

## Between Two Worlds

### A Phenomenological Critique of the Medical and Social Models of Disability<sup>(1)</sup>

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#### Introduction

Imagine you are engaged in some activity, maybe watching television, and the telephone rings. Your attention is disrupted as you answer and you miss part of the programme. Now imagine, if you can, that you live with cerebral palsy (CP), a condition which can prevent or distort your movement<sup>(2)</sup>. You want to answer the telephone, you may form an intention to do so, but you cannot physically complete the act. As someone with CP you will have known no other way of experiencing the world except as constant and yet unpredictable disruption between intention and action.

Most of our abilities as human beings, such as walking, talking, or for instance, tying shoelaces, are skills we learn at an early age. As adults we do not remember learning these skills, but now we are proficient; we just do them. Walking is perhaps the most fundamental of these skills. We move with little thought as to how; our body just does it. But what if the body did not do as you wanted, but as it wanted, and what if what it seemed to want was chaotic, unpredictable and worse, untrainable. What if our best attempts to constrain our bodies' own movement fail? Some people with cerebral palsy have to be aware of their body all the time to move. Their everyday life is dominated by the disruption of intention into action which most of us never consider. Disruption of movement by one's own brain, whilst not the essence of CP, is one of its major characteristics. To understand the effects this disruption has on a person and their ability to carry out everyday tasks, we shall explore the experiences of two people with CP.

First, a person with CP which has left him hemiplegic; semi-paralyzed down his left side. With poor control of volitional movement all he can do reliably is, essentially, to 'grab and release' with his left hand after a fashion, and to walk with the help of a walking stick. Second, a woman with athetoid CP who has trouble holding herself in an upright and steady position to sit, and often shows involuntary movements, in particular when she speaks. For her, it takes work and concentration even to speak.

## Michey's Tale: Questioning Incorporation

### *Case 1: There is no such thing as just going for a walk.*

*As soon as he leaves the house he has to alter his position and posture, making tiny alterations every second. Every movement of his foot, swing of the stick and grip on the stick handle has to be carefully co-ordinated. Without fluidity in his walking, he needs constant planning of every move. He is always aware of his body as an object to be controlled, not really 'part of me', and yet-and at the same time-it is certainly 'my body' which he needs to constantly reorganize. The world, that is, Michey's surrounding environment appears as something hostile, and something he is part of, but certainly not 'in' as an object which one must continually manipulate, as opposed to being a friendly place, somewhere where Michey feels at ease or at even at home. Within this hostile world, other people appear as obstacles to be avoided, not just because he fears bumping into them and hurting himself, and them. Even a hand offering help with shopping bags can appear hostile as it is an unexpected disruption to his 'walking plan'. It is to live in a world which assails the body and self, and he lives in constant hope that his last adjustment will allow him to survive.*

To deepen an understanding of the experience of CP, we wish to use phenomenology. Phenomenology is a method used to describe the lived experience of human beings, albeit one using a new lens or apparatus. It prioritises notions of human beings and the world as vital and alive over the idea of their being 'mere things,' a conceptualisation inherited from Cartesianism. Phenomenology seeks not explanation but description, revealing the world as 'always already there' <sup>(3)</sup>. It gives a good lens by which the world can be revealed to you, but no new 'explanation'. As Havi Carel states:

Phenomenology is a philosophical approach advocating a description of lived experience and consciousness. It focuses on what it is like to exist as humans in a world. It is a simple, descriptive approach that rejects complex philosophical constructions of reality and puts aside questions about the nature of this reality. Instead, it focuses on the experience of an individual, the ways in which we perceive things (*phenomena*) as they appear to us. (Carel 2008: 8)

Phenomenology, because of its emphasis on description offers a possibility of understanding the nature of impairment which previous research, both in the sciences and humanities have overlooked. Phenomenology offers the theorist certain tools for describing the world not found in previous studies. Examples of these tools, pertinent to our investigations are the

notions of *ready* and *present*. The *ready* is the world of the available, the useful, the objects which one can use, be it a computer keyboard, piano or chess piece, these objects are *ready* for our use. The *present* refer to unusable things which merely exist. For Michey, the world is diminished in the ready and expanded in the present. However, before going further we return to the walker.

Michey has to adjust his body constantly, even though he never knows which adjustments will have to be made *exactly*, or if they will work. Though his left side is affected his right is normal, making his experience of the world, and of his body, fractured and binary; one side is obedient without thought, the other side is chaotic and unpredictable despite attempts to control his movements. On the right side, the world can be engaged with, what the phenomenologist Martin Heidegger called 'readiness-to-hand':

The hammering does not simply have the knowledge about the hammer's character as equipment, but it has appropriated this equipment in a way that could not possibly be more suitable ...the more we seize hold of it and use it the more primordial does our relationship to it become, and the more unwieldy is it encountered as that which it is-as equipment. The hammering itself uncovers the specific 'manipulability' of the hammer. The kind of Being which equipment possesses-in which it manifests itself in its own right-we call *readiness-to-hand*. (Heidegger 1962: 69)

Objects on the right side are available, they can be used and enjoyed, but on the left side only unusable things exists, with an environment one cannot really enjoy but has to negotiate with great care. Worse still, things on the left assault Michey, forcing him to constantly adjust his posture, stance and plans; they merely disrupt his ability to get from A to B. Things on the left cannot be usually employed, they are merely things. Michey experiences his right and left side as if they were two components of a machine that just did not work together, and their being 'broken', for want of a better term, means that he lacks integration with his surroundings. It is difficult to describe Michey's agency; it is not just that his agency is disrupted, it is split, his relationship to his left side being entirely different in character to that with his right. When Michey was much younger this need to negotiate with his left and right side independently of each other created a sense of physical bi-polarity, as if Michey had two bodies to deal with and it affected agency. It could appear at times to him as if he had two selves, each in charge of one side of his body. After thirty-three years of being alive, Michey's split embodied, subjectivity creating disrupted world has to *some degree* been incorporated, but enough only to make dealing with the world easier; there still is a fundamental disruption and disincorporation between Michey and his body, self and world.

The disabled person's<sup>(4)</sup> life is a disturbed assignment. The unusability of the left side not only disrupts the walker, forcing him to make changes (if any can be made) but also shows, or 'announces' to use Heidegger's term<sup>(5)</sup>, the world to be hostile, full of obstacles, where the slightest mistake could lead to him falling. Because of the attention he must give to his body and the world, paradoxically, his body and the world remain alien to him, since he cannot ever become lost and at one in the flow with them. True, he exists in the physical world with other people but, to him, it remains foreign, and he is merely a guest in that world, whilst they are in it. Others are intimately acquainted with their bodies; his body appears as foreign to him. He lacks what Maurice Merleau-Ponty calls 'Incorporation':

If I want to get used to a stick, I try by touching a few things with it, and eventually, I have it 'well in hand', I can see what things are 'within reach' or out of reach of my stick. There is no question here of a quick estimate or any comparison between the objective length of the stick and the stick and the objective distance away of the goal to be reached... To used to a hat, a car and a stick is to be transplanted into them, or conversely, to *incorporate* them into the bulk of our body. (Merleau-Ponty 1998 [1962]: 69)

With this passage Merleau-Ponty, started a whole discourse about skills, abilities which the intentional agent 'incorporates', understood best by Drew Leder in his book *The Absent Body*. Leder reminds us that incorporation, which literally means to "bring within a body" (Leder 1990: 31) is *related to*, although is not the same as *skill acquisition*. Swimming, tennis, chess playing, these are all skills, they are learnt, through repetition and adaptation to the point when they become automatic, done 'without thinking'. For people other than the walker, it is easy to 'incorporate,' to make something such as a backpack or shopping bag 'part of me', but for the walker, the disruptive and unpredictable nature of his CP renders such incorporation impossible. He cannot grasp the skill because of his own body; since there can be no 'incorporation', no 'bringing within the body' despite his desire to achieve such ability, there can be no skill acquisition.

This has been articulated before, by Iris Marion Young as 'inhibited intentionality' which, she explains, "reaches toward a projected end with an 'I can' and withholds its full bodily commitment to that end in a self-imposed 'I cannot'" (Young in Welton 1998: 265). Merleau-Ponty suggests that to every action a person brings their whole situation; people have not only a physical and experiencing body, also but histories and thoughts about the past and future. Whatever a person does, they do as situated subjects. This works the other way for the walker with CP. After a failed attempt to grasp the cane, he may try again, but

each failure reminds him of other times when he failed to complete such an action. Trying a second time, he may begin the task thinking that 'I' can do this, but memories of past failures turn that 'I can' into an 'I cannot' and lead him to withhold the necessary bodily orientation to accomplish the task. He fails because the very need to adjust and predict his involuntary bodily disruptions turn his failure to grasp the walking stick into a self-fulfilling prophecy.

What cannot be over emphasised is the existential nature of inhibited intentionality. The difficulty the walker faces threatens not only his agency, his ability to commune with other human beings, but also his very existence. Walking down the street is about more than *just* walking. Inhibited intentionality must be seen as a shrinking of one's social world, in part because of one's inability to act in a way which would open up the world, and reconstitute it as a world of possibility. But perhaps more importantly he is always seen as someone with CP and a person second; he is always on show, always displaying his disordered intentionality. His body and its problem threaten to swamp other's perceptions of him as a person.

### **Minae's Tale: Questioning Normative Intelligibility and Fluency**

Minae has a form of athetoid CP which leaves her limb movement intact but prevents easy head control and constantly disrupts her speech.

#### ***Case 2.1: An able-bodied or able-spoken normative?***

*When I volunteered to be a guinea pig for clinical practices for fourth year speech language pathology students in Australia, I felt uneasy. They taught me how to pronounce each word in the Received Australian Phonological Standard, but I could not pronounce them correctly. In particular, when speech language pathology students looked at the patterns of vowels and consonants which I could produce, I found it very difficult to be in the clinical room. For example, when the students asked me to pronounce words which start 'p', 'b', 't', 'd', 'k', and 'g', they found some problems with my way of distinguishing 'p' and 'b'. They tried to fix my pronunciation. Then, I found it very difficult, because my first language is Japanese, I did not have any knowledge of English phonology. When they said that 'p' was a voiceless stop and that 'pai' and 'bat' were different words and sound different, I thought I pronounced 'p' and 'b' differently, even when, obviously, they could not distinguish my pronunciations of 'p' and 'b'. When I consciously tried to pronounce them correctly, my body froze up and I could not speak at all.*

Trouble with communicating is a big issue for Minae. She moves her facial muscles into the right position to allow her to speak. She understands what normative pronunciations of both English and Japanese languages should sound like; she also knows that she does not pronounce them correctly. It was impossible for her to pronounce these words as the speech

language pathology students advised. She has so many problems moving her mouth to form words correctly. When Minae hears background noise, she cannot focus on listening to what people are saying and she cannot speak to them with ease. It is not helpful to fix the movements of her mouth and tongue, as some have suggested that she improve her speech, because she has already developed her own way of communicating and her facial muscles have adapted to certain ways according to her embodied subjectivity.

When the speech language pathology students asked her to say words, to close her mouth, or to stick out her tongue, she found it very difficult, because her whole body froze up when she felt nervous. To Minae, it may be helpful to make a social setting where she feels relaxed and comfortable to speak. However, in reality, society does not work for her. In contrast, computer technology, in particular the Internet helps her a lot. To help her communicate more effectively, it is not so important to fix or articulate her speech in a normative way, but it is vital to seek help for her needs (e.g. providing alternative technological devices, a quiet space, and other methodologies of making her feel relaxed). These are important to build lines of communication between her and others. Minae believes that the e-mail and online chat systems relieve the frustration of ambiguous communication on both sides.

***Case 2.2: There is no such a thing as just giving a speech.***

*When I give a talk at a workshop or a conference, I always feel uneasy because I not only feel nervous like everyone else, but also I know I am going to be frustrated at myself. Of course, it might be because English is a second language to me (my first language is Japanese), but it is not only that. When I speak, I have to think of which words I can pronounce easily. Even if I want to say more complex terms and long sentences, I cannot. I always need to avoid those words I cannot pronounce and I need to think how to make my speech very short, and shorter than my thoughts and ideas. My thoughts and arguments are thus constrained not by knowledge or my creativity but by the link between me and the vocalisation part of my brain.*

*When I hear noise during my speech, it disrupts my whole self: I cannot continue speaking at all, since my body shuts down. It is as if my brain just ordered me to stop speaking and to acquiesce to a forced silence, because my brain assumes that no-one can hear my voice over the noise or because I feel uneasy with people who feel uncomfortable asking me to repeat what I said, more simply, and to be with those who simply cannot understand me. Moreover, when I speak, my body moves involuntarily, jerking back and forth, from left to right. Some people have assumed that I might be drunk, with my unintelligible speech and involuntary movements. Without a signifier, a wheelchair, a walking stick or a guide dog, I have nothing to indicate my impairment.*

Similar speech disruptions can be found in personal accounts of stuttering. For example, Dale F Williams' *Stuttering Recovery: Personal and Empirical Perspectives*:

For people who stutter...the disorder is far more than disfluency. It is also anxiety, worry, guilt, shame, self-consciousness, and a host of other auxiliary features. It is energy spent trying to hide disfluencies, be it via bodily movement, the rephrasing of utterances, substituting words, or any number of other behaviours that individuals have employed for this purpose. In other words, people who stutter deal with not only their speech, but also with secondary behaviours, emotions, attitudes, and fears about speaking. (Williams 2006: 2)

As Williams mentions above, these fears are due to others and how they perceive people who stutter. Similarly, Minae has these "secondary behaviours, emotions, attitudes, and fears about speaking" (Williams 2006: 2) to which Williams refers. She has to speak in front of people so, before she gives a paper, she explains her disability and her vocal condition to her audience and asks them to read the subtitles of her speech on the computer screen using PowerPoint. Though common amongst scientists, this remains unusual in philosophy, at least in the UK. Her audience often pays attention to the screen, and the conference room is usually quiet.

It is, however, not always the case in her day-to-day life. For example, when she tried to ask for directions in London, she wrote down on a small piece of paper: "*I have a physical disability, in particular, speech impairment, and cannot speak to you. Could you please tell me where Kings Cross Station is?*" Though able to speak, she felt uneasy speaking in a public space, such as busy London, assuming that people would be shocked or panicked because they would not be able to understand what she was saying. It was easier to be mute. She also had to consider what would happen if her speech was unintelligible; her body would freeze up. When Minae tried to get attention, most people just ignored her, before eventually someone stopped to assist. She wondered if this was because, in the UK, she looks East Asian and so could have been mistaken for a tourist. She also wondered if it would have been easier if she had been recognised as a disabled person, because then people might have treated her better and not have been shocked. She does not want to scare people.

Minae's bodily disruptions appear first in the lips, tongue, and jaw, and quickly spread to other parts of the face, head and neck. Pain from contractions of her neck muscles, over which she has no control, adds to the irregular and jerky movements which block speech further. Tremor is the first to appear, and then her body freezes up. It often begins when if she thinks her speech is not intelligible and acceptable to others, or when she tries to

regain control of her speech and to make it flow. Then, she feels out of control of her body and, more specifically, out of control of her ability to speak. Both the jerky movements and the fear of not-being-understood lead her into the darkness of being silent. In addition to her primary disruptions of movement and tremor, Minae also experiences more complex, secondary, disruptions.

These arise as reactions to the fear of not-being-understood. Minae's fears are heightened by the possibility of a negative response from her listeners and she tries to avoid unintelligibility, often substituting words that are easier to pronounce for the ones she fears are too difficult to say. Sometimes, she avoids talking altogether. She tries to cover up her condition; for instance a hand over the mouth while talking or writing notes. Minae's fear is people's assumption that, like the Sapir-Whorf hypothesis<sup>(6)</sup>, our thoughts are determined by our language. Merleau-Ponty argues that our thoughts lead our speech, in that speech is a way of articulating our thoughts:

Whether the stimuli, in accordance with the laws of neurological mechanics, touch off excitations capable of bringing about the articulation of the word, or whether the states of consciousness cause, by virtue of acquired associations, the appearance of the appropriate verbal image, in both cases speech occurs in a third person phenomena. There is no speaker, there is a flow of words set in motion independently of any intention to speak. (Merleau-Ponty 1998 [1962]: 174–5)

In this respect, Merleau-Ponty condemns the Sapir-Whorf hypothesis according to which language is determined by thought. He argues that there is something added on to our thoughts in order to make our inner ideas communicable to others; this ability to communicate is achieved by our adopting a certain linguistic expression. For Merleau-Ponty, the subject is not a 'speaking' one but a 'thinking' one; speech does not merely convey thought, but rather brings about or fulfils it. Even so, he does not define thought and language. He suggests examining the cases of aphasia-some experiences in which one cannot fully hit upon the right word and also cases in which a part of the thought itself remains missing. For Minae who has speech problems due to her CP and uses two languages-one with her British husband and friends in day-to-day life, another with her friends and family members in Japan to chat on the Internet, there are times when she cannot identify certain words until she has positioned herself in either an English or Japanese linguistic space, and also there are times when she cannot pronounce certain words and she needs to think of other words that are easier for her to pronounce.

Merleau-Ponty maintains that it is insufficient to state that speech indicates thought:

Speech and thought would admit of this external relation only if they were both thematically given, whereas in fact they are interinvolved, the sense of being held within the word, and the word being the external existence of the sense... The word and speech must somehow cease to be a way of designating things and thoughts, and become the presence of that thought in the phenomenal world, and, moreover, not its clothing but its token or its body. (Merleau-Ponty 1998 [1962]: 182)

Thus, Merleau-Ponty argues that thought and word are interrelated and that speech is not the 'clothing' of thought, but rather the body of thought. He develops a gestural theory of language. He states:

[When I speak] I reach back for the word, as my hand reaches toward a part of my body which is being pricked; the word has a certain location in my linguistic world and is a part of my equipment. (Merleau-Ponty [1998] 1962: 180)

For Merleau-Ponty, to speak is to gesture in a particular way of being in our linguistic environment. When one points to a flower in the garden which is shared by those who look at it and recognize it as the same flower, there is a shared system with regards to understanding the flower, we all stand in an intersubjective relation to each other and the flower. Merleau-Ponty argues that linguistic expressions have to be shareable. Whilst no one knows all linguistic expressions, in order to be a linguistic expression, it must be learnable, or intersubjectivity would not be possible. We are able to recognize a flower, because we all understand the meaning of the word 'flower'. For Minae, CP disrupts communication, not least because of its effects on speech production and the limits this imposes on language use and, indeed, thought, but because her CP cannot be separated from the experience of her own body and people's reactions to her embodied self. Her articulation slows and can impoverish her speech and thoughts, but it also draws attention to her difference and to the battle between her thoughts, intentions and her poorly controlled body and speech production. Her mind and her body are part of her own being, and the perceptions of her own body influence what is perceived by her embodied mind just as they affect others' view of her.

### **Are the medical and the social model adequate? Towards a phenomenological model**

We have explored two people's physical limitations and their disruptions between intention

and action. In Michey's case, those disruptions make problematic his bodily incorporation within the world, while Minae's disruptions occur because of people's reactions to her visible difference and unintelligible voice. There are many, other, different experiences of CP. Why explore them? Conventionally, impairment has been viewed in two ways, the medical and the social models; we want to suggest that the experiences of Michey and Minae show the need for a third, phenomenological model, and to make a provisional suggestion.

The renowned sociologist of disability studies, Mike Oliver, wrote:

[D]isability is structurally represented by the vocations of doctors and the para-medical professions, and we load responsibility for the restrictions that disabled people experience on to disabled people themselves, who are restricted because of the functional or psychological limitations imposed by their individual impairments rather than by the social restrictions imposed by society... [T]he disabled individual is an ideological construction related to the core ideology of individualism and the peripheral ideologies related to medicalisation and normality. (Oliver 1990: 58)

And in a later work:

The whole medical and rehabilitation enterprise is founded upon an ideology of normality and this has far reaching implications for rehabilitation and treatment... Its aim is to restore the disabled person to normality, whatever that may mean. (Oliver 1996: 36)

Here, Oliver maintains that the individual or medical model of disability considers disability as a personal tragedy which has happened to the individual and therefore a 'cure' is required. Both Michey and Minae are very good examples of Oliver's critical perspectives on the 'medicine and rehabilitation enterprise'. Michey just wants to obtain a pair of shoes which allow him to walk. He does not want an orthotics specialist to fix his posture, because he experiences his own body and he knows that his posture and his legs will never work like other peoples. If his posture changed, he would not walk properly in his own embodied way. Minae just wants to communicate to people. She does not want a speech language therapist to fix her pronunciation, because she has experienced her own body and she knows that her pronunciation will never be 'normal speech.' If she tried to alter her pronunciation, she would not speak properly, in her own embodied way. Oliver's observation that the medical model perpetuates the idea that individuals are 'amended' or 'normalised' through some form of medical intervention seems apposite. Michey and Minae can never be normalized and instead feel they should be assisted to be the best they can be, while retaining their individuality and

creativity within the confines of CP.

In response to the oppressive nature of the medical model of disability, the social model of disability was developed by Oliver and others:

[D]isability, according to the social model, is all the things that impose restrictions on disabled people; ranging from individual prejudice to institutional discrimination, from inaccessible public buildings to unusable transport systems, from segregated education to excluding work arrangements, and so on. Further, the consequences of this failure do not simply and randomly fall on individuals but systematically upon disabled people as a group who experience this failure as discrimination institutionalised throughout society. (Oliver 1996: 33)

The social model of disability, as Oliver argues, considers the problems faced by disabled people as a social group, and locates the responsibility for those problems within society, rather than with the individual. Thus, the social model suggests that disability is a form of social oppression. It suggests that disabled people are subject to a common oppression by the able-bodied world. Perhaps surprisingly, it therefore has little to do with the body itself:

Ironically that is precisely what the social model insists, disablement is nothing to do with the body. It is a consequence of social oppression. But the social model does not deny impairment is closely related to the physical body. The social model does not deny that some illnesses have disabling consequences...(Oliver 1996: 35)

Michey and Minae, however, experience both bodily restriction and social oppression. For them embodiment must be placed at the heart of disability discourse. One way that the medical model has failed is that it approaches impairment from the perspective of a normalized 'healthy' commonality. But for many with various bodily impairments their problems must be understood from their own perspective, empathetically, through a richer, deeper phenomenological approach, where the normal is expanded to include many forms of embodiment for instance Michey's and Minae's normal embodiment. The individual experience of embodiment (in this case, cerebral palsy) must have a part in any debate about physical disability. The social model of disability can be limited by downplaying the different experiences and embodiments of disability and impairment. It does not work for both Michey and Minae with their many different experiences of physical impairments. In addition, by focusing on disabling environments, the social model focuses on restrictions in access and opportunity at the expense of other forms of restrictions such as, in Minae's

case speech, language and thought. It also seeks to dismiss or diminish the stigma of visible difference.

We favour instead a model of impairment which includes the social and the medical, but also first personal individual experience. The use of language and its relation to experience is also important here. The social model requires an individual to identify themselves as disabled by society. Michey and Minae do not regard themselves as disabled. Rather they feel themselves impaired by other's impoverished understanding. They know they will never be medically 'normal' and can never escape other's social gaze as being different. But they do aspire to the simple and yet profound hope that they might be understood and this requires the third, phenomenological, approach.

We suggest that medical and social care practices that ignore first personal experience of being impaired may, in turn, contribute to disability. Since both stay outside the lived individual experience, medical and social models are not true opposites.

[T]he distinction between the biological reality of a disability and the social construction of a disability cannot be made sharply, because the biological and the social are interactive in creating disability. They are interactive not only in that complex interactions of social factors and our bodies affect health and functioning, but also in that social arrangements can make a biological condition more or less relevant to almost any situation. (Wendell 1996: 35)

A phenomenological sociology of the body-what Nick Crossely...calls a 'carnal sociology of the body'-proposes a paradigm in which 'the social is embodied and the body is social'. If we take this argument/aphorism, and redeploy it relative to a critical interrogation and collapse of the concepts of impairment and disability, it would read: disability is embodied and impairment is social. (Hughes & Paterson 1997: 335)

Phenomenology holds that the world is the perceived world. The medical model and the social model oversimplify the lived reality of that world. They affirm the absolute mutual exteriority of parts of the world: bodies in the world are external to and independent from one another. Phenomenology holds that the elements of the perceived world have blurred boundaries and are internally connected; the internal connections between perceived bodies are neither logical nor causal but relations of expression and meaning. Both models find difficulty in the indeterminacy or fluidity of the world which phenomenology encompasses.

Medical discourse also simplifies and categorizes for therapeutic purposes. CP is "a persistent but not unchanging disorder of movement and posture due to dysfunction of

brain...” (Griffiths & Clegg, 1988: 11). A phenomenological account has less emphasis on the similarities that each variation of CP has to each other and more on emphasis on individual experience. Our two examples consider themselves very different. For the walker, his disability (his embodiment and his physical pain) is mainly with the body, whilst for the speaker, it is bodily, expressive and social. Their embodied experiences raise many questions about the way in which people with CP see themselves socially and how much this perception depends on their own bodily differences, the time of becoming disabled, and on social relations with others.

By its analysis, the notion of embodied experience has become once more a question for Michey and Minae. Living with CP one accepts it, but stepping outside a little, for phenomenological investigation, reawakens observation and is the beginning of refined awareness. Though phenomenology is descriptive and built on observation rather than theoretical analysis it can have the effect of revitalizing the embodied experience of CP. Understanding is not simply something for others to explore but something for us to deepen self-reflectively.

## Conclusion

As stated at the beginning of this paper, we stated that disruption and unpredictability, whilst not *the* essence of CP, are characteristic of both spastic and athetoid CP. These features were revealed by first person phenomenological description, and perhaps could only have been revealed completely, and in relation to those living with them, by it. Descriptions built *solely* on the social or the medical model may have downplayed the *experience of the body* that is disrupted. The social model of disability discounts medical phenomena such as the impaired body and medicine is sometimes less sensitive to individual experiences for therapeutic reasons. Phenomenological approaches can also be limited and need to be expanded to include descriptions of lived-experiences. However, a phenomenological approach may be the only approach which, by paying attention to individual lived-experience, can use the best of both models and produce an accurate picture of what it means to live with a condition, or impairment.

## Notes

- (1) Based on a talk given by Michael Gillan Peckitt at the University of Tokyo, Komaba campus on October 6th 2012 and on the unpublished paper ‘On the phenomenology of cerebral palsy: disruption and unpredictability of intention, action and being’ by Peckitt, Inahara and Cole.

- (2) Margaret Griffiths and Mary Clegg in *Cerebral Palsy: Problems and Practice*, cite one of the most comprehensive definitions of cerebral palsy, which comes from the World Commission for Cerebral Palsy: Cerebral Palsy is 'a persistent but not unchanging disorder of movement and posture due to dysfunction of brain, excepting that caused by progressive disease, present before its growth and development are completed. Many other clinical signs may be present.' (Griffiths & Clegg, 1988:11)
- (3) 'always already there' is a commonly used expression that summarised Heidegger's ideas regarding human existence or *Dasein* as having a primordial understanding of itself-it is 'always already' understanding itself and that it is ecstatic in nature, *Dasein* literally meaning the 'there-being'. See Heidegger, M. 1962 *Being and Time*, Robinson, E. & Mcquarrie, J. (trans.), Oxford: Blackwell, p24–28, p32–39 & p376.
- (4) The authors wish to make it clear that the use of the word 'disabled' is because it is a recognised term. But we are aware of its limitations and connotations and would prefer the more neutral term 'impairment' or even better 'condition', which is less value laden in terms of the person's ability to function with the condition. The authors are aware that normally one would write of a person with a disability, not a disabled person, showing the person first and their disability as being but part of them. But some disabled people do define themselves in terms of that disability and so are happy with the first phrase. As ever language has a political and social dimension.
- (5) A reference to "...the world *must not announce itself*." To be found in Heidegger, M. (1962). *Being and Time*, Robinson, E. & Mcquarrie, J. (trans.), Oxford: Blackwell, p106.
- (6) American linguists Edward Sapir and Benjamin Lee Whorf paid attention to the relationship between language and thoughts. However, neither of them officially wrote the hypothesis nor supported it with empirical evidence, but through a study of their writings about the relationship between language and thoughts, many researchers have found two main theories. First, a theory of linguistic determinism that states that the language we speak forms the way in which we understand the world around us. Second, a theory of linguistic relativism that argues that language influences our thoughts about the world. Both remain controversial.

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## Abstract

Michael Gillan Peckitt, Minae Inahara, and Jonathan Cole, "Between Two Worlds: A Phenomenological Critique of the Medical and Social Models of Disability". In Ishihara, K. and Inahara, M. (eds.), *UTCP Uehiro Booklet*, No.2. *Philosophy of Disability & Coexistence: Body, Narrative, and Community*, 2013, pp.139 – 153.

Research into disability is guided by two models. The first model is the medical model, which states that disability is a medical condition to be catalogued and if possible, treated. The social model, which was initially advanced by advocates of disability rights in the 1970's, states that disability is a social condition, not something to be 'fixed' by medicine. These two models, or a version of them guides all research into disability, and yet each model leaves some aspect of disability out, the medical ignores the social aspects, and at its strongest variant, the social model denies the disability has anything to do with medicine. In this talk we shall argue that whilst both models have been useful, since both ignore crucial aspects of disability, both ultimately fail to provide an accurate picture of disability. Using the phenomenology of Merleau-Ponty, we shall present a phenomenological description of two people with cerebral palsy, an umbrella term for a condition which affects them socially in entirely different ways. By presenting such a phenomenology, we aim to show that phenomenology may offer a third way of understanding disability, that can take the best of the social and the medical models and arrive at a more accurate depiction of disability.

