

## “This is my way”: reimagining disability, in/dependence and interconnectedness of persons and assistive technologies

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**Purpose:** Postmodernism provides a radical alternative to the dominant discourses of Western societies that emphasize autonomy and independence. It suggests a reimagining of the relationship between the self and the body and the increasingly blurred boundaries between biology and machine. The purpose of this article is to explore in/dependence through a discussion of interconnectedness of persons and assistive technologies.

**Key messages:** Drawing on postmodern theories, we discuss the interconnections inherent in disability experiences through the case example of Mimi, an adolescent girl with severe physical disabilities. We consider how Mimi, her assistive technologies and her parents can be viewed as assemblages of bodies/technologies/subjectivities that together achieve a set of practices. An examination of these various couplings suggests different understandings of disability that open up possibilities for multiple connections and reimagines dependencies as connectivities. **Conclusions:** Connectivity can be embraced to explore multiple ways of being-in-the-world for all persons and problematizes the goals of independence inherent in rehabilitation practices.

**Keywords:** Assistive technology, children, disability, independence, postmodernism, subjectivity

“I need this wheelchair. It helps me get on in life. We all have different ways of getting on in life. This is my way.”

This article explores human subjectivity and in/dependence through a discussion of interconnectedness among persons, their carers and assistive technologies. Drawing from postmodern theory, we discuss the interconnections inherent in disability experiences through the case example of Mimi, an adolescent girl with severe physical impairments. An examination of Mimi’s interconnections with others and with technologies suggests that the self is not static or contained

### Implications for Rehabilitation

- “Dependency” has a negative social connotation that is challenged by postmodern ideas of dynamic connectivity.
- Connectivity offers an alternative lens for conceptualizing relationships between disabled people, their technologies and caregivers.
- Connectivity suggests a rethinking the goals of independence inherent in rehabilitation practices.

and suggests limits to prevailing rehabilitation discourses that contrast independence with disability.

### Assistive devices and technologies

Technology offers a route to address disabling impairments in the lives of disabled people. In this issue for example, papers by Lange et al. and Lewis and Rosie [1,2] outline how emerging virtual reality technologies can be added to the therapist’s toolbox to augment rehabilitation interventions. In the daily lives of disabled people, complex and simple machines also do the work of supporting critical biological functions, e.g. breathing with ventilators or eating via gastrostomy tubes. Assistive devices, such as wheelchairs, walkers, environmental control units and adaptive switches, address functional impairments, provide access to the world and facilitate social participation.

Rehabilitation research has focused on understanding why technologies are taken up or abandoned primarily from a psychological perspective, that is, through assessment of individual expectations and preferences to inform the prescription and design of technologies [3–6]. Wendy Seymour has argued that while this work is important, it fails to take into account

the broader social contexts where disability, rehabilitation and technology operate and are given meaning [7]. She suggests the social and cultural meanings associated with technologies' impact on the self-identities of disabled people.

We want to take this viewpoint a step further. Seymour's work goes beyond an idiosyncratic view by locating individuals and their technologies in a broader context, but assumes a static understanding of the self as fixed, separate and contained. Winance [8,9] and Moser and Law [10] instead have drawn from Actor Network Theory to explore how people and devices are mutually shaping. In doing so, they raise questions of what is a person and how action is made possible. Similarly in previous work, we have suggested that disability "dependencies" on humans, animals and technologies can be reconfigured as "connectivities" that open up possibilities for an altered ethics of the body [11]. In this article, we explore this notion further by examining fluid interconnections between disabled bodies, other bodies/people and assistive devices. We conclude with discussing the implications for rehabilitation.

### Connectivities and assemblages

Mimi is a bright 12-year-old girl with a rare neuromuscular condition. She breathes via a tracheostomy tube and ventilator and has a gastrostomy tube to assist with meeting her nutritional needs. Her primary mode of mobility is a power wheelchair. For many years of her life, she lived in a hospital with 24 h nursing care. She now lives in an apartment with her father and mother. Her father works outside the home and her mother provides the bulk of the assistance Mimi requires with activities of daily living. Mimi also has a night nurse five nights a week, and an attendant who accompanies her to school. She is never left alone because of the risks associated with ventilator disconnection or mucous plugging. Mimi has limited opportunities for activities outside of home and school but states that she "doesn't mind." She enjoys school, her friends, writing stories and listening to music.

The data presented in the paper come from two projects in which Mimi participated. The first was a forthcoming documentary film about the experiences of kids with multiple impairments and their families. During filming, we conducted a parallel critical observational study examining the making of the documentary as a social process. The second was a research study that explored disabled children's experiences of recreational activity settings. As part of the latter project, Mimi took photographs and videos that were discussed in a qualitative interview. Both studies received ethics approval from the local university or rehabilitation centre.

Below, we explore the notion of "dependence" in relation to Mimi's various forms of human and nonhuman connections. In doing so, we focus on processes of "becoming" that resists finalizing individuals as fixed, contained and separate, and instead explore actions, productions and possibilities afforded through the movements in and out of human-machine assemblages.

"I'd rather be a cyborg than a goddess." This is the conclusion of Donna Haraway's "Cyborg Manifesto" [12], a startling

postmodern comment on the profound connections between humans, animals and machines. The "postmodern turn" in contemporary theorizing has led to new considerations of the "leakiness" or fluidity of the subject. Shildrick [13] has suggested that this confusion of boundaries plays out most tellingly in the notion of the prosthesis, defined not only as an artificial limb, but any of the multiple technologies of contemporary life from computers and cell phones to organ transplants and medical charts. She comments that the body is never complete and bounded but is "irreducibly caught up in a web of constitutive connections that disturb the very idea of the human being" (p.13). Building on this idea, self-identity is not necessarily defined by unity or distinction from other people or things. All of us, according to Shildrick, are "always already prosthetic" (p.12).

It is here that we situate the discussion of connectivity. The binary division between independence/dependence has its roots in the assumptions of the sovereign, autonomous self which is contained within a physical body – the division of self/other as individuated subjects. These binaries have their origins in Cartesian dualism – the separation of mind from body. Dualistic thinking is deeply embedded in the social conscious. It suggests all kinds of separations including the separation of persons into distinct selves. In other words, we take for granted a clear ontological distinction between self and other or "me" and the "you." These ideas are reproduced in the dominant discourses of Western society and institutions such as medicine and rehabilitation which emphasize autonomy and independence. The valorization of independence has as its starting point the assumption that we are separate and distinct from other beings and things.

Independence as a taken-for-granted goal of rehabilitation is slowly being modified by the notion of "interdependence" [14,15]. Interdependence emphasizes the reciprocity and mutuality that pervades human existence. We want to extend the idea of interdependencies using a postmodern lens. Thus we discuss, for example, not only how Mimi and her mom are interdependent but also, more profoundly, how their selves connect and merge into assemblages and later disconnect and reconnect with others to form different assemblages. Within these assemblages there are no clear distinction between persons or between persons and technologies. The very notion of the "person" itself is called into question.

Deleuze and Guattari [16,17], like other postmodern theorists, posit the fluidity of the subject, such that static position of the self-as-individual is called into question. From this perspective, selves are distributive, confined to individual bodies and simultaneously connected, overlapping with other bodies, nature and machines. Deleuze and Guattari do not comment on disability; however, their deconstruction of the autonomous subject suggests a reconceived ethics that troubles the separation of concepts such as disabled/nondisabled, dependent/independent [18].

Instead of independent subjects, Deleuze and Guattari's talk of the multiple and fluid assemblages. Disabled people, like all people, move in and out of multiple assemblages: human-machine assemblages of bodies, ventilators,

wheelchairs; human–animal assemblages with pets and service animals and/or human–human assemblages with carers. We have used carer here deliberately to problematize the one-way relationship inherent in the term “caregiver.” Caring is at least a two-way relationship that involves caring about and for each other [19]. It can be enriching but also has disabling peripheral effects as we will discuss. Importantly, to think through some of the assemblages in which disabled people are implicated is not to suggest they are unique. Rather their unique configurations help in reimagining independence/dependence divisions that limit human becoming for all persons.

### Mimi/wheelchair

Mimi was soon to start high school and was concerned about how other students would react to her physical differences. She was asked by the filmmaker what message she would like to send to them. She replied,

Don't be scared of my wheelchair, because some people are. It's just part of me. I need it to help me get around, and if you can't deal with it, then oh well. I'm normal. Treat me the same. We're all humans. We can all get hurt.

Later she added,

On the outside, I know that people know that I'm in a wheelchair because it's visible. I'm used to people watching me wherever I go, but I don't really care. This is what makes me me. On the inside I'm a helpful, caring, sweet person. Well, I think!

Mimi makes a plea in these comments for the acceptance of her unique configuration of body-wheelchair. “It's just part of me” is a plea to accept all her parts, biological, plastic and metal, as Mimi, as her “self”: “This is what makes me me” (hence, our choice of “Mimi” for her pseudonym). It's not that she has a technology that is added to some essential self, or that she “uses” to enhance her functions. The wheelchair is incorporated into a body that has no start or end point but remains open. Mimi entreats her imagined future classmates to see that she is configured in a particular way that is “normal.” We take her claim to normality as an appeal for recognition of the array of bodily configurations that are part of the human condition. So, instead of focusing on her differences, she highlights what makes her the same: her positive traits, and her vulnerabilities. She recognizes that her particular physical configurations are socially stigmatized and works to change these perceptions.

Mimi is not “confined to” a chair, she is not “in” her chair nor does she “use” her chair, rather she is her chair, but sometimes she isn't. More precisely, her technobody is one transitory version of Mimi, not a static or finalized composition of person–machine. Her multiple ways of being-in-the-world [20] are accomplished through moving in and out of various assemblages with other bodies and technologies. Later in the filming, Mimi is at a public event where she mobilizes both with her wheelchair and through

assisted walking. The research assistant recorded the following observations:

For the first time we see Mimi stand and walk, which none of us knew she could do [her Mom stands behind her with her arms thrust forward under Mimi's armpits, to help her move without the chair]...As it comes to a close, Mimi is seated in her wheelchair and once she is able to move on her own, she quickly moves around to the other side to talk to a young women ... I'm struck by how much freer Mimi is to move in the chair.

Mimi's wheelchair may be a part of her, but it is a replaceable part, part of her movements in some instances but not others – intimately incorporated in one moment and abandoned in the next. This frees up opportunities for different movements and experiences. The efficient body-wheelchair and the maneuverable body mom have different functionality but are also differently identified in the world. Just as the biological body can have replaceable parts – the daily shedding and building of new cells, the movement in and out of the body of various biota, food and air, and of course the biological prosthesis of organ transplants [13] – so too is the technological body reconfigured to mobilize different contextual competencies. This opens up multiple possibilities for, in Haraway's words, “reconstructing the boundaries of daily life” and “building and destroying machines, identities, categories, (and) relationships” [12] (p.150).

### Becoming

For Deleuze and Guattari, a subject is reimagined as a continual “becoming” neither encased by skin and organs nor defined by static binary categorizations such as disabled/able-bodied, male/female, person/thing or even myself/other [21]. Becoming is identity-in-motion through an open system of assemblages that can be torn down and reconfigured. It is a process, not a way of being. It is also not goal – or outcome oriented – but rather emphasizes experimentation and multiple connections across time and space [11].

Out of this emerges an ethic of openness that is not simply about rejecting dependency in favor of interdependency. Instead “becoming” suggests moving between dependence, independence and interdependence where different assemblages have different effects on their various human actors. Some assemblages are fruitful and enabling, others hurtful and disabling, most have multiple effects but none are static. Rather than promoting independence, the project becomes a minimization of the harms associated with different assemblages. Doing so requires a change in the social imaginary wherein dependence is not in and of itself seen as a personal failure or poor rehabilitation outcome.

### Mimi/mom/(dad)

All of Mimi's activities require another person to be present because of the risks of ventilator malfunction (at least this family is not willing to risk her being alone). When Mimi is engaged in solitary activities at home, someone needs to be

readily at hand. Anything that involves her going outside of the home requires accompaniment. Mimi thus has limited opportunities for activities in the community. Mimi arrived at her interview for the second study with her mother. The research assistant recorded the following note:

Mimi and her mom asked about whether or not Mom should wait outside the door or stay in the room. They made it clear that she needs to be very close at hand because of the ventilator. I told them that it was their choice and both options were fine. They opted for Mimi's mom to join us. At times during the interview, Mimi's Mom spoke up and asked if she could add a comment about what was being said. It did not seem that she wanted to contradict Mimi; just that she wanted to add a perspective that she felt was important. She frequently was listening and nodding agreement as Mimi spoke. It appeared that these two have very close, intimate, loving and respectful relationship.

Mimi was asked how frequently she engaged in activities outside the home:

Mimi: Not very often. Because my parents are busy, you know? Even though my Mom doesn't work, I don't want to put too much stress on her. It's easier to just leave me at home and let me do whatever, which I don't mind. If I really want to go, then I'll ask her, but most of the time I don't mind.

Interviewer: Coming back to what you were mentioning before, it sounds like these are sort of hard decisions? You wouldn't mind going out, but you also understand that you can't do it on your own and that you feel funny asking all the time.

Mimi: I don't feel funny, it's just like I don't want them to work too hard 'cause they do so much for me already.

Mimi and her mother can be viewed as a different kind of assemblage that achieves a set of effects. The where, what and when of the elements of the assemblage change (wheelchair, ventilator, bed, mom, nurse and dad) in an ebb and flow that facilitates some activities and constrains others according to a rhythm that works (or not) for this family. The mom/Mimi/technology assemblage sustains Mimi's body, provides for her mobility and her comfort. It addresses the tasks that need to be carried out by a separate-but-connected mom and Mimi. Mom cannot be too far away from Mimi, so mom is disabled in her own way. But, she has her daughter at home instead of in an institution which enables the family to care for and about each other, to do family.

Technologies do things – they enable and disable, provide opportunities and constraints, what Winance [8] calls “knots” – some can be untied and others cannot. Mom facilitates Mimi's activities, practices and well-being by constructing a set of bounded possibilities for action. The assemblage organizes what is possible and practical and might be reconfigured to enable other actions. But, the change is not limitless. Mimi can breathe without the ventilator but not for very long. She can walk but only if someone walks with her, just as we all rely on different technologies and people to achieve different functions.

Thus, in “doing family,” we can trust Mimi's assertion that she does not “mind” when she cannot go out. This is how her family works; it is their “way,” which does not necessarily preclude a desire for more independence. Her dependencies

present as extraordinary to others but, as Mimi states in the quotation that opened this article, “We all have different ways of getting on in life. This is my way.” Nondisabled people's dependencies are not as readily recognized because they are banal instead of extraordinary, but they still open and close possibilities and actions. Mimi works within the interview to establish that her dependencies should also be considered unremarkable, but this requires resisting pervasive negative discourses of disability.

## Implications

The notion of multiple becoming assemblages suggests different conceptualizations of independence and dependence that question the ideal of the self-sufficient individual. While “dependency” is a disadvantage in some situations, we argue that it is one of many modes of achieving and doing-in-the-world, i.e. Mimi's “this is my way” that works for her. If dependencies are considered fluid states – that are neither inherently negative or positive but becoming that we all move in and out of – then rehabilitation opens up to new possibilities to support and encourage different ways of being and doing.

Rehabilitation is focused on maximizing a person's functional abilities, enabling social participation and well-being [22]. Through rehabilitation individuals learn to effectively “do,” adjust and readjust to new ways of being-in-the-world as the body changes (either through trauma, growth or aging) [23]. In asking what assemblages are the most productive and the least harmful to individuals and their carers, the task of rehabilitation shifts to facilitating creative assemblages rather than (only) independence. The goal becomes helping persons to live well through making and breaking connections. We do not mean to suggest that rehabilitation does not already do this in a number of creative ways. However, we are suggesting that reflecting on current practices and the tacit assumptions that underpin our work may help to liberate new and creative rehabilitation approaches. Two examples help to clarify these points.

Papadimitriou [23] has examined the process of becoming “enwheeled” by individuals with newly acquired spinal cord injuries (SCI). Drawing from observations in an SCI rehabilitation unit, she describes the process of wheelchair incorporation. Adults, she observes, are assisted by rehabilitation staff to learn to functionally use a wheelchair. At the same time, however, they are negotiating a new bodily style. Becoming enwheeled thus refers to not only learning to use a wheelchair (the primary clinical focus) but also how it becomes incorporated into the body schema. She argues that this process raises existential struggles for individuals. In becoming “newly abled” through the freedom of movement afforded by a newly configured technobody, individuals with SCI also newly and vividly experience stigma. Well-intentioned therapists however may not acknowledge or engage in this experience.

One of her study participants, George, stated,

The (therapists) say “oh you are just as normal as any other person, you can do just as much as a walking person.” NO you cannot... There is a discrimination out there against disabled people.

Presumably, the therapist was working to accentuate George's abilities and help him "accept" his newly abled body. However, George viewed this as a lack of empathy or, in other words, a failure to understand all the experiences (physical, psychological and social) of becoming enwheeled. Clinicians thus have to negotiate a tricky path in helping persons to incorporate technologies and see the potentials in certain assemblages, while being sensitive to the real harms imposed by the social devaluation of some dependencies. Assemblages can both enable and disable in myriad ways. Papadimitriou's work helps to demonstrate how the functional possibilities offered by human and nonhuman dependencies cannot be easily separated from the ways they form and transform what the person is, does, and how s/he experiences self.

Recognition of these struggles as well as reimagining dependencies as ways of doing and being-in-the-world can inform how rehabilitation is conceived and delivered. Social discrimination and marginalization will not be changed overnight. Rehabilitation however is a key site for challenging and transforming negative social discourses surrounding disability and what technologies are valorized or discredited. To assist clients and families, rehabilitation as a field, as well as its practitioners, need to maintain a reflexive stance on the assumptions that underpin practices and programs.

In another example, the notion of "transitioning" disabled youth into adulthood too often relies on unexamined assumptions about what constitutes the right and proper roles of adults including "independent living" [24] (p.106–109). Instead, independent living can be understood as one of many living arrangements, each potentially enabling or disabling depending on the individual and the context. Living at home with parents is not necessarily assessed as a failure to transition when these implicit value judgments are unpacked. More broadly, transitioning to adulthood does not need to be viewed as a linear or unidirectional process of moving from one identity category (child) to another (adult) [24]. Instead, individuals can move in and out of these fluid categories, exploring multiple becomings. Whether or not extended living with parents versus "independent living" is the right option then becomes less of a black and white decision and has to be considered in terms of care, harm and the enabling of doing and being for children and parents.

We would like to be clear that we are not suggesting that rehabilitation stop providing valuable interventions, but rather that we view what we do and what patients experience through different lenses. Disability and dependence reconceived as connectivities have much to teach us about the limits of independence for all persons. Dependence does not have to be viewed negatively, and independence is not always the goal.

In their paper in this issue, Kayes and McPherson [25] ask if rehabilitation has achieved the right balance between technical competence and humanness. Here, we consider that the technical and the personal are intimately intertwined and ask, "How can we promote more humane and productive assemblages?" If patients are assemblages of bodies and technologies, so too are clinicians, as is amply demonstrated in the papers in this issue. Together, client, therapist, therapy

technology and assistive device come together to achieve a set of effects and practices that are inescapably constituted through mutual engagement. Which outcomes are seen as positive evolves from immersion within dominant social and rehabilitation discourses. Assemblages that promote human flourishing to be recognized, might, in some instances, require that traditional rehabilitation knowledge, skill and interventions be reimagined or even set aside. Other human skills, such as caring for, about and with one an/other, may be more warranted.

## Conclusion

In this article, we have explored in/dependence through a discussion of interconnectedness of persons and assistive technologies illustrated by a case example. We have proposed viewing persons, their carers and their assistive technologies as assemblages of bodies/technologies/subjectivities that together achieve a set of practices. Assemblages, we suggest, are not stable but transient states that connect and disconnect in constant flux. Reimagining dependency as connectivities of multiple assemblages opens up a theoretical space within rehabilitation to rethink the goals of independence inherent in treatment, evaluation and research practices. Assemblages have the potential to be helpful or harmful in multiple ways that need to be assessed beyond narrow conceptualizations of function or well-being. Furthermore, as a unit of analysis, assemblages shift focus from the patient, to include a consideration of all entities implicated in the assemblage (e.g. client, carers and technologies) and if/how they work to achieve practices. These ideas also contribute to potentially fruitful but largely untapped areas for further research and scholarship that draw from postmodern philosophy to examine pressing issues in rehabilitation.

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