

RESEARCH PAPER

Parallels and problems of normalization in rehabilitation and universal design: enabling connectivities

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Abstract

Purpose: Universal design (UD) is oriented to creating products, buildings, outdoor spaces and services for use by all people to the fullest extent possible according to principles of enabling equal citizenship. Nevertheless its theoretical basis has been under-explored, a critique that has also been leveled at rehabilitation. This commentary explores parallels between UD and dominant rehabilitation discourses that risk privileging or discrediting particular ways of being and doing. **Methods:** Commentary. **Results:** Drawing from examples that explore the intersection of bodies, places and technologies with disabled people, I examined how practices of normalization risk reproducing the universalized body and legitimated forms of mobility, and in so doing perpetuates the “othering” of difference. To address these limitations, I explored the postmodern notion of multiple creative “assemblages” that are continually made and broken over time and space. Assemblages resist normalization tendencies by acknowledging and fostering multiple productive dependencies between human and non-human elements that include diverse bodies, not just those labeled disabled. **Conclusion:** In exploring the potential of enhancing creative assemblages and multiple dependencies, space opens up in UD and rehabilitation for acknowledging, developing, and promoting a multiplicity of bodily forms and modes of mobility.

Keywords

Assemblages, disability, independence, postmodern, universal design

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► Implications for Rehabilitation

- Universal design and rehabilitation both risk perpetuating particular ideas about what disabled people should be, do, and value, that privilege a limited range of particular bodily forms.
- The notion of “assemblages” provides a conceptual tool for rethinking negative views of dependence and taken for granted independence goals.
- In exploring the potential of enhancing various dependencies, space opens up for reconsidering disability, mobility and multiple ways of “doing-in-the-world”.

Introduction

In this paper I explore parallels between Universal Design (UD) and rehabilitation that risk reproducing legitimated forms of bodies and mobilities, and in so doing perpetuating the “othering” of difference. To do this I explore the notion of *connectivities*, that is, the profound connections between persons, technologies and places using a number of examples of so-called disability dependencies. Postmodern thinking provides a point of departure for considerations of the “leakiness” or fluidity of the subject, such that ideas about the subject as a static and contained individual are contested [1]. This perspective provides a radical alternative to dominant western discourses that emphasize autonomy and independence. By attending to intimate

connections between everything – places, people, nature and technologies – the parallel ideals of independence and universalism are revealed as problematic.

Universal design (UD) is oriented to creating products, buildings, outdoor spaces, and services for use by all people to the fullest extent possible according to democratic principles of enabling equal citizenship [2,3]. I am not by any means an expert in the field of UD and do not provide any kind of analysis of its practices or operating principles. My goal is instead philosophical – to problematize the concept of universalism and its parallel expressions in clinical rehabilitation. I do this not to suggest that these are wrong or bad, because they may be right and good in many ways, but rather to explore how the idea of the “universal” is risky from the outset because it will always rely in some way on a view of legitimated and standardized bodies. As Imrie [4] has noted, the definition and usage of the term “universal” in UD raises broad issues of the desirability of universal solutions given that impaired bodies always experience interactions with the designed environments as particularities [4, p. 879]. He further

states that UD may be unwittingly “asserting a universal subject or a generic human-type (that is an) essentializing and homogenizing of the other from above” [4, p. 878]. Even as UD admits for bodily variations and strives to maximize accessibility for as many people as possible, it will always need to rely on some version of sameness, of some fixed assumption regarding what kinds of bodies and mobilities orient design [5]. In designing for mobility, for example, the variants might include the use of wheelchairs, walkers, canes, baby strollers and typical upright walking, but inevitably will exclude other forms (I explore some examples below).

Universal design is meant to promote inclusion [3], but principles of inclusion unavoidably suggest a pre-existing normative centre that the “excluded” are meant to strive towards [6]. As Graham and Slee note, the differentiation and spatialization of bodies as included or excluded requires a common referent [6]. For disabled people this referent has historically and pervasively been constructed in relation to approximating the norm of typical bodily forms. This has been demonstrated in the work of Ravaud and Stiker [7,8] who describe how, over time and place, conceptualizations of the universal slip from the promotion of individual equality to a desire for sameness and assimilation. Inclusion through universalization thus risks a kind of erasure of multiplicity and difference by assuming and (re)producing a pre-determined range of bodies and ways of doing-in-the-world.

Rehabilitation operates according to similar assumptions through interventions designed to approximate normative bodies and independent function. For at least 40 years, disability studies activists and scholars have critiqued normalization practices in rehabilitation [8–11], and more recently these critiques have been echoed by voices within rehabilitation [12–16]. Stiker [8], in his detailed exposition of the history and philosophical moorings of rehabilitation, discusses normalization in terms of an “integration of oblivion” [8, p. 133]. He suggests that, in the name of equality, rehabilitation attempts a kind of erasure of disability, of “integrating too well” [8, p. 132], to approximate an identicalness that strives to efface difference.

In everyday clinical rehabilitation practices, assessments of good or poor outcomes rely on standardized measures, such as the ubiquitous functional independence measure (FIM™), which classifies individuals according to their abilities to carry out activities independently versus the need for technological or human assistance [17]. Greater independence (higher scores) are equated with better rehabilitation outcomes. Measures and interventions like the FIM designed to identify and ameliorate dependencies thus always already “function to obscure and (re)secure the order of things” [6]. However, the idea that independence is good (desirable, preferable), and dependence is bad (undesirable, to be avoided) is not a given, but relies on a particular normative understanding of the subject and what constitutes a good life [18]. Inherent in a problematization of independence is a questioning of some of the philosophical under-pinnings of much of what gets done in the name of helping disabled people, whether it is through design, policy, clinical treatment, social services, education, or the like. Independence can be thought of in many different ways that overlap and are often conflated: freedom, self-determination, sovereignty, self-sufficiency, living alone and control. But at its most fundamental, independence relates to the enlightenment notion of humans as fixed beings, composed of individuated minds which are encased in biological bodies. Questioning this core assumption as part of the post-modern turn in contemporary theorizing has opened up a world of possibilities for rethinking human differences [1]. If we take seriously the idea that subjects are being constantly constructed of different bits of matter and significance, we might ask if universalism and

independence are antithetical to the postmodern subject that is continually made and unmade across place and time. How might we re-imagine relations between body-subjects, technologies, and places implicated in design and rehabilitation practices?

To explore these questions, in what follows I draw on a number of examples of connectivities in relation to persons who are categorized as “disabled” to suggest that “dependencies” can be reconfigured as “assemblages” that open up possibilities for an altered ethics of the body [19,20]. In so doing, I explore questions of what is a person, where the body begins and ends, and how action is made possible [21]; and consider the role of a creative particularism in supporting diverse abilities [4,22]. The paper is divided into three parts. In the first part I briefly introduce the post-modern approach that frames the discussion, particularly the notion of assemblages. Next I discuss examples of assemblages that include persons labeled as disabled, and finally I conclude with a discussion of the implications for UD and rehabilitation.

The ideas explored in this paper draw from critical and post-modern traditions of avoiding complacency by continually asking, what are the effects of our practices and how can we do better? [6]. Post-modernism seeks to challenge prevailing notions about “the order of things” and the assumptions that underpin ingrained principles of western science [23]. Covering a wide range of scholarship, postmodern approaches critique power and the ways that power is linked to the dominance of particular types of knowledge and understanding [24]. By asking questions about how current conceptualizations of phenomena came to be dominant, postmodern approaches can be used to examine how things could be otherwise. One way this is achieved is through reversing the positivist tendency to reduce and finalize concepts by seeking a diversity of relational meanings. Multiple meanings are used to disrupt common understandings, and encourage thinking otherwise. The notion of “assemblages” that I further explore below, comes from the work of Deleuze and Guattari [25] who describe collections of heterogeneous elements that in coming together produce particular effects [25, pp. 323–50]. For my purposes here, the primary elements of interest are bodies, identities, technologies, and places, but assemblages can include an endless variety of elements from physical objects to events to utterances. Importantly, assemblages are not stable or closed systems, but rather temporary connections that continually come together and then break apart, forming different assemblages with other elements that produce different effects. For example, assemblages formed between bodies, wheelchairs, and places are not permanent states, but temporary connections that enable certain actions and activities and constrain others. To refer to a person as “wheelchair-dependant” carries with it stable notions of ability and disability that belie the myriad possibilities of a body-wheelchair-place assemblage. A wheelchair can provide significant advantages in one time/place, i.e. making movement easier or faster, and disadvantages in others, if movement is limited by stairs, for example. Thus talk of dependence and disability becomes re-configured as moments of possibility realized through multiple temporary assemblages [19].

In the examples that follow, I further explore and un-pack the notion of assemblages in relation to disability experience. The examples are chosen from a range of sources including my own research. They were not selected using any particular criteria other than their heuristic potential, and to that end are more or less arbitrary, and not scientifically “sampled”. Rather they are intended as particularly compelling connectivities that help illuminate the philosophical points advanced in the paper.

Ventilators and bodies without organs

The first example comes from research with young men who rely on ventilators for their breathing [26]. In the study, each of 10 participants (ages 22 to 36 years) created a video that reflected “who he is” and “what life is like”, and participated in an interview where the videotape was viewed and discussed. The ventilator is life-sustaining and the men could only be “disconnected” for a few moments at a time. A portable battery-operated ventilator was mounted to their power wheelchairs during the day and another ventilator, plugged into an electric wall socket, was at the bedside for night use. I mention the power sources because these helped form different assemblages and connectivities. Most of the men were connected to their ventilators via an endotracheal tube through a hole created in their trachea (tracheotomy). They also relied on other technologies to sustain life and/or enable particular tasks. In an earlier paper [20], I explored the connectivities between persons, technologies and nature using Deleuze and Guattari’s [25] notion of the Body without Organs (BwO) as follows:

The disabled man who breathes with a ventilator, eats through a gastrostomy tube, talks through a voice synthesizer, moves with a wheelchair, is (or could be) becoming a BwO, playing with identity. He is a fluid body, not a subject, but a conglomeration of energies. He has replaceable parts. When the biological part fails it is replaced by a metal and plastic one. When that fails it is upgraded. New shiny smooth parts replace old obsolete ones. The body both ages and at once becomes younger. The number of body holes is increased and filled with tubes, liquids and gases. Invaded, but also in contact – exposed, vulnerable, outside and inside. The trachea, the urethra, the stomach, and the larynx form circuits with machines that are plugged into electrical sources. The transfer of energies, the electrified body flowing through power lines connected to the hydroelectric dam, receiving power (desire) from the river, from gravity that motivates the river. And energy is exchanged with other bodies that maintain the dam, manufacture the machines, and service the body. The man, the cyborg, refuses to be an individual organism and re-fuses into an individual organism. His organs are here, there and everywhere. He is an excitation, a point of contact, a relay on a power grid, a plot point on the plane of consistency. The cyborg is connected to the cosmos, no more or less so than all bodies, but perhaps is a reminder of that flow and its possibilities. [20, pp. 191–2]

I quote this example to introduce the idea of connectives in the context of so-called disabled bodies and medical devices. The term “cyborg” is taken from Donna Haraway [27] and is not used to invoke negative connotations regarding disabled people but rather to re-imagine all bodies. Her point is that we are all cyborgs – what Deleuze and Guattari [28] might call assemblages. All bodies, whether categorized as disabled or non-disabled, can be said to “leak” into other bodies, machines and objects such that the where the body begins and ends is open-ended and changing. As Shildrick and Price [29] note, this indeterminacy signals the vulnerabilities of all connected bodies. Rather than threatening bodily integrity, the figure of the unstable cyborg-subject addresses oppression and domination by dispensing with identities that inhere in so-called natural distinctions such as sex, race and, for my purposes here, dis/ability [30].

Similar to the image of the cyborg, the BwO suggests fluid identities, continual *becomings* rather than fixed subjects encased in skin [25]. The body resists closure and leaks into heterogenous human and non-human elements. These concepts challenge

prevailing discourses of disability and independence. They trouble, break, and complicate the binaries of dependence/independence, disability/ability, subject/object and self/other. The “ventilator-user” is also a “wheelchair-user” who also relies on a number of other technologies to achieve daily tasks from toothbrushes to public transit. “User”, a relatively common way of describing the relation of disabled people to their devices, is also revealed as inaccurate because it puts the body/subject at the centre of the assemblage as if s/he is somehow whole and contained, with the other inert bits added on or “used”. Assemblages instead have no centre, the subject is never stable, but it is the production that is being constantly made and unmade; the mutually shaping parts vary over time and space and can include other humans, things, or places. Assemblages that include disabled people perhaps provide compelling examples of these connections, but are examples only. Recognizing assemblages, extraordinary or mundane, helps to problematize independence and recognize multiple dependencies in all our lives. In so doing it signals a revised body ethics that resists characterizing dependence as a moral failure.

Dances of flesh and machine

Connectivities are further exemplified in the work of Hugh Herr, Director of the Biomechatronics Group at The Massachusetts Institute of Technology and a double amputee. Herr has several sets of artificial legs that achieve different purposes. His legs are the antithesis of universal design, and rather speak to the hybridity of the person, of the fragmented body-subject, whose elements are dispersed across space. Herr argues that his replaceable legs are superior to biological legs because they provide enhanced function, thus not “just as good” as fleshy legs but better. He described this relationship as follows:

I was able to climb at a more advanced level after my accident with my artificial limbs that I was ever able to achieve before my accident with normal biological limbs. To achieve this level of success I had to view my own body in distinct way from how society was viewing my body...I viewed my artificial limbs not as curse but as an opportunity...They are part of my identity...and because the artificial part of my body is upgradeable it’s immortal...(They are) intimate inorganic extensions of (my) body. When I walk there’s an exchange of energy, there’s an exchange of force between my biological self and my artificial self...A collaborative seamless dance between flesh and machine. [31]

Herr discusses multiple selves, his “biological self” and his “artificial self” but within the context of a singular identity. Deleuze and Guattari discuss the BwO as a “singular multiplicity” to capture the paradox of subjectivity as at once univocal and multiple, partial and transitory [25, p. 160]. This suggests an opening up of how bodies and subjects are understood, and an exploration of the limits of prevailing discourses about the nature of persons. They describe beings as both dispersed amongst heterogeneous elements (different legs, batteries, bodies) and retaining a singular, though malleable, form. Similarly, Shildrick [1] has emphasized that recognition of hybrid subjectivities does not suggest an abandonment of individuality:

A responsible ethic must be sensitive to need to be with others in a variety of different ways that do not erase the specificity on either side...(T)he task for all of us, however we are embodied, is to develop a mode of intercorporeality without a complete dissolution of personal identity. [1, p. 118]

We can perhaps think of what Herr referred to as his pre-amputation “normal biological legs” as examples of universal design. They are multi-purpose, “go anywhere” legs. This of course relies on a built environment that is designed for these kinds of legs. Universal design in most cases focuses on either building prostheses that approximate typical legs, or adapting environments to fit a standardized conception of typical legs. What Herr’s work and that of others do, however, it shows how particularity complicates the appeal of universalism [4,22]. Specificity and interchangeability of Herr’s legs form various networks of elements that can enhance ability through capitalizing on different kinds of dependency. In short, his dependencies create advantage beyond the usual limits of accessibility and the body normal. Moreover subjectivity is decentred and malleable – some of him is at home in the closet, some is climbing a mountain. He is dispersed, dependent and ever-changing – like all persons who move in and out of various connectivities and dependencies to achieve practices.

Doing hockey

A final example comes from our research with young people who have physical impairments that are commonly labeled as “severe” [32,33]. The research explored place-based mediators of activity participation with 20 youth ages 14 to 23 years with multiple communication and/or mobility impairments. Participants were provided with adapted cameras to photograph two home or community-based activities which were then discussed in individual qualitative interviews. In the study we explored how disabled youth, their carers, assistive technologies and places could be viewed as assemblages that enable action, as an alternate way to imagine rehabilitation practice. This line of analysis was inspired by Winance’s [21] work drawing on actor network theory to show how people and assistive devices are mutually shaping. Through particular kinds of action with and through devices and other bodies, she demonstrates how persons are made, transformed, and shaped through their relationships to other human and non-human entities, which are also transformed in the doing. Describing a “process of adjustment” to wheelchair use, Winance demonstrates how actions are made possible that may be enabling or disabling to the various actors in the networks.

In our research with disabled youth, we identified networks of people, places, and technologies that enabled specific activities. These assemblages usually included another person in addition to the youth. Thirteen (of 20) participants were unable to produce speech, communicating through some combination of gestures, communication device, and/or human communication partners. Partners were often pivotal to helping the youth convey ideas with the least amount of energy expenditure. These communication networks could be enabling and constraining in different ways, in different circumstances and for different actors.

An example is provided by Andrew and his friend Charlie engaged in playing a hockey-based video game. Andrew was not able to produce independent speech or operate the game controller with his hands. To achieve action in the game, Charlie placed the controller on Andrew’s forehead and responded to movements transmitted through Andrew’s head and other bodily gestures. The research assistant recorded the following observational note:

Andrew responded with constant head movement to control the joystick of the controller which Charlie held against Andrew’s forehead, and with lots of vocalizations that seemed to imply things like groaning over a missed shot, excited outbursts, and lots of laughing.

“Doing hockey” was thus achieved through a unique assemblage of heterogeneous elements: a place that allowed Andrew and Charlie to position themselves, the creative use of the controller, and the bodily improvisations between the two. The place included the accessible room and the wheelchair which positioned Andrew for play, the chair that Charlie used, and the human dimensions of the space which include Mom who, although not directly participating, enabled the activity by attending to Andrew’s bodily needs as required.

Of note, this assemblage is temporary, creative, and specific to these actors, these bodies, this activity. Other activities come out of different assemblages of people, places, and technologies. This particular experience was positive (Andrew later commented: “What boy doesn’t like to play hockey!”). Nevertheless other assemblages might be less successful. Most have multiple effects. The research assistant made these additional notes:

The connection and synchronicity between these two youth were truly palpable as they “merged” their bodies and their movements in such atypical ways to aim their player and the puck toward a goal. They didn’t seem at all self-conscious and scoring a goal seemed to be all they had on their minds.

Action is created through a number of creative, specific and temporary connections that together achieve particular practices and have particular effects. Andrew does not play the game like this with anyone but Charlie, not because someone else could not be taught how to do it. Rather hockey is *their* activity, their opportunity to have fun together as friends. They merge for this activity, in this place, with these technologies and then break apart and form other assemblages with other human and non-human elements to achieve other actions.

Relational mobilities

These examples point to the limitations of Western enlightenment notions of independence, autonomy and the universal subject, which rely on unitary, fixed and contained subjects. Considering the multiple interconnections between bodies, technologies, and people across different places and spaces, and how these are in a constant state of flux, creates new opportunities for enabling practices in both design and rehabilitation. Reimagining the ontology of the body-subject creates opportunities for new contingent bodily forms and new ways of doing-in-the-world that do not rely on existing mobilities or pre-conceived uses of technologies and spaces. It supports a re-imagining of design and practices, and new, particularized, and creative modes of action. Without this openness to exploring diverse ways of doing and being, as Lid [22] has noted, “UD risks being nothing more than a new and perhaps slightly more inclusive minimum standard for inclusion” [22, p. 213].

Assemblages themselves are vulnerable to discursive interpretations and moral judgments depending on how they affirm or negate normative ways of being and doing. Disabled people mobilize in a variety of ways that may be valorized or discouraged according to these parameters. Unusual modes of mobility can evoke different reactions as illustrated by two contrasting examples as follows. Bill Shannon has devised an innovative mode of mobility that uses a skateboard and specialized “crutches” that he designed [34]. The skateboard symbolizes a kind of counterculture that juxtaposes with often negatively marked assistive devices such as medical crutches, wheelchairs, or walkers. Shannon’s moves through space are fluid and elegant; he is speedy, he is attractive, his impairments are largely invisible. He has achieved celebrity status.

Lina's mobility perhaps provides a contrast. Lina (pseudonym) was a 12-year-old girl with cerebral palsy who participated in a study exploring the mobility values and practices of disabled children and their parents [35]. She used a variety of methods for mobilizing depending on a number of factors including energy expenditure, the activity and the environment. Her repertoire included crawling:

Lina: In peoples' houses I crawl... then I don't have to bring my walker or my canes. And it's kind of faster if I'm around big obstacles and small obstacles at the same time.

Lina's crawling provides perhaps an even more radical example than Bill Shannon's skateboard, because it may be unsettling, and powerfully illuminates the social value assigned to different mobilities. Bill Shannon's creative use of a skateboard might be considered "cool", "progressive", or "enhancing" (like Herr's multiple legs), but Lina's crawling is more likely to evoke negative reactions. Nevertheless both raise questions about the design of technologies and places, and assumptions about what kinds of bodies, movements, and devices are taken for granted in putatively "universal" design. Should spaces be designed for crawlers? Certainly rehabilitation does not traditionally focus on supporting crawling ability (or for that matter innovative uses of skateboards). Indeed as Lina ages, she is more likely to be actively discouraged from engaging in what is considered a "developmentally inappropriate" activity. Similarity in regards to UD, Hamraie [36] has suggested that design "fits or misfits" are produced through material-discursive practices that shape what kinds of bodies appear to be possible and likely to live in the world. Because design is a value-based activity, she notes that not all bodily differences will necessarily be counted as part of the universal. Bill and Lina's creative mobilities help to illuminate this tension.

The negative coding of some bodies and movements thus limits possibilities for action and the making and breaking of creative assemblages across spaces. Universal design and rehabilitation both risk reproducing particular forms of bodies and mobilities while striving to promote diversity and inclusion. Intervention whether through rehabilitation or design, could however provide key sights for resistance to normalization. For example, to counter the assumptions that disabled people want or should want to be "normal" or "independent", Swain and French [37] have proposed an "affirmation model of disability". The model promotes a positive identity of impairment (not just disability) that actively repudiates discourses of normality. These ideas echo the notions of respect for and celebration of diverse bodily forms that trouble the idea of the universal.

Conclusion

In this paper I have drawn on a number of examples to problematize the notion of static independent subjects encased in individuated fleshy bodies. By exploring the radical notions of connectivity achieved through multiple and shifting assemblages of heterogeneous elements, my goal has been to open up possibilities for an expanded ethics of the body that can inform rehabilitation and design. UD and rehabilitation risk perpetuating particular ideas about disabled people, what they should be, do, and value, that closely aligns with western notions of normative bodies and independence. In exploring the potential of enhancing creative connectivities and multiple dependencies, space opens up for reconsidering disability, mobility and multiple ways of doing in the world.

A shift towards enabling creative dependencies exposes the unavoidably value-laden and political nature of rehabilitation and

design practices. Hamraie [36] has suggested that the lack of access to physical environments is often due to the stigmatization of dependencies in liberal democratic societies, whereby non-normative bodies and subjectivities are characterized as problems to overcome or eliminate. The refusal to acknowledge dependencies, she states, ignores the interdependence of all bodies for sustenance, community and care. As I have argued in this paper, UD risks limiting possibilities for new ways of doing and being depending on what kinds of bodies are included within the scope of the "universal". A focus on the general over the particular risks producing its own parameters of inclusion and exclusion. Hamraie notes that: "When the content of the universal is unspecified, UD can slip into vague notions of "all" or "everyone" that assume normate users and de-center disability" [36, p. 12]. The task then for both the fields of design and rehabilitation is an acknowledgment and deep reflexivity of the values and assumptions that underpin practices. Continually questioning Universalist values about the kinds of bodies and subjectivities that are valorized, helps expand creative possibilities and flexible practices.

Again I want to be clear that my purpose is not to dismiss universal design or condemn rehabilitation practices both of which have made significant strides in improving the lives of disabled people. Rather the point is to broaden the course, illuminate conceptual commitments and consider creative directions for exploration. In the words of Ferguson "In our society dominant discourse tries never to speak its own name. Its authority is based on absence" [6, p. 288]. Discourses of disability, independence and autonomy underpin practices intended to help disabled people. Ongoing dialogue helps to uncover their multiple effects and ask if and how things could be (done) otherwise.

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