



Beyond Words: Progressive Design for/with People with Severe Brain Injury

Pirkko Raudaskoski

To cite this article: Pirkko Raudaskoski (2012) Beyond Words: Progressive Design for/with People with Severe Brain Injury, Design Philosophy Papers, 10:1, 53-61

To link to this article: <http://dx.doi.org/10.2752/089279312X13968781797599>



Published online: 29 Apr 2015.



Submit your article to this journal [↗](#)



Article views: 14



View related articles [↗](#)



Citing articles: 1 View citing articles [↗](#)

Beyond Words

Progressive Design for/with People with Severe Brain Injury

Pirkko Raudaskoski

Pirkko Raudaskoski is Associate Professor, Department of Communication and Psychology, University of Aalborg, Denmark. She is Project Leader of Late Brain Injury Centre at Aalborg University and a member of the Centre's/Living Lab's advisory board. Her research and teaching are focused on materiality, interaction/intra-action and practices.

Design research often concentrates on the translation process from the knowledge gathered to the final design. Methodological dilemmas can arise on how to undertake participatory or other forms of 'progressive design' so that the end results will be beneficial for those involved. Seldom are the various data collection scenarios studied closely as interaction situations in which the material and social setup serves as an 'apparatus'¹ through which certain results are achieved. However, sometimes the core people in a design process have difficulty in participating by any means. This is the case with people with severe brain injury that the present paper concentrates on. The claim is that, in spite of often taking the design communication for granted, the acceptance of innovative and creative methods in the field makes it possible to explore intuition and hunches – especially those experienced by family members – as valid forms of intersubjectivity. The paper discusses the implications of the basic idea of intersubjectivity for translatory multimodal data collection and continuously developing organizational practices in a soon to be opened care home/'living lab'.

Increasingly, the focus in design studies has turned to situated (in time and material environment) practices as the site of meaning-making and emergence of entities, be it interactions between people, the use of objects, or research and design undertakings themselves. The present paper starts with this paradigm as the most promising way to understand and help people with severe late brain injury. The paper ends with a design research concept for a care home/living lab that is based on a similar dynamic understanding of all phenomena, be they observable or not. To get there, similar relational approaches in fields relevant to late brain injury other than design, are discussed.

Andy Crabtree, in his practical guide to ethnomethodologically-informed ethnography for designing collaborative systems argues that design cannot rely on natural or social sciences, as natural sciences were developed for understanding physical phenomena and not the everyday life of people, whereas social scientific research methods take too much time to be used in practical design work.² However, Crabtree and some other ethnographers with backgrounds in ethnomethodology are not happy with the recent turn to the so-called lightweight literary and rhetorical interpretive procedures in, for instance, the increasing use of cultural probes as ways to facilitate creative design.³ This worry resembles that of some cultural ethnographers⁴ who would like to undertake holistic, multimodal analyses of social life in its detail, rather than go, for example, after emphatic observations about individual actors' experiences that some of the cultural probes research could be seen as doing.

In the following, the claim will be that instead of deeming individual experiences as uninteresting to start with, and invisible (for the analytical gaze), they should be treated theoretically in the same way as the publicly available interpretations in and of the lifeworld: as intentional ways of orienting to the world. The design challenge is how to do systematic data collection about these experiences in such a way that they would turn from individual experiences to shared ones – and thus be able to form the basis of continuous organizational and maybe also personal development.

Living Lab Research

When people with late brain injury move to a home that is at the same time a living lab (that is, they and/or their carers agree to be part of certain type of research practices in the building) in a Danish town in 2012, they will have undergone rehabilitation and will have been diagnosed as having certain types of bodily and social injuries, and, therefore, as needing certain types of care. This means that as citizens, and not patients, they do not have to be studied, for instance, under the paradigm of medical research. As the aim of the living lab is to increase the residents' well-being and quality of life, the research necessarily resides in diagnosing⁵, in finding

out what could be improved in their everyday circumstances. With Büsscher and others, we can turn to design as a way to improve the process of diagnostics to find out which Baradian apparatus⁶ (i.e., which specific material-discursive configuration of the world) would provide the best possible effects. This is the interpretative work that academics can undertake. With Crabtree and company we want to stay close to the everyday life of the residents in the home. As the setting is one with people with severe disabilities, unlike those in most of the diagnosing research that Büsscher and others discuss, it means that the whole setup might be one big diagnostic problem in the sense that able-bodied people encountering the residents cannot necessarily communicate with them through language and often not even with gestures. In a situation like this, participant orientation and participant interpretive work that normally constitute the research object of ethnomethodologically-informed ethnography or participatory design can become the core design problem instead of solving design issues, in the same way as it can be a problem for the healthcare professionals that have diagnosed the residents.

Family members and close friends are, however, often in a different position as their encountering the resident is different from, for example, that of a new member of staff: the resident has a history, they can be connected to other places, times and actions as able-bodied. This experience or a meeting of Bergsonian durations⁷, of consciousnesses with unlimited memories of all things past, might be crucial for the everyday practice of treating the person as if they were their former self. Another issue is that family members, especially, sometimes claim they can understand the person in a way that others cannot. This ability could be related to Bergson's intuition, the ability to see another duration for what they are in a direct experience, unlike the analytical work we do when interpreting the world around us to enable action.

In order to make it possible to get to the sense-making that is going on at and with people with severe late brain injury, a socio-technical system needs to be designed that could best capture the nature of the encounters with the residents as sites of meaningful action through accounts. The aim is that these transformations from the situation itself to spoken, written, visual or other type of resemiotizations⁸ would constitute the basic information that the Home as an organization could learn to use as an independent distributed knowledge system (that is, without the presence of researchers) to change the ways of treating, seeing and being with the residents.

Relational Approaches

The material basis of late brain injury is dealt with in the field of neurosciences. In a study into neural activity⁹, Hosek and Freeman discuss sensing from an ecological perspective as a bodily, and

ultimately social, phenomenon. They emphasize the emergent nature of this electro-chemical process and in so doing join all those who accentuate embodiment in meaning-making, this time connecting under-the-skin processes with past social experiences, that is, with learning or memory. Consciousness according to them is the update of the meaning about the body that constitutes the self. In this, Hosek and Freeman come close to Barad's definition of minds as "material phenomena that emerge through specific intra-actions".¹⁰ To accentuate the emergent nature of their theory of the neural activity that ends up being closely connected to the so-called outer world, Hosek and Freeman make a parallel between what they say about neuroactivity and what postmodernists such as Butler and Foucault have had to say about subjects and practices: we manage to sense and make sense, though in an unpredictable way, as sensing bodies, cultural subjects and populations.

Affect is another aspect that is undeniably important for care situations and is increasingly acknowledged as crucial for design. One field from which inspiration and guidance is sought and which also often becomes part of the care package is counselling and/or psychotherapy. When neurodynamics – with its understanding of organisms as becomings rather than beings – discusses the ultimately relational and anti-Cartesian nature of individual sensing, in talk-based therapies, the "inner" of the other has become an unknown that is reached basically through talk. As discussed by Del Loewenthal in a special issue on the relational in psychotherapy and counselling,¹¹ according to the founding father of psychology, William James, three types of relationality are at issue when trying to help people in therapeutic situations: intersubjectivity, intermateriality and intermethodology.¹² A recent publication on psychotherapy and conversation analysis¹³ shows how intersubjectivity and affect can be researched as relational phenomena that are publicly available to analytical scrutiny. What is maybe lacking from this kind of research is a serious look at intermateriality: What is the impact of not just the embodied presence of the participants but that of the whole material setup? In social psychology, Middleton and Brown¹⁴ have widened the publicly observable nature of talk and embodied action with Bergsonian materiality which accentuates so-called inner, or psychological processes, as always being action (and, therefore, material world) oriented: our past, duration, is with us all the time and helps us understand the world directly (intuition); we act in the world through actualizing certain parts of the duration or memory.

James' intermethodology draws attention to the fact that in a therapy session, certain methods are used in order to get results. The ultimate situatedness of what is going on is considered by Cayne and Leuwenthal¹⁵ as sometimes reaching the unknown through a shared experience that is separable from the session as one of clinical meaning-making. No textbook can apparently tell the

therapist how to get to this experience; one should just stay open to the situation. It seems that in psychotherapy, as in design¹⁶, the mysterious nature of human experience has been accepted as something to be used and explored. However, sometimes in psychotherapy and counseling, the exploration is deemed as an individual mystical experience, rather than something that could be systematically researched or taught. At the other end of the spectrum are those who want to translate the hunches and intuitions into research objects for clinical evidence-based methods. It seems that the middle ground is peopled with researchers that concentrate on the now of the multimodal complexity of interaction and emotions.¹⁷

As mentioned earlier, also in design studies, close analyses are done using conversation analysis and ethnomethodology to provide reliable results of the participants' interpretations in situ. However, even here it might be easier under the rubric of design to broaden the scope of analysis from finding the "seen but unnoticed" actions as embodied doings in a materially meaningful environment to exploring the "unseen but noticed" interpretative work that especially family members do with their loved ones when they claim they can understand what the resident feels or wants.

The ethnomethodologist David Goode, who followed families with mentally disabled blind and deaf children, described some of the skills of family members in understanding their child as 'esoteric'.¹⁸ Instead of ignoring those experiences, he acknowledges them as possibilities that the present scientific approaches cannot explain. However, he also reminds the reader that a careful examination of the practices themselves can show which of them rely on indexical, non-linguistic, meaning-making that might escape clinical and other language-based research. One of the points Goode makes is that interacting with severely disabled children is similar to any other interactions in that we always rely on approximations and seldom have a clear picture of the subjectivities of others. That is, even our able-bodied, linguistic, reactive interactions are based on obscurity. We also rely on embodied ways of interacting, but, with the language bias in many scientific approaches, those ways have often been ignored. Goode treats intersubjectivity as covering all subjectivities, not necessarily only humans and not necessarily through language or other means of communication.¹⁹ What is important is not just the pure sensing separately (as often is the case with clinical trials or diagnoses), but also where in the routines of everyday life those sensings take place.²⁰

The Design Challenge: Translation 1

For progressive design to be 'for the people', both ethnomethodological analyses of their concrete practices and new ways of theorizing (including cultural and literary) human interpretative actions are needed. When the residents have

changed from being normally functional youngsters or adults to not being able to communicate through (sign) language or gestures, it is essential to try and capture what it is that is going on between them and those who claim to understand what is going on: different affordances for intersubjectivity and action result in different forms of common understanding.

In progressive design studies, the aim usually is to understand the lifeworld of the members of society. Above, design studies were appreciated as one outlet for talking about hunches and intuitions. Let us now turn back to the process philosopher Bergson who claims that brain injury does not erase memories (that he does not think reside in the human material body but in the realm of the mystical), only the material connections that can be made from them to act in the world. In the following, a suggestion is made that this processual claim can also serve as the progressive conceptual basis for designing for the living lab socio-technical system.

If we regard the everyday practices in the Home as the continuous distributed becoming in which individuals as well as other entities and phenomena such as knowledge emerge, also through intuition, we could conceptualize the phenomenon or Baradian apparatus that the data collection design is trying to create an organizational sensing, a “shared frequency”²¹ that would be based on the socio-cultural history of the participants, the place and the ways of doing. It is considered as the Bergsonian matter that mediates between the duration of the everyday practices in the Home and the actualisation that takes place in organizational decision making, to which we next turn.

The Organizational Challenge: Translation 2

The material process of collecting data about intersubjective moments is considered as intentionally oriented to action and change in that it helps actualize decisions that then form the basis of the update of the meaning about the bodies that constitute the selves, to rephrase Hosek and Freeman (see 20). In other words, the organization as a living lab is aware of its constitutive practices and can help reconstitute the residents as subjects through conscious socio-technical data collection.

Concluding Discussion

The discussion in this paper has concerned progressive designing for a home / living lab for people with severe late brain injury who cannot talk for themselves. Instead of turning to friends, family and care professionals for knowledge about the “unknown”, we can also find out about the theoretical ideas that prevail in fields that often are central for understanding and treating brain injury. The reading has been selective in concentrating on relational approaches to do with brain injury (treatment) and design and that regard relationality and emergence as central. In psychotherapy and counseling,

as in design, hunches and intuitions have been taken on board. However, instead of leaving these issues to the sphere of magic as in some psychotherapy or treating them as methods for so-called “out-of-normal-situations creativity” as sometimes in design, the present paper wants to claim that, thanks to these fields, maybe especially design which produces tangible results, it is possible to turn to intersubjectivity as an emergent, multimodal and material, phenomenon that covers not just seen but unnoticed but maybe also unseen but noticed phenomena. This kind of research (and not just popular accounts) on intersubjectivity as a complex and sometimes mysterious entanglement would most probably not be possible within medicine or other fields where evidence is defined within especially statistical methods.

Sometimes recent advances in theoretical physics are regarded also as mysterious and unscientific.²² Maybe they are unscientific only in challenging the traditional ideas of science, not in somehow being less rigorous. Similar difficulty lies in convincing those who want to do rigorous close analyses of interaction: in ethnomethodology, what you see is what you get in that you can only make claims of phenomena that are observable. Middleton and Brown have been among the first to combine the rigour of observational research with ideas of Bergsonian duration, and they paved the way to doing rigorous analyses in which hints and other subtleties are also welcomed.

Let us go back to where we started: James and his idea of psychologists being involved in issues of intersubjectivity, intermateriality and intermethodology. We could draw a parallel between these three themes from counseling and those of design situations: instead of just being able to achieve shared understandings (intersubjectivity) and in so doing take into account how the material setup is part and parcel of any situation (intermateriality), knowledge about relational approaches to the situation at hand (intermethodology) might help do design that could be called more reliable. In other words, progress lies in inter- and transdisciplinary undertakings. The three-part division could also be related to epistemology (intersubjectivity), ontology (intermateriality) and methodology (intermethodology) that Biggs and Büchler discussed recently in relation to the academicization of design practice.²³ They end up stating that design practitioners need a research model that fits their worldview in which material objects and individual experiences are central. Maybe there is no need for new models if we accept, for example, Barad’s offer of ethico-onto-epistemology in which not only are questions of being and knowing inseparable, but also the ethical nature of all our doings in the world is unavoidable.²⁴

Intuition has in design and in sciences been cherished as a way to be creative and innovative so as to benefit (a part of) the population.²⁵ The present living lab project is definitely part of

that kind of progressivity, but the core interest lies not so much in performing innovative design as in tackling how intersubjectivity itself is achieved and using this knowledge in making good design choices. However, research into intuition in design has lent a helping hand in being able to deal with intersubjective intuition as a researchable phenomenon in interactions between carers and residents with severe late brain injury.

Notes

1. Karen Barad, *Meeting the Universe Halfway*, Durham: Duke University Press, 2007.
2. Andy Crabtree, *Designing Collaborative Systems*, London: Springer, 2003.
3. Andy Crabtree, Tom Rodden, Peter Tolmie and Graham Button, 'Ethnography Considered Harmful' CHI 2009.
4. Paul Atkinson, Sarah Delamont and William Housley, *Contours of Culture: Complex Ethnography and the Ethnography of Complexity*, Lanham: AltaMira, 2008.
5. Monica Büscher, Jacki O'Neill and John Rooksby, 'Designing for Diagnosing' CSCW 18, 2009.
6. Barad, *Meeting the Universe Halfway*.
7. David Middleton and Steven D. Brown, *The Social Psychology of Experience*, London: Sage, 2005.
8. Rick Iedema, 'Multimodality, 'Resemiotization' *Visual Communication* 2, 2003.
9. Jennifer Hosek and Walter Freeman, 'Osmetic Ontogenesis, or Olfaction Becomes You' *Configurations* 9, 2001.
10. Barad, *Meeting the Universe Halfway*, p. 361.
11. Del Loewenthal, 'The magic of the relational?' *European Journal of Psychotherapy & Counselling*, 12, 2010.
12. William James, *The Principles of Psychology*, New York: Holt, 1890.
13. Anssi Peräkylä, Charles Antaki, Sanna Vehviläinen and Ivan Leudar (eds.), *Conversation Analysis and Psychotherapy*, Cambridge: CUP, 2008.
14. Middleton and Brown, *The Social Psychology of Experience*.
15. Julia Cayne and Del Leuwenthal, 'The Unknown in Learning to Be a Psychotherapist', *European Journal of Psychotherapy and Counseling*, 9/4, 2007.
16. See Editorial, 'Sacred Design', *Design Philosophy Papers* 1, 2010.
17. Daniel Stern, *The Present Moment in Psychotherapy and Everyday Life*, New York: Norton & Company, 2004.
18. Goode, *A World without Words*, Philadelphia: Temple University, Press, 1994.
19. David Goode, *Playing with My Dog Katie*, West Lafayette: Purdue University Press, 2006.
20. Hosek and Freeman, 'Osmetic Ontogenesis'.

21. Hosek and Freeman, 'Osmetic Ontogenesis'.
22. David Tacey, 'The Gift of the Unknown: Jung(ians) And Freud(ians) at The End of Modernity', *European Journal of Psychotherapy and Counseling*, 9/4, 2007.
23. Michael Biggs and Daniela Büchler, 'Some Consequences of the Academicization of Design Practice', *Design Philosophy Papers* 1, 2011.
24. Barad, *Meeting the Universe Halfway*.
25. For example, Larisa V. Shavinina (ed.), *The International Handbook of Innovation*, San Diego: Elsevier, 2003; Asta Raami, Samu Mielonen and Miia Keinänen, 'Designers' Experiences of Intuition', paper presented at Cumulus38°, November 12–14, 2009.