PHILOSOPHY AND DESIGN FOR ALL

Guest Editor: Manja Unger-Büttner

Department for Philosophy of Technology
Technical University Dresden

Tom Bieling / Gesche Joost
Designers & Design Researchers,
Design Research Lab Berlin/Germany

HACKING NORMALCY – DISABILITY FROM A DESIGN RESEARCH PERSPECTIVE

Tom Bieling is a Design Researcher and PhD candidate at Design Research Lab/ Berlin University of the Arts, where he heads the Social Innovation cluster.

Since 2011 he is a visiting professor in Applied Sciences and Art at the German University in Cairo. Tom is author and editor of several books, including 'Design (and) Activism' (2018), 'Gender (und) Design' (2018), 'Inklusion als Entwurf' (t.b.a.), 'Gender Puppets' (Lit, 2008). Furthermore he is Chief-Editor at www.designabilities.org, co-founder of the Design Research Network and founder of the Institute for Applied Fantasies (Institut für angewandte Fantasie).

Numerous guest lectures and workshops at international universities (e.g. Mumbai, São Paulo, Rio de Janeiro, Cairo, Basel, Bern, Luzern, Milan, Portland, Spokane, Edinburgh, Brussels, Nottingham, Tallinn, Bremen, Budapest, Dresden, Potsdam, Hildesheim, Eindhoven or Rotterdam).

Exhibitions in New York, London, Berlin, Vienna, Manchester, Sheffield, Milano, Munich, Dresden, St. Etienne, Karlsruhe, St. Gallen, Eindhoven, St. Quirin, Darmstadt, Paderborn and Cologne. In his previous work as communication- and interaction- and user experience designer and design researcher he worked with clients including Daimler-Chrysler, T-Mobile USA, Museum Ludwig, Smart or Dokumentationszentrum für Popkultur.

Before he moved to Berlin, for joining the technical University of Berlin in cooperation with Telekom Innovation Laboratories in Berlin/Germany in 2007, he studied Design at Köln International School of Design (KISD) at the University of Applied Sciences, Cologne (Germany) and Universidade Federal do Paraná (UFPR), Curitiba (Brasil).

In his research projects he mainly focuses on social and political dimensions of design, and aspects of design for social innovation, interaction and inclusion, with a current major research interest on the coherence between design and dis/ability. In 2014 he was announced "Young Innovator of the Year" by the Falling Walls Consortium.

www.tombieling.com

Gesche Joost is Professor for Design Research at the Berlin University of the Arts and since 2005 heading the Design Research Lab.

With international partners, she conducts research and development projects in the areas of human-computer-interaction, wearable computing, as well as user-centered design and participation. Until 2010, she was junior professor for Interaction Design & Media at the Technical University of Berlin in cooperation with Telekom Innovation Laboratories. As a visiting professor, she taught Gender and Design at the HAWK Hildesheim.

In 2009, she received the young talent award for science from the mayor of Berlin. She is the chairwoman of DGTF e.V. (German Society for Design Theory and Research) and board member of Technologiestiftung Berlin. She is member of the board of the German National Adademic Foundation (Studienstiftung des deutschen Volkes), appointed member of the Synod of the evangelical church in Germany (EKD) as well as full member of the Goethe Institute.

She is co-founder of the non-for-profit company Calliope engaging in digital education for school children in Germany. In 2014, she was appointed as a Digital Champion for the EU commission. Since 2015, she is member of the Advisory Board of SAP SE. Since 2016, she is also board member of the Einsteincenter for Digital Future in Berlin.

Hacking Normalcy – Disability from a Design Research Perspective

Tom Bieling, Gesche Joost

Introduction

In the conceptualisation and development of information–communication–technologies as well as in policy making, the needs, experiences and knowledge of socially marginalised people – especially those with disabilities – are still often not considered and incorporated. Targeting non-disabled majorities even reinforces the processes of social exclusion. The more marginalised certain communities are, the stronger they are excluded from several forms of information, communication and participation. This article draws from critical theories of design and technology to describe and situate some of the challenges and opportunities for design in terms of social inclusion.

Design Matters: Engagement, Representation and Politics-in-Action

Ine Gevers claims the margins of society as the 'best laboratories for democratic renewal.' By describing how democracy develops in these margins, she argues that its 'current decline can perhaps partially be attributed to the ever-decreasing visibility of the "others" in our society' (Gevers et al. 2010). Referring to Giorgio Agamben who speaks of a 'post-democratic spectacle society', she raises fundamental questions: *'Which democratic practices still have a right to speak in today's post-political climate? To whom and to what should we listen if we want to restructure [...] society in such a way that increasing numbers of new minorities, [...] and as yet unfamiliar voices get heard? How do these ideas relate to a society that with its aim of achieving order and perfection seems increasingly to distinguish between citizens and 'other' citizens, with the latter apparently not automatically in a position to claim the rights that the status of citizenship should*

lend them? How can we bring about a society that doesn't turn its back on its own most fundamental values – diversity, interdependence and asymmetry?' (Ibid.)

Not least, these questions are also design questions, as design is often directly or indirectly involved in steering, enabling, accompanying, interpreting and evaluating such processes.

In recent years, the social[1] and political dimensions of design have gained increasing importance (Bieling, Sametinger, & Joost, 2014). Critical and cross-cultural as well as inclusive and socially-informed design approaches have helped form an understanding of design as a practice with a high potential for societal transformation. A strong characteristic of these approaches becomes obvious in their intention to satisfy the needs of underserved or marginalised populations (Margolin & Margolin 2002), as well as to improve and contribute to human wellbeing, participation, self-organisation or alternative forms of political action.

In previous publications we have discussed the different effects that occur when these marginalised communities are regarded as 'target groups' in terms of potential consumers instead of as an active source of innovative, social sustainable development which contains added value to a broad range of non-intended use and initially non-addressed users (Bieling, Goellner, & Joost 2013; Bieling, Gollner, Joost 2012; Joost & Bieling, 2012).

The research cluster 'social innovation' at the Design Research Lab at the Berlin University of the Arts unravels the social and political dimensions of design, prioritising interrogating design as an enabler and negotiator within social, cultural, economic, political, ecological and ethical parameters. Following an inclusive and diversity-based[2] approach for transformational change and activism in underrepresented and disadvantaged communities, this research cluster

---

[1] The concept 'social' is understood here in a general sense as related to aspects of cohabitation or collective co-existence of humans, their intentional or non-intentional interaction with each other, as well as corresponding organisational patterns.

[2] We are following a concept of diversity that includes a variety of demographic characteristics, including gender, class, ethnicity or ability amongst others. Different models of diversity have recently been discussed in the field of diversity studies, often aligned with a critical thinking about these social and cultural categories that constitute society. One of their central characteristics is embodied in a commitment or aim to social justice and change, emphasising to identify and critique the processes and effects of institutionalised oppression, social inequality or dominant group privileges. As Bessing and Lukoshat (2013) indicate, diversity has increasingly been discussed and shown to contribute to the field of 'innovation'.

addresses issues such as dis/ability, poverty, ageing, health, gender, social movements, protest or intercultural dialogue. Within the framework of the social innovation cluster, one central approach is to focus on the assumption that developments in the fields of the "underrepresented" also bring an added value to a variety of other users (Bieling, Sametinger, Joost, 2014).

Disability: a matter of perspective

This obviously also tackles the issue around the processes of social exclusion and inclusion raised by technology, opening up important questions in regard to the politics of design, research and technology development. One of these is to clarify the positions design and design research can have in the social sphere and its construction, and thus in the structuring of society. One approach is to more fully integrate disadvantaged, disregarded or marginalised groups through the design process – and in this sense, design also means the determination of decisions, situations and processes or participation.

Design and technology have long become indispensable in broad fields of human ecology. Both are omnipresent in everyday life, and often we do not realise once we become accustomed to and reliant upon them (Goggin & Newell 2003, p. 3). Both play a fundamental role in developing, understanding and sustaining our identities. Both can (even simultaneously) allow or deny access, and so they are often (if not generally) responsible for social and cultural inclusion or exclusion.

Thus design and technology are never socially neutral. And the design processes around understanding and addressing specific user needs as well as developing innovative technologies, can be described as *'an activity that influences and is influenced by the balancing of interests among different social groups that participate in its process and deal with objects or systems'* (Couto & Ribeiro, 2002). Furthermore, technology is never neutral, since *'technological artefacts [...] can be used for certain goals but not, or far more difficulty or less effectively, for other goals'* (Stanford Encyclopedia of Philosophy 2013). [3]

---

[3] This conceptual connection between technological artifacts, functions and goals makes it hard to maintain that technology is value-neutral (ibid.)

Technology thus appears to be an exertion of human power[4], which Hans Jonas describes as a form of action constantly exposed to moral verification (Jonas 1993).

Assuming that human-made constructions and technologies have influence upon the individual, it becomes comprehensible that technologies 'enforce normalcy'[5] (Davis 2002). Therefore, they have an effect of 'reproducing an ableist framework, rather than building in, creating and contributing to new modes of living which embrace difference and diversity' (Goggin 2008, p.11). In this respect, the 'design perspective' can play a significant role in altering these frameworks and allowing for diversity. Design is especially able to engage with such tasks, since it automatically influences learning as a human activity that is socially situated and mediated through artefacts.

Goggin and Newell (2003, p. 147) have shown how society 'consciously and unconsciously, has built in disability into digital technologies' and how disability is 'constructed in and through technology' (p. 12). In regard to the enabling and disabling practices triggered and represented by technology, the knowledge and perspectives of people with disabilities appear to have a high value of (social, emotional and not least economical) benefit. Both society and industry can benefit, if a broad and diverse range of citizens and communities are involved in the process of critical and sustained reflection and development. And in regard to alternative modes of policy exchanges, Goggin and Newell state, that 'such subaltern knowledge can make an important contribution [...], and help to shape the emerging social and technological systems that are becoming today's and tomorrow's norms' (p. 80).

Design: Interpreter between object and user

---

[4] German: *Macht*

[5] Lennard Davis indicates how the term 'normal' coincides with the birth of statistics and eugenics in the mid nineteenth century, while replacing the former concept of 'ideal' as the regnant paradigm in relation to bodies (Davis 2005). He further claims that 'the introduction of the concept of normality [...] created an imperative to be normal.' An understanding of the built environment as a key actor that privileges certain bodies and excludes others by producing barriers that construct disability (Davis, 2002, p. 31; Wendell, 1996, p. 55) has established a basis towards a 'shift form the ideology of normalcy to a vision of the body as changeable, unperfectable' (Davis, 2005).

Design can play an important role here in that its artefacts – in the form of products, services or interventions – can create awareness and can motivate alternative patterns of behaviour. As such, design is required to reflect on the scope of its actions and on the responsibility of the designed artefact's possible effects. It is a question of the social responsibility of design and the potential to design social responsibility.

Thus the participatory shift, which can be observed in various fields of research, design and development over the recent years, plays a key role. The principal orientation of participatory design is to integrate different groups of participants in the design process and to thereby create equal roles for the designers and 'non-designers'. These 'non-designers' are potential end users, employers, public representatives or members from other interest groups. These participants can be subsumed under the concept 'stakeholder', which is to say, every participant possessing a certain, (in)direct interest in the design process, its conception, realisation, implementation or resulting consequences. From the development of questions concerning the generation of ideas and their realisation to the marketing of the products, these participants can be closely integrated in this process in a variety of ways (Sanders 2013). A more political oriented variant of participatory design can be found in Pelle Ehn (2001) and Ezio Manzini (2007). Here the focus is on the inclusion of citizens in societal processes as well as the authorisation for independent improvements of living conditions.

In light of the disabling and enabling dimensions of technology, the level of stakeholder involvement will undoubtedly shape the future impact of technology.

Design: Border between disability and 'normal'

Our common understanding of normalcy is negotiated on a daily basis and therein lies potential for design. If one assumes that the cultural production of normalcy is an act of *creation* that is not founded on pure biological predispositions, then design and normalcy are closely related. The conception of 'normal'[6] is often reinforced by design, not only by means of the images produced by advertisements, but also due to the fact that the design itself excludes certain users from using specific services and technologies.

---

[6] Since what is considered 'normal' is relative to cultural practices, definitions and locations in which the social interactions take place, the term appears in quotation marks throughout the paper.

Thus for design research, the question as to how to overcome the established stereotypes of 'disabled' and 'normal' arises. Especially, if design engages in strongly technology-related, or even more tricky: technology-driven fields. Technology marks the border between disability and normalcy, and is eventually involved in their cultural production, as well as in their social, institutional or individual interpretation (see Dederich 2013). Thus a critical reflection in the development and implementation of technology about common understandings and definitions of 'normal' is needed, especially aiming at empowering viewpoints of people with disabilities themselves (Behrisch & Bieling 2015). Therefore some reflections for participatory and inclusive technology design and development need to be discussed. Moreover, in the context of information–communication–technologies and the related media cultures, a critical perspective is needed. As Goggin and Newell describe, disability is shaped or 'made' in them. (Goggin & Newell 2003, p. 4). This raises the question of how to define design as a social (relevant) activity and to propose design as a process of social interaction.

Normalcy as a Design Playground

Goggin and Newell argue that there should be a *'clear process for the dynamic redefinition of universal service in [technology] that takes into account the changing socio-political spaces of consumers and technology. This means that people with disabilities, as well as all other citizens and consumers, must be able to participate in policy making, research, and knowledge construction on new media'* (Goggin & Newell 2003, p. xviii).

To understand normalcy as a design playground, in which more parties are involved than just the designers, is a special point of view that indirectly allows a fundamental reinterpretation of widely anchored social evaluations and understandings of 'normal'. Adopting a design perspective can be a promising resource to bring about system innovation in which individual interests converge with those of society.

Exploring the opportunities and challenges design represents for the social inclusion of people (not only those with disabilities) opens up new opportunities to restore meaning and value to participatory and inclusive approaches as a counterpart to a purely technology-driven innovation.

For the future development – especially in terms of digital transformation, the enabling and disabling practices of technology need to be critically reflected upon in order to avoid replicating and propagating inaccessibility from the physical into the digital world.

Without doubt technology can provide people who previously existed outside society with means of access to it (Gevers et al., 2010, 212). Yet, if one goes beyond the clichéd perceptions as to how 'disabled' or 'non-disabled' people would tend to use certain products and listens instead to what real individuals have to say, then new, unexpected and potentially fairer solutions occasionally arise. It becomes clear that concentrating on 'normalcy' issues repeatedly requires reflecting upon how much standard roles are thereby implicitly strengthened. It does not necessarily mean that derived concepts contribute to an emancipated, inclusive role understanding per se.

This is for sure a critical junction, since it makes the limits of participation clear and also brings the responsibility for the product back to the designers. Dealing with the results of participatory design processes and inclusive design outcomes therefore requires a high amount of empathy and reflection as to what can be achieved through the products or services originating in this manner.

Nevertheless a large potential is opened up by bringing together people from a variety of contexts (whether those be cultural, social or demographic) into the processes of technological and/or social innovation. Not least in order to clarify that the awareness that society is diverse can also be of aid in developing alternative concepts extending far beyond the stereotypical image of so-called norm- or standard-users.

Nevertheless, interrogating our existing and future technologies helps to reflect upon the values and lived social policy (Goggin & Newell 2003, p. 154), as well as to understand how the associated interpretations of 'normal' could be modified and re-designed. After all, this remains valid not only within a disability context, but for any marginalised group. Thus including the perspectives of people with disabilities in the networked digital society is not only a technological question, but a political one.

This article is a revised and shortened version of a chapter entitled „Interactive inclusive – Designing tools for activism and empowerment" by Tom Bieling, Tiago Martins and Gesche Joost, first published in: Kent, M. & Ellis, K. (2017): Disability and Social Media. Taylor & Francis, Routledge, London.

References

Behrisch, B., & Bieling, T. (2015): Partizipative und inklusive Mensch-Technik-Interaktion: Technikunterstützung im Rahmen Sozialer Bewegungen. *Lecture at Friedrichshainer Kolloquium 2015: Technikgestaltung – Die Perspektive Behinderung im Kontext der Innovations- und Technikentwicklung.* Institut Mensch, Ethik und Wissenschaft, Berlin.

Bessing, N., & Lukoschat, H. (Ed.). (2013). Innovation durch Perspektivenvielfalt – Impulse für die industrielle Praxis aus der Gender- und Diversity-Forschung. (Innovation through a diversity of perspectives: Impulses from gender- and diversity studies for the industrial practice). Opladen: Verlag Barbara Budrich.

Bieling, T., Goellner, S., & Joost, G. (2013). Design driven diversity – Diversity driven Design. *Proceedings of IASDR 2013 – 5th International Congress of International Association of Societies of Design Research: Consilience and Innovation in Design, Shibaura Institute of Technology.* Tokyo, Japan. ISBN 978-4-9980776-3-3 C3072

Bieling, T., Gollner, U., & Joost, G. (2012). Information und Inklusion begreifen. In J. Sieck, & R. Franken-Wendelstorf. *Kultur und Informatik: Aus der Vergangenheit in die Zukunft.* VWH Verlag, Fachverlag für Medientechnik und -Wirtschaft. Bolzenburg. ISBN 3-864880165/

Bieling, T., Joost, G., & Sametinger, F. (2014). Die soziale Dimension; in Fuhs, Brocchi, Maxein & Draser (Hg.). Die Geschichte des nachhaltigen Designs; VAS, Bad Homburg, (pp. 218–229)

Bieling, T., Sametinger, F., & Joost, G. (2014). Social dimensions of design research. In Baltic Horizons, No 21 (118), II. Social, ethical and political aspects of research in design. October 2013, EuroAcademy Series Art & Design, Euroakadeemia, Tallinn, Estonia (pp. 35–40).

Couto, R., & Ribeiro, F. (2002). Projeto em Curso des Design sob o Enfoque do Design em Parceria. Retrieved February 5, 2007, from http://www.puc-rio.br/sobrepuc/depto/dad/lpd/download/designemparceria.rtf

Davis, L. J. (2002). Bending over backwards: Disability, dismodernism, and other difficult positions. New York, NY: New York University Press.

Davis, L. J. (2005). The tyranny of normalcy: Diverse ability. *SGI Quaterly*, http://www.sgiquarterly.org/feature2005Jly-2.html, Accessed May 7, 2015.

Dederich, M. (2013). Philosophie in der Heil- und Sonderpädagogik. Stuttgart: Kohlhammer.

Ehn, P. (2001). On the collective designer. Keynote lecture at Cultural Usability Seminar, UIAH Helsinki, April 2001; as quoted in Diaz-Kommonen 2002

Gevers, I., Addlahka, R., & Callon, M. (2010). Practices of Democracy. In Difference on Display – Diversity in Art, Science and Society. Nai010 Publishers, Rotterdam, (pp. 288–289).

Goggin, G. (2008). Innovation and disability. *M/C Journal of Media and Culture,* *11*(3). Queensland University of Technology, Australia.

Goggin, G., & Newell, C. (2003). Digital disability. The social construction of disability in new media. Rowmann & Littlefield, Maryland.

Jonas, H. (1993). Warum die Technik ein Gegenstand für die Ethik ist: Fünf Gründe. In: H. Lenk & G. Ropohl (Hrsg.), Technik und Ethik, Stuttgart: Reclam.

Joost, G., & Bieling, T. (2012). Design contra a Normalidade. Traduzido do inglês por Paulo Ortega. in: V!RUS, Sao Carlos, n. 7, Jun. 2012. "ações culturais e meios digitais" NOMADS. USP journal. ISSN 2175-974x. Disponível em [pdf]

Manzini, E. (2007). Design research for sustainable social innovation. In R. Michel. *Design research now.* Birkhäuser, Basel.

Margolin V., & Margolin, S. (2002). A 'social model' of design: Issues of practice and research. *Design Issues. 18*(4),24–30.

Sanders, E. (2013). Perspectives on participation in design. In C. Mareis, M. Held, & G. Joost (Hg.) Wer gestaltet die Gestaltung? Tagungsband DGTF-Jahrestagung, transcript Verlag, Bielefeld.

Stanford Encyclopedia of Philosophy (2013). Philosophy of Technology. http://plato.stanford.edu/entries/technology/ [22.04.2015]