Assembling activity/setting participation with disabled young people

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Abstract   Rehabilitation research investigating activity participation has been largely conducted in a realist tradition that under-theorises the relationship between persons, technologies, and socio-material places. In this Canadian study we used a post-critical approach to explore activity/setting participation with 19 young people aged 14 to 23 years with complex communication and/or mobility impairments. Methods included integrated photo-elicitation, interviews, and participant observations of community-based activities. We present our results using the conceptual lens of assemblages to surface how different combinations of bodies, social meanings, and technologies enabled or constrained particular activities. Assemblages were analysed in terms of how they organised what was possible and practical for participants and their families in different contexts. The results illuminate how young people negotiated activity needs and desires in particular 'spacings' each with its own material, temporal, and social constraints and affordances. The focus on assemblages provides a dynamic analysis of how dis/abilities are enacted in and across geotemporal spaces, and avoids a reductive focus on evaluating the accessibility of static environmental features. In doing so the study reveals possible 'lines of flight' for healthcare, rehabilitation, and social care practices.

Rehabilitation research on the activity[1] participation of disabled young people[2] has been largely conducted in a realist tradition that under-theorises the relationship between persons, technologies, and the socio-material places in which they are immersed. While critical work investigating how places mediate the activity experiences of disabled young people has been conducted within the social sciences and humanities, little of this work has engaged rehabilitation practitioners or been explicitly oriented to transforming rehabilitation practices. Moreover the research to-date has largely excluded those with 'complex conditions' who rely on varied

forms of technological and human assistance in their everyday lives, and who may face particularly discriminating social and material barriers in the places in which they live, play, and learn. Understanding these experiences has implications for transforming rehabilitation and other professional services and creating life opportunities for young people.

A growing corpus of rehabilitation research outlines the importance of activity participation for disabled young people (Imms 2008, Kinney and Coyle 1992, King *et al.* 2010, 2013, Livesey 2010, Palisano *et al.* 2009, Poulsen *et al.* 2004). This work suggests that in comparison to non-disabled peers, disabled youth engage in less diverse leisure activities, more 'passive' recreational activities (such as watching television) and fewer social activities. The conclusion reiterated across these studies is that disabled young people are at high risk for social isolation and lack of satisfying engagement in leisure, which negatively affects their self-esteem, identity, and sense of belonging (King *et al.* 2005, 2006, Stewart *et al.* 2006).

The knowledge gained from the extant research has informed rehabilitation practices but it is limited in two important ways. First there has been very little research on the experiences of youth with complex continuing care needs and/or little or no functional speech (for some exceptions, see Batorowicz *et al.* 2014, Rabiee *et al.* 2005, Wickenden 2011) who are typically excluded from research due to communication challenges and erroneous assumptions about their competencies (Christensen *et al.* 2000). Second the rehabilitation literature is dominated by biomedical/individualist framings of what constitutes a 'good' or more meaningful life for young disabled people. For example, deviations from normal developmental trajectories (Burman 2013, Walkerdine 1993) and/or the attainment of functional and psychological independence are taken for granted as problems which are reproduced in study questions and embedded in standardised outcome measures (Gibson 2016).

Other fields of postmodern and critical inquiry, including disability studies and science and technology studies, have a long tradition of reframing dis/abilities and tracing how they emerge within everyday relations (Galis 2011, Winance 2016) but little of this work has translated to the rehabilitation sciences. In this study we sought to develop a better understanding of the interacting socio-material and personal forces that shape activity participation with no prior assumptions about the benefits of particular activities or the different forms they take. Our task was to engage a team of rehabilitation researchers and clinicians to empirically interrogate how activity was done and talked about by young people who are traditionally thought to be at risk for diminished activity participation, and in so doing contribute to reimagining rehabilitation research and practice

A post-critical approach

A post-critical approach and key ideas from human geography were employed to explore activity/setting experiences with disabled youth. Post-critical approaches reflect elements of both critical theory and postmodern scholarship through analysis of the relationship between power and knowledge and the effects of classificatory hierarchies on social life (Agger 1991, Gibson 2016, Kincheloe *et al.* 2011). This relational lens was employed to examine dis/ability as produced through the intersectionality of bodies, social meanings, and technologies in particular settings. Drawing on human geography, we took the view that activity in any setting is mediated by the material structure of the space and the people and objects within it, as well as the normative social cues of what types of behaviours and practices are usual and/or acceptable (Freund 2001, Cummins *et al.* 2007).

The forward slash we use in 'activity/setting' is meant to convey the co-constituting relationship between the two. Settings are particular places that are shaped by people within them

and the activities undertaken and thus are more than static containers but 'spacings' that are always in the process of change and becoming (Horton and Kraftl 2006). Similarly, activities are always accomplished with and through material things – the technologies that can range from mundane objects to sophisticated machines – that are taken up in creative ways that morph from situation to situation (Gibson 2014, Horton and Kraftl 2006, Timmermans and Berg 2003). This relationship between bodies, spacings and material technologies is contingent, particular, and always in flux, shifting in the everyday 'doing' of activity. Activities, or more generally human action, play out in multiple unanticipated ways through various sets of relations between embodied subjects, objects, places, and shared meanings. In the study we were particularly oriented to interrogating the co-constituting relationships between activities and settings that could be enabling and/or disabling in different ways.

Working with this framing, we examined the shifting interconnections between persons, technologies and places in terms of assemblages. Assemblage is Deleuze and Guattari's (1987) term that captures the constantly shifting connectivities between heterogeneous elements, including but not limited to bodies, social meanings, places and technologies. Each element constitutes its own continually shifting assemblage of parts. Bodies, for example, change over time – they shed cells, age, ingest and excrete food/water/gases/microorganisms; organs soften/harden and are removed or replaced, incorporating a range of internal and external technologies – clothing, heart valves, mobile phones, prosthetic hips, wheelchairs, ventilators, bicycles (Gibson 2006, Shildrick 2015). Where the body (and/or person) begins and ends is thus less obvious than it might appear. As we explore below, the profoundly connected nature of everyday life revealed in assemblage analysis troubles dominant notions of the independent subject that continue to pervade health and rehabilitation practices despite a shift towards ideas of 'interdependence'.

All parts of an assemblage are composed of other assemblages each of which is never static but continually morphing and connecting in other ways. Deleuze and Guattari (1987:161) refer to assemblages as 'machines' that can be 'plugged in' to other machines to achieve 'intensities'. The machine is a collection of desires, objects, affects and forces that do things in the world. Assemblages are thus neither stable or closed systems, but rather temporary entanglements that continually come together and then break apart, forming different machines with other elements that can produce different effects. Things and settings 'act-back' to constitute body-subjects differently in different moments. For the study, we were interested in the shifting assemblages formed amongst different bodies and technologies through different spacings, and how these connections mediated disabled young people's activity/setting experiences.

Post-critical approaches to conceptualising the relationship between bodies, technologies, spacings, and dis/abilities have emerged in the last two decades at the point of intersection between science and technology studies, disability studies, and the sociology of health (e.g. Blume *et al*. 2014, Galis 2011, Goodley and Runswick-Cole 2016, Lupton and Seymour 2000, Mauldin 2012, Moser 2006, Moser and Law 1999, Shildrick 2010, Sulik 2009, Winance 2006). Collectively this work decentres the autonomous subject of the Western neoliberal imaginary by analysing the interactions between human and non-human entities without privileging one over the other. In so doing a space is created for interrogating how people's abilities and inabilities are produced and how different forms of subjects are enacted through various configurations of elements.

We see tremendous potential for this work to inform rehabilitation practice and research. While rehabilitation has been slow to shift away from biomedical conceptions of disability, there is a growing engagement with post-critical approaches (Abrams and Gibson 2016, Gibson 2016, Edwards *et al*. 2014, Fadyl *et al*. 2015, Hanisch 2013, Johansson *et al*. 2010, Nicholls 2012). This study contributes to building a reconceived 'ethic of openness' (Gibson

2016, Shildrick 2005) that informs the identification of opportunities for changes in rehabilitation practices through a fine grained analysis of socio-technical interactions.[3]

Study context

The results outlined in this paper were part of a large multi-team rehabilitation project that developed methods and measures for studying activity/setting participation of two groups of young people with physical impairments: (i) those designated as needing 'complex continuing care' (CCC) due to multiple impairments and/or long-term ventilation, and (ii) those with little/no functional speech who relied on augmentative and alternative systems to communicate (AAC) (King *et al*. 2014a, King *et al*. 2014b, Gibson *et al*. 2014). We were interested in youths' experiences of both home activity/settings (e.g. residential homes, long-term care facilities), and community activity/settings (e.g. informal or formal recreational activities and programs). Participants were recruited from four children's rehabilitation centres in the southern region of Ontario, Canada. Research ethics approval was obtained from participating centres. A total of 19 young people aged 14 to 23 years (12 AAC and 7 CCC) and their families participated. Participant details are listed in Table 1. All names are pseudonyms.

Design and Methods

The qualitative methods focused on in-depth explorations that could illuminate particular activity/setting experiences as well as explore the broader socio-material mediators of activity with

Table 1 *Participant Details (N = 19)*

Pseudonym	Age (years)	Gender	AAC/CCC[1]
Mimi	14	F	CCC
Eric	16	M	AAC
Isma	16	F	CCC
Brenda	17	F	CCC
Kendra	17	F	AAC
Kara	17	F	AAC
Juno	17	F	CCC
Ashley	17	F	CCC
Jack	17	M	AAC
Andrew	18	M	AAC
Jessica	18	F	AAC
Nicola	18	F	AAC
Brian	19	M	AAC
Candice	20	F	AAC
Faith	20	F	AAC
Jana	20	F	AAC
Akash	20	M	CCC
Jamie	22	M	AAC
Hannah	23	F	CCC

[1]AAC = young person who uses augmentative and alternative communication systems and/or devices; CCC= young person designated as requiring 'complex continuing care'.

the participants. These methods included photo-elicitation, observations, electronic interviews and face-to-face semi-structured interviews. In Phase 1 we developed and refined the methods with eight participants. This initial work helped us to determine how best to integrate the different arms of the larger study (see Gibson *et al*. 2014 for details), and develop feasible and effective methods for engaging participants, particularly those with limited or no speech. Phase 2 engaged an additional 12 participants (one young man, 'Andrew' was included in both phases and also served as an advisor to the study). The primary differences between the two phases were the additions in Phase 2 of participant observation during the activities, and optional electronic questions to supplement the interviews as described below.

Data generation

In both phases, each participant met with two research assistants (RAs) on multiple occasions. One of these RAs was an experienced qualitative researcher (the other was engaged in collecting quantitative data). Of the seven RAs who participated across the two phases of the study, five were rehabilitation clinicians (occupational therapists). The first meeting in the participant's home was oriented to getting to know participants' daily activities, and their communication methods and preferences. At this meeting participants chose two activities for the study and learned how to use the camera to photograph their experiences. In Phase 1, participants engaged in the activity and took photographs on their own. In Phase 2, the RA acted as a participant-observer, engaging the young person in discussions about the activity and recording detailed observations (Carpiano 2009). The nature of these interactions varied depending on the activity.

Face to face interviews were conducted with each participant once both activities had been completed. Data generated prior to the interviews guided the discussions. In Phase 2 we also emailed questions to all participants after each activity and asked them to return their responses prior to the interview. We learned in Phase 1 that participants who used an AAC device often found the interviews fatiguing because of the time and effort required to construct responses. With the e-questions they were able to answer at their own pace and type longer responses either on their own or with assistance (Teachman *et al*. 2014). The RAs conducting the interviews were highly trained researchers/clinicians who had experience with interviewing disabled young people including those with limited abilities to produce speech. Participants were encouraged to communicate using their preferred methods which in eight cases included a communication partner.

Analysis

Consistent with the conceptual underpinnings of the study, we approached the research as a co-creation wherein study information was shaped not only by the perspectives and interactions between participants and researchers but through the wider social, political, material and cultural contexts within which the study was embedded. Analysis was thus understood as a mixing of the interpretive acts of all involved, each of whom drew on their particular histories, social locations, and their interpretations of the research purposes to make sense of experience. This co-creation was evident across the study in, for example, participants' presentation of self in talk and pictures; the RAs' in-the-moment choices of what to ask, where to look, and how to interpret what they were observing/hearing; and the research team's efforts to construct a coherent narrative from the data. Analysis was thus viewed as an ongoing and entangled process that brought together overlapping elements to shape the narrative 'results'.

We emphasise the interpretive co-creation of the research for two reasons. First we want to be clear that, while we were interested in 'giving voice' to young disabled people whose perspectives have been mostly excluded from research, we recognise that perspectives are always

multiple and embedded in particular contexts, connections, and interpretive logics. Thus re/presenting participant voices requires more than reporting their talk and images, but an examination of the multiplicities inherent in all 'individual' perspectives. Second, co-creation cannot be neatly separated into processes of data generation and analysis. We approached analysis as a sense-making act of researchers and participants that shapes how data is collected, presented, reduced, and understood in an ongoing iterative and messy process throughout the course of any study. So while the research team engaged with analytic techniques, these were only part (although a vital part) of the assemblages of knowledge-producing acts that constitute the resultant narrative.

The team used several techniques to makes sense of and organise the data into the narrative presented here. These included multiple readings of the data, iterative coding and memoing cycles, comparative memos, concept mapping and monthly analysis meetings of the large team that included clinicians, students and researchers from diverse fields of disability studies, social psychology, occupational therapy, physiotherapy, and geography (Dierckx de Casterlé 2012). All data (observation notes, photos/video, electronic and face to face interviews) were analysed throughout the study to inform subsequent data generation. Interim reports were also discussed with diverse audiences of disabled people and families, clinicians, managers and researchers through meetings and rounds, which informed subsequent interpretations. These rich and diverse approaches helped to identify recurring relationships in the data towards understanding young people's activity/setting experiences and the implications for practice.

Activity/setting assemblages

In what follows we describe the assemblages of bodies, social meanings, technologies, and places identified in the data, how they functioned to achieve practices that could be both enabling and constraining, and the work participants undertook with others to establish a 'good fit' between elements that supported positive activity experiences. Goodness of fit is understood not as a static or all or nothing state of affairs, but a temporary connection that works to enhance a capacity to act in one moment but may be abandoned in the next (Gibson *et al*. 2012, Ruddick 2012). Affective elements – which can be described as 'unformed intensities' transmitted between bodies (Shouse 2005) – were implicated in connectivities which may or may not have been experienced as successful or pleasurable. Through this exploration we critically reflect upon the presumed benefits of activity and participation that undergird dominant rehabilitation discourses towards a more nuanced analysis of their multiple effects.

In the accounts, activities emerged from particular arrangements of replaceable parts, assembled from available human and non-human elements to achieve action. Participants relied on multiple medical technologies (whether they were life sustaining technologies like ventilators, or assistive devices like wheelchairs) and paid and unpaid caregivers to maintain health and assist with personal care. Those with communication differences used an array of methods to make themselves understood including verbal utterances, gestures and technologies that ranged from simple analogue communication boards to sophisticated speech-generating technologies. Many of these methods also involved another person ('communication partners') to interpret and convey meaning to others. Bodies-technologies formed assemblages that were 'spaced' across different settings each with its own configurations of elements, affordances, and expected practices. These entanglements emerged in the practices of 'doing-activity', such as doing-watching TV, or doing-card play with various degrees of success. In what follows, we explore specific exemplars of the activity/setting assemblages and participants' movements

amongst these in terms of: (i) the shifting nature of communication; (ii) home and other activity spacings; and (iii) assemblic 'breaks'.

Shifting assemblages: communicating machines

The shifting nature of assemblages was evident in the different configurations that enabled communication across social spaces. As noted, communication assemblages could include AAC devices and/or other persons (body-subjects) who interpreted the young person's utterances and bodily movements. A body that communicated in a way that was only intelligible to a select few others coupled with another who held the translation 'code' for rendering the signs intelligible. In this assemblage, multiple elements come together to make communication possible: the code is part of the assemblage, as are the receivers of the translation and their interpretations of spoken language. Together this temporary communication-machine functions in specific ways with varying degrees of success across placings. In the following exchange, Brian's mother suggests that she and Brian form a more effective communication assemblage than Brian-Dad:

> Brian's Mum: Does Dad understand everything? Does he understand as much as what Mummy understands? No?
> Brian: [affirmative utterance] [All Laugh]
> Brian's Mum: This is true, 'cause (Dad) says 'I don't know what he wants'. Remember when he said that? And I just keep bugging you until I figure it out.

A communication assemblage functioned as a coherent but temporary whole with a limited array of replaceable human and non-human parts. The connection formed presents as a kind of other-worldly achievement of a bonded togetherness, a good fit that enables action, as further reflected in Jamie and his father's allusions to telepathy:

> Jamie's Dad: I read your thoughts. Yeah, you knew I did. [Laughs] Yeah, I do that a lot.
> Jamie: [affirmative utterance and body language]

'Reading Jamie's thoughts' is a collective practice that forms a single communicative machine. It involves the shared work of conveying/interpreting bodily gestures, utterances, and expressive tonality. This human-human body work is honed over time, it is a temporary coming together of elements that is returned to repeatedly. The effect is a singular communication that is achieved through the exchange of two (or more) speakers, each of which is imbricated in multiple other assemblages simultaneously. These movements within, between and towards are in a constant state of connected flux that is always becoming-other. For example, in the interview with Jamie and his father, the RA was part of the assemblage as were other elements of the home spacing where the interview occurred. The tape recorder is implicated, as are the questions and assumptions regarding why they are all there, what the research is for, and how it will be consumed. So they are all 'doing communication' and 'doing research', and in the next moment will be 'on to' other things through new connections. Assemblages are thus in motion and not easily reducible to their component parts which are always already composed of and connected with other elements. As we further discuss below, these flows and movements have implications for how disability is addressed in professional rehabilitation and other health and social care practices.

Activity/spacings

Across the accounts, participants' home spacings were most likely to enable positive activity experiences. As noted, 'spacings' is a term meant to acknowledge that spaces, places, or

settings are more than static and closed physical containers, but a set of shifting relations of people, objects, expectations, discourse, and power which are always dynamic, multiple, open, and becoming (Horton and Kraftl 2006). Participants' home spacings were re/configured to enable the doings of activities through semi-permanent physical changes (for example, to facilitate wheelchair movement), but also the human orderings of 'who is where and when' to enable domestic doings for parents and children that included work, play, and care activities. Bodies were enabled to 'fit' with each other and across the spacing of home in that they could move, act, and interact according to a working rhythm that differed substantially from spacings outside the home. With all the participants, we saw home spacings in which particular activity assemblages emerged. Jessica, for example, discussed activities that crossed two home spacings: a city house and a summer family cottage.

Jessica was an 18 year old who lived with her parents, younger sister, grandmother, a paid caregiver, and the family dog. Her activities were described by her and her mother in terms of the human connections that enabled each, for example, some activities were a 'Dad thing' or a 'Grandma activity'. Movements amongst these discreet assemblages achieved particular 'Jessica' activities. For example:

> Grandma-Jessica-dining room-computer = playing cards
> Mum-Jessica-parents' bedroom-desk-computer-whiteboard = homework
> Dad-Jessica-basement-TV/console-others = video games
> Dad-Jessica-Mum-cottage-kite/boat/jet ski = summer fun

Describing an assemblage is always risky because there is no clear boundary of what is 'in' or 'out', where to focus, how to categorise the 'elements', or capture the dynamism. In the above examples, for instance, we have left out Jessica's wheelchair and how it was tethered on the boat (which involved a lot of trial and error and eventually a new boat), and the chair in which Grandma sat to play cards. Affective and discursive elements were also at play including physical pain and pleasure, the rules of the card game, the joy of winning, the time allotted for play, etc. Description thus serves only as a placeholder for a wider set of dynamic and open relations that are not easily captured by static representations. Nevertheless they help illuminate the multiplicity of entangled becomings that constitute 'Jessica' and her activity/settings that can be further explored.

Attention to the seemingly nondescript 'everydayness' of activity/settings provides a way of understanding the specific emplaced relations and doings of young people and how they may be enabling or disabling (Horton and Kraftl 2006). One of Jessica's chosen activities for the study involved playing a video game with her family in the basement of their home. In the game, Dad and Jessica are partnered together against an opponent and Jessica explained that this was not a partnership of equals. She described herself as 'the player' and Dad as the operator of the game controller who enabled her to play. Jessica's description of the activity demonstrates how control of the game was negotiated in a give and take between actors.

Jessica: My dad and I made choices, sometimes I chose and sometimes he did. But we both had to agree . . . It is very important that my partner listens to me, or I am not really playing.

'Really playing' for Jessica did not mean she physically controlled the game console but was actively engaged. The Dad-Jessica-game controller assemblage required affective and physical work, acts of translation, manipulation, and cooperation that were negotiated in situ as part of the larger game-playing assemblage of human and nonhuman actors and placings. The goodness of fit of these elements enabled Jessica to 'really play' video games. This was a positive

experience but also demonstrates the mental and physical work necessary from the various actors to 'really play' using the tools at hand. This continuous tinkering (Winance 2010) has multiple effects on the human actors enmeshed in the work.

Jessica's multiple activity assemblages suggest that home-spacings were not necessarily confined to a particular dwelling. The family home enabled the 'doing of family' but family was active and mobile, created across time-spaces through shifting socio-material relations. The family 'unit' had porous borders of bodies, technologies and spacings whose pieces may have been geographically dispersed without losing a (fuzzy) coherence. In any family, new bodies are added or subtracted (with birth, death, marriage, divorce, pets, etc.) and are entangled with the everyday technologies that mediate how 'family' is enacted. Brian's Mum described how the 'right van' enabled this kind of doing-family through all the ways that Brian-body-wheel-chair connected with the elements of the van, the passing scenery, and other family members.

> Interviewer: What's special about the van?
> Brian's Mum: (I)t's larger for Brian to go in, and he can look out all the windows and see everything that's around him ... But the biggest thing for Brian is that he's able to sit up, be comfortable ... he has a big picture of what's outside ... enjoy the scenery and stuff where he probably couldn't have done that before. It's quiet and he's not in the back, he's part of the family.

The family-van example reveals the interactive and dynamic relations between bodies and technologies implicated in doing-family. When mum notes that Brian is 'not in the back', she references a previous configuration that did not work. Family is made and unmade through technologies, placings, and people. While Brian may always be counted as a family member, he was not 'part of' the family in the van unless the assemblage was organised in a particular way. Assemblages thus have effects; they afford opportunities and impose constraints. The van does not simply facilitate transportation; it may or may not enable the family assemblage to re-form outside of home spacings.

Outside of the home, activities were almost always described as more challenging, limiting opportunities and the kinds of connections that were possible or practical. Participants described the limited availability of other individuals who had the knowledge and skills to help with medical needs, personal care, and communication. For example, AAC-users needed time to communicate that often did not fit with the temporalities of the spacings they encountered. Thus bodies, technologies, information, and temporal expectations interacted in different ways to enact communication in particular social spacings. How action was achieved was not predetermined but involved creative processes and adjustments from moment to moment. This hard work was precarious and unsuccessful at times, or deemed to be 'not worth the effort' but also afforded opportunities to make new connections outside of the home that participants linked to 'freedom'.

Freedom in the accounts was most often associated with novel physical and affective sensations, connecting with people outside of the family, and activities outside of daily routines. Andrew and Akash both spoke about freedom in relation to the activities they chose for the study which included riding an all-terrain vehicle (Andrew) and visiting a local park (Akash):

> Interviewer: Can you tell me a little bit more about what that means to you, freedom? [long pause as Andrew types] Can I read?
> Andrew [read aloud by interviewer]: Being away from the house for once, and playing with friends.

Andrew had photographed an activity where he, a friend, and his uncle went off-track driving in an all-terrain vehicle (ATV). Andrew was strapped into the passenger seat of the ATV

using a jerry-rigged method that included a considerable use of duct tape to hold him in place. He discussed the physical pleasure and exhilaration he experienced while riding, and as his mother noted, he was able to 'get dirty and rough and tumble and laugh . . . and do whatever he want(ed) to'. Andrew enjoyed these somewhat rare breaks from the usual constellation of activities and connections that characterised his life. His speech and other physical limitations meant that he spent much time on his computer which enabled communication, socialisation, entertainment, homework and other activities, but was also physically laborious.

Andrew's example demonstrates how assemblages of bodies and technologies can simultaneously enhance capacities and restrict them. 'Andrew-computer' could be said to be a dominant form of Andrew. It enabled a multitude of activities, but Andrew stated that he yearned for time away from the computer. His desire to experience new sensations was enabled through the breaking and making of different connections. Andrew-mum was also a recurring connection, wherein multiple activities of daily life were achieved with and through mum. For Andrew the freedom of the ATV was a 'freedom from' and a 'freedom to'. A freedom from the computer, from mum, and freedom to experience speed, dirt, physical pleasure and (male) camaraderie. The ATV assemblage also freed mum to make other connections, to take a break (by making a break) from the particular doings that surround Andrew, and instead to connect differently. Thus assemblages do things. They offer affective and material freedoms and constraints. Mum is freed to make other connections by disrupting Andrew-mum. We return to the notion of breaking assemblages below.

Akash also discussed 'freedom from' and 'freedom to' in regards to various activity/settings. Akash was 20 years old and had muscular dystrophy. He discussed how his wheelchair both enabled him to pursue activities like visiting his local park, while lamenting the number of safety precautions he was subjected to across spacings. With regard to the park, he noted:

> I like the freedom, I just like going there and being free to . . . you know, I just turn my phone off and I sit there . . . I can just forget everything and everyone that is bothering me. Also I love to be free of rules.

While Akash-wheelchair-park enabled a freedom from others – an assemblage that enabled solitude – the wheelchair was implicated in restrictive safety regimes that constrained freedom. Akash related a story, similar to Andrew's, of enjoying a ride in the trailer of an ATV, but complained that his Dad 'made him' wear a safety strap both during the ride and in other contexts. For Akash, these kinds of safety precautions restricted his capacities to experience freedom and pleasure that he saw his peers enjoying:

> Akash: My whole life, I've been wearing this thing. [lifts up his seatbelt] I dunno, I'm not that kind of person. I'm the kind of person that would take risks. I don't want to just live my life as a boring person – seeing everyone do awesome stuff and me doing nothing, that's stupid. But (the ATV ride) felt so good, even though I was sitting on the wheelchair with a seatbelt on. I felt like 'oh my God' 'cause they were letting me go free. That was awesome.

Mobility devices coupled with the built environment afforded not just physical access to activity/settings, but were also implicated in the quality of that access and how it allowed Akash to experience the freedom he sought. He was excluded from 'awesome stuff' that his brothers and peers were enjoying, such as riding rollercoasters at an amusement park. This limited not only how he did activities but also how he 'did Akash', that is, what forms of identity and self-expression were available to him. Although the wheelchair enabled mobility and freedom,

it limited other ways of doing and being. These limitations were not inherent to the materiality of the wheelchair but emerged through the connections with Akash's body and how disability is constructed as deficient and at risk. The body-wheelchair-seatbelt-risk discourse comes together to effect action in ways that both enable and constrain. For the participants, freedom was hard work, precious and never taken for granted.

Assembling breaks and breaking assemblages

In the examples above, we began to identify 'breaks' from the home-based activity/setting assemblages that dominated participants' lives and which we expand on further here. The break can be understood in its usual sense as a pause or escape from a routine, but also as a fracturing of connectivities that moves towards engaging with different experiences and sensations. We saw this again with Jana who described her mum 'needing a break' from her care responsibilities from time to time. Jana was a 21 year old woman with an undiagnosed progressive condition characterised by fatigue, weakness, and intermittent painful muscle spasms. She could walk unassisted but frequently used a walker or power wheelchair. Because of her unpredictable muscle spasms, she was never left alone and was most often with her mother. In her interview, Jana described some of her relationships with others and the activities they do together including going to the mall with her 12 year old nephew, learning to cook with an adult friend or, as in the passage that follows, 'hanging out' with her personal support worker (PSW):

> I got lucky with my PSW because she is only supposed to stay an hour. WHAT can you do in an hour? You know? I need a bath, and need help with my exercises and if I have a spasm in the tub, you have to wait awhile. So, she comes in and helps me tidy up my room. We're working on a scrapbook. She helps me with cleaning, making things more accessible for me to reach. I've been with her for almost eight years now. And if she doesn't have (her daughter) with her, she stays three, four or five hours here ... to hang out with me. [Interviewer: Do you do things outside of the house with her?] No. Well, we do walk up and down the street but she can't take me anywhere. But we laugh, we make fun of each other [huge smile], we play jokes on each other.

This passage illustrates how different doings of 'Jana' are enabled by breaking apart 'Jana-mum'. Jana further commented on spending time with a family friend outside the house, another break from mum which had positive effects for both her and her mother:

> Jana: It gets me out of the house and it gives my Mom a break ... Because I need
> 24 hour care and he's able to look after me.

The break is an opportunity to reconnect in other ways that have other effects both enabling and constraining. Another participant, Mimi, a ventilator-user who was also never left alone, similarly described the need to give 'mom a break' from caring for her (see Gibson *et al.* 2012). Thus, the configuration has different possibilities for different human actors. Mimi-mum and Jana-mum enable a host of activities that can be disabling in that they constrain both young person and parent from doing and being otherwise. Enabling activity, from a therapeutic rehabilitation perspective, may thus be less concerned with 'increasing participation' and instead oriented to analysing the opportunities for making and breaking connections, exploring how to unleash flow between different configurations, enhancing positive encounters. Where are the breaks and connections? What are their effects on human actors? How can this exploration inform health and social care practices?

Discussion

Post-critical approaches provide a methodology for 'making the familiar strange' that in turn suggests new possibilities for an otherwise rehabilitation practice. We set out in this study to better understand the activity/setting experiences of youth with complex physical and communication impairments using a conceptual approach that afforded a nuanced analysis of enablement and disablement. We have outlined how young disabled people negotiate activity needs and desires in particular socio-material 'spacings' to better understand the material, temporal, and social constraints and affordances that mediate action. This analysis, grounded in the concept of assemblages, suggests a number of 'lines of flight' towards developing with young people the 'goodness of fit' that works best in and across activity/settings without *a priori* assumptions about the benefits of particular activities. As a team of child rehabilitation researchers and clinicians, we see a number of possible ways forward in our own field but also for the various disciplines, practices, and programmes that work with disabled people.

Assemblages remind us of the connected nature of human existence and trouble the negative coding of dependence that pervades healthcare and is built into the measures and practices that are meant to serve disabled people (Gibson 2016, Gibson *et al.* 2012). Elsewhere we have suggested that the shift towards 'interdependence' principles in rehabilitation provides a vehicle for dampening the negative registers associated with dependency by acknowledging that receiving and giving help are common to the human condition (Gibson 2014, 2016). We do not contest the value of this shift, however we agree with Kittay and Feder (2003) and Weicht (2011) that the reliance on mutual exchange in most formulations of interdependence reveals an ongoing discomfort with situations of profound dependence wherein a presumably inherent negativity (needing) is offset by a moral good (giving). Moreover, the privileging of independence persists in rehabilitation where, for example, interdependence goals are promoted as more 'realistic' for disabled people (Stewart *et al.* 2009, p. 20). While acknowledging the dependencies of all persons, talk of interdependence remains largely targeted at (disabled) persons who require particular forms of ongoing assistance.

Assemblages trace and celebrate the multiple dependencies that constitute all our lives. Analysing which dependencies enable activities provides a novel approach to working with young people to help them thrive. We are not suggesting that the pursuit of independence is always or necessarily misplaced, but rather we are suggesting that dependencies are important and necessary for human flourishing (Weicht 2011). Thus at times facilitating a dependency may be a more fruitful rehabilitation goal than enabling independence. Our research demonstrates creative opportunities for re-conceptualising disability in terms of the possibilities inherent in making and breaking multiple attachments. Instead of eliminating or reducing dependencies, the project becomes one of analysing which assemblages produce what effects, and sorting through how to maximise the goodness of fit. Doing so requires clinicians to work with young people and their families, together exploring what 'really works' across the multiple spacings in which they live (Stephens *et al.* 2015). Determining what constitutes a fruitful attachment will always be specific to context, provisional, and open to revision.

This open and particularised approach recognises that good outcomes cannot be known *a priori* but must be determined in situ. For example, the use of an AAC device may be viewed as an achievement of 'independent communication' and produces a better score on a standardised measure such as the Functional Independence Measure (Granger 1998) than reliance on a human communication partner. Our study demonstrates however that coupling with an AAC device is not always the most enabling configuration for young people. Moreover while independence from parents and others was sought in some instances, participants had other needs and desires that often took precedence such as conserving energy or being better understood.

The types of assemblages that are possible shape and limit activity choices. Alternatively creative assemblages were also produced through the unleashing of desires. Our research demonstrated that young people and families traded off the advantages and disadvantages of particular assemblages by moving amongst different connections through breaks in routines and through pursuing novel connections. Wheelchairs and AAC devices, for example, enabled some activities but constrained others. The technologies afforded time away from parents (and parents time away from their children) but imposed restrictions on where, with who and for how long. The social logics of placings shaped how body-technology assemblages were interpreted, accepted, or stigmatised and what connections were possible, practical, or risky. Every assemblage of attachments has multiple effects, some experienced as 'good' and others 'bad', and the same effect may be good and bad in different ways (Gibson 2016).

Conclusion

Improving young people's activity experiences by analysing assemblages opens up new possibilities and questions for a reconceived rehabilitation ethics. How do different assemblages enable and disable? How can they be enhanced, reconfigured? Rehabilitation practices are inescapably normative. Interventions that are helpful in one way can in the same moment function to contain and normalise; to produce and sustain particular modes of being and doing (Shildrick 2005). In bridging a divide between rehabilitation and post-critical work, our hope is that this study contributes to re-imagining rehabilitation by setting aside prior ethical commitments regarding the benefits of particular activities or their different modes of achievement.

Improving activity/setting experiences must account for the materiality of placings but also their sedimented logics and how social meanings are negotiated in place (Stephens *et al*. 2015). The desires and preferences of disabled young people which were articulated in the study – to experience freedom, speed, risk, solitude, and other forms of pleasure – are not often captured in institutional and programmatic goals and priorities. Professionals are in a position to help create, maintain or facilitate enabling assemblages that move away from goals of normalising bodies and abilities that are so often a part of 'therapeutic activities' for disabled children and young people.

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Notes

1 'Activity' was broadly conceptualised in the study to include any structured or unstructured form of leisure and play.

2 We use the term 'disabled young people' as consistent with current usage in disability studies, emphasising individuals are disabled by physical and social barriers in the environment, as opposed to 'with disabilities' which suggests persons are disabled solely by their bodily impairments (Titchkosky 2001) . Nevertheless we also problematise this reductive environment/person distinction in the paper.
3 Thank you to one of the anonymous reviewers for this phrasing.

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