Research Article

Holding and Professional Care: On Self-Determination for Persons With Profound Intellectual and Multiple Disabilities

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Abstract
Persons with profound intellectual and multiple disabilities (PMID) are in danger of not being granted the human right to experience self-determination. Attitudes questioning the relevance of the rights of persons with significant support needs and a lack of guidance on how to practically go about ensuring self-determination might explain this. Providing knowledge about this matter, this article contributes through an ethnography highlighting the relationship between persons with PIMD and professionals. The concept of holding another's identity was found to be a possible, fruitful approach toward self-determination in this context. Descriptions of holding dialogues with an ethics of care suggest specific conditions for moving practices toward self-determination: recognize the role of the professional, emphasize embodied empathy, and enable involvement. The ethnography suggests a broadened understanding of self-determination, pinpointing the importance of sensitivity toward the other's particularity.

Keywords
profound intellectual and multiple disabilities, self-determination, holding, professional practice, ethnography, ethics of care

To experience self-determination is a universal right (United Nations [UN], 1948). The Convention on the Rights of Persons with Disabilities (UN, 2006) made it clear that all humans have this right. Practice, however, shows that persons with profound intellectual and multiple disabilities (PIMD) are in danger of being denied this right (Skarstad, 2018). One reason might be that Western philosophy associates personhood with rationality, thereby devaluing persons with PIMD as being without agency (Vehmas & Mietola, 2021). Similar views have also been revealed in legal systems, leading to the denial of rights to persons with disabilities (Flynn & Arstein-Kerslake, 2014). Linking self-determination to rationality makes it irrelevant to persons with reduced cognitive abilities (Voss et al., 2021). This is in stark contrast to a social-ecological model of disability (Shogren et al., 2018) arguing that all persons have strengths and limitations, and rather than dismissing rights, the appropriate support that individuals need to be enabled must be implemented. Although awareness that all are subjects with rights is growing, opposing views continue to prevail.

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Professionals providing services to persons with PIMD (e.g., schools, day-centers or homes) play an important role in providing support. Research, however, has pointed to reduced opportunities related to professionals' low expectations of individuals' capabilities (Talman et al., 2019). Furthermore, it has identified a paucity of knowledge about how to practically go about ensuring the support to enable self-determination (Nicholson et al., 2021). While professionals might endorse the principle of self-determination, knowledge about how to support it is lacking (Vehmas & Mietola, 2021). A model such as the circle of support (Watson, 2012) provides fruitful structures for the related concept of supported decision-making (Watson et al., 2019), but filling the void regarding *details in the relationship* between the professional and the person with PIMD can inform best practices.

Persons with PIMD constitute a heterogenous group, yet they share several characteristics, such as the use of nonverbal communication, encompassing intellectual disabilities and profound neuromotor impairments (Nakken & Vlaskamp, 2007). These lead to potentially complicated caring situations characterized by dependence and asymmetry (Kittay, 2019); however, dependence should not be treated as a characteristic limited to those with PIMD. According to Kittay (2019), it is a human condition, and the dependence persons with PIMD experience sheds light on the dependency that all people occasionally experience. As such, it might be argued that the exploration of this perspective is relevant for everyone.

Regarded as challenging to include (Nind & Strnadova, 2020), persons with PIMD have, traditionally, been excluded from research. In this article, arguments will be more explicitly grounded in the perspectives of the persons in focus. The nonverbal being necessitates a somewhat indirect approach to portraying lived experience, and as such, ethnographic methods have been asserted to be appropriate (de Haas et al., 2022; Gjermestad et al., 2022; Simmons & Watson, 2015; Vehmas & Mietola, 2021). This study explores the lives of three persons with PIMD, namely Erik, Vera, and Karen (pseudonyms), interacting with professional caretakers within relations hallmarked by dependence.

Theoretical Framework

Self-determination is often equated with independence and self-sufficiency (Kittay, 2019). However, we follow Ryan and Deci (2017), who defined self-determined actions as behaviors that are "congruent with one's authentic interests and values" (p. 10). They described this as a congruence between actions and identity, which they further detailed as those concepts one holds about oneself. This is supported by Agich (2003), who suggested that being self-determined does not require being able to manifest rational choice but rather to have a developed identity. Self-determination is, thereby, extended beyond independence to include having one's identity understood. Ryan and Deci (2017) stressed the support needed from others; identity work is not conducted alone but unfolds within relations.

These insights arguing the importance of support in identity work leads to the key theoretical framework in this article: American philosopher Hilde Lindemann's concept of *holding another in identity*. Lindemann (2010, 2014) argues that identity is formed and supported narratively. She argued that identity "consists of tissues of stories and fragments of stories, generated from both first- and third-person perspectives" (Lindemann, 2014, p. 4). While she insisted that all humans need to be held, she also acknowledged that this is particularly critical for persons with high support needs. Lindemann used the term "holding" to describe a specific form of careful interactions, that is, situations where a person needs support to be understood in terms of his or her identity. Such interactions are often identified by narrative agency. When one holds another in his or her identity, one often tells stories that respect the person's autonomy (Lindemann, 2014) while, at the same time, being able to capture the movement of a self (Lindemann, 2010). This sometimes involves letting go, weeding out stories that no longer fit, and constructing new ones that do. Lindemann (2014) described how identity work goes beyond the verbal realm to involve the bodily expressions that constitute human personality. Holding is a matter of understanding who someone is and treating the person accordingly. Kukla (2007) advanced this idea, demonstrating how our self is both expressed and sustained by our bodies. Holding the body of a person with high support needs involves complicated and fragile moral work. Kukla argued for an active approach from the person holding, emphasizing that it can involve the transformation of identity through acts of "enabling-to-be" (p. 398). Finally, holding can be relational in a

wider sense: familiar places, beloved objects, and cherished rituals can also help us maintain our sense of self, providing a socio-material scaffolding (Lindemann, 2010).

Persons with PIMD depend continuously on others due to nonverbal communication and high support needs. To be understood, regardless of how one's identity is communicated, is important in counteracting ableism connected to rationality and verbal language (Forber-Pratt, 2020). The concept of *holding another in identity* is, therefore, relevant to that context. Lindemann's concept of holding is explored mostly regarding dementia and holding in nonprofessional contexts (Kukla, 2007; Lindemann, 2014). Therefore, this article adds to the theorisations that focus on holding within professional practices for persons with PIMD and the appropriate support needed and aims to answer the following questions:

- How is holding unfolded in professional caring relations with persons with PIMD?
- Can holding inform the realization of self-determination within professional practices?

Method

Traditionally, research involving persons with PIMD has emphasized deficits, mostly through the voice of proxies (Nind & Strnadova, 2020). This study aims to ground arguments on lived experiences, valuing the lives of persons with PIMD (Vehmas & Mietola, 2021). Thus, it calls for methods that can include such perspectives, and a qualitative approach (Bryman, 2016) was applied. The emic perspective (i.e., the insider's view of reality) is at the heart of most ethnographic research and aims to give people a voice in their local context, often through thick descriptions (Fetterman, 2020). Hence, for strategic reasons, the inquiry is ethnographic (Hammersley & Atkinson, 2019) with the aim of grasping everyday accounts.

Design

Persons with PIMD communicate in unique ways through bodily movements. These must be understood in context (e.g., turning their head toward a person or making a distinct facial gesture, wrinkling the nose or smiling [although at times a "smile" can indicate the start of crying or an epileptic seizure—underscoring the importance of contextual knowledge] and through the use of verbal sounds, indicating, for example, despair or joy). Hence, the ethnographic approach is inspired by sensory ethnography (Pink, 2015), highlighting embodied ways of being and focussing on the senses involved in interactional processes. More fundamentally, this study is based on the belief that humans have the capacity to understand others (Fuchs, 2017), particularly through intuitive, emotional experiences. In tracing embodied, nonverbal agency, ethnographic sensitivity was also inspired by the method of infant observation (Rustin, 2012) and this method's "migration" into comparable research frontiers such as dementia (Datler et al., 2012). Close observations focusing on what could be sensed in the relations as well as sensitivity to emotional experiences that these situations generated were included (Hollway, 2016). Although considered a helpful entry to possible perspectives, the uncertainty of the interpretations is still present, underscoring the mediating condition impacting the lives of persons with PIMD (Cluley, 2017).

The context of the study, completed during the COVID-19 pandemic, required the researcher to maintain physical distance from the participants. Although touch is an important sense (Pink, 2015), these conditions did not make the ethnographic situation less embodied. In fact, by keeping a physical distance, the researcher was able to maintain a position of noninterference (Rustin, 2012). This may have enhanced sensitivity by allowing the researcher to sense the actions of the participants more specifically.

Participants and Recruitment

Vera, Erik, and Karen are in the age group from 11 to 26 years and live in the south-western part of Norway. They are ethnic Norwegians who come from average, middle-class families. Their motoric abilities vary from little self-initiated movement to being able to use one arm. All use wheelchairs and need support for movement and intimate care. Two can chew food and one is tube-fed. All have sensory impairments

involving a total lack of or reduced sight and/or hearing. They receive public services and live in housing facilities structured as individual apartments located together, with day and night staff providing care.

Vera, Erik, and Karen were recruited by contacting leaders of health and welfare services in several municipalities. Following this, we recruited one family member for each of the three individuals. In Vera's case, five professionals were recruited representing three different institutions: the housing facility, the school, and the cultural school. In Erik's case, three professionals were recruited, two from the housing facility and one from the cultural school. In Karen's case, four professionals were initially recruited (from two institutions). However, pandemic-related restrictions at the time of data collection as well as ethical considerations led us to minimize social contact by reducing the number of institutions to one (i.e., Karen's housing facility). Thus, two professionals working with Karen participated. The recruited professionals are trained as social educators, in addition to a health care worker, a music therapist and a pedagogue. They represent the middle class, and all speak fluent Norwegian. Only professionals considered competent, knowing the person with PIMD well were recruited. Hence, the findings do not represent all possible encounters but pertain rather to "success stories" that can indicate possibilities for improved practice (Benner, 1984).

Procedures

Between September 2020 and June 2021, the first author collected two types of data, namely observational data and interviews and dialogue meetings with professionals and family members. The informants included three family members and 10 professionals.

In each case, the data collection started with initial conversations with both family members and professionals aimed to introduce essential information about the person with PIMD (i.e., details on communication and interests and, importantly, suggestions on how the researcher ought to approach the person with PIMD). After this initial stage, the first author spent a total of 124 hours observing, distributed among the three cases. Each observation lasted from 30 minutes to 4 hours, depending on the activity or situation. The aim was to gain an impression of daily life, and they were conducted during mundane activities like eating or relaxing as well as during less-common activities like going to the pool, the idea being that glimpses of self-determination might be found in all kinds of situations throughout the day. Observations focussed on details in the relationship and on what could be sensed in the situations (Pink, 2015). They have been complemented with the use of video in delimited situations to enhance the ability to capture complex interactions (Kaley et al., 2019). A total of 16 situations were videotaped, for a total of 2 hours and 22 minutes. Field notes were written shortly after the observations and comprised observational descriptions and the reflections and emotions that these generated. Interviews were conducted during and at the end of fieldwork at times that suited in each case (e.g., during rest time) with the aim to acquire verbal descriptions of lived experiences related to self-determination. The interviews were semi-structured (Bryman, 2016) and consisted of predefined topics: how is self-determination unfolded in the relationship, what professional competencies, and which systemic conditions are described as essential for supporting self-determination. All topics were expanded and contextualized within the cases with the goal of grasping the essentials of the phenomenon. The interviews were not only opportunities for data collection but also for analysis, reflecting on how to understand communication in context and the possible perspective of the person with PIMD. Finally, each case ended with a dialogue meeting in which family members and professionals participated and which aimed to validate preliminary beliefs and convey the stakeholders' knowledge (Watson, 2012). The material consisting of field notes, transcripts of video recordings, interviews, and dialogue meetings amounts to approximately 400 pages.

Data Analysis

Since we aimed to grasp the emic perspective (Fetterman, 2020), exploratory analysis was necessary. More specifically, we relied on Finlay's (2013) description of reciprocal movements between reduction and reflection. This involves the shift between keeping an open mind and curious interest in the data before engaging in preconceptions and theories in a process of reflection. The first round of analysis was

undertaken with a lens searching for moments understood to foster self-determination and hallmarks of the relationship. Following Finlay's (2013) understanding of a phenomenological process, it became clear that self-determination unfolded as a process of understanding the person displayed through the professionals' attempts to figure out the person's preferences and trying to grasp his or her identity. This practice can be understood as abductive (Alvesson & Sköldberg, 2018) in the sense that theories on self-determination, as well as Lindemann's concept of *holding another in identity*, were introduced and broadened our theoretical framework in the movement between data and reflection. Hence, the analysis was increasingly directed toward existential dimensions of the relationship. Through further reflection, the notion of holding emerged as even more fruitful. Accordingly, the final stage of analysis was broadened, leading to a more interpretive approach to the asymmetry and dependence entailed in this situation.

Ethics

Persons with PMID are marginalized and overlooked in knowledge production (Nind & Strnadova, 2020), and including their perspectives is an ethical choice. To minimize harm, it was made clear that the project involved no intervention or altering of services. In addition, observations were not undertaken during intimate situations (e.g., changing diapers). The study, guided by the Helsinki Declaration (World Medical Association, 2013), was endorsed by the Regional Ethical Committee for Medical and Health Research (ref. no. 107188).

In addition to reflections regarding minimizing harm, issues of consent were important and complex. Besides seeking consent from proxies, which were obtained in written form in all three cases, an ongoing process of assessing communicative signals and possible distress was implemented (Tuffrey-Wijne et al., 2008). In two of the cases, no such incidents were observed, but the researcher still chose to withdraw from a situation experienced as distressing during a seizure and aborted an observation because of high stress in both the person with PIMD and the professional. In one case, it was experienced that the person to some extent reacted to the additional person in the room. The potential influence on interactions was an ongoing reflection together with the professionals, demanding sensitivity.

Conducting research during a global pandemic raises specific ethical concerns. When fieldwork was initiated, local infection rates were low, and the participants had no restrictions, attending day activities as usual. In dialogue with staff and family members, it was thus agreed that observations could be completed, taking into consideration the guidelines for social distancing. This situation changed when planning the final case due to a revision in the national guidelines calling for fewer social contacts. This initially led to a postponement of observations and later halted them temporarily because of an increase in local infection rates.

Findings

The ethnography, focussing on self-determination as intertwined with being understood based on one's identity, suggests two entries to being held. One represents spontaneous occurrences in everyday interactions, and the other displays the professionals' more explicitly planned facilitating efforts. Together, these comprise four different, yet often overlapping, ways of holding through here-and-now interactions and through preferred, familiar, and joint experiences. Two more headings are included that demonstrate specifics of this holding: letting go and losing hold. Findings entail both the act of holding and how this might be experienced by the person with PIMD and is included to meet the aim of portraying the possible perspective of the person with PIMD, implying some intertwining between findings and preliminary interpretations. A more explicit interpretation of holding in this specific context (i.e., PIMD within professional practice) is then suggested, leading to the discussion on whether practices of holding might inform practices toward self-determination.

Holding Through Here-and-Now Interactions

There are several examples of the professional recognizing and responding to the expressions of the person through everyday interactions, as the following demonstrates.

> Vera has just awoken, and carer Line starts to untangle the braid that Vera has been sleeping with. She touches the hairbrush against Vera's hand, letting her feel it, telling her that she will now brush her hair. She starts brushing gently; Vera sits motionless, displaying a distinct wrinkle over her nose.

During the observation, Line comments that, when younger, Vera would cry for hours after hair brushing. Thus, she brings to the situation a narrative of Vera not enjoying this activity. She exposes a sensitivity, recognizing Vera's wrinkle as a communicative sign of skepticism. She verbally apologizes to Vera in a tone filled with warmth, moving the brush gently, perhaps allowing holding in ways where narrative and bodily action are intertwined.

As shown by Line, the use of narratives is experienced as steering interactions in all the cases. The professionals have several stories describing the persons—what they like, dislike, and how their identity might be understood. Maria and Eva, caring for Karen, describe her, as well as others, enjoying physical activities (e.g., dancing to loud music or going to amusement parks). These narratives are based on knowledge built over time and through close collaboration with Karen's family. Erik's carers reflect upon when they first started working with him and how they depended on close contact with his parents for guidance and for gaining relevant understandings. In a dialogue meeting, this was recognized as a necessary way of getting hold of Erik's subtle way of being. Erik's mother pinpointed the staff's curiosity about understanding as beneficial but also emphasized the narrative, saying that a lot of Erik's ways remain a mystery. In addition to guidance through narratives, the professionals display holding through the primacy of the body, as the following might demonstrate.

> Karen is about to eat dinner. Carer Eva is seated face-to-face with her, supporting her feet on Karen's wheelchair, their legs so close that they are touching. Eva takes a spoon of food and holds it under Karen's nose, telling her that food is coming. Karen turns her head to the side, her mouth closed. Eva asks her if she wants to taste, holding the spoon with her one hand, the other resting on Karen's arm. Karen moves her head back, and opens her mouth. She chews, turns her head, and closes her eyes. Eva keeps her gaze on her, holding the spoon for her to smell, patiently waiting for Karen to open her mouth, sometimes stroking her arm.

Eva is seated physically close to Karen, their bodies connected through their interlaced knees and hands, perhaps contributing to a sense of intercorporeality, where one body acts as an extension of another. Eva has her eyes fixed on Karen and is patiently adjusted to her tempo, letting Karen determine the pace. This interconnection of bodies is observed on several incidents (e.g., by holding hands, touching, or stroking the person). This might enhance the recognition of the person's communicative body, grasping not only likes and dislikes but also feelings through affect attunement. Fieldwork also contributed with descriptions about how difficult it remains to interpret the person, a verbal sound, or a movement that in one context might indicate joy and in another imply distress. This highlights the uncertainty involved in recognizing bodily signals and acting accordingly. This was a recurrent reflection among the professionals (e.g., Eva's saying, "I believe that we all try to interpret her in a best possible way, but we can't be sure if we are right, but at least we try").

From the perspectives of Erik, Karen, and Vera, these different situations of being recognized and responded to through embodied and narrative holding might be experienced as confirming bodies and, thereby, the self. Sensing the professionals' gentle approaches during intimate situations and the reactions these generated from the individual elicited an emotional feeling of the person being valued and recognized.

Holding Through Preferred Experiences

In addition to here-and-now interactions, the professionals facilitated systematically for experiences the person might prefer. Erik, for example, is understood to enjoy floating in water, an activity carer Hanna is eager to facilitate. The following might demonstrate why:

> Erik cries in the move from the changing room to the pool, signaling discomfort. While lowering his body into the water, floating on his back, his face changes into a gentle aspect. His eyes are open, he is making chewing movements. Carer Hanna holds him in her arms, his back against her chest. She tells me that she can sense him relaxing while imitating the chewing movements he is known to make when content.

Erik is described by both family and professionals as an enigma, and engaging him in activities is difficult. In this situation, however, Erik demonstrates what can be understood as enjoying the sensation of water and being engaged in a preferred activity. Hanna can observe this not only through his chewing movements and the narrative that this implies contentment but also by sensing his body relaxing through her own. Over time, this experience has led Hanna to describe Erik as a person who enjoys the water, thus facilitating activities thereafter.

Yet, often, facilitation of experiences comes with dilemmas and signals that are ambiguous to interpret. Carer Maria reflects upon this on one occasion when she decided to terminate Karen's rest to prepare her for an outing with her grandparents. This was done while Karen was half asleep, and Maria stated that she did not like doing that (i.e., dressing her when she was not fully awake). But in this situation, she made a judgment that meeting with her grandparents, a treasured activity for Karen, was more important than sleeping. Maria comments, "Sometimes I have to take a chance and risk misinterpretation." In other examples, the professional pursues the person's preferences by carefully interpreting signals and adjusting activities accordingly, as the following example might demonstrate.

> Vera and carer Tiril are at the "green room," a place Vera has previously enjoyed. Vera is now demonstrating discontentment through a stiff body, crying. Tiril lifts her onto her lap, stroking her. The crying ceases and Tiril asks if she wants to try again. She puts her back on the floor, trying to engage her in an activity. Vera provides few visible responses, and Tiril concludes that this perhaps wasn't interesting and decides to move to the "white room." As Vera is rolled into the room, she immediately responds with "aaa," displaying a relaxed face, the wrinkle over her nose disappearing. Tiril comments, "This was where you wanted to be!." Whilst seated in a beanbag in dim light, soft light links enclosing her, Vera's body relaxes.

This example depicts the ongoing work of interpreting and understanding the person's preferences. In this situation, Vera clearly communicated both discontent and content, and while seated in the bean bag chair, her serenity could be sensed. Thus, Tiril was able to hold her in ways that, arguably, were aligned with her preference. But professionals also describe how difficult it might be to know when to abort an activity and when to introduce new ones, as well as the occasional problem of perhaps expecting too many signals of acceptance in regard to the facilitation. Sensing the person's own initiative and not pushing on with too many stimuli are found to be challenging at times because of the individual's sometimes very detailed and subtle ways of communicating.

From the perspectives of Erik, Vera, and Karen, being held through preferred experiences might contribute to sensations of being viewed as persons with agency and that the world is facilitated in congruence with their own needs and wants. That said, there are still possibilities for misinterpretation, where understandings of silent contentment might, instead, be the person's resignation due to misrecognitions and failures to be held.

Holding Through Familiar Experiences

Across cases, the importance of exposing the person to experiences that are familiar as a way of providing guidance and points of recognition is highlighted. This is done by means of familiar communicative strategies and familiar activities, places, and persons. Several of the professionals use additional communicative strategies in place of talking. Some use hand signals, others tactile symbols, attempting to make communication familiar not only through words but also through the person feeling with his or her body. For example, in Vera's case, the professional raises one hand while saying "up" when Vera is to be transported by the sling in the lift. All professionals also familiarize the day through involvement in daily tasks and activities, as the following example might demonstrate.

> Carer Maria is about to cook dinner. She is collecting ingredients from the fridge. Karen is seated close by, moving her upper body rhythmically to the music playing. Her arm is moving, touching the door of the fridge. Maria says with a smile, "Don't close the door while I'm still fetching the food." Karen keeps dancing with a smile. Maria is at the counter peeling an onion. She cuts it in two, taking one half to Karen and presenting it to her to smell.

Seated close to the action, Karen might pick up through her senses what Maria is doing, in addition to Maria engaging her in a conversation about what is going on. Maria is attentive toward Karen's bodily movement, verbalizing and incorporating her understanding of it in the dynamics of the interaction. She assists Karen in grasping the situation by presenting her with the ingredients. Understanding that this represents actions with familiar sounds and smells, the professional displays a belief that this might help to frame what is going on, thus compensating for reduced senses. There are also examples demonstrating how the familiarity of home can be experienced by the person and can be a holding situation.

> Erik is at the day-centre. He is crying. Carer Kristina strokes his cheek, asking him what is wrong. With her continued stroking, his crying eases off. She tells me that she could sense him not having the best day even before they left home, and she was uncertain about whether to go. She decided to go, knowing that music group was on the schedule, an activity he is believed to enjoy. He starts to cry again. She strokes him, and it stops for a while but soon starts again. After trying to comfort him for a while, she decides to drive him home.

The author who was conducting fieldwork withdrew from the observation at this point, not wanting to contribute to further distress. When meeting Kristina and Erik later that week, Kristina said that, when he got back home, his distress was relieved, and the crying stopped. Kristina has knowledge of him enjoying being at home. Hanna, Erik's primary carer, also reported during fieldwork that Erik often responds in positive ways, such as his body relaxing, when returning home. During fieldwork, the expression observed when he returned home after a day out was experienced as one of his most unambiguous signals of communication, interpreted as a sense of contentment, thus indicating holding through familiar places. There are also examples of how the person seems to respond positively to interaction with known professionals in contrast to those who are unfamiliar, thereby enhancing the possibility of holding through trust. Maria described how, when she first started working with Karen, she had to work hard to establish trust before Karen would show interest in interacting with her.

From the perspectives of Erik, Vera, and Karen, being subjected to familiar experiences might help to maintain a sense of one's body and one's self. When perception is reduced, support and guidance may contribute to making the world seem more intelligible. Although not unambiguously communicated, there are examples where the person's wrinkle over her nose or other signals of unease could be due to a situation of low recognition. Likewise, although what Erik's crying indicates is not always clear, the decision to bring him home might have contributed to soothing him through the familiarity of place and perhaps through a feeling of having one's appeal acknowledged and acted upon.

Holding Through Moments of Joint Experiences

Each person's need for familiar support, necessitating close interaction, is vivid in the material. The professionals are, in several instances, found to use such situations to create a common ground for joint experiences that can perhaps be viewed as possibilities of holding, as the following might demonstrate.

> Vera is seated next to the piano; music lesson is coming to an end. Carer Jon starts playing the closing song. Vera makes a sound of "aa," moving her head towards the chimes. Jon sings, "Yes, great! Music session is over for now," whilst Vera says "aa," again moving her head towards the chimes. "Yes!," Jon sings while playing the piano, "Music session is over for now." Vera moves her head back, making a louder "aa." 'It is Vera that sings so nice,' Jon continues, while Vera makes an "aa" sound. Her head touches the responding chimes, and Jon singing, "Yes, hurray! It is Vera that is singing so nice."

Here, Vera and Jon might be understood to communicate with each other through the language of music. Jon describes how he, through the musical sensations, aims to enable Vera to experience her own contributions and enlarge on them, attempting to meet the person's way of being, mirroring sounds, and movements with the music. He matches her tone of "aa" to interact and communicate, perhaps adding to her awareness of self, through her connection with him and with the music. There are also several other examples where the professional aims to facilitate joint experiences as ways to connect, as the next example demonstrates.

> Karen has been resting in her bed after a long day at school. Carer Maria is waking her, preparing the move from bed to wheelchair. She tells Karen that she will put the sling under her. She touches her shoulder and asks her if she can turn to one side. Karen lies still with a great smile. She laughs. Maria asks her if she just wants to make jokes and laughs together with Karen. Maria bends over her and tickles her belly lightly. Karen laughs, and then turns her head away from Maria for a few seconds before returning. "Do you want some more?," Maria asks. Karen's gaze is filled with anticipation, and Maria tickles her.

Maria is sensitively approaching Karen, interpreting potential opportunities for having fun together. After tickling her, she waits for Karen to signal that she wants more by turning toward Maria. Maria describes how this kind of interaction would not have taken place if a strong relationship did not exist between them, thus underscoring the holding power of intimate, familiar relations. In the example, the reciprocity of the relationship is present in that Maria actively seeks to engage and laugh together with Karen. This sort of interaction is something that Maria treasures, and as such, Karen holds Maria as well.

From the perspectives of Erik, Karen, and Vera, these different efforts to provide joint experiences might contribute to experiencing togetherness. All of them are, at times, experienced as withdrawing from interaction, making joint experiences difficult. The professionals all demonstrate how challenging—but also how important—they believe these situations of fellowship to be, treasuring them as ways in which the professional might hold the person. This might lead to the person being validated for his or her self and own identity.

Letting Go

The demonstrated acts of holding are hallmarked by temporality; they are conditioned with a need to let go. The professionals put into words how demanding it can be to stand in close, intimate relations and, thereby, needing to let go occasionally to provide a break from the intensity of the interaction. Sometimes, this occurs in a planned manner (e.g., in the facilitation of alone-time for the person). The professional might let go in a holding manner, facilitating in ways that the person might experience support, as the following may illustrate.

> Vera's feeding tube is prepared, and carer Line tells her that she will put on music for her during mealtime. She touches her ear to indicate "listen to music." She tells her that she will now leave. Vera is sitting still, food dripping into her belly, Katie Melua singing on the radio. Vera moves her head and makes soft sounds of "aa." After a while, Line enters silently. She goes to change the bed. The machine delivering the food beeps, indicating that feeding is finished. Line reaches for Vera, touches her and says, 'Now I'm here; the food is finished.'

Line has a routine for how she facilitates feeding. She has opinions about the kind of music Vera prefers and where she prefers to sit. She leaves her alone, but in a way that might afford her getting a grip on the situation, thus doing it in a holding manner. When Line returns, she waits until the feeding is over to approach Vera, aiming to respect what she believes is a salient time of eating. When encountering her, she tries to re-establish her active holding. Just as common as this are situations where the professional must let go, without the possibility to continue holding, thus emphasising the impossibility of permanence. The professional leaves for the day, is assigned to work with others, or retires or takes a different job, thus having to let go. Carer Berit reflects upon this and says, "We should remember to say goodbye properly when our shift is over. We are together with her for a couple of hours, and suddenly someone new comes to relieve us, and sometimes we leave without informing her." This reflection touches upon the condition of letting go and all the breaches that follow from professional relations.

Losing Hold

Another detail previously touched upon is the uncertainty characterizing holding. There are descriptions emphasizing situations of potential misrecognition, where the professional's uncertainty gains dominance, as the following may depict.

> Vera is together with her classmates and carer Berit. The class is about to move to the kitchen where they are to prepare a meal with potatoes. It's a bit chaotic and cramped for space as Berit tries to make room for Vera. The other pupils talk and laugh, and Berit assists some of them before returning to Vera with a bowl of potatoes. She tries to lead Vera's hand into the bowl for her to feel, at the same time responding to a colleague. She comments that it was hard to get her stiff hand into the bowl. After a short while she says, 'I don't feel that I can manage this,' deciding that they will go back to Vera's room.

Back in Vera's room, Berit says that she felt unable to include Vera in a good way. When asked whether Vera signaled discontentment, she reflects that it was most probably her own experience of not being able to involve her as she wanted to that steered her actions. The situation might have been experienced as one that made holding challenging because a lot of other activities were going on. All the same, Vera is believed to enjoy participating with the rest of the class, taking pleasure in what might be familiar, holding sounds. As such, this might have represented a situation that could have involved holding but instead, the professional's uncertainty dominated, perhaps terminating the activity on the wrong premises.

These are situations marked by a sense of losing the other, pointing to the fragility in holding. In such situations, holding has in some way been disturbed (e.g., when having to juggle several assignments and splitting the focus). On these occasions, the person's initiatives and gestures might be overlooked; in others, the professional has many plans scheduled, and the person's own initiative disappears in the bustle. Failures and missed recognitions are part of the holding practice; in the intention to hold, losing holding will sometimes occur.

Further Interpretations on Holding

Our findings suggest that Lindemann's (2014) concept of holding sheds important light on professional work with persons with PIMD. However, there are at least two aspects of this context that fall outside Lindemann's scope. Hence, it is important to supplement with additional interpretations on this specific relation guided by the work of Kittay (2019).

First, Lindemann's focus on dementia links holding not only to an asymmetrical *now* but also to a more symmetrical *before*. Much like a reversal of caring for children—where a *now* marked by dependence is taken to precede a future marked by independence—Lindemann's portrayal of identity work remains related to independence and autonomy. In contrast to dementia or a delimited crisis, the lives of persons with PIMD are hallmarked by dependence and high support needs that have been always present and, thus, involve an ongoing need to be held through co-constructive identity work, actualising the notion of "enabling-to-be" as suggested by Kukla (2007). The relationship between a professional and a person with PIMD is of a temporary nature and often does not involve reciprocity (Kittay, 2019). The asymmetry must, according to Kittay (2019), be recognized and managed to avoid oppressive services and requires carers to be responsive to the genuine needs of the other.

Second, professional work with persons with PIMD must often be conducted without the intimate, familial knowledge that both Lindemann (2010) and Kukla (2007) emphasized. But although Lindemann argued that strangers cannot adequately provide the care embedded with holding, she recognized the need for society to play a role in relieving the family of total responsibility. She suggested that practices could be arranged "so that the goods of home were integrated into the other forms of care" (p. 168). This suggestion necessitates consequences for professional practices. Kittay (2019) argued that love, empathic concern, and loyalty are important motivations for acting on behalf of another. The same author further argued that the PIMD context engenders a different way of ascribing moral value (Kittay, 2020). She asserted that moral actions should be guided by the relational idea that we are all "some mother's child" (Kittay, 2020, p. 21). This claim to equality is based on recognizing that the status of being *a* person is achieved when one succeeds in being *this* person (i.e., in particularity). It is through the uptake of someone's identity that one can support someone's personhood. In this way, the other's uniqueness is of importance in an ethics of care (Kittay, 2019). Kittay's (2019) emphasis on empathic concern also sheds indirect light on the role of the concept of personhood. Questions regarding personhood are more often addressed by philosophers than others, yet assumptions about these matters influence how we act toward others (Lindemann, 2014). If

views linking personhood to rationality dominate, then persons with PIMD risk being dehumanized. Our ethnographic findings suggest that the persons themselves should be those facilitating our understanding.

Building upon Kittay's (2019) most recent book, *Learning from My Daughter*, we make the interpretation that at least three relational aspects are important for avoiding misrecognition and a failure to hold. First, our ethnography supports Kittay's (2019) recommendation that caring practices must move beyond custodial care and toward open responsiveness to the other's needs. Second, this openness seems to presuppose a sensitivity to embodied nonverbal ways of being in this world. Kittay's (2020) argument of "seeing the person whose body it is" (p. 164) is particularly relevant in encounters with persons with PIMD. Finally, one must make an active attempt to avoid linking moral worth with properties of rationality.

Discussion

This article began with an assumption that self-determination and identity work are intertwined. The ethnography has confirmed this in two ways. First, it has demonstrated that careful identity work is a precondition for the experience of life being "congruent with one's authentic interests and values" (Ryan & Deci, 2017, p. 10). Second, it has shown that respect for uniqueness—that plays out when persons with PIMD are included in a discourse of self-determination—is a precondition for identity work in this context.

The different examples of holding have demonstrated that the process of recognizing and responding to what is believed to reflect a person's identity is a necessary and fundamental component of self-determination. This is, of course, not specific to life with PIMD: All human beings need recognition and connections with others to facilitate interactions that can be experienced as congruence. As Kittay (2019) pointed out, the dependence brought forth in encounters with persons with PIMD is crucial to everyone. However, the ethnography also demonstrated that supporting self-determination is what Kukla (2007) referred to as fragile moral work. Sometimes, the support may be in opposition to the person's expressed preferences, as the example of Karen and her wish to sleep illustrated. Lindemann (2014) described dilemmas in holding a person with dementia experiencing disintegration and reflecting upon whether holding should respect a person as he or she was or is now; she presented no clear answers but urged reflection. Despite the view that holding should respect a person's autonomy, both Lindemann and the ethnography point to challenges. The ethnography confirms this in several ways—not only through various forms of holding but also through the initial reluctance of some professionals to describe their work in terms of self-determination, perhaps expecting it to involve acts of independence. This disinclination indicates embedded uncertainties that both research and practice must consider. To move practices of holding toward the realizations of self-determination, essential aspects of the relationship must be addressed. These will be discussed below, and implications for professional practices will be presented.

Recognize the Role of the Professional

There is a moral claim to fulfill the right to experience self-determination (UN, 2006), and in a relational understanding, the claim points to the professional's responsibility to enhance autonomy through support (Stefánsdóttir et al., 2018). The ethnography has consistently demonstrated that recognition in general—and self-determination in particular—depends upon professional work and recognizes the important role of the professional. However, it has also presented situations that demonstrate the challenges embedded in this reliance on the professional, manifested in small actions in everyday practice. One of the professionals stated this as a concern when describing that, frequently, the person with PIMD is just "dragged along," placed in situations, and often not given an opportunity to communicate whether he or she is okay with this. In this lies a potential for not holding the other as a person, perhaps fortified by the embedded asymmetry. Lindemann (2014) described how treating someone as a nonperson and as "merely bodies to be washed" (p. 156) is to be deprived of relationships conducive to humanity. Just as proper support can enable the person (Shogren et al., 2018), the absence of such support can hinder self-determination.

A moral claim should involve professionals having both support from their leaders in this matter and the skills required to carry this out. Has the professional been given proper training and support in how to care

for this distinct individual, thereby being capable of ensuring the fulfillment of rights to be self-determined? Kittay (2019) described how the carer depends on a provisioner for ensuring that necessary goods and services are made available (e.g., through an institution's formal and informal priorities). Services must be arranged in ways that enable the professional to provide the support needed; one should not unjustly thrust responsibilities upon a carer (Kittay, 2020). If professional practice is organized in ways in which, for example, the professional is not familiarized with the person's unique communication style, then holding and, thus, enabling the person's opportunities to experience self-determination will be in vain.

Self-Determination Through Embodied Empathy

Kittay's (2019) notion of being open and responsive also sheds light on how professionals can be sensitive to the person's specific ways of letting her or his identity come forth. She demonstrated how we are inclined to believe that we understand others without regard to their bodies when, rather, the body is what reveals the self and, thereby, should inform professionals' efforts to understand and support another. The ethnography has highlighted the importance of grasping the communicative body of the other through visual observation but, even more so, through the embodied encounters in which the professional uses his or her own body. When one lives in a body that is in need of constant support, the physical closeness provided by the carer (e.g., through bodily guidance during feeding) might assist one in experiencing what is happening more clearly. In examples, where holding might be experienced as challenging, physical holding might enhance experienced access of the other, underscoring the intertwining of mind and body. Merleau-Ponty (1962/1998), a proponent of this view, argued that our bodies are what assert our existence: "the body can symbolise existence because it realises it and is its actuality" (p. 164). Through this notion of intercorporeality, the interacting bodies might be attuned to each other through empathy (Fuchs, 2017). Close embodied encounters have been demonstrated in the ethnography, implying empathic sensitivity toward the other's needs, thus facilitating self-determination.

Yet there are limits to empathy and risks of misinterpretation. Svenaeus (2018) pointed to situations where the interacting bodies have such differences or where the "empathiser" is lacking relevant experience as potential limitations. The lives of the professionals and the persons with PIMD might represent antipoles with little recognition, thereby challenging notions of empathy, which may imply that moral guidelines should be based on generalized principles rather than on emotions and attachments. Yet, according to Kittay (2019), these should not be dismissed as epistemic resources but instead cultivated. This should involve explicit training in directing attention to embodied ways of being, recognizing that empathy might be both obstructed and facilitated (Fernandez & Zahavi, 2020). The ethnography has depicted how both professionals and family members demonstrate doubt in interpretations, giving substance to Kittay's (2010) notion of epistemic modesty (i.e., know what you don't know). The recognition of this and the avoidance of being stuck in fixed narratives (Lindemann, 2010) are thus important.

Self-Determination Through Enabling Involvement

What can we demand of the professional relationship? Must the professional care in ways that are comparable to the care provided within a family in order for self-determination to be possible? On one hand, it might be argued that the work of scholars like Lindemann (2014) and Kittay (2019) "demands too much." On the other hand, our findings support Cluley's (2017) argument that the lives of persons with PIMD necessitate active mediation; their lives require support. The professionals offered several testimonies of such interactions and their importance. Carer Jon reflects, "If not displaying an attitude where the other is the focus, one risks the person getting accustomed to not being meet, not being seen, not being understood, with the consequence of isolation." But these endeavors to meet the other's needs come with several challenges related to the specific dependence and asymmetry that is involved in a professional relationship. There are risks of paternalism and neglect (Kittay, 2019) as well as the risk that caregivers may develop preferences on behalf of the person. In co-created identity work and aiming toward supporting the other's self-determination, one might lose sight of the separateness of the person one cares for and oneself.

The ethnography has provided examples of this through the descriptions of the difficulties encountered by balancing dilemmas—not knowing what is portraying the "real" self of another—that demonstrate the challenges embedded in holding as ongoing processes. This was demonstrated in the situation where carer Maria choose to wake Karen and dress her although she was half asleep, arguing that meeting her grandparents was the most prominent of her needs, reflecting her self-determined will more than her here-and-now wish to sleep. In this situation, the professional had to use her judgment. Perhaps she based her choice on Lindemann's (2014) view arguing that identity cannot be perceived as a snapshot showing who one is only at a particular time but rather something depicting one's life over time. It might have been easier and made Maria's job less demanding to let Karen sleep, and arguably, in her act of choosing, she demonstrated a certain attitude of putting Karen's need first. This, in Kittay's (2019) phrasing, might be described as an attitude of care, and arguably, the relation was of such a nature that meaningful identity construction (Ryan & Deci, 2017) was possible.

The ethnography does not present an exact term of *what* this attitude is, although it can be reasoned that all the professionals displayed an attitude of feeling for or connecting with the person. Several reported that they can be very moved when interacting with the person if they get a smile or experience a positive situation that might lead to an emotional response. Data also suggest that the professionals are proud of the person and of their achievements. Some have held their jobs for several years, developing strong relationships (Kittay, 2019) that have clear reciprocity. Several put into words how dependent they are on the person and how taking care of that person defines them, thereby indicating that they, too, are being held.

To manage the asymmetrical dependence in holding ways, it might be argued that some degree of involvement is necessary. Forster (2020) described the importance of sitting alongside and listening sensitively in such interactions. This, it might be argued, is futile unless a strong relationship exists. When the professional contexts involve the integration of "the goods of home" (Lindemann, 2014, p. 168), they do so because dependence is recognized and met with affective bonds.

Analytical Risks and Implications

In this ethnography, concepts related to self-determination were not only applied interpretively but also voiced during fieldwork. This engendered interesting dialogues but also confusion. An initial response from several professionals involved questioning whether self-determination was possible at all. An understanding linking self-determination to the ability to act and make choices independently prevailed for many. Nevertheless, we hope that we have demonstrated how, merging with the ethnography, this concept became fruitful.

Hence, the ethnography has supported the argument that the concept of self-determination should be broadened based on a relational understanding of life with PIMD (Stefánsdóttir et al., 2018). Arguably, it should be viewed as processes of being understood, not merely choice-making (Skarsaune et al., 2021). The ethnography has also suggested the importance of seeking for small moments where self-determination might occur, underscoring Shogren's (2020) argument that even minor situations contribute to the enhancement of self-determination. Since the way we define a word influences our understanding of it (Wehmeyer, 2005), advancing the concept is likely a necessity if we are to achieve self-determination for persons with PIMD. Nevertheless, this process of advancing the concept must be regulated, for instance, by insights derived from the social-ecological model of disability (Shogren et al., 2018). Rather than dismissing the right to self-determination because of a lack of rationality, it is important to enable a person to be successful in the environment through support, thus counteracting ableism (Bogart & Dunn, 2019). Moreover, for the right to self-determination to prove relevant, one must—first and foremost—be recognized as someone entitled to justice. Although empathy and other forms of holding are crucial in "enabling-to-be" (Kukla, 2007), we must not lose sight of the fact that persons with PIMD are *already* entitled to justice.

This recognition of rights involves specific responses. Both empathy and normative arguments are futile if the conditions to fulfill them are not present. Stating rights in political documents, and claiming responsibilities are in vain if approached in simplistic ways. Mercieca (2013, p. 3) argued that "words evocative of grand gestures haunt these texts." This possible hollowness also points toward what we have attempted

to achieve through the ethnography: Rather than simply making arguments in line with, for example, philosophical or political documents, we have presented thick descriptions of *how* to deal with the specifics of PIMD in a professional context. This is a topic that requires further exploration, and to move forward, future research should address methodological aspects of how to include the perspectives of persons with PIMD in sensitive ways. As both Vorhaus (2014) and Kittay (2019) argued, theory and practice should be informed by the individual, learning from the persons in regard.

Conclusion

To dismiss the need of a person with PIMD to experience self-determination might easily occur because of embedded complexities arguing that to know the self of a person with high support needs unable to vocalize verbally makes the effort in vain. Doing so, however, undermines human rights. We argue that the act of holding another, engaging in recognition and responses of another's bodily expression both in day-to-day interactions and in the more-systematic facilitation, provides a fruitful path toward the realization of self-determination within professional care. This underscores the importance of relationships and demands practices that are arranged in ways that enable the professional to address the other's particularities in sensitive ways. Although embedded with uncertainties, these are the conditions of dependent relationships. If a professional cannot hold the other in identity, then the likelihood of realizing self-determination is weak.
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