crip into access intimacies that are not signs of failure but affirmative reconceptualisations of doing research with blindness. Blind fellows really helped to carve my way, and I would like to recommend each visually impaired person to connect with the learned expertise of others while enfolding any aspiration.

Being an insider causes finding balance between transparency and academic performance: you must make experiences visible without becoming excessive. As Titchkosky et al. (2022) state, 'Our future depends on a robust yet balanced discussion that finds disabled people and their allies at the centre. Without such a discussion, we run the risk of disappearance' (p. 221). I want to emphasise the effects of doing research with a disability by consciously stating that recognition and differentiation are fundamentally appropriate to keep the specifics in the foreground. It is a serious commitment to address universities on this, especially while researching with disability from inside.

One massive challenge inherent to the world of research and academia is that many researchers depend on funding and are uncertain about their academic careers. Writing the research proposal for this PhD took me a whole year of volunteering effort without any guarantees, but with necessary assistance because of blindness. When I received funding for this project, I had the chance to do research for five years. And what is next is again uncertain, so this already provides discomfort about my academic future. Possible follow-up could entail translations and valorisations of scientific publications, like the chapters included in this PhD, towards engagements with public environments. Appearances and disappearances of blindness might be studied in the context of heredity, artificial intelligence or religion, as these dimensions were acknowledged but not yet systematically analysed. Future work could explore how entanglements unfold in other social, political and economic landscapes while focusing on the translatability across geopolitical and cultural contexts. The endless activist affordances and, above all, the intriguing moments of data collection and analysis that have led to this PhD hold me absolutely enthusiastic about conducting further research. I would like to complete the publication process for various other threads that have emerged in crochet projects throughout the PhD trajectory, that are always based on lived experiences (concerning studying in higher education and moments of (mis)recognition for instance). And I would be delighted to conduct further research into what becomes possible when blind perceptions encounter other disciplines such as design thinking or policy making. I could write a funding request for a personal postdoc, with these and other lines in mind. But I am aware of extra disability-related efforts that will be required to set up a sustainable career, and I expect a similar need for help because of my disability, which is not easily accessible while being in-between contracts. Despite the impossibility of knowing whether I will be the executive investigator, it is possible to acknowledge this issue and launch discussion for improving research policy and practice.

Having traced multiple ways in which blindness is lived, felt and co-created, the following final section gestures not towards conclusion but openness: it opens towards what remains unsaid, unseen and still becoming. Beyond all conceptualisations offered so far, there lingers a quiet sense that blindness is still, and could be, more—that it might exceed language, categories and definitions.

Revealing 'the more': open-ended understandings beyond normativity

Doing this research, from the inside and following a disability studies approach, taught us that the existential nature of blindness is never universal, nor is the meaning of blindness ever certain or fully settled (Bolt, 2023; Titchkosky et al., 2022). As this research shows, blindness does not arrive at a single truth. It reveals itself through contradiction, relation and the persistent sense that there is still more to know, feel and imagine. The meaning of blindness resists closure. It is never fully settled, never fully seen. It remains a shifting presence, unfolding through stories, silences and shared lives, through (re)conceptualisation, (dis)appearance and revealing what might be more. One-sided stereotypes—a medical diagnose, a fixed biomedical category, a problem/deficit/inaccessibility, an individual's lack of independence—trigger a disability studies perspective. When only one story is told, a quiet yet significant yearning remains: surely, there is more to be said and felt. There must be more to this story; something else, something not yet told. What if blindness is more than we think it is? What if there's something else, still hidden, still unfolding? There is a longing to believe that blindness holds more than the story most often told. Bolt (2023) believes that 'it is only by reflecting upon multiple and often competing stories that we can come to a more nuanced understanding of blindness' (p. 10). This provokes us to imagine disability otherwise by retelling, reconfiguring and revisiting blindness from different but connected angles. This invites us to reconsider the meaning of blindness: to (re)think and to feel (differently) about blindness, human and non-human animals, and engagements with the world (Michalko & Goodley, 2023). Michalko (1998) endorses this by stating that 'the question "What is blindness?" is never answered once and for all'

(p. 7). He personalises this opinion by saying: ‘What my blindness comes to, now that I have come to it, is the wonder of its mystery, a mystery which is so revealing that it grows more mysterious the more I unravel it’ (p. 157).

This doctoral research does not aim for a dense conclusion around visual impairment. It does not simply connect a problem with a need or solution; it doesn’t provide an archive of expertise; it formulates neither normative guidelines for parents and professionals to engage with someone who lives with visual impairment, because pressures and contexts are variously at play. Different encounters, places, interpretations, complexities, tensions, contradictions and ways of mattering of blindness are always possible (Michalko & Goodley, 2023; Titchkosky et al., 2022).

The PhD goes back to the complexities of blindness, the multilayered entanglements at play. It foregrounds blindness as a relational, situated and affective phenomenon, and returns to various repertoires of interacting, experiencing, living and togethering blindness. The research explores a broader and more recognisable narration and understanding of blindness, which tells something about how people approach and engage with each other. Especially as a relational expression of the processing of one’s contextuality as a blind subject who continuously becomes within assemblages, the research focuses on never-ending, always dynamic and unique (re)conceptualisations of blindness. This requires appearance and disappearance; what is seen and unseen to collide; amid this collision, other meanings of blindness may be revealed (Healey, 2022).

Literature and encounters based on lived experiences helped to learn to think differently about blindness, because they de-centre a dominant expert position and they de-centre the disability as such. This is the potential of contextually reconceptualising blindness, as it honours the collective commitment to revealing ‘more’. Disability is always more, interwoven with so much more, that there remains more to tell. It is possible to uncover something more than what is already known, and to represent ‘disability as always more and other than what society makes it and believes it to be’ (Titchkosky et al., 2022, p. 4) if we start from blind perceptions. The PhD continuously searches for more: it focuses on realism-based representations of blindness in a manner that reflects its complexity, and it also connects (re)conceptualisations of blindness with disability-related aspects: perspectives, life domains, more-than-human entanglements and more than omnipresent dynamics.

This research recognises and respects the many-ness of blind perceptions of knowing the world. By gathering contextualised lived experiences with blindness, personal and collective accounts of blindness expose unresolved tensions: traditional medical model beliefs, the interplay with the dominant sighted society in which blindness emerges, the richness of (non-)human entanglements that give blindness its meaning, stories of being oppressed by ableist expectations and ocularcentric representations of blindness, how blind people and their network figures reframe the blindness experience into valuable blind perceptions, and so much more. It critically reimagines understandings of materiality, normativity and accessibility, and emphatically rethinks metanarratives and stereotypes. It challenges dominant ocular-normative frameworks and reframes blindness as something that is co-constituted with others—human and non-human—and always in the making. Shaped by encounters, frictions and dialoguing with participants and scholars, the research evolves understandings of blindness, the ethics of participation and accessibility, and provides a meaningful contribution to a more holistic examination of blindness.

In conclusion, this PhD does not seek to resolve blindness as a definable entity or prescribe a unified understanding. Instead, it opens up blindness to multiplicity, friction and becoming. It embraces blindness as something lived and co-created through relationships, practices, resistance and care. By working with lived experiences, not as illustrations but as sites of theorising, this study foregrounds the richness of disabled life. It invites scholars, educators, policymakers and allies to listen differently, not only to what is said but also to how blindness is felt, negotiated and imagined. Ultimately, the value of this PhD lies not in finality, but in its invitation to continue thinking with blindness—to remain curious about what else it might reveal.

This doctoral research recommends an equal recognition of experiential knowledge alongside scientific, professional and societal knowledge. Disabled people and their networks are companions, valuable partners in epistemology. Ethically taking experience seriously contributes to empowering participation and allows the world to see more of what disability can entail. Insights based on lived experiences enable support practices, research and policy to bring forward innovative questions and foster qualitative and accessible interactions. Without emergent listening to lived experiences, well-intentioned efforts miss their target. Therefore, centralising experiential knowledge is essential.

A key recommendation of this PhD is to account for blind perceptions while reconceptualising societal interaction, professional practice, research and policy. Blindness becomes a meaningful lens through which society, practice, science and policy can validate experiential knowledge. Blind people are experts in their own disability—in navigating ableist and ocularcentric norms, in cripping access, and in imagining activist affordances. Their perspectives disrupt normative narratives and can structurally inform domains such as education, work, mobility, cultural participation and family life.

Centring experiential expertise reconfigures the hierarchy of knowledge. It puts the dominance of professionals and prevailing discourses into perspective by making them part of the assemblage, rather than placing them above or outside it. This shift offers a powerful critique of exclusionary epistemologies and opens up the possibility of reconceptualisation that includes disabled people as active co-creators of knowledge.

Blindness and access are not fixed or static but relational and affective processes. This calls for contextualisation, situatedness and tailored support through the co-creation of moments of access intimacy. Living blindness together highlights interdependence, allowing us to guide (rather than normalise) individuals in their specific contexts. Each actor has agency—the ability to move and respond—enabling intra-action and connectedness. A shift from individualisation to relationality requires further theorisation and translation into how we shape interaction, care, research, and who we are and want to be.

In doing so, meaning emerges through imagination, materiality and connection: crocheting an entangled process and relational encounter in which new stories are co-created within ever-evolving creative assemblages. Through lived experiences, this PhD reveals other conceptualisations of blindness, different modes of interaction, and new openings for political and creative thinking and doing. Blindness gains meaning through a multilayered interplay of connections, not a singular narrative. This dismantles the dominant medicalised view and allows other, often unconventional, meanings to emerge.

Such reconceptualisations invite us to imagine not only what a blind person might become but also what assemblages might become and what blindness itself might become. By recognising this never-complete process—dynamic, embodied, relational and contextual—we can creatively rethink how accessibility is built. In doing so, experiential knowledge becomes a driver of design, action and transformation.

Relational and creative practices show how people can assert themselves within systems of inaccessibility, and how local solutions can ripple into incremental systemic change. Experiential expertise reveals these processes. Responsivity to multiple ways of knowing, thinking, telling and doing brings energy to inspire moments of (re)conceptualisation, interdependency and intra-action. Thus, assemblage thinking becomes not just a theory but a tool for creating broader engagement and deeper involvement across contexts.

If we approach the world from this perspective, powerful movements of trying, experimenting and imagining otherwise can take shape. Being open to difference in all its multiplicity, engaging in liberatory thinking and acting ‘outside the box’, even cracking the box open and transforming it, enables us to negotiate, navigate, vary, reassemble and challenge the ways of living blindness.

Lived experiences matter. Acknowledging them enables a more connected and attuned experience of disability within a world that becomes more accessible through relation. This brings us to the core implication of this doctoral research: a consequential call to action that invites everyone to engage with the richness of lived experiences and the knowledge it holds.

Although it requires time and effort to cultivate open interactions and build relational assemblages, these spaces of movement hold immense potential to explore friction, spark micro-revolts, and make space for all that remains untold. Approaching disability through relational and embodied perspectives allows various conceptualisations to emerge—ways disability can be lived, valued and flourish.

The stories presented here make visible so much more than what is commonly known. And the unheard stories contain even more ‘mores’. This is the untapped potential, whereby experiential knowledge might shape belonging, access, participation and knowledge production.

References

Bansel, P., & Davies, B. (2014). Assembling Oscar, assembling South Africa, assembling affects. *Emotion, Space And Society*, *13*, 40–45. https://doi.org/10.1016/j.emospa.2014.04.002

Barad, K. (2007). *Meeting the universe halfway: Quantum physics and the entanglement of matter and meaning*. Duke University Press.

Bolt, D. (2013). *The metanarrative of blindness: A re-reading of twentieth-century Anglophone writing*. US: University of Michigan Press. https://doi.org/10.3998/mpub.5725818

Bolt, D. (2017). Enabling the classroom and the curriculum: Higher education, literary studies and disability. *Journal of Further and Higher Education*, *41*(4), 556–565.

Bolt, D. (Ed.). (2023). *Finding blindness: International constructions and deconstructions*. Routledge.

Bulk, L. Y. (2021). *Being blind and belonging in academia* [Doctoral thesis, University of British Columbia]. https://doi.library.ubc.ca/10.14288/1.0395453

Corcoran, T., Claiborne, L., & Whitburn, B. (2019). Paradoxes in inclusive education: A necessary condition of relationality? *International Journal of Inclusive Education*, *23*(10), 1003–1016. https://doi.org/10.1080/13603116.2019.1625453

Davies, B. (2021). *Entanglement in the world's becoming and the doing of new materialist inquiry*. Routledge.

Davis, L. J. (2012). Foreword. In D. Bolt, J. Rodas & R. Donaldson (Eds.), *The madwoman and the blindman: Jane Eyre, disability, and the ethics of being human* (pp. xi–xiii). University of Michigan Press.

Devos, P. (2018). Dancing beyond sight: How blindness shakes up the senses of dance. *Disability Studies Quarterly*, *38*(3).

Dokumaci, A. (2023). *Activist affordances: How disabled people improvise more habitable worlds*. Duke University Press.

Goodley, D. (2024). Depathologising the university. *Pedagogy, Culture & Society*, *33*(3), 1001–1018. https://doi.org/10.1080/14681366.2024.2316007

Goodley, D., & Runswick-Cole, K. (2014). Becoming dishuman: Thinking about the human through dis/ability. *Discourse Studies in the Cultural Politics of Education*, *37*(1), 1–15. https://doi.org/10.1080/01596306.2014.930021

Grealy, L., & Kleege, G. (1965). Chapter 2: Tyranny of the visual. In S. B. Mintz (Ed.), *Unruly bodies: Life writing by women with disabilities*. University of North Carolina Press.

Hammer, G. (2018). 'This is the anthropologist, and she is sighted': Ethnographic research with blind women. *Disability Studies Quarterly*, *33*(2).

Hammer, G. (2019). *Blindness through the looking glass: The performance of blindness, gender, and the sensory body*. University of Michigan Press. https://doi.org/10.3998/mpub.9271356

Hamraie, A. (2017). *Building access*. https://doi.org/10.5749/j.ctt1pwt79d

Healey, D. (2017). Eyeing the pedagogy of trouble: The cultural documentation of the problem-subject. *Canadian Journal of Disability Studies*, 6(1), 85. https://doi.org/10.15353/cjds.v6i1.334

Healey, D. (2021). *Dramatizing blindness: Disability studies as critical creative narrative*. Palgrave Macmillan.

Healey, D. (2022). Chapter 10: Blind perception: DisAppearing blindness ... with a twist. In T. Titchkosky, E. Cagulada, & M. Dewelles (Eds.), *DisAppearing: Encounters in disability studies*. Canadian Scholars

Healey, D. (2023). Chapter 12: Sighted-blindness-consultants and the ever-lasting station of blindness. In D. Bolt (Ed.), *Finding blindness: International constructions and deconstructions*. Routledge.

Kleege, G. (1999). *Sight unseen*. Yale University Press.

Kleege, G. (2018). *More than meets the eye: What blindness brings to art*. Oxford University Press.

Mazzei, L. A. (2014). Beyond an easy sense. *Qualitative Inquiry*, *20*(6), 742–746. https://doi.org/10.1177/1077800414530257

Michalko, R. (1998). *The mystery of the eye and the shadow of blindness*. University of Toronto Press.

Michalko, R. (2002). *The difference that disability makes*. Temple University Press.

Michalko, R. (2009). The excessive appearance of disability. *International Journal of Qualitative Studies in Education*, *22*(1), 65–74. https://doi.org/10.1080/09518390802581885

Michalko, R. (2010). What's cool about blindness? *Disability Studies Quarterly*, *30*(3/4).

Michalko, R., & Goodley, D. with Smokie (2023*). Letters with Smokie: Blindness and more-than-human relations*. University of Manitoba Press.

Michalko, R., & Titchkosky, T. (2020). Blindness: A cultural history of blindness. In D. T. Mitchell & S. L. Snyder (Eds.), *A cultural history of disability in the modern age* (pp. 61–78). Bloomsbury Academic.

Mingus, M. (2011, May 5). Access intimacy: The missing link. *Leaving Evidence*. https://leavingevidence.wordpress.com/2011/05/05/access-intimacy-the-missing-link/

Mingus, M. (2017, April 12). Access intimacy, interdependence and disability justice. *Leaving Evidence*. https://leavingevidence.wordpress.com/2017/04/12/access-intimacy-interdependence-and-disability-justice/

Omansky, B. (2006). *Not blink enough: Living in the borderland called legal blindness.* University of Queensland.

Omansky Gordon, B. (2004). *Researching the social construction of blindness*. University of Queensland.

Omansky Gordon, B., & Rosenblum, K. E. (2001). Bringing disability into the sociological frame: A comparison of disability with race, sex, and sexual orientation statuses. *Disability & Society*, *16*(1), 5–19. https://doi.org/10.1080/713662032

Price, M. (2024). *Crip spacetime: Access, failure, and accountability in academic life*. Duke University Press.

Rodas, J. M. (2009). On blindness. *Journal of Literary & Cultural Disability Studies*, *3*(2), 115–130.

Scott, R. A. (1969). *The making of blind men: A study of adult socialization*. Russell Sage Foundation.

Symeonidou, S. (2024). Teacher education for disability focussed anti-oppressive pedagogy: The case for reconceptualisation. *Disability & Society*, *40*(5), 1404–1424. https://doi.org/10.1080/09687599.2024.2360430

Taguchi, H. L. (2012). A diffractive and Deleuzian approach to analysing interview data. *Feminist Theory*, *13*(3), 265–281. https://doi.org/10.1177/1464700112456001

Titchkosky, T. (2011). *The question of access: Disability, space, meaning*. University of Toronto Press.

Titchkosky, T., Cagulada, E., & DeWelles, M. (2022). *DisAppearing: Encounters in disability studies*. Canadian Scholars.

Titchkosky, T., Healey, D., & Michalko, R. (2019). Blindness simulation and the culture of sight. *Journal of Literary & Cultural Disability Studies*, *13*(2), 123–139. https://doi.org/10.3828/jlcds.2018.47

Titchkosky, T., & Michalko, R. (2025). Foreword to the second edition. In C. McMaster & B. Whitburn (Eds.), *Disability and the university: A disabled student's manifesto* (2nd ed.). Peter Lang.

Vandenbussche, H., & De Schauwer, E. (2017). The pursuit of belonging in inclusive education: Insider perspectives on the meshwork of participation. *International Journal of Inclusive Education*, *22*(9), 969–982. https://doi.org/10.1080/13603116.2017.1413686

Vandenbussche, H., De Schauwer, E., & Van Hove, G. (2019). Diffractive lenses catching stories: The meaning of belonging through the voice of adolescents. *Participatory methodologies to elevate children's voice and agency* (pp. 275–294).

Vandenbussche, H., Van Goidsenhoven, L., Vandekerckhove, A., & De Schauwer, E. (2024). 'The university is made for those who can climb the stairs': Dialoguing with counterstories in higher education. *Qualitative Inquiry*, 1–13. https://doi.org/10.1177/10778004241254393

Van Havermaet, J., Carette, L., & De Schauwer, E. (in press). [Review of the book *DisAppearing: Encounters in Disability Studies*, by T. Titchkosky, E. Cagulada, & M. DeWelles with E. Gold]. *Journal of Literary & Cultural Disability Studies*.

Whitburn, B. (2014a). Accessibility and autonomy preconditions to 'our' inclusion: A grounded theory study of the experiences of secondary students with vision impairment. *Journal of Research in Special Educational Needs*, *14*(1), 3–15.

Whitburn, B. (2014b). The indelible ink of the special stamp: An insider's research essay on imprints and erasures. *Disability & Society*, *29*(4), 624–637. https://doi.org/10.1080/09687599.2013.844097

Whitburn, B., & Goodley, D. (2019). Storying disability's potential. *International Journal of Inclusive Education*, *26*(4), 1–14.

Whitburn, B., & Michalko, R. (2019). Blindness/sightedness: Disability studies and the defiance of di-vision. In N. Watson & S. Vehmaas (Eds.), *The Routledge handbook of disability studies* (pp. 219–233). Routledge.

Whitburn, B., & Riffo-Salgado, P. (2024). Negotiating access, access and belonging in a higher education institution: A postqualitative narrative. *Higher Education*, *89*, 1129–1143.

Appendices

APPENDIX 1: SUMMARY

- *In English*
  - Introduction
  - A chapter overview
  - Main findings
  - Reveal 'the more'
- *In het Nederlands*
  - Inleiding
  - Een overzicht van de hoofdstukken
  - Belangrijkste bevindingen
  - Onthul 'de meer'
- *References*

APPENDIX 2: ACKNOWLEDGMENTS

APPENDIX 3: CONTRIBUTIONS TO THE PUBLIC DOMAIN

APPENDIX 4: DATA MANAGEMENT

- *Data Storage Fact Sheet 1*
- *Data Storage Fact Sheet 2*
- *Data Storage Fact Sheet 3*
- *Data Storage Fact Sheet 4*

Appendix 1: Summary

In English

With my own eyes? — Re-conceptualizing visual impairment through lived experiences

Introduction

This doctoral research adopts a disability studies perspective by examining how disability—and blindness in particular—appears and is made visible through interactions, expectations, and cultural and technological systems (Bolt, 2023; Healey, 2021; Whitburn & Michalko, 2019). It approaches blindness ethically and contextually, treating it as both a valid and valuable way of being (ontology) and knowing (epistemology). From this standpoint, attention is given to the emotional fabric of everyday life, the entanglement of bodies and technologies, and the nuanced realities of lived experience. Central to this PhD project are ‘blind perceptions’: thinking from blindness or with blind people to grasp the complexities of how lived realities are understood (Bolt, 2013; Michalko, 1998; Titchkosky, 2011). In doing so, the doctoral research aligns with the broader disability studies invitation to think otherwise (Michalko, 2002; Titchkosky et al., 2022). It encourages openness to ambiguity, contradiction, and situated knowledge, and positions research as a tool for solidarity and reimagining what it means to live together in a diverse world (Michalko & Goodley, 2023). Reconceptualising blindness in this sense is about keeping space open for new stories, questions, and meanings—listening to what blindness has been made to signify while remaining attentive to what else it might become.

In addition to the incorporation of this disability studies approach, it is crucial to examine how blindness has traditionally been understood. Blindness is seen primarily as a sensory condition, a biomedical failure or a personal tragedy that is aligned with confusion, ignorance or inferiority. The word carries a heavy load of symbolic weight and negative associations tied to darkness and fear; looking through the lens of ‘a problem in need of a solution’ (Titchkosky et al., 2022). This view reduces blindness to a deficit located within the body or mind of the person, that can be corrected or compensated for. Blindness becomes something to manage, to adjust to; what often is aimed at normalisation—supporting people to appear more functional, more ordinary, more sighted (Michalko, 1998). These logics are underpinned by taking sight as the most reliable mode of knowing, learning and being. It equates visual perception with objectivity, clarity and intelligence: to see is to understand, seeing is knowing, and seeing is believing. To not see is to lack. If one cannot see, one is assumed to know less, or not at all. This deeply rooted cultural privileging of vision in Western culture, also named ‘ocularcentrism’ (Bolt, 2013, 2023), is often grounded in hypothetical figures and tends to be defined by sighted professionals.

Taking this together, this doctoral research focuses on reconceptualising visual impairment through lived experiences, or in other words: rethinking blindness from the inside. Its central research question asks: How does visual impairment appear, and through what practices, narratives, relationships and environments does blindness come into being? It traces how blindness is named, represented and interpreted. It attends to how conceptions of blindness are contextually formed, circulated and lived; attending to its layered framings (as it isn't experienced in isolation). The PhD project embraces the richness and contradictions of how blindness is felt, shared, and imagined in context. It pays attention towards the entangled ways blindness is lived—with others, through others, and in connection with the world. This PhD project aims for a dynamic understanding that welcomes complexity and lived variations. Building on these explorations, this doctoral research also asks: How might we think otherwise? It wants to open up space for alternative lived realities. It contributes to a more nuanced understanding—one that respects the complexity of blind ways of being, knowing and belonging, and one that resists reductionism. Thereby, it questions the dominance of clinical or outsider views and initial assumptions about blindness. It challenges often sighted, deficit-based knowledge. It critiques normalcy thinking that is oriented to capacity and able-bodiedness. This doctoral research crafts knowledge through assembling practices and processes that invite repetition, variation and responsiveness to what emerges. Each chapter returns to a different domain where visual impairment appears in coexistence with themes of embodiment and relationality to explore how they can be (re)conceptualised.

A chapter overview

This doctoral research examines how blindness matters in everyday life. The PhD project explores blindness through the lenses of seeing, parenting, education and social participation, materiality and scholarly positionality.

'Chapter 2: Unseen? A qualitative study on how mothers and fathers living with a visual impairment experience parenthood' gives visibility to the lived, multi-layered experiences of thirteen parents with a visual impairment. It focuses on three themes: daily parenting practices, a parental urge to prove themselves, and relational parenting with partner and children. It captures how visually impaired parents experience the upbringing of their children and how they deal with views on 'ideal parenting'. And it offers a bottom-up understanding of how parenthood and blindness are entangled.

'Chapter 3: Living with blindness: unravelling contextualised lived experiences of James and his networks' diffractively explores blindness as a relational practice through the lens of interdependency across the life span. This in-depth case study of James, a young man with a visual impairment and members of his network, examines both educational choices and connections with others.

In 'Chapter 4: A counter-narrative: the world according to the white cane', the material object of the white cane stories its complicated relationship with its user. The study unravels the material, personal and symbolic meaning of the white cane and sheds light on the functionalities, relationalities and ways of being and becoming in the world with and without a white cane. The white cane—with all its meanings—matters to blindness; it influences its conceptions as it is an integral part of the assemblage of blindness and is always entangled with its user, allies and material surroundings.

'Chapter 5: Positioning' turns the gaze inward, showing how the embodied presence of a blind researcher shapes the research process. It reflects on insider research, lived resonance, and the methodological and ethical implications of positioning oneself within (disability) research. Two intermezzos, ‘Accessible participation in academic conferences if you are visually impaired’ and ‘Cripping time: temporalities in academia’, expand this reflection by addressing accessibility in academic contexts, highlighting obstacles, strategies, and calls for institutional change.

Main findings

This doctoral research offers layered, experience-based reconceptualisations of blindness that challenge conventional understandings. It highlights assemblage-informed perspectives while confronting the pervasive impact of ableism, ocular-normativity and access normativity. By tracing how these dynamics intersect, the PhD project positions the research itself also as situational and transformative.

The doctoral research identifies seven interrelated ways of reconceptualising blindness from lived perspectives:
First, blindness as many-ness: blindness manifests in multiple, dynamic, and fluid ways. Blindness can take many forms, each with its own logic, emotion and rhythm. A diverse range of blind experiences, meanings and feelings are possible.
Second, blindness as different sensorial ways of doing: blindness reshapes what perception or looking can mean and gives rise to creatively and inventively used alternative strategies–seeing differently; touch, hearing, smell, memory and imagination–for navigating and engaging with the world.
Third, blindness as a way of being in the world: blindness is an embodied ontology and epistemology, a permanent companion to every facet of life. It can be something existential that is lived with.
Fourth, blindness as learned social roles, in cohabitation with a dominant sighted culture, refers to how a network of social, cultural, generational and historical influences construct blindness and that blind people adapt to those meanings.
Fifth, blindness as a teacher: blindness brings awareness about, and offers critical reflections on, normalcy, knowledge, ability, difference and human variation. It is an occasion for personal, scientific and societal learning that provokes thoughts about possibilities, self, others and the world.
Sixth, blindness as something to love takes it affirmatively as worthy, valid and valuable. Blindness is a positive difference that can be celebrated and enrich life: ‘It can be a shitload of fun….’ (Michalko & Goodley, 2023, p. 113), something that can be appreciated or embraced for its source of joy, pride, connection, creativity and emotional depth.
And, seventh, blindness as relational understanding is one more conception added to the rich repertoire of blindness. Blindness emerges through interdependence, co-creation, and interactions with others and environments. Blindness is actively and affectively co-shaped in and through relational living. This doctoral research underpins conceptions of blindness as lived in relation and relational blindness. Blindness is entangled with many entities, each providing an entry point to different versions of blindness.

Despite rich reconceptualisations of visual impairment, ocular-normative expectations remain deeply ingrained (Bolt, 2013, 2023). The PhD project highlights constant confrontations with ableism and ocularcentrism, while also showing how blind people manoeuvre these dynamics. What happens invisibly or differently in these normative situations? What is the repertoire to move on while dealing with these circumstances? Blind perceptions manifestly confirm the massive urge to prove oneself as independent and valuable. Participants describe a constant need to emphasise their competence and worth (Healey, 2021; Michalko, 1998, 2002). Blind people creatively navigate these pressures: through micro-resistance, storytelling, and performance. Such strategies affirm interdependency, belonging, and the dignity of embodiment, yet the effort is burdensome, often masking structural exclusions. This ‘cost of normativity’ (Hamraie, 2017; Price, 2024)—raises questions about who bears the burden of change: the individual or the system. Blindness thus evolves through tension while exposing the need to rethink the norms that define participation and worth.

Similarly, blind perceptions also respond to access normativity (Hamraie, 2017; Price, 2024). Access emerges not as a fixed condition but as a dynamic, context-dependent process. This doctoral research draws on dis/appearing access (Titchkosky, 2011; Titchkosky et al., 2022) to show how access is improvised. The PhD project exemplifies ‘access intimacy’ (Mingus, 2011, 2017) and ‘activist affordances’ (Dokumaci, 2023). Moments of friction highlight how blind people enable access through timing, interaction and shifting expectations. These experiences call for ‘crip access’ (Goodley & Runswick-Cole, 2014; Price, 2024)—an ongoing negotiation rather than a one-size-fits-all solution.

Urges to prove oneself, moments of access intimacy, and activist affordances also appeared in doing the research (see Chapter 5). Taking these experiences seriously does justice to non-sighted epistemes (Goodley, 2024; Symeonidou, 2024) and opens an ontological-methodological debate on doing academia differently. Blind scholarship contributes by unsettling conventional academic practices shaped by ocular-normativity and inaccessibility. Working within structures not designed for disabled bodies or minds generated unique perspectives, questions, and concepts that enrich scientific inquiry. The research also reflects on the methodological and ethical implications of disability studies commitments, rethinking knowledge production and legitimate participation. It thereby highlights the importance of ‘intersectionality’ (Goodley, 2024; Titchkosky et al., 2022; Whitburn & Michalko, 2019). It is highly relevant to engage with all the tensions and complementarities that occur. Recruitment of a participant group that relates to other forms of division or minority required efforts; but this doctoral research captures the intersectional complexities inherent in the participating assemblages of blindness.

Reveal ‘the more’

Having traced multiple ways in which blindness is lived and co-created, the PhD project gestures towards openness: openness towards what remains unsaid, unseen and still becoming. The meaning of blindness resists closure (Bolt, 2023; Titchkosky et al., 2022). Blindness is never fully settled or seen but remains dynamic and unfolding. Blindness gradually reveals itself through the persistent sense that there is still more to know, feel and imagine, more to perceive, more to reimagine, more to tell. Beyond all conceptualisations offered so far, there lingers a quiet sense that blindness is still, and could be, more. Different encounters, places, interpretations, complexities, tensions, contradictions and ways of mattering of blindness are always possible. Showing how blindness takes shape in context (as a complex, embodied, relational, situated, affective and interdependent phenomenon), let us iteratively return to various ways of interacting, experiencing, living and togethering blindness. This triggers the continuation of a disability studies perspective, as this may lead to a better understanding of blindness and may provide a meaningful contribution to a more holistic examination of blindness. The invitation echoes: explore further what blindness holds more than the story most often told; think with the multiplicity, fluidity and relationality of blindness and consider how identity, worth and access are co-constituted in and through human and non-human encounters. Keep imagining disability otherwise by retelling, reconfiguring and revisiting blindness from different but connected angles (Michalko, 1998; Michalko & Goodley, 2023). Blindness matters through (re)conceptualisation, (dis)appearance and revealing what might be more. Reconceptualising blindness requires appearance and disappearance; what is seen and unseen to collide; amid this collision, other meanings of blindness may be revealed.

This brings us to the core implication of this doctoral research: a consequential call to action that invites everyone to engage with the richness of lived experiences and the knowledge it holds. Blind perceptions help to think differently about blindness, because they de-centre a dominant expert position, ocular-normativity, access normativity and the disability as such. Focusing on realism-based representations of blindness reflects its complexity, and it also connects (re)conceptualisations of blindness with disability-related aspects: perspectives, life domains, more-than-human entanglements and more than omnipresent dynamics. Experiential knowledge shapes belonging, access, participation and knowledge production. Through lived experiences, other conceptualisations of blindness, different modes of interaction, and new openings for political and creative thinking and doing may be revealed. Responsivity to multiple ways of knowing, thinking, telling and doing brings energy to inspire moments of (re)conceptualisation, interdependency and intra-action. Working with lived experiences, not as illustrations but as sites of theorising, essentially requires listening differently to how blindness is lived. Ethically taking experiential knowledge seriously contributes to empowering participation and allows the world to see more of what disability can entail. It enables us to continue thinking with blindness to remain curious about what else it might reveal.

This is the potential of contextually reconceptualising blindness, as it honours the collective commitment to uncover something more than what is already known. Approaching disability through relational and embodied perspectives allows various conceptualisations to emerge, ways disability can be lived, valued and flourish. Such reconceptualisations invite us to imagine not only what a blind person might become but also what assemblages might become and what blindness itself might become. In doing so, experiential knowledge becomes a driver of design, action and transformation. If we approach the world from this perspective, powerful movements of trying, experimenting and imagining otherwise can take shape. Being open to difference in all its multiplicity, engaging in liberatory thinking and acting ‘outside the box’, even cracking the box open and transforming it, enables us to negotiate, navigate, vary, reassemble and challenge the ways of living blindness. This holds immense potential to explore friction, spark micro-revolts, and make space for all that remains untold.

In het Nederlands

Met mijn eigen ogen? — Visuele beperking re-conceptualiseren door geleefde ervaringen

Inleiding

Dit doctoraatsonderzoek past een disability studies perspectief toe, door te onderzoeken hoe beperking–en blindheid in het bijzonder–tot uiting komt en zichtbaar wordt gemaakt door interacties, verwachtingen, culturen en technologische systemen (Bolt, 2023; Healey, 2021; Whitburn & Michalko, 2019). Het benadert blindheid op ethische en contextuele wijze en behandelt het als een geldige en waardevolle manier van zijn (ontologie) en weten (epistemologie). Vanuit dit standpunt wordt aandacht besteed aan de emotionele structuur van het dagelijks leven, de verstrengeling van lichamen en technologieën, en de genuanceerde realiteit van geleefde ervaringen. Centraal in dit doctoraatsproject staan 'blinde percepties': denken vanuit blindheid of met blinde mensen om de complexiteit te begrijpen van hoe geleefde realiteiten worden begrepen (Bolt, 2013; Michalko, 1998; Titchkosky, 2011). Daarmee sluit het doctoraatsonderzoek aan bij de bredere oproep van disability studies om anders te denken (Michalko, 2002; Titchkosky et al., 2022). Het moedigt openheid aan voor ambiguïteit, tegenstrijdigheden en gesitueerde kennis, en positioneert onderzoek als een instrument voor solidariteit en het heroverwegen van wat het betekent om samen te leven in een diverse wereld (Michalko & Goodley, 2023). In die zin gaat het her-conceptualiseren van blindheid over het openhouden van ruimte voor nieuwe verhalen, vragen en betekenissen–luisteren naar wat blindheid is gaan betekenen, terwijl we alert blijven voor wat het nog meer zou kunnen worden.

Naast het integreren van deze disability studies benadering is het cruciaal om te onderzoeken hoe blindheid traditioneel wordt begrepen. Blindheid wordt voornamelijk gezien als een zintuiglijke aandoening, een biomedisch falen of een persoonlijke tragedie die gepaard gaat met verwarring, onwetendheid of minderwaardigheid. Het woord heeft een zware symbolische lading en negatieve associaties die verband houden met duisternis en angst; het wordt gezien als 'een probleem dat moet worden opgelost' (Titchkosky et al., 2022). Deze visie reduceert blindheid tot een tekort in het lichaam of de geest van de persoon, dat kan worden gecorrigeerd of gecompenseerd. Blindheid wordt iets om mee om te gaan, om je naar aan te passen; wat vaak gericht is op normalisatie–mensen ondersteunen om functioneler, gewoner en meer ziend over te komen (Michalko, 1998). Deze logica wordt onderbouwd door het zien als de meest betrouwbare manier van weten, leren en zijn te beschouwen. Het stelt visuele waarneming gelijk aan objectiviteit, duidelijkheid en intelligentie: zien is begrijpen, zien is weten, en zien is geloven. Niet zien is een tekortkoming. Als iemand niet kan zien, wordt aangenomen dat hij minder of helemaal niets weet. Deze diepgewortelde culturele bevoorrechting van het vermogen te zien in de westerse cultuur, ook wel 'ocularcentrisme' genoemd (Bolt, 2013, 2023), is vaak gebaseerd op hypothetische voorstellingen en wordt meestal gedefinieerd door ziende professionals.

Alles bij elkaar genomen richt dit doctoraatsonderzoek zich op het her-conceptualiseren van visuele beperking aan de hand van geleefde ervaringen, of met andere woorden: het heroverwegen van blindheid van binnenuit. De centrale onderzoeksvraag luidt: hoe komt visuele beperking tot stand, en door welke praktijken, verhalen, relaties en omgevingen ontstaat blindheid? Het onderzoekt hoe blindheid wordt benoemd, weergegeven en geïnterpreteerd. Het besteedt aandacht aan hoe opvattingen over blindheid contextueel worden gevormd, verspreid en beleefd, met aandacht voor de gelaagde omkaderingen ervan (aangezien blindheid niet geïsoleerd wordt ervaren). Het doctoraatsproject omarmt de rijkdom en tegenstrijdigheden van hoe blindheid wordt gevoeld, gedeeld en voorgesteld in context. Het besteedt aandacht aan de verweven manieren waarop blindheid wordt beleefd – met anderen, via anderen en in verbinding met de wereld. Dit doctoraatsproject streeft naar een dynamisch begrip dat complexiteit en doorleefde variaties omarmt. Voortbouwend op deze verkenningen stelt dit doctoraatsonderzoek ook de vraag: hoe kunnen we anders denken? Het wil ruimte creëren voor alternatieve geleefde realiteiten. Het draagt bij aan een meer genuanceerd begrip – een begrip dat de complexiteit van blinde manieren van zijn, weten en erbij horen respecteert en dat zich verzet tegen reductionisme. Daarmee stelt het de dominantie van klinische of buitenstaandersvisies en aanvankelijke aannames over blindheid ter discussie. Het daagt vaak ziende, op tekortkomingen gebaseerde kennis uit. Het bekritiseert het denken in termen van normaliteit dat gericht is op capaciteiten en lichamelijke gezondheid. Dit doctoraatsonderzoek creëert kennis door praktijken en processen samen te brengen die uitnodigen tot herhaling, variatie en responsiviteit op wat zich aandient. Elk hoofdstuk keert terug naar een ander domein waar visuele beperking samengaat met thema's als belichaming en relationaliteit, om te onderzoeken hoe deze (her)geconceptualiseerd kunnen worden.

Een overzicht van de hoofdstukken

Dit doctoraat onderzoekt hoe blindheid van belang is in het dagelijks leven. Het project verkent blindheid vanuit het perspectief van zien, ouderschap, onderwijs en sociale participatie, materialiteit en wetenschappelijke positionering.

‘Hoofdstuk 2: Ongezien? Een kwalitatief onderzoek naar hoe moeders en vaders met een visuele beperking het ouderschap ervaren’ brengt de veelzijdige ervaringen van dertien ouders met een visuele beperking in beeld. Het richt zich op drie thema's: dagelijkse opvoedingspraktijken, de drang van ouders om zichzelf te bewijzen en relationele opvoeding met partner en kinderen. Het geeft weer hoe ouders met een visuele beperking de opvoeding van hun kinderen ervaren en hoe zij omgaan met opvattingen over ‘ideaal ouderschap’. Daarnaast biedt het een opwaarts inzicht in hoe ouderschap en blindheid met elkaar verweven zijn.

‘Hoofdstuk 3: Leven met blindheid: een analyse van de contextuele ervaringen van James en zijn netwerken’ onderzoekt blindheid als een relationele praktijk door de lens van onderlinge afhankelijkheid gedurende de hele levensloop. Deze diepgaande casestudy van James, een jonge man met een visuele beperking, en leden van zijn netwerk focust daarbij zowel op onderwijskeuzes als op relaties met anderen.

In ‘Hoofdstuk 4: Een tegenverhaal: de wereld volgens de witte stok’ vertelt het materiële object, de witte stok, over zijn gecompliceerde relatie met zijn gebruiker. De studie ontrafelt de materiële, persoonlijke en symbolische betekenis van de witte stok en werpt licht op de functionaliteiten, relationaliteiten en manieren van zijn en worden in de wereld met en zonder een witte stok. De witte stok–met al zijn betekenissen–is van belang voor blindheid; hij beïnvloedt de opvattingen daarover, aangezien hij een integraal onderdeel is van het geheel van blindheid en altijd verweven is met zijn gebruiker, andere betrokkenen en materiële omgevingen.

‘Hoofdstuk 5: Positionering’ richt de blik naar binnen en laat zien hoe de belichaamde aanwezigheid van een blinde onderzoeker het onderzoeksproces vormgeeft. Het reflecteert op insideronderzoek, geleefde resonantie en de methodologische en ethische implicaties van het positioneren van jezelf binnen onderzoek (naar beperking). Twee intermezzo's, ‘Toegankelijke deelname aan academische conferenties als je slechtziend bent’ en ‘Tijd crippen: tijdsopvattingen in de academische wereld’, breiden deze reflectie uit door toegankelijkheid in academische contexten aan te kaarten, obstakels en strategieën te belichten en op te roepen tot institutionele verandering.

Belangrijkste bevindingen

Dit doctoraatsonderzoek biedt gelaagde, op ervaring gebaseerde her-conceptualiseringen van blindheid die het conventionele begrip ervan uitdagen. Het benadrukt assemblage-gebaseerde perspectieven en confronteert tegelijkertijd de alomtegenwoordige impact van normativiteit die op valide lichamen, kunnen zien en toegankelijkheid zijn gebaseerd. Door na te gaan hoe deze dynamieken elkaar kruisen, positioneert het doctoraatsproject het onderzoek op zichzelf ook als situationeel en transformerend.

Het doctoraatsonderzoek identificeert zeven onderling verbonden manieren om blindheid te her-conceptualiseren vanuit geleefde perspectieven:
Ten eerste, blindheid als veelzijdigheid: blindheid manifesteert zich op meerdere, dynamische en vloeiende manieren. Blindheid kan vele vormen aannemen, elk met zijn eigen logica, emotie en ritme. Er is een breed scala aan blinde ervaringen, betekenissen en gevoelens mogelijk.
Ten tweede, blindheid als verschillende zintuiglijke manieren van doen: blindheid geeft een nieuwe vorm aan wat waarnemen of kijken kan betekenen en leidt tot creatief en inventief gebruikte alternatieve strategieën – anders zien; tast, gehoor, reuk, geheugen en verbeelding – om te navigeren en om te gaan met de wereld.
Ten derde, blindheid als een manier van zijn in de wereld: blindheid is een belichaamde ontologie en epistemologie, een permanente metgezel in elk facet van het leven. Het kan iets existentieels zijn waarmee geleefd wordt.
Ten vierde verwijst blindheid als aangeleerde sociale rol, in samenhang met een dominante ziende cultuur, naar hoe een netwerk van sociale, culturele, generatiegebonden en historische invloeden blindheid construeren en dat blinde mensen zich aanpassen aan die betekenissen.
Ten vijfde, blindheid als leraar: blindheid brengt bewustzijn over en biedt kritische reflecties op normaliteit, kennis, bekwaamheid, verschil en menselijke variatie. Het is een gelegenheid voor persoonlijk, wetenschappelijk en maatschappelijk leren dat aanzet tot nadenken over mogelijkheden, jezelf, anderen en de wereld.
Ten zesde, blindheid als iets om van te houden: blindheid wordt affirmatief beschouwd als iets dat de moeite waard, geldig en waardevol is. Blindheid is een positief verschil dat

gevierd kan worden en het leven kan verrijken: ‘Het kan ontzettend leuk zijn…’ (Michalko & Goodley, 2023, p. 113), iets dat gewaardeerd of omarmd kan worden vanwege de bron van vreugde, trots, verbondenheid, creativiteit en emotionele diepgang die het biedt. En ten zevende is blindheid als relationeel begrip een nieuwe conceptualisering die wordt toegevoegd aan het rijke repertoire van blindheid. Blindheid ontstaat door onderlinge afhankelijkheid, co-creatie en interacties met anderen en omgevingen. Blindheid wordt actief en affectief mede gevormd in en door relationeel leven. Dit doctoraatsonderzoek ondersteunt concepten van blindheid als geleefd in relatie en relationele blindheid. Blindheid is verweven met vele entiteiten, die elk toegang bieden tot verschillende versies van blindheid.

Ondanks rijke her-conceptualiseringen van visuele beperking blijven oculair-normatieve verwachtingen diepgeworteld (Bolt, 2013, 2023). Het doctoraatsproject belicht voortdurende confrontaties met validisme en oculaircentrisme, en laat tegelijkertijd zien hoe blinde mensen met deze dynamieken omgaan. Wat gebeurt er onzichtbaar of anders in deze normatieve situaties? Wat is het repertoire om verder te gaan terwijl men met deze omstandigheden te maken heeft? Blinde percepties bevestigen duidelijk de enorme drang om zichzelf als onafhankelijk en waardevol te bewijzen. Deelnemers beschrijven een constante behoefte om hun competentie en waarde te benadrukken (Healey, 2021; Michalko, 1998, 2002). Blinde mensen gaan creatief om met deze druk: door middel van micro-verzet, verhalen vertellen en performance. Dergelijke strategieën verwijzen naar onderlinge afhankelijkheid, erbij horen en belichaamde waardigheid, maar de inspanning is zwaar en maskeert vaak structurele uitsluitingen. Deze ‘normativiteitskost’ (Hamraie, 2017; Price, 2024) roept vragen op over wie de last tot verandering draagt: het individu of het systeem. Blindheid ontwikkelt zich dus door spanning en legt tegelijkertijd de noodzaak bloot om de normen die participatie en waarde definiëren, te heroverwegen.

Op dezelfde manier reageren blinde percepties ook op normativiteit omtrent toegankelijkheid (Hamraie, 2017; Price, 2024). Toegankelijkheid komt niet naar voren als een vaste toestand, maar als een dynamisch, context-gebonden proces. Dit doctoraatsonderzoek baseert zich op hoe toegang verdwijnt en verschijnt (Titchkosky, 2011; Titchkosky et al., 2022) om te laten zien hoe toegang geïmproviseerd wordt. Het doctoraatsproject illustreert ‘toegangsintimiteit’ (Mingus, 2011, 2017) en ‘activistische verwezenlijkingen’ (Dokumaci, 2023). Namelijk laten momenten van wrijving/spanning zien hoe blinde mensen toegang mogelijk maken door middel van timing, interactie en verschuivende verwachtingen. Deze ervaringen vragen om toegankelijkheid te ‘crippen’ (Goodley & Runswick-Cole, 2014; Price, 2024)–voortdurende onderhandeling in plaats van uniforme oplossingen.

De drang om zichzelf te bewijzen, momenten van intieme toegankelijkheid en activistische verwezenlijkingen werden ook zichtbaar tijdens het onderzoek doen (zie Hoofdstuk 5). Deze ervaringen serieus nemen doet recht aan niet-ziende kennisvormen (Goodley, 2024; Symeonidou, 2024) en opent een ontologisch-methodologisch debat over een andere manier van academisch onderzoek doen. Wetenschap door blinde onderzoekers levert een bijdrage door conventionele academische praktijken, die zijn gevormd door oculaire normativiteit en ontoegankelijkheid, te verstoren. Het werken binnen structuren die niet zijn ontworpen voor lichamen of geesten met een beperking, leidt tot unieke perspectieven, vragen en concepten die het wetenschappelijk onderzoek verrijken. Dergelijk onderzoek reflecteert ook op de methodologische en ethische implicaties van disability studies, waarbij kennisproductie en legitieme participatie opnieuw worden bekeken. Het benadrukt daarmee het belang van 'intersectionaliteit' (Goodley, 2024; Titchkosky et al., 2022; Whitburn & Michalko, 2019). Het is zeer relevant om in te gaan op alle spanningen en complementariteiten die zich voordoen. Het werven van een groep deelnemers die te maken heeft met andere vormen van verschil of minderheid vergde inspanningen, maar dit doctoraatsonderzoek legt de intersectionele complexiteit vast die inherent is aan de deelnemende assemblages van blindheid.

Onthul 'de meer'

Na verschillende manieren te hebben verkend waarop blindheid wordt beleefd en mede gecreëerd, verwijst het doctoraatsproject naar openheid: openheid voor wat onuitgesproken, onzichtbaar en nog in ontwikkeling is. De betekenis van blindheid laat zich niet in een hokje plaatsen (Bolt, 2023; Titchkosky et al., 2022). Blindheid is nooit volledig vaststaand of zichtbaar, maar blijft dynamisch en in ontwikkeling. Blindheid openbaart zich geleidelijk door het aanhoudende gevoel dat er nog meer te weten, te voelen en te verbeelden valt, meer te waarnemen, meer te herinterpreteren, meer te vertellen. Voorbij alle concepten die tot nu toe zijn aangedragen, blijft een stil gevoel hangende dat blindheid nog steeds meer is, en meer zou kunnen zijn. Verschillende ontmoetingen, plaatsen, interpretaties, complexiteiten, spanningen, tegenstrijdigheden en manieren om blindheid betekenis te geven, zijn altijd mogelijk. Door te laten zien hoe blindheid vorm krijgt in de context (als een complex, belichaamd, relationeel, gesitueerd, affectief en onderling afhankelijk fenomeen), kunnen we herhaaldelijk terugkeren naar verschillende manieren om met blindheid om te gaan, deze te ervaren, te beleven en samen te leven. Dit zet aan tot het voortzetten van een disability studies perspectief, aangezien dit kan leiden tot een beter begrip van blindheid en een zinvolle bijdrage kan leveren aan een meer holistische benadering van blindheid. De uitnodiging klinkt als volgt: onderzoek verder wat blindheid meer inhoudt dan het verhaal dat meestal wordt verteld, denk na over de veelzijdigheid, fluïditeit en relationaliteit van blindheid en overweeg hoe identiteit, waardigheid en toegankelijkheid mede worden gevormd in en door ontmoetingen tussen mensen en wat-mensen-overstijgt. Blijf een andere kijk op beperking ontwikkelen door blindheid vanuit verschillende maar onderling verbonden invalshoeken te her-vertellen, te her-configureren en opnieuw te bekijken (Michalko, 1998; Michalko & Goodley, 2023). Blindheid doet ertoe, via (her)conceptualisering, het verdwijnen en verschijnen, en het onthullen van wat er nog meer zou kunnen zijn. Het her-conceptualiseren van blindheid vereist het samengaan van verschijnen en verdwijnen; het zien en niet-zien moeten met elkaar samengaan en te midden van dit samengaan kunnen andere betekenissen van blindheid worden onthuld.

Dit brengt ons bij de kern van dit doctoraatsonderzoek: een oproep tot actie die iedereen uitnodigt om zich te verdiepen in de rijkdom van geleefde ervaringen en de kennis die deze bevatten. Blinde percepties helpen om anders over blindheid te denken, omdat ze een dominante deskundigenpositie, normativiteit van zien of toegang, de beperking als zodanig uit het middelpunt halen. Door te focussen op realistische voorstellingen van blindheid wordt de complexiteit ervan weerspiegeld en worden (her)conceptualisaties van blindheid gekoppeld aan aspecten die verband houden met beperking:

perspectieven, levensdomeinen, meer dan menselijke verwikkelingen en meer dan alomtegenwoordige dynamieken. Ervaringskennis geeft vorm aan erbij horen, toegang, participatie en kennisproductie. Door middel van geleefde ervaringen kunnen andere conceptualisaties van blindheid, verschillende vormen van interactie en nieuwe mogelijkheden voor politiek en creatief denken en handelen aan het licht komen. Responsiviteit voor meerdere manieren van weten, denken, vertellen en doen brengt energie om momenten van (her)conceptualisering, onderlinge afhankelijkheid en intra-actie te inspireren. Werken met geleefde ervaringen, niet als illustraties maar als plaatsen van theoretisering, vereist in wezen dat we anders luisteren naar hoe blindheid wordt beleefd. Door ervaringskennis ethisch serieus te nemen, wordt participatie gestimuleerd en krijgt de wereld meer inzicht in wat een beperking kan inhouden. Het stelt ons in staat om te blijven nadenken over blindheid en nieuwsgierig te blijven naar wat het nog meer kan onthullen.

Dit is het potentieel van het contextueel her-conceptualiseren van blindheid, omdat het de collectieve toewijding om meer te ontdekken dan wat al bekend is, eer aandoet. Door beperking te benaderen vanuit relationele en belichaamde perspectieven kunnen verschillende conceptualisaties ontstaan, manieren waarop beperking kan worden beleefd, gewaardeerd en tot bloei kan komen. Dergelijke her-conceptualiseringen nodigen ons uit om ons niet alleen voor te stellen wat een blinde persoon zou kunnen worden, maar ook wat assemblages zouden kunnen worden en wat blindheid zelf zou kunnen worden. Hierdoor wordt ervaringskennis een drijvende kracht achter ontwerp, actie en transformatie. Als we de wereld vanuit dit perspectief benaderen, kunnen krachtige bewegingen van proberen, experimenteren en anders denken vorm krijgen. Door open te staan voor verschil in al zijn veelzijdigheid, door bevrijdend te denken en buiten de kaders te handelen, zelfs door de kaders open te breken en te transformeren, kunnen we onderhandelen, navigeren, variëren, herschikken en de manieren waarop we met blindheid omgaan uitdagen. Dit biedt een enorm potentieel om wrijving te verkennen, micro-opstanden te ontketenen en ruimte te maken voor alles wat nog niet verteld is.

References

Bolt, D. (2013). *The metanarrative of blindness: a re-reading of twentieth-century Anglophone writing.* US: University of Michigan Press. https://doi.org/10.3998/mpub.5725818

Bolt, D. (Ed.). (2023). *Finding blindness: International constructions and deconstructions.* Routledge.

Dokumaci, A. (2023). *Activist affordances: How disabled people improvise more habitable worlds.* Duke University Press.

Goodley, D. (2024). Depathologising the university. *Pedagogy, Culture & Society*, 33(3), 1001-1018. https://doi.org/10.1080/14681366.2024.2316007

Goodley, D., & Runswick-Cole, K. (2014). Becoming dishuman: Thinking about the human through dis/ability. *Discourse Studies in the Cultural Politics of Education*, 37(1), 1-15. https://doi.org/10.1080/01596306.2014.930021

Hamraie, A. (2017). Building access. https://doi.org/10.5749/j.ctt1pwt79d

Healey, D. (2021). *Dramatizing blindness: Disability studies as critical creative narrative*. Palgrave Macmillan.

Michalko, R. (1998). *The mystery of the eye and the shadow of blindness*. University of Toronto Press.

Michalko, R. (2002). *The difference that disability makes*. Temple University Press.

Michalko, R., & Goodley, D. with Smokie (2023). *Letters with Smokie: Blindness and more-than-human relations*. University of Manitoba Press.

Mingus, M. (2011, May 5). Access intimacy: The missing link. Leaving Evidence. https://leavingevidence.wordpress.com/2011/05/05/access-intimacy-the-missing-link/

Mingus, M. (2017, April 12). Access intimacy, interdependence and disability justice. Leaving Evidence. https://leavingevidence.wordpress.com/2017/04/12/access-intimacy-interdependence-and-disability-justice/

Price, M. (2024). Crip spacetime: Access, failure, and accountability in academic life. Duke University Press.

Symeonidou, S. (2024). Teacher education for disability focused anti-oppressive pedagogy: The case for reconceptualisation. *Disability & Society*, 40(5), 1404-1424. https://doi.org/10.1080/09687599.2024.2360430

Titchkosky, T. (2011). *The question of access: Disability, space, meaning*. University of Toronto Press.

Titchkosky, T., Cagulada, E., & DeWelles, M. (2022). *DisAppearing: Encounters in disability studies*. Canadian Scholars.

Whitburn, B., & Michalko, R. (2019). Blindness/sightedness: Disability studies and the defiance of di-vision. In N. Watson & S. Vehmaas (Eds.), *The Routledge handbook of disability studies* (pp. 219-233). Routledge.

Appendix 2: Acknowledgments

‘Thank you’ – I always used to skip this slimy part in publications. I like to be direct, to stay authentically focused on the essence of things. All that extra small talk — ‘fabulous’, ‘amazing’, ‘sorry’, ‘thank you’ — is not really in my nature. And yes, sometimes it’s a little strategic or even manipulative of me to show gratitude or constructiveness as a way to get things done — but that’s how I’ve learned to survive (or conserve energy).

Still, the silly truth behind many of my academic decisions is often just ‘because someone told me and believed in it’. In other words, because through exchanges with others, it becomes clear that there is something in there that is interesting to explore, that it matters. Many choices I made were shaped by moments in which someone else saw potential, or when an encounter sparked something to follow. For all of that, I am deeply thankful.

I am highly thankful that personal connections were crucial in this PhD journey—of coming to understand blindness—that has been a relational process, a process of becoming. I look back with great gratitude. Gratitude for the opportunities I have been given, but especially for the warm people who have surrounded me. I want to thank everyone who was part of this process: the many people I encountered and shared paths with during this personal and professional trajectory.

My family always supported the idea that the sky is the limit. My grandfather had confidence in the intellectual development of his grandchildren, having been a teacher and holding a PhD himself. He supported going to university for intellectual development. My grandmother learned by life to be diligent, persistent and creative in running a household alone and inventive crafting. I owe them my deepest gratitude, for their way of being in the world. Their legacy gave nourishment to firm roots from which to grow.

Geert once told me, after my master's thesis, that there was more in those interviews than I had unpacked. I am thankful for the invitation to build further on the initial explorations. His collaboration with, and follow-up by, Elisabeth ensured a smooth PhD trajectory in which I felt deeply supported. I highly respect the moments of confusion provoked by my supervisors, and members of the advisory committee, because they were always right with planting small seeds that grew into big trees. Many thanks for putting me in touch with significantly fascinating people, relevant literature and thoughts. By doing so, reflecting on privilege, for instance unfolded into normativism, a massive voice in the story of blindness.

The close colleagues of the research group Jardin offered guidance through the doctoral procedures, along with hands-on advice, always infused with a disability studies perspective. They deserve intense appreciation for thinking together with me, endlessly writing ping-pong-wise and discussing large amounts of literature. Particularly, we returned to the materiality of disability through reading groups about visual impairment literature, which flowed into putting the white cane in the voice of a protagonist (Chapter 4) and we enjoyed reading *DisAppearing: encounters in disability studies* (by Titchkosky et al., 2022), which flowed into a robust book review (Van Havermaet et al., in press).

Without Jardin, the garden to flourish in wouldn’t have existed. Thank you for thinking and experimenting with me.

To Chelsea and Aïsha — two master’s thesis students involved in this doctoral project — it was a pleasure to guide you. Thank you for asking challenging questions and for bringing meaning and colour to complex research puzzles. I wish you both the very best, in Special Needs Education and far beyond.

I would also like to thank the people who have taken up an assistive role, because assistance has taken on all kinds of modalities through the whole PhD process. Without the three orthopedagogues, my master’s thesis had never been the basis for a PhD. Without job students, I still would have been busy with doing the lay-out for presentations and setting up accounts on journal websites. Without the personal assistance of Eliane, I would never have gone to Southampton. And without the support of colleagues and my professional aunty Silke the PhD would never be wrapped up in this booklet.

I am deeply grateful for moments of recognition. I didn’t widely share that my presentation at the International Conference on Disability Studies (ICDS, 2022) received an award, but I was moved that my commitment and work ethic were appreciated. That various organisers invited me to webinars and professional gatherings to exchange ideas—and that this helped my confidence grow—meant a lot.

My psychotherapist who shared recognition for my weaknesses and authentic admiration for resistance, constructiveness, inspiration, ... motivated me to read *Threads: the delicate life of John Craske* by Julia Blackburn (2015) which was helpful to use as a metaphor for my process of knowledge making.

I’m not a book addict—except when it comes to the autobiographical literature I kept returning to for this PhD, and which rightly holds a central place in it. My gratitude to these authors is profound. Their foundational work felt intimate — as if read in confidence. I felt a deep connection with Rod, Tanya, David, Beth, Devon, Georgina, and Ben. Meeting some of them in person only deepened this connection. I continue to be moved by Ben’s sharpness in calling out ableism—'where ableist people don’t give a shit’—while also offering the parental care and generosity that allowed me to fully experience my time abroad in Southampton.

But most of all, my sincerest gratitude goes to the participants, for giving voice to their lived experiences. There would never have been a PhD without you. Our dialogues were absolutely fundamental for this research. I am seriously impressed by all the experiences you have openly shared with me. You have given an awful lot. Thank you for making time, letting me into your home, sharing your story. Your enthusiasm for the research, the relevant questions you posed and so much more have touched and warmed me. I sincerely hope that this research honours your story and acknowledges your story and perseverance. Thanks to your trust, interest and involvement, this project could come about. Thank you — truly — for everything.

Appendix 3: Contributions to the public domain

List of publications

De Schauwer, E., Van Havermaet, J., Blockmans, I.G.E., Hellin, H., & Davies, B. (accepted). Re-turning to stories of recognition and the ongoing search for creative-relational belonging: a collective biography of lives lived with disability. *Disabilities*.

Dewitte, J., & Van Havermaet, J. (2021). Ouderschap met een visuele beperking. *Knipoog – Tijdschrift van Licht & Liefde*, 20-24.

Poppe, L., Van Havermaet, J., & Rowaert, S. (2022). Personen met een visuele beperking. In E. De Schauwer, S. Vandevelde, C. Claes, S. De Pauw, & W. Vanderplasschen (Eds.), *Orthopedagogiek als handelingswetenschap* (pp. 151-190). Borgerhoff & Lamberigts.

Scherrens, C., Van Havermaet, J., & De Schauwer, E. (accepted). Inzicht in sociale netwerkrelaties bij het ouderschap van moeders en vaders met een visuele beperking. *Orthopedagogiek: onderzoek en praktijk*.

Van Havermaet, J. (2025). Chapter 2: Cripping time: Temporalities in academia. In C. McMaster & B. Whitburn (Eds.), *Disability and the university: A disabled student's manifesto, 2nd edition* (pp. 11-18). Peter Lang.

Van Havermaet, J., Carette, L., & De Schauwer, E. (in press). [Review of the book *DisAppearing: Encounters in disability studies*, by T. Titchkosky, E. Cagulada, & M. DeWelles with E. Gold]. *Journal of Literary & Cultural Disability Studies*.

Van Havermaet, J., Daelman, S., Van Hove, G., & De Schauwer, E. (2025). A counter-narrative: the world according to the white cane. *Scandinavian Journal of Disability Research,* 27(1), 162-172. http://doi.org/10.16993/sjdr.1222

Van Havermaet, J., De Schauwer, E., & Van Hove, G. (2021). Unseen? A qualitative study on how mothers and fathers living with a visual impairment experience parenthood. *DiGeSt Journal of Diversity and Gender Studies, Parenthood: norms and experiences*, 7(2), 68-80. http://dx.doi.org/10.21825/digest.v7i2.17565

Van Havermaet, J., De Schauwer, E., & Whitburn, B. (under construction). The language test: an exemplification of disability-related distractions. *Higher Education*.

Van Havermaet, J., & Vandamme, E. (2024). Uitwisseling met Southampton: collega Jentel op schok. *Orthogazet*.

Van Havermaet, J., & Vandamme, E. (2024). Our experience at Southampton Education School. *Education School Newsletter*.

Van Havermaet, J., van de Merbel, L., Van Hove, G., & De Schauwer, E. (2023). Accessible participation in academic conferences if you are visually impaired. *Journal of Disability Studies in Education*, 3(2), 148-165. https://doi.org/10.1163/25888803-bja10020

Van Havermaet, J., Van Hove, G., & De Schauwer, E. (2024). Living with blindness: unravelling contextualised lived experiences of James and his networks. *Disability & Society,* 40(5), 1158-1175. https://doi.org/10.1080/09687599.2024.2331725

Van Hee, M., Van Havermaet, J., & De Schauwer, E. (under construction). Projectverslag: Studeren met een visuele beperking in het hoger onderwijs.

Verroest, A., Van Havermaet, J., & De Schauwer, E. (accepted). Een blik op de toekomst door jongvolwassenen met een visuele beperking. *Orthopedagogiek: onderzoek en praktijk*.

Appendix 4: Data management

Data Storage Fact Sheet 1

Name/identifier study: Parenting
Author: Jentel Van Havermaet
Date: 28 August 2025

1. Contact details
==
1a. Main researcher

- name: Jentel Van Havermaet
- address: Ghent University, Department of Special Needs Education, Henri Dunantlaan 1, 9000 Ghent, Belgium
- e-mail: jentel.vanhavermaet@ugent.be

1b. Responsible Staff Member (ZAP)
- name: Elisabeth De Schauwer
- address: Ghent University, Department of Special Needs Education, Henri Dunantlaan 1, 9000 Ghent, Belgium
- e-mail: elisabeth.deschauwer@ugent.be

If a response is not received when using the above contact details, please send an email to data.pp@ugent.be or contact Data Management, Faculty of Psychology and Educational Sciences, Henri Dunantlaan 2, 9000 Ghent, Belgium.

2. Information about the datasets to which this sheet applies
==
* Reference of the publication in which the datasets are reported:
Van Havermaet, J. (2019). Ongezien? Moeders en vaders met een visuele beperking (Masterproef, Universiteit Gent). Promotor: Geert Van Hove.
Van Havermaet, J., De Schauwer, E., & Van Hove, G. (2021). Unseen? A qualitative study on how mothers and fathers living with a visual impairment experience parenthood. DiGeSt Journal of Diversity and Gender Studies, Parenthood: norms and experiences, 7(2), 68-80.
* Which datasets in that publication does this sheet apply to?:
This DSFS applies to the data in the corresponding article and chapter:

3. Information about the files that have been stored
==
3a. Raw data
----
* Have the raw data been stored by the main researcher? YES
* On which platform are the raw data stored?
 - researcher PC
 - other: back-up on an external hard drive & shared folder with supervisor
* Who has direct access to the raw data (i.e., without intervention of another person)?

- main researcher
- responsible ZAP

3b. Other files

* Which other files have been stored?
- file(s) containing processed data. Specify: pseudonymised transcripts with names/places replaced by participant number/abstract description
- file(s) containing analyses. Specify: annotated transcripts with fieldnotes, themes, supporting quotes, drafts of papers and interpretations
- files(s) containing information about informed consent
- a file specifying legal and ethical provisions: PDF files of approval from Ethische Commissie UGent Faculteit Psychologie en Pedagogische Wetenschappen: 2021/59 (and 2022/146

* On which platform are these other files stored?
- individual PC
- other: back-up on an external hard drive & shared folder with supervisor

* Who has direct access to these other files (i.e., without intervention of another person)?
- main researcher
- responsible ZAP

4. Reproduction

Have the results been reproduced independently?: NO

Data Storage Fact Sheet 2

Name/identifier study: Context James
Author: Jentel Van Havermaet
Date: 28August 2025

1. Contact details
==
1a. Main researcher

- name: Jentel Van Havermaet
- address: Ghent University, Department of Special Needs Education, Henri Dunantlaan 1, 9000 Ghent, Belgium
- e-mail: jentel.vanhavermaet@ugent.be

1b. Responsible Staff Member (ZAP)

- name: Elisabeth De Schauwer
- address: Ghent University, Department of Special Needs Education, Henri Dunantlaan 1, 9000 Ghent, Belgium
- e-mail: elisabeth.deschauwer@ugent.be

If a response is not received when using the above contact details, please send an email to data.pp@ugent.be or contact Data Management, Faculty of Psychology and Educational Sciences, Henri Dunantlaan 2, 9000 Ghent, Belgium.

2. Information about the datasets to which this sheet applies
==
* Reference of the publication in which the datasets are reported:
Van Havermaet, J., Van Hove, G., & De Schauwer, E. (2024). Living with blindness: unravelling contextualised lived experiences of James and his networks. Disability & Society, 40(5), 1158-1175. https://doi.org/10.1080/09687599.2024.2331725
* Which datasets in that publication does this sheet apply to?:
This DSFS applies to the data in the corresponding article and chapter:
- audio-recordings of interviews
- pseudonymised transcripts of interviews
- informed consent forms

3. Information about the files that have been stored
==
3a. Raw data
----
* Have the raw data been stored by the main researcher? YES
* On which platform are the raw data stored?
- researcher PC
- other: back-up on an external hard drive & shared folder with supervisor
* Who has direct access to the raw data (i.e., without intervention of another person)?
- main researcher

- responsible ZAP

3b. Other files

----

* Which other files have been stored?
- file(s) containing processed data. Specify: pseudonymised transcripts with names/places replaced by participant number/abstract description
- file(s) containing analyses. Specify: annotated transcripts with fieldnotes, themes, supporting quotes, drafts of papers and interpretations
- files(s) containing information about informed consent
- a file specifying legal and ethical provisions: PDF files of approval from Ethische Commissie UGent Faculteit Psychologie en Pedagogische Wetenschappen: 2021/59 (and 2022/146)

* On which platform are these other files stored?
- individual PC
- other: back-up on an external hard drive & shared folder with supervisor

* Who has direct access to these other files (i.e., without intervention of another person)?
- main researcher
- responsible ZAP

4. Reproduction

===

Have the results been reproduced independently?: NO

Data Storage Fact Sheet 3

Name/identifier study: Context Lucie and context Alice
Author: Jentel Van Havermaet
Date: 28August 2025

1. Contact details
===
1a. Main researcher

- name: Jentel Van Havermaet
- address: Ghent University, Department of Special Needs Education, Henri Dunantlaan 1, 9000 Ghent, Belgium
- e-mail: jentel.vanhavermaet@ugent.be

1b. Responsible Staff Member (ZAP)

- name: Elisabeth De Schauwer
- address: Ghent University, Department of Special Needs Education, Henri Dunantlaan 1, 9000 Ghent, Belgium
- e-mail: elisabeth.deschauwer@ugent.be

If a response is not received when using the above contact details, please send an email to data.pp@ugent.be or contact Data Management, Faculty of Psychology and Educational Sciences, Henri Dunantlaan 2, 9000 Ghent, Belgium.

2. Information about the datasets to which this sheet applies
===
* Reference of the publication in which the datasets are reported:
Van Havermaet, J., Daelman, S., Van Hove, G., & De Schauwer, E. (2025). A counter-narrative: the world according to the white cane. Scandinavian Journal of Disability Research, 27(1), 162-172. http://doi.org/10.16993/sjdr.1222
* Which datasets in that publication does this sheet apply to?:
This DSFS applies to the data in the corresponding article and chapter:
 - audio-recordings of interviews
 - pseudonymised transcripts of interviews
 - informed consent forms

3. Information about the files that have been stored
===
3a. Raw data
----
* Have the raw data been stored by the main researcher? YES
* On which platform are the raw data stored?
 - researcher PC
 - other: back-up on an external hard drive & shared folder with supervisor
* Who has direct access to the raw data (i.e., without intervention of another person)?
 - main researcher

- responsible ZAP

3b. Other files
----

* Which other files have been stored?
 - file(s) containing processed data. Specify: pseudonymised transcripts with names/places replaced by participant number/abstract description
 - file(s) containing analyses. Specify: annotated transcripts with fieldnotes, themes, supporting quotes, drafts of papers and interpretations
 - files(s) containing information about informed consent
 - a file specifying legal and ethical provisions: Pdf files of approval from Ethische Commissie UGent Faculteit Psychologie en Pedagogische Wetenschappen: 2021/59 (and 2022/146); and Commissie Medische Ethiek UZ Gent (central committee): BC-10661.
* On which platform are these other files stored?
 - individual PC
 - other: back-up on an external hard drive & shared folder with supervisor
* Who has direct access to these other files (i.e., without intervention of another person)?
 - main researcher
 - responsible ZAP
 - other: co-authors Prof. dr. Geert Van Hove, dr. Silke Daelman

4. Reproduction
==

Have the results been reproduced independently?: NO

Data Storage Fact Sheet 4

Name/identifier study: Participating in conferences
Author: Jentel Van Havermaet
Date: 28August 2025

1. Contact details
==
1a. Main researcher

- name: Jentel Van Havermaet
- address: Ghent University, Department of Special Needs Education, Henri Dunantlaan 1, 9000 Ghent, Belgium
- e-mail: jentel.vanhavermaet@ugent.be

1b. Responsible Staff Member (ZAP)

- name: Elisabeth De Schauwer
- address: Ghent University, Department of Special Needs Education, Henri Dunantlaan 1, 9000 Ghent, Belgium
- e-mail: elisabeth.deschauwer@ugent.be

If a response is not received when using the above contact details, please send an email to data.pp@ugent.be or contact Data Management, Faculty of Psychology and Educational Sciences, Henri Dunantlaan 2, 9000 Ghent, Belgium.

2. Information about the datasets to which this sheet applies
==
* Reference of the publication in which the datasets are reported:
Van Havermaet, J., van de Merbel, L., Van Hove, G., & De Schauwer, E. (2023). Accessible participation in academic conferences if you are visually impaired. Journal of Disability Studies in Education, 3(2), 148-165.
* Which datasets in that publication does this sheet apply to?:
This DSFS applies to the data in the corresponding article and chapter:

3. Information about the files that have been stored
==
3a. Raw data
----
* Have the raw data been stored by the main researcher? YES
* On which platform are the raw data stored?
 - researcher PC
 - other: back-up on an external hard drive & shared folder with supervisor
* Who has direct access to the raw data (i.e., without intervention of another person)?
 - main researcher
 - responsible ZAP
 - other: co-author Leendert van de Merbel

3b. Other files

* Which other files have been stored?
file(s) containing analyses. Specify: annotated dialogues with fieldnotes, themes, supporting quotes, drafts of papers and interpretations
* On which platform are these other files stored?
  - individual PC
  - other: back-up on an external hard drive & shared folder with supervisor
* Who has direct access to these other files (i.e., without intervention of another person)?
  - main researcher
  - responsible ZAP
  - other: co-authors Prof. dr. Geert Van Hove, dr. Leendert van de Merbel

4. Reproduction

Have the results been reproduced independently?: NO