

RESEARCH

Self-Determination: What can we Learn from Persons with Profound Intellectual and Multiple Disabilities?

Synne Nese Skarsaune, Halvor Hanisch and Anita Gjermestad

VID Specialized University, NO

Corresponding author: Synne Nese Skarsaune (synne.skarsaune@vid.no)

Self-determination is often equated with independence and individual choices, which limits its relevance for persons with profound intellectual and multiple disabilities (PIMD) due to their dependency. This paper challenges the notion of independence by arguing for a rethinking of self-determination that is sensitive to lives characterised by dependency and non-verbal being. An ethnographic study informed by phenomenology emphasising embodiment shed light on how self-determination can unfold in the lives of persons with PIMD in relationships with professionals. These data are engaged in a theoretical discussion, dialoguing with theories of self-determination and ethics of care. We advocate that a rethinking involving embodied communication, partnership and ongoing processes of being understood can offer a sound way of grasping the phenomenon of self-determination, both for persons with and without PIMD.

Keywords: persons with profound intellectual and multiple disabilities; dependency; self-determination; ethnography; phenomenology; embodiment

Introduction

Article three of the Universal Declaration of Human Rights states that everyone has the right to liberty (UN 1948). This is further described in the Convention on the Rights of Persons with Disabilities (CRPD) (UN 2006), upholding the overall principles of ‘respect for inherent dignity, individual autonomy, including the freedom to make one’s own choice and independence of person’. This depends upon self-determination, a core principle throughout the human rights (Skarstad 2018). In the field of disability, the concept of self-determination, emerging in the 1990s, has largely been described as skills related to choice-making and acting as causal agents (Shogren 2020). Conceptualisations of self-determination often come with a presumption of self-sufficiency, with the connotation of independence (Kittay 2019).

Although some consider these suggestions less relevant to the lives of people with profound intellectual and multiple disabilities (PIMD) (Bostad & Hanisch 2016), these presumptions remain forceful even in this research area. Choice-making or independency are topics in most studies involving self-determination and persons with severe disabilities. This includes for instance research concerning preference assessments (Fleming et al. 2010), technological devices (Roche et al. 2015) and legal rights (Murphy, Clegg & Almack 2011).

However, that way of viewing self-determination, with a language emphasising freedom through being independent and making choices for oneself, affords little room for persons utterly dependent and unable to vocalise their choices in conventional ways. The view risks overlooking the potential for self-determination amongst persons with a profound need for support (Watson 2012). They are, in the words of Kittay (2019: 17), ‘hard cases’ who warrant rethinking: ‘If we want others to believe that people with severe disabilities can become more self-determined, the concept needs broadening’ (Wehmeyer 2005: 118). Although there are attempts at such broadening, such as Stefánsdóttir, Björnsdóttir and Stefánsdóttir’s (2018) use of the concept of relational autonomy and Arnstein-Kerslake and colleagues’ (2017) rethinking of decision-making in terms of legal rights, there is still an important lacuna.

We agree with Mercieca (2013) that this rethinking can only take place if we listen to—and learn from—the lives of persons with PIMD. Although the article’s primary purpose is to contribute to the theoretical discussion, the endeavour still starts in ethnographic territory. Through the sensitivity of fieldwork, we aim to ground the perspective in the lives of the persons with PIMD (Cluley 2017; Mietola, Miettinen & Vehmas 2017). The theorising grows out of a phenomenologically inspired (Fuchs 2017; Merleau-Ponty 2002) ethnography in Norway, with the overall aim of tracing conditions for self-determination for persons with PIMD in the context of professional practices. In this article, accounts of the life of Vera and Erik (pseudonyms) and professionals working in their homes, school and day-center will be given, aiming to shed light on how the phenomenon of self-determination might be understood.

The approach, therefore, is abductive: From an ethnographic beginning, we move into dialogue with self-determination theory (Ryan & Deci 2017) and ethics of care (Kittay 2019) before proceeding into theorisations, aiming to address two key questions:

- How is self-determination unfolded in caring relationships between persons with PIMD and professionals?
- How can these processes contribute to a theoretical rethinking of the phenomenon of self-determination?

We suggest, in line with Vorhaus (2014), that the answers to such questions are not specific to people with PIMD. Insights from their lives can and should inform general understanding of self-determination in all human lives.

Theoretical framework: Self-determination as congruence

Ryan and Deci (2017: 10) have described *self-determination* as a psychological need that has to be satisfied in order to experience well-being, one hallmarked by 'behaviours that are self-endorsed or congruent with one's authentic interests and values'. Although approaches in the field of disability arguing for the view of causal agents (Shogren 2020) correspond well with that notion of self-endorsement, Ryan and Deci (2017) further underscore an experience of *congruence*, a life that agrees with one's desires. That added understanding can inform a broadening involving aspects beyond acting as causal agents and making choices, thereby suggesting that congruence might arise without necessitating independence. Ryan and Deci's (2017) thinking are thus open to a relational understanding of self-determination.

Extending that conceptualisation, Kittay (2019) has characterised independency as an illusion and dependency as part of the human condition. Along those lines, the belief that one can totally free oneself of dependency is mistaken, for regardless of social arrangements made to minimise it, some dependency will always exist. This involves that all of us, in varying degrees, stand in dependent relations to others, for example the caregiver and the manager, one depending on the manager for the pay-check and the other depending on staff for ensuring services, being interdependent. But at some points the dependency will not entail a mutual interdependency, meaning that the dependent depends on the other in ways that aren't reciprocated (Kittay 2019). The asymmetry that follows from this might be one explanation why people thus seek to transcend dependency. Amongst other effects, such asymmetry involves difference in relational power and allows, for example, professionals to extend or withhold support and thus influence potentials for self-determination. But despite this asymmetry, reciprocity still can exist in the relationship (Vorhaus 2014), through, for example, love or affection (Kittay 2020: 61). In that vein, Young (1997) has introduced the concept of asymmetrical reciprocity, which emphasises the recognition of differences between oneself and others and allows a person to approach another with wonder and openness, thereby making the other's contribution fully visible. The human condition of dependency should thus not be viewed as an impediment to living well, but as a value providing a rich and interconnected life, if managed wisely (Kittay 2019).

According to Kittay (2019), such reciprocity involves a particularly close form of interactions, which become meaningful through intersubjectivity (Stern 2005), understood as the ability to share in another's lived experience. Merleau-Ponty (2002) identifies the concept of intercorporeality, that people perceive and communicate with their bodies, as a key element of intersubjectivity (Moran 2017). He states that each individual is essentially expressive, in silence, gesture and lived behaviour, and that others can appear as extensions of coexistence, 'like organs of one single intercorporeality' (Merleau-Ponty 1964: 168). Intercorporeality also denotes that one's own body is affected by the other's body as much as vice versa, which leads to embodied interaffectivity and the ability to understand one another (Fuchs 2017).

Method

Doing research that includes persons with PIMD presents several challenges (Maes et al. 2021), one of which is choosing an appropriate method. Our work involved exploring the relationship between persons with PIMD and professionals and, in that process, sought to build an understanding of what might be Vera's and Erik's perspective. That undertaking is risky business, however, and it can be argued that we can't know explicitly a person with PIMD's perspective. After all, it requires relying on others' interpretations (Cluley 2017), which entails significant risks of ignoring or not sufficiently sensing others (Watson 2012). Mediating relationships is nevertheless decisive in the lives of persons with PIMD (Cluley 2017). This epistemic risk of misrepresenting another's life is discussed by Vehmas and Mietola (2021: 33), and we agree with their conclusion that researchers still have an obligation to try to make sense of and represent these 'voices'. This appeal for methods that are sensitive and attentive towards the other through the condition of mediation. Phenomenology, offering rich accounts on intersubjectivity and the minds of others (Zahavi 2019), has thus served as an overall guide in the endeavour of describing everyday living in ways that can inform the theoretical discussion regarding the concept of self-determination.

A mediated ethnography

To achieve the necessary closeness with research participants, several researchers in the field of profound disability have argued that ethnographic methods are suitable (Mietola, Miettinen & Vehmas 2017; Simmons & Watson 2015). In line with that, we argue that even if communication is non-verbal, ethnographic interpretation allows researchers to share the viewpoints of persons with PIMD, at least partly, arbitrating understandings of their communication. In this

effort we lean on an understanding on communication as presented by Teachman and colleagues (2018), underlining that meaning is always dynamic, relational and involving uncertainty. They oppose the notion of autonomous speakers whose voice can be 'captured' through a research process (Teachman et al. 2018: 37); instead, it should be understood as a mediated co-production between persons. Therefore, the research design aimed for what Liamputtong (2007: 19) has called a 'polyphony' of voices. The study involves several persons who know the person well, functioning as mediators representing their understanding of the person's perspective. Ethnographic knowledge and possible understandings of Vera's and Erik's perspectives were thus co-constructed and mediated by Erik, Vera and participating professionals and family members together with us, the researchers.

Sensory ethnography (Pink 2015) has been inspirational to our efforts to remain sensitive to the non-verbal agency of Erik and Vera. The approach acknowledges that sensoriality is fundamental to how researchers understand and represent others' lives. That understanding coincides with Merleau-Ponty's view that makes sensation central to human perception (Pink 2015: 29). The ethnography has thus focused on providing rich accounts of what could be sensed in regard to, for instance, smell, vision and sound. Additionally, the study added to these senses and also dwells on emotions experienced during fieldwork. This as a possible entry to what Erik and Vera's perspective might be. Relying on phenomenology arguing that mind and body are intertwined, and that access to another mind is mediated by an individual's behaviour (Zahavi 2019), our study was based on the notion that humans have the capacity to gain understanding of the thoughts and feelings of others through embodied and emotional engagement (Fuchs 2017; Merleau-Ponty 2002). Elements from the knowledge base of the method of infant observation (Bick 1946) has also inspired our approach to fieldwork. The approach aims to understand and gain awareness of the complexities in non-verbal interaction, intending to make sense of the feelings and thoughts of others (Music 2012). The method recognises the subjectivity of the researcher (Hollway 2016), arguing that over time and with repeated reflection researchers can get valuable information from intuitive, emotional experiences—guiding the understanding of others. In addition to writing down close descriptions of what could be sensed by the interaction between Vera and Erik and their professionals, emotional reflections that these situations generated in the researcher was thus included. This could, for instance, be reactions of joy, enthusiasm or despair, emotions triggered by observing the interactions. These emotional reflections added to the understanding (Fuchs 2017), providing a sense of salient features of a situation. This was, both during fieldwork and afterwards, experienced as a helpful entrance that opened for possible interpretations of Vera and Erik's perspectives, while still being aware of the co-creation of meaning and the uncertainty that follows from this condition (Teachman et al. 2018).

Participants

Participants were recruited by contacting leaders of services provided in municipalities. Although the label 'persons with PIMD' represents a highly heterogeneous group (Nind & Strnadova 2020), both Erik and Vera met the criteria of the International Classification of Diseases (WHO 2019), including a profound disorder of intellectual development. Communication with both is based on gestures, facial expressions, sounds and touch. Family and professionals sometimes describe them as being mysteries, reflecting the uncertainty involved in how to understand their communication. Both Erik and Vera have only minimal bodily control, are wheel-chair users and need help in all practical aspects, like being dressed, fed and intimate care.

They both receive their daily care primarily through formal carers: Erik (26 years) living in a housing facility and attending a day-centre and Vera (11 years) living in a housing facility and attending school. They both receive individual music training provided by the municipality. Seven professionals representing these five institutions participated, in addition to Erik and Vera's family. The majority of the professionals are trained social educators, one is a health and care worker and one is a music therapist. The professionals, with one exception, have known Erik and Vera for four to nine years.

Data collection

To enhance current understandings of the unique communication and lives that unfold at a slow pace (Mietola, Miettinen & Vehmas 2017), data collection lasted for 19 weeks, from September 2020 until February 2021. Each observation lasted between 30 minutes and 3.5 hours. Field notes were written shortly after observations, although sometimes, if convenient, short jottings were written during fieldwork to aid memory. In addition, to capture slow, detailed interactions, observations were supplemented with video in certain delimited situations (Greathead et al. 2016). Arguably, that addition increased Vera's and Erik's presence in a material that otherwise gives most of the space to the researchers' perceptions (Kaley, Hatton & Milligan 2019).

Observational data were supplemented with two other forms of qualitative data: interviews with professionals and family members about their lived experiences (Gallagher & Francesconi 2012) and a dialogue meeting (Hoppe et al. 2019) with participating professionals and family members at the end of fieldwork. During formal interviews and informal talks, elaboration and sometimes correction was sought in order to better understand Erik and Vera. The dialogue meetings aimed to leverage their intimate knowledge as stakeholders (Watson 2012) and allow them to validate preliminary understandings and inform further analyses (Miles, Huberman & Saldaña 2020). Those meetings provided feedback to the researchers, suggesting that their understanding and way of portraying Vera and Erik resonated well with family and professionals.

The data material consists of 94 hours of observations distributed over 43 occasions, including 12 videotaped situations, interviews with 2 family members prior of starting up, interviews with 7 professionals during fieldwork, and 2 concluding dialogue meetings.

Analysis

Analysis was guided by Finlay's (2008) search for the 'phenomenological attitude'. That approach describes processual phenomenological analysis as a dance of improvised steps, including both reduction and the researcher's reflection, in a shift between bracketing pre-understandings and exploiting them as a source of insight. In the process, the concept of reflexive embodied empathy (Finlay 2008) was a guiding light, one described as a process of sensing another person, being especially attentive to participants' expressive bodily gestures. This involved a focus on being sensitive towards the unpredicted, letting the experiences in field inform analysis, before turning towards reflections and theorisations.

Fieldwork and the further analysis were informed by the research question presented in the introduction, thus influencing the researchers gaze towards the phenomenon of self-determination. In this process, Ryan and Deci's (2017) notion of self-determination as congruence was of guidance. Through an abductive process, moving between data and theory (Alvesson & Sköldbberg 2018), we shifted between lingering over the material, identifying crucial episodes of potential self-determination, opening up to new understandings and using pre-understandings, historicity and theories in a process of reflexivity (Finlay 2008). In the search for and understanding of what might portray a person experiencing congruence, this shift between reduction and reflection led us to adjust and refine our theoretical perspectives.

The analysis emerged through several steps: doing the fieldwork and writing down the episodes and emotional reflections (Hollway 2016), by reading the field notes as well as analysing filmed material trying to get hold of essential descriptions, through reflective discussions between the co-authors regarding the essentials, and also dialoguing with the research field—presenting preliminary findings in dialogue meetings, testing out ways of putting it into words. This latter step led us to new rounds of attending to the material, lingering and taking time. In this process, we became aware of the phenomenon of closeness as a possible existential dimension in understanding the material (Finlay 1999). This further guided our analysis and the process of finding words to categorise the material, through episodes that we found to describe congruence.

Ethics

Our study was guided by the Declaration of Helsinki (WMA 2013), which states that the potential gains of including a participant unable to formally consent have to outweigh the possible harms. In line with Norwegian national guidelines warning about possible dangers by excluding vulnerable groups from research (NESH 2016), we see the research design as a form of counteracting the marginalisation of persons with PIMD.

In our case, there were arguably three sets of possible harms: some related to the risk of direct harm, some related to the participants' inability to consent to participation in formal ways and some related to Covid-19. Because the study did not involve any direct intervention and did not change or influence service provision, there was little risk of direct harm. Nevertheless, the researcher chose to stay in the background during times of distress and, on one occasion, stopped observations in order to prevent additional stress. The researcher also withdrew during certain intimate situations (e.g., diaper changes). With regard to risks related to the lack of formal consent, the participants' responses were assessed during fieldwork for signs of protest against or distress due to the presence of the researcher. No such signs were observed, however, and a form of 'process consent' was thus arguably achieved (Tuffrey-Wijne, Bernal & Hollins 2008). Covid-19 has clearly changed what it means to do ethnographic research. In our case, we altered the research design in several ways to account for Covid-related risks. The sensory aspects of the ethnographic methodology were reduced (e.g., not using the sense of touch) in order to follow strict measures regarding hygiene and social distancing. Moreover, the researcher conducting the fieldwork followed particularly strict measures in her private life before and during fieldwork. Fieldwork was postponed initially when the pandemic hit and only took place in periods when the regional infection rates were very low. At the time of fieldwork, there were few restrictions in Vera's and Erik's life; they attended school and day-center. Conducting the fieldwork was done in close agreement with both family and leaders of the institutions, assessing the researcher's presence as being of low risk.

All participants have been given pseudonyms in order to ensure their anonymity. The project was approved by the Norwegian Centre for Research Data (ref. no. 472016) and the Regional Ethical Committee for Medical and Health Research (ref. no. 107188). Written informed consent was obtained from all participants—in Erik's and Vera's case, by proxies.

Findings

All the included situations that are found relevant to describe the phenomenon of self-determination are characterised by some form of movement or action towards a possible congruence. These movements take different forms, and from the perspective of the persons with PIMD, we have named them voicing, acting and choosing. For persons with PIMD, profound dependency involves having some actions performed by others, including the professionals in our study. Thus, following the three mentioned ways of movement, we formulated three possible ways that self-determination might unfold, each presented as two sides of the same coin: 'voicing and being voiced for', 'acting and being acted for' and 'choosing and being chosen for'.

Self-determination is often understood as a matter of distance, typically captured in sentiments of independence that position individuals as being in control of their lives (Shogren 2020). Erik's and Vera's life, by contrast, demand closeness to others. This can be experienced both as a physical closeness, due to the intimate properties of the relationship, and as an emotional closeness. Often overlapping and both being important in furthering intersubjectivity, calling the professionals attentiveness towards Erik's and Vera's utterances. Due to the existentiality of this notion (Finlay 1999) and the varying ways it unfolds in the material, closeness served as an analytical lens.

Voicing and being voiced for

'Voicing and being voiced for' consists of utterances that might be understood to contribute to the co-creation of meaning regarding the person's wants and needs, thus informing movement towards congruence. For example, Vera and Erik clearly demonstrated ways of communicating their contentment—in Erik's case, by making chewing motions. In those situations, when familiar with idiosyncratic communication, professionals could understand without engaging in undue interpretation and, in turn, reduce the degree of closeness required. By comparison, distress was communicated in highly familiar ways as well, albeit often with the need to interpret others' communication in order to determine means of relieving the distress. In that case, emotional closeness was needed to understand the message and facilitate congruence. On that point, the field log captures the following interaction:

Vera and her carer, Line, are on the floor training. Vera's body is stiff, which makes training difficult. She makes high-pitched sounds of distress; Line tries to comfort her and decides to bring her back in the wheelchair. Vera continues to make high-pitched sounds indicating discomfort, and they increase in intensity. Line says, 'Now you're trying to tell me something that I can't understand'. Line positions herself close to Vera and holds her hand. Vera makes another high-pitched 'aah' sound, and she touches her chin to Line's hand that's firmly holding her own. With her chin against Line's hand, she closes and opens her eyes; the 'aah' sounds end. She turns away from Line's hand for a few seconds before returning her chin to rest on Line's hand.

The interaction began with Vera clearly voicing distress but with little clarity regarding her needs. Her high-pitched sounds were despairing to listen to, and Line's frustration with not understanding Vera's needs was genuine. In response, the conversion of Vera's distress into serenity due to Line's sensitivity seemed essential in the moment. The way in which Line positioned herself and Vera to promote closeness affected their intersubjectivity, and Vera arguably sensed Line's emotional and physical presence due to her voice and touch, which might have caused Vera to experience a sense of being listened to and understood on her emotional utterances. The description thus entails a rudimentary form of self-determination: a glimpse into a moment in which the bodily encounter prompts intersubjectivity. Although Line had planned other activities, she postponed them in order to recognise Vera's voicing of her needs and, upon Line's recognising those needs, her contented silence.

The professionals also occasionally raised their voices on Vera's and Erik's behalf. The field log also includes the following example:

Erik sits next to the piano where music therapist Jon is playing. Jon has arranged the chimes over Erik's hands, thus making sounds when Erik moves. Jon continues to sing: 'It is Erik that is here/He is listening to music/We can listen together'. Erik is sitting in silence with his eyes half-open, while Jon's eyes are fixed on him. Erik begins to yawn when his hand moves and touches the chimes. Jon sings, 'And he is playing the chimes with his hand/We can make some music'. Erik sits with his eyes open and makes chewing motions.

In that example, Erik engaged in voicing by making chewing motions to indicate contentment. Beyond that, Jon aimed to make Erik's communication and contribution to the interaction more audible by giving voice to what was happening. Jon thus amplified Erik's bodily movement—touching the chimes—by simultaneously describing that movement in song. In such cases, an aspect of the professional's voicing might be to assist in making sense of the other's being and compensating for what senses they lack. In turn, by enhancing the person's awareness, that aspect can serve as an important precondition for self-determination. Observing Jon's attentiveness, his fixed gaze on Erik and his ability to capture Erik's initiative felt poignant and could be interpreted to reveal how the language of music allowed them to develop a closeness and sense of togetherness where Erik's way of being was acknowledged. Added to that, Erik could be assumed to have sensed Jon's presence and respectful acceptance of his own being. Knowing that Erik often communicates in subtle ways that can be easily overlooked or ignored adds to the impression of the importance of someone's voicing for him to render him more present to both himself and others.

Acting and being acted for

Although similar to the prior, 'acting and being acted for' is demonstrated via bodily movement of the interacting persons. The following episode from the field log is a case in point:

It's time for dinner, and Kristina, Erik's carer, raises a spoonful of food into Erik's mouth. Erik sits motionless, and Kristina waits for him to chew. 'Perhaps it's not enough for you to really get a taste', she comments. She

takes a bit more on the spoon, again raises it into his mouth and moves it around. Erik continues to sit still and not chew. She waits for a few seconds and then starts to stroke his chin. She touches his hand, but he remains motionless. She places the bowl on the table, takes both of his hands in her own and shakes them lightly. 'Are you in dreamland, Erik?' she asks. After Kristina moves his arms some more, Erik starts to chew. The meal continues with the same interplay: Erik chewing and Kristina occasionally touching him and moving his arms to make him aware.

In general, because Erik controls the act of chewing and can show interest in food, not chewing might indicate that he does not want any more food. However, in the professionals' experience, such situations call for their attentiveness and the co-creation of meaning in order to fully sense what such bodily actions or inactions indicate. As observed in the study, Erik often needed professionals to help him to recognise, at his own pace, what is happening. The episode thus captured that Erik's somewhat self-directed acting can nevertheless require the other's understanding and response, which demands that the professional be present and close or else risk overlooking bodily signals. In that light, the situation also captured Erik's reliance on the professional in order to ensure congruence. One interpretation of the episode may thus be that Kristina, through her presence, assisted Erik in sensing the context and enabled him to perform a desired act—the act of eating—at his own pace.

Although both Erik and Vera indeed communicated intentions with their bodily movements, the professionals more often had to act on their behalf, as shown in the following instance:

Erik's carer, Hanna, keeps her gaze fixed on Erik. He makes an 'ehh' sound. 'Mmm' replies Hanna. Erik makes chewing motions. Hanna lifts the bib from his chest and starts to rub his chest again. The massage is so deep that Erik's body begins moving in the chair. He makes an 'ehh' sound, and Hanna keeps massaging him. Erik then burps, and Hanna says, 'Ah, there it is'.

During the course of a day, Erik sometimes cried. His family and the professionals have discussed what Erik wishes to communicate by crying, and the most valid explanation thus far is that it relates to trapped air and abdominal pain. In turn, they have sought ways to regularly rid his body of excess air. That and several other examples in the material capture how professionals can act as extensions of another's body—for instance, by sensing their bodily discomfort or carefully positioning their bodies in their wheelchairs. At times, being close to the person's body is sufficient to sensing their wants and needs; at other times, the body is difficult to read, and professionals have to add their interpretations, informed by the opinions of significant others (e.g., family members) and/or medical experts.

Thus, 'acting and being acted for' captures a profound closeness, both physical and emotional, that was observed on several occasions in Erik's and Vera's interactions with the professionals. On occasions, these actions were powerful and dignifying—for instance, when the professionals fixed their gazes on the person, thereby holding them in their mind in order to not overlook any communicative signals, or touching them in order to feel their responses. On other occasions, however, the actions felt overwhelming—for example, when several professionals were needed to assist the person in secure ways or in intimate situations. In those situations, the impression was that the professionals' bodies and hands assumed control over all actions, risking marginalisation of the person being acted for and upon, thus actualising the potential threats of asymmetrical relationships.

Choosing and being chosen for

The movement involving 'choosing and being chosen for' illuminates the dynamics of the co-construction where the professional suggests and facilitates a situation or an activity and the consideration of the person's responses as a decision-making about whether or not they want to engage. In some cases, the intention was clearly to reduce the influence of professionals by clarifying the person's means of communicating choice with the aid of devices. For instance, the field log contains the following interaction:

Vera and her carer Tiril, are practising the use of a voice-based micro-switch. Vera needs to touch the switch with her chin to indicate that she wants more music. Tiril has paused the music, and holding the switch to Vera's chin, she asks Vera whether she wants to listen to more music. Vera moves her head towards the switch, then swiftly withdraws it before making a more obvious movement of her head towards the switch. When she makes contact, a pre-recorded response says 'More!' Tiril replies, 'OK, so you want to hear more. Let's put the music back on'.

With the micro-switch, Vera may be able to make choices without depending on the professional's closeness or interpretation, which perhaps minimises the likelihood of misinterpretation. Even with that purpose, the use of the device aroused ambiguous feelings. On the one hand, Vera seemed to use numerous strategies to communicate her desire to hear music, in which case the switch could be understood as more of a hearing aid for the professional than a communicative aid for Vera. On the other, and for that reason, introducing the device suggested that her profound way of communicating with her body was not recognised. That possibility was counteracted in a later observation, however, when a choice-making situation favouring distance became an interaction hallmarked by closeness:

After a long, hectic day at school, Tiril places Vera in the beanbag to relax. Tiril turns on music, and Vera's relaxed face and body signal her contentment. After a couple of songs, Tiril finds the micro-switch and invites Vera to indicate that she wants more music by touching it with her chin. After a few somewhat reluctant efforts, Vera turns her head away from the switch. Sensitive to the situation, Tiril asks, 'Is this not what you wanted?' She moves the switch close to Vera's chin to give her another chance, but Vera remains motionless. 'You're quite right, Vera. You should be allowed to listen to music without having to press the switch'.

The episode captured what might be interpreted as Vera experiencing congruence in life because Tiril acknowledged her bodily communication. Observing Tiril tuning into Vera and her ability to adjust in a moment of intersubjectivity and embodied interaffectivity was an emotionally powerful experience, one filled with a sense of respect for Vera, her way of being.

Choices made on another's behalf emerged time and again in the material. However, according to the professionals, their choices reflect what they believe the person with PIMD would prefer. In various situations, the professionals even asked Erik and Vera what they prefer—for instance, 'Would you like to relax a bit on the bench?' Although aware that they would not receive a verbal answer, they nevertheless asked in order to allow choice, and professionals' efforts to perceive the person's response were obvious.

Discussion: Rethinking Self-Determination

Ryan and Deci (2017) have developed a useful framework for exploring the phenomenon of self-determination amongst persons with PIMD. Their definition, which emphasises congruence in life, provides a fruitful entry point for including persons utterly dependent on others, one expanded to involve more than mere self-endorsed behaviour or the actions of individual agents. What is not made explicit in their framework, however, are the ways in which the aim towards congruence can be managed without compromising 'one's authentic interests and values' (Ryan & Deci 2017: 10), when communicated through lives hallmarked of dependency and non-verbal ways of being.

We thus propose that an emphasis on congruence should not overshadow the ways of interacting and co-construction of meaning that, after all, facilitate congruence. We have suggested, through three forms of movement, different ways in which congruence can unfold. The portrayals have suggested that both movements performed by Erik or Vera and by the professionals might lead to congruence. But most often the path towards experiencing congruence needs to be viewed as a form of cooperation, which underscores the importance of the interpersonal relationship. In line with embodied phenomenological approaches (Merleau-Ponty 2002) and ethics of care (Kittay 2019), we suggest that self-determination increases along with the degree of closeness and possibilities for co-construction in a caring relationship.

Awareness of the diversity of how congruence may manifest adds a new aspect to the understanding of self-determination. Facilitating self-determination in lives where it is often overlooked requires professionals becoming sensitive to the ways in which self-determination unfolds via embodied communication in partnership in an ongoing process.

Embodied communication, not mere words

The acceptance of human difference is pivotal in relationships with all human beings. For people with PIMD in particular, however, communication is more than words or obvious gestures and should be recognised. As the example of the micro-switch demonstrated, communication have to be viewed as being possible in all behaviour, not merely conventional forms of symbolic communication. In the example, when Vera rejected the switch, Tiril replaced the device with her body, thereby actualising Merleau-Ponty's (1964: 166) notion that 'my body is the field which my perceptive powers are located'. Through mutual incorporation (Fuchs 2017), Tiril sensed what might be understood as Vera's authentic want and need, with her body clearly communicating that she wanted to listen to music. In effect, those practices imply a broadened understanding of how meaning can arise via the embodied being.

Partnership, not individualised acts of independence

The CRPD (UN 2006) underlines the right to freedom, interconnected with self-determination. Freedom—much like self-determination—is often reduced to aspects of independence. Against this, Kittay (2019) argues that this thought of independence should be dismissed and replaced by the condition of dependency. However, closer examination of freedom in the lives of people with PIMD documents that freedom do take place, but that the concept of 'freedom within dependence remains embryonic' (Bostad & Hanisch 2016: 381).

The lives of Vera and Erik, as it has emerged in the ethnographic data, gives several clues to understanding the role of freedom and self-determination in the context of PIMD. First, it becomes clear that self-determination is not a matter of independence. As Kittay (2019) has pointed out, the context of PIMD is a situation characterised by asymmetrical dependency.

Secondly, our investigation demonstrates that congruence—indicating self-determination—takes place when people without PIMD accept the differences that dependence and asymmetry bring to a relationship; the professionals should show humility and acknowledge that one person may not always understand another—for example, when Vera, in her distress, might have tried to tell Line that she wanted to feel her proximity. It was Line's openness that made her able to reach a possible understanding of Vera's wants. Vera's self-determination thus emerged in a partnership with mutual

respect despite the inherent asymmetry. This dependency must be managed, that is, dealt with responsibly (Kittay 2019). Typically, such management requires that support is given in sensitive ways, focusing on dignifying the person's body and being. Recognising the person's need for intimate support and acting on behalf of, as well as reflecting on how this process might risk overlooking the person's own initiative, thus managing the possible conflicts and the asymmetrical power that co-construction might entail, is essential.

Thirdly, our findings attest to the idea that closeness to others is not optional and that congruence unfolds only with the contributions of both parties. The ethnographic data suggest that this management—with the closeness—is in fact a partnership. Sometimes the interaction between the person in regards and the professional is what makes some choices preferable, rather than it solely being an authentic want already existing in the persons. In order to achieve this co-construction, professionals must move beyond the lens of independence and acknowledge the reciprocity that even takes place in asymmetrical relations marked by dependence.

Ongoing processes, not delimited situations of choices

When theories of self-determination are not sensitive to the diverse ways in which congruence may arise, the cause may be an overemphasis on the planned, controlled making of individual choices. Experiencing congruence in life can occur not only in decisions about where to live or how to spend money, but also in ongoing processes of being understood—for instance, help with burping after eating or being met on the need for proximity. The latter can be viewed as rudimentary forms of self-determination, interacting encounters prompting intersubjectivity and understanding of each other. These are situations that should receive attention when ensuring the right to be self-determined. An emphasis on choice alone excludes many persons (Kittay 2011) and ignores the reality that self-determination occurs persistently in a person's everyday life. The ethics of care and Kittay's (2019) descriptions of how to manage dependency demonstrate that carers should, above all, facilitate the flourishing of the individuals whom they care for by being attentive to their wants and needs. An adequate concept of self-determination should therefore recognise the persistence of possibilities for self-determination in all everyday activities.

Risks

Acknowledging asymmetry in relationships and co-constructed communication is an endeavour fraught with uncertainty. Incorporating embodied communication, interpreting and acting on behalf of others may cause what theories of self-determination view as the opposite of congruence: an alienating relation that positions the person as passively compliant or reactively defiant (Ryan & Deci 2004: 456). Even though this can easily accommodate acts that alienate them, we argue that the risks should be identified and managed. Instead of dismissing the phenomenon of self-determination altogether, the diverse ways in how congruence might be disclosed must be recognised.

Conclusion

Ensuring the human right and need for self-determination requires moving beyond understandings of the concept that emphasise independence and making individual choices to recognise the ways in which meaning is created. Although that approach towards broadening the idea of self-determination poses significant risks, it follows from strict obligations to human rights (Skarstad 2018).

Although the term *broadening* may seem to position means of self-determination as somewhat peripheral or marginal, such is not the case. The aspects of being in the world that we have traced in the lives of Vera and Erik are true of every human life. Their lives are shaped by dependency in specific ways; however, a more inclusive rethinking of self-determination would change current views on every person's self-determination, not only theirs. The sensitisation that we observed in the various relationships is thus as political and existential for everyone.

That being said, it is important to remain aware of the specifics of the lives of every person with PIMD. If sensitivity to various non-verbal ways of being can be achieved and insights universalised, then we might lose sight of the singularity to which we originally became sensitive. Therefore, it is crucial but not entirely sufficient for professionals to acknowledge that self-determination unfolded in partnerships is what makes congruence in life possible for persons with PIMD. It is also not sufficient for professionals to understand embodied communication or direct their attention to all everyday situations as bearing the potential for self-determination. By contrast, professionals, via their sensitised bodies, need to remain open, curious and aware of uncertainty as well as strive to ensure self-determination even when facilitating it seems impossible. Self-determination is fragile, and all situations that might lead to the person's experiencing congruence might also lead to ignoring or overlooking that potential.

Acknowledgements

Thanks to Vera and Erik, their families and professionals who have participated in the research.

Competing Interests

The authors have no competing interests to declare.

Author Contributions

All authors contributed substantially to this article.

References

- Alvesson, M., and K. Sköldbberg. 2018. *Reflexive methodology: New vistas for qualitative research* (Third edition). SAGE.
- Arnstein-Kerslake, Anna, Joanne Watson, Michelle Browning, Jonathan Martinis, and Peter Blanck. 2017. "Future direction in supported decision-making." *Disability studies quarterly* 37(1). DOI: <https://doi.org/10.18061/dsq.v37i1.5070>
- Bick, Esther. 1946. "Notes on infant observation in psycho-analytic training." In *Surviving Space: Papers on Infant Observation (2002)* edited by Andrew Briggs. London: Routledge.
- Bostad, Inga, and Halvor Hanisch. 2016. "Freedom and Disability Rights: Dependence, Independence, and Interdependence." *Metaphilosophy* 47(3): 371–384. DOI: <https://doi.org/10.1111/meta.12192>
- Cluley, Victoria. 2017. "Using photovoice to include people with profound and multiple learning disabilities in inclusive research." *British Journal of Learning Disabilities* 45(1): 39–46. DOI: <https://doi.org/10.1111/bld.12174>
- Finlay, Linda. 1999. "Applying Phenomenology in Research: Problems, Principles and Practice." *The British journal of occupational therapy* 62(7): 299–306. DOI: <https://doi.org/10.1177/030802269906200705>
- Finlay, Linda. 2008. "A Dance Between the Reduction and Reflexivity: Explicating the 'Phenomenological Psychological Attitude'." *Journal of phenomenological psychology* 39(1): 1–32. DOI: <https://doi.org/10.1163/156916208X311601>
- Fleming, Courtney V., Geoffrey M. Wheeler, Helen I. Cannella-Malone, Abby R. Basbagill, Yi-Chieh Chung, and Kristall Graham Day. 2010. "An evaluation of the use of eye gaze to measure preference of individuals with severe physical and developmental disabilities." *Developmental Neurorehabilitation* 13(4): 266–275. DOI: <https://doi.org/10.3109/17518421003705706>
- Fuchs, Thomas. 2017. "Intercorporeality and Interaffectivity." *Phenomenology and mind* (11): 194–209. DOI: <https://doi.org/10.1093/acprof:oso/9780190210465.003.0001>
- Gallagher, Shaun, and Denis Francesconi. 2012. "Teaching phenomenology to qualitative researchers, cognitive scientists, and phenomenologists." *Indo-Pacific Journal of Phenomenology* 12(3): 1–10. DOI: <https://doi.org/10.2989/IPJP.2012.12.1.4.1112>
- Greathead, Scot, Rhiannon Yates, Vivian Hill, Lorcan Kenny, Abigail Croydon, and Elizabeth Pellicano. 2016. "Supporting children with severe to profound learning difficulties and complex communication needs to make their views known: Observation tools and methods." *Topics in Language Disorders* 36(3): 217–244. DOI: <https://doi.org/10.1097/TLD.0000000000000096>
- Hollway, Wendy. 2016. "Emotional experience plus reflection: Countertransference and reflexivity in research." *The Psychotherapist* 62.
- Hoppe, Silke, Laura Vermeulen, Annelieke Driessen, Els Roding, Marje de Groot, and Kristine Krause. 2019. "Learning in Collaborative Moments: Practising Relating Differently with Dementia in Dialogue Meetings." *Anthropology in Action* 26(3): 10–22. DOI: <https://doi.org/10.3167/aia.2019.260302>
- Kaley, Alexandra, Chris Hatton, and Christine Milligan. 2019. "More Than Words: The Use of Video in Ethnographic Research With People With Intellectual Disabilities." *Qualitative Health Research* 29(7): 931–43. DOI: <https://doi.org/10.1177/1049732318811704>
- Kittay, Eva Feder. 2011. "The Ethics of Care, Dependence, and Disability." *Ratio juris* 24(1): 49–58. DOI: <https://doi.org/10.1111/j.1467-9337.2010.00473.x>
- Kittay, Eva Feder. 2019. *Learning from my daughter: The value and care of disabled minds*. New York: Oxford University Press. DOI: <https://doi.org/10.1093/oso/9780190844608.001.0001>
- Kittay, Eva Feder. 2020. *Love's labor: Essays on women, equality, and dependency* (Second ed.). New York: Routledge. DOI: <https://doi.org/10.4324/9781315108926>
- Liamputtong, Pranee. 2007. *Researching the vulnerable: A guide to sensitive research methods*. London: SAGE. DOI: <https://doi.org/10.4135/9781849209861>
- Maes, Bea, Sara Nijs, Sien Vandesande, Ines Van keer, Michael Arthur-Kelly, Juliane Dind, Juliet Goldbart, Geneviève Petitpierre, and Annette Van der Putten. 2021. "Looking back, looking forward: Methodological challenges and future directions in research on persons with profound intellectual and multiple disabilities." *Journal of Applied Research in Intellectual Disabilities* 34(1): 250–262. DOI: <https://doi.org/10.1111/jar.12803>
- Mercieca, Duncan P. 2013. *Living Otherwise: Students with Profound and Multiple Learning Disabilities as Agents in Educational Contexts*. Leiden, Boston: Brill|Sense. DOI: <https://doi.org/10.1007/978-94-6209-131-3>
- Merleau-Ponty, Maurice. 1964. "The Philosopher and his Shadow." In *Signs*, 159–181. Evanston, Ill.: Northwestern University Press.
- Merleau-Ponty, Maurice. 2002. *Phenomenology of perception. Phénoménologie de la perception*. London: Routledge. DOI: <https://doi.org/10.4324/9780203994610>
- Mietola, Reetta, Sonja Miettinen, and Simo Vehmas. 2017. "Voiceless subjects? Research ethics and persons with profound intellectual disabilities." *International Journal of Social Research Methodology* 20(3): 263–274. DOI: <https://doi.org/10.1080/13645579.2017.1287872>
- Miles, Matthew B., A. Michael Huberman, and Johnny Saldaña. 2020. *Qualitative data analysis: A methods sourcebook*. Fourth edition. Los Angeles, Calif: SAGE.
- Moran, Dermot. 2017. "Intercorporeality and Intersubjectivity. A Phenomenological Exploration of Embodiment." In *Embodiment, enaction, and culture: Investigating the constitution of the shared world*, edited by Christoph Durt, Thomas Fuchs and Christiand Tewes, 25–46. Cambridge, Massachusetts: The MIT Press.

- Murphy, Elizabeth, Jennifer Clegg, and Kathryn Almack. 2011. "Constructing Adulthood in Discussions About the Futures of Young People With Moderate-Profound Intellectual Disabilities." *Journal of Applied Research in Intellectual Disabilities* 24(1): 61–73. DOI: <https://doi.org/10.1111/j.1468-3148.2010.00565.x>
- Music, Graham. 2012. "How do we know the ways in which infants experience the world? Lessons from research." In *Infant Observation and Research. Emotional Processes in Everyday Life*, edited by Cathy Urwin and Janine Sternberg. Hove and New York: Routledge.
- NESH. 2016. *Guidelines for Research Ethics in the Social Sciences, Humanities, Law and Theology*. Retrieved from https://www.etikkom.no/globalassets/documents/english-publications/60127_fek_guidelines_nesh_digital_corr.pdf.
- Nind, Melanie, and Iva Strnadova. 2020. "Changes in the lives of people with profound intellectual and multiple disabilities." In *Belonging for people with profound intellectual and multiple disabilities. Pushing the Boundaries of Inclusion*, edited by Melanie Nind and Iva Strnadova. Oxon and New York: Routledge. DOI: <https://doi.org/10.4324/9780429260711>
- Pink, Sarah. 2015. *Doing sensory ethnography*. 2nd ed. Los Angeles, Calif: Sage. DOI: <https://doi.org/10.4135/9781473917057>
- Roche, Laura, Jeff Sigafoos, Giulio E. Lancioni, Mark F. O'Reilly, and Vanessa A. Green. 2015. "Microswitch Technology for Enabling Self-Determined Responding in Children with Profound and Multiple Disabilities: A Systematic Review." *Augmentative Alternative Communication* 31(3): 246–258. DOI: <https://doi.org/10.3109/07434618.2015.1024888>
- Ryan, Richard M., and Edward L. Deci. 2004. "Autonomy Is No Illusion. Self-Determination Theory and the Empirical Study of Authenticity, Awareness and Will." In *Handbook of Existential Psychology*, edited by Jeff Greenberg, Sander Koole and Tom Pyszczynski. New York: The Guilford Press.
- Ryan, Richard M., and Edward L. Deci. 2017. *Self-determination theory: Basic psychological needs in motivation, development, and wellness*. New York: Guilford Press. DOI: <https://doi.org/10.1521/978.14625/28806>
- Shogren, Karrie A. 2020. "Self-Determination, Preference, and Choice." In *Choice, Preference, and Disability: Promoting Self-Determination Across the Lifespan*, edited by Roger J. Stancliffe, Michael L. Wehmeyer, Karrie A. Shogren and Brian H. Abery. Cham: Springer International Publishing AG. DOI: https://doi.org/10.1007/978-3-030-35683-5_2
- Simmons, Ben, and Debbie Watson. 2015. "From Individualism to Co-construction and Back Again: Rethinking Research Methodology for Children with Profound and Multiple Learning Disabilities." *Child Care in Practice* 21(1): 50–66. DOI: <https://doi.org/10.1080/13575279.2014.976179>
- Skarstad, Kjersti. 2018. "Ensuring human rights for persons with intellectual disabilities?" *The International Journal of Human Rights* 22(6): 774–800. DOI: <https://doi.org/10.1080/13642987.2018.1454903>
- Stefánsdóttir, Guðrún, Kristín Björnsdóttir, and Ástríður Stefánsdóttir. 2018. "Autonomy and People with Intellectual Disabilities Who Require More Intensive Support." *Scandinavian Journal of Disability Research* 20(1): 162–171. DOI: <https://doi.org/10.16993/sjdr.21>
- Stern, D. 2005. "Intersubjectivity." In *The American psychiatric publishing textbook of psychoanalysis*, 77–92. Arlington, VA, US: American Psychiatric Publishing, Inc.
- Teachman, Gail, Peggy McDonough, Colin Macarthur, and Barbara E. Gibson. 2018. "A Critical Dialogical Methodology for Conducting Research With Disabled Youth Who Use Augmentative and Alternative Communication." *Qualitative Inquiry* 24(1): 35–44. DOI: <https://doi.org/10.1177/1077800417727763>
- Tuffrey-Wijne, Irene, Jane Bernal, and Sheila Hollins. 2008. "Doing research on people with learning disabilities, cancer and dying: Ethics, possibilities and pitfalls." *British Journal of Learning Disabilities* 36(3): 185–190. DOI: <https://doi.org/10.1111/j.1468-3156.2008.00519.x>
- UN. 1948. The Universal Declaration of Human Rights.
- UN. 2006. "Convention on the Rights of persons with Disabilities (CRPD)." Retrieved from <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>.
- Vehmas, Simo, and Reetta Mietola. 2021. *Narrowed Lives: Meaning, Moral Value, and Profound Intellectual Disability*. Stockholm: Stockholm University Press. DOI: <https://doi.org/10.16993/bbl>
- Vorhaus, John Simon. 2014. "Philosophy and profound disability: Learning from experience." *Disability & Society* 29(4): 611–623. DOI: <https://doi.org/10.1080/09687599.2013.831749>
- Watson, Joanne. 2012. "Supported decision making for people with severe or profound intellectual disability: 'We're all in this together, aren't we?'" *Paper presented at the 6th Roundtable on Intellectual Disability Policy 'Services and Families Working Together'*, Bundoora: LaTrobe University.
- Wehmeyer, Michael L. 2005. "Self-Determination and Individuals with Severe Disabilities: Re-examining Meanings and Misinterpretations." *Research & Practice for Persons with Severe Disabilities* 30(3): 113–120. DOI: <https://doi.org/10.2511/rpsd.30.3.113>
- WHO. 2019. ICD-11. International Classification of Diseases for Mortality and Morbidity Statistics. Eleventh Revision. Retrieved from <https://icd.who.int/browse11/l-m/en>.
- WMA. 2013. "Declaration of Helsinki." Retrieved from <https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/>.
- Young, Iris Marion. 1997. *Intersecting Voices. Dilemmas of Gender, Political Philosophy, and Policy*. Princeton University Press. DOI: <https://doi.org/10.1515/9780691216355>
- Zahavi, Dan. 2019. *Phenomenology: The Basics*. New York: Taylor and Francis. DOI: <https://doi.org/10.4324/9781315441603>

How to cite this article: Skarsaune, Synne Nese, Halvor Hanisch and Anita Gjermestad. (2021). Self-Determination: What can we Learn from Persons with Profound Intellectual and Multiple Disabilities? *Scandinavian Journal of Disability Research*, 23(1), 317–327. DOI: <https://doi.org/10.16993/sjdr.830>

Submitted: 28 April 2021 **Accepted:** 11 October 2021 **Published:** 01 November 2021

Copyright: © 2021 The Author(s). This is an open-access article distributed under the terms of the Creative Commons Attribution 4.0 International License (CC-BY 4.0), which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited. See <http://creativecommons.org/licenses/by/4.0/>.



Scandinavian Journal of Disability Research is a peer-reviewed open access journal published by Stockholm University Press.

OPEN ACCESS The Open Access logo, consisting of the words 'OPEN ACCESS' followed by a circular icon containing a padlock with a diagonal slash through it, symbolizing unrestricted access.