

ABSTRACT: Digital communication technologies and online social networking services are often referred to as systems of opportunities for social inclusion of people with disabilities, not least through the facility of communicating in relative anonymity, potentially free of certain prejudices and other social barriers. They are further described as tools for activism, empowering individuals and fostering autonomy (Shakespeare 2008). This opens up important questions in regard to participatory design approaches and political implications of collaborative research and technology development. In this discussion paper we will carve out a specific case study: a participatory design research project developed in the context of deaf-blind communication, interaction, empowerment and activism.

KEYWORDS: activism, deaf-blind, design research, empowerment, inclusion, interaction, social innovation

Design, as an innovative cultural practice, is deeply entangled in our everyday life and is therefore intrinsically connected to the social sphere. In recent years, the social and political dimensions of design have seemed to increasingly gain importance¹. Critical and cross-cultural as well as inclusive and socially-informed design approaches have helped to form an understanding of design as a practice with a high potential for societal transformation. (Papanek 1971; Lund/Lund 2014; Yelavich/Adams 2014)

It seems to be a logical consequence that a social orientation in design is now gaining currency. A "social active design," as Alastair Fuad-Luke has called it, focuses on society and its transformations toward a more sustainable way of living,



working and producing (Fuad-Luke 2009:1978). Ezio Manzini describes the necessity for cultural change that can be propelled by a new awareness in society and by establishing new models of behavior (Manzini 1997:43-51). Design can play an important role here in that its artifacts – in the form of products, services or interventions – can create awareness and can motivate alternative patterns of behavior. As such, design is required to reflect on the scope of its actions and on the responsibility of the designed artifact's possible effects. It is a question of the social responsibility of design and the potential to design social responsibility.

The perspectives described above are based upon a crucial social challenge: namely, how to deal with diversity² in everyday life. A strong characteristic of humans is their diversity (Heidkamp et al. 2010, 8). This variety is also reflected in human-made artifacts and can, by implication, also be addressed by looking at the design of such artifacts. As such, a large potential is opened up to bring 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 to clarify: the awareness that society is diverse can also be of aid in the design process in developing new and alternative approaches extending far beyond the stereotypical image of so-called standard users (Joost & Chow 2010). Such a standard or "normal" user stands in contradistinction to diversity and is thus far from reality.

But diversity in everyday life also entails calling the existing constructs of normalcy³ into question: that is, which body is "normal"⁴, and which behavior is "socially acceptable"? The conception of "normal" 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 can discourage or exclude certain users from using specific services and technologies.

Design and Inclusion

Based on the assumption that there is a fundamental relationship between design and disability⁵ (Bieling 2010), two different phenomena – "to be handicapped" and "to be hampered" – seem to be inextricably woven together. In particular, the link between people, artifacts and their relationships to one another plays an important role (Latour 2001; Moser & Law 1999; Winance 2006). Thus, a wheelchair

98

GJSS Vol. 12, Issue 2

user becomes especially aware of their disability when confronted with designed things, such as stairs or sidewalks.

This raises the question whether "impairment" itself is the problem design should concentrate on or whether the focus should be on the culture dependent settings that produce such exclusions⁶. According to the Social Model of Disability, which blames the systemic and artificial barriers as well as societal processes of exclusion, design itself can be identified as one of the main contributing factors towards disability. Its operation range does obviously involve both a facility to "compensate" impairment (\rightarrow Medical Model) and the potential to help modifying the culture dependent settings (\rightarrow Social Model), thus changing or counteracting processes of exclusion.

In relation to the proximity of the two parameters "design" and "disability," design theory and practice proposes approaches to be disseminated under different concepts: first and foremost, "universal design" (Erlandson 2008; Herwig 2008; Mace *et al.* 1991; Mitrasinovic 2008), "design for all," "design for accessibility," barrier-free design," "transgenerational design" or "inclusive design" (Imrie & Hall 2001).

Universal design and inclusive design / design for all from the start contested a thinking in polarities and promoted an understanding that aligns design decisions with requirements that serve for all humans. Universal design strongly highlighted the importance of standards, norms and the legal basis that is needed to reach this goal. Inclusive design in comparison more practically suggested design approaches that aim at including the diversity of users' needs that manifest in a "variation in capabilities, needs, and aspirations".

An inherent conflict to these approaches is that any attempt to define most clearly in which way any special needs has to be respected, will also induce the reduction and uniformization of the possible variety in design – the underlying moral obligation left out. And *including* people also means to declare somebody being previously excluded – which again entails critical debates.

If one assumes that technology design plays a role in social and cultural inclusion and exclusion as well as in the participation of social processes, then it becomes clear to what degree the influence of access to information has on the facilitation and initiation of social inclusion.

One potentially important message is that one should not necessarily emphasize the less positive aspects (that is, the disability), but instead recognize the real

Bieling, Martins, Joost: Internet of Everyone

skills and expertise of the disabled – a lesson that is as important for designers as for others. To understand disability as an expertise is a special point of view that indirectly allows a fundamental reinterpretation of widely anchored social evaluations and understandings of disability and normalcy.

Empowering Interaction

In the research project *Interaktiv Inklusiv*⁸ we have been exploring possibilities and challenges in the design of assistive technologies within a context of communication with or between deaf-blind individuals.

Deaf-blindness is a dual sensory-impairment with a combined loss of hearing and sight. The lack of a common language makes it difficult for deaf-blind people to connect with the outside world. Particularly people with deaf-blindness acquired late in life have the opportunity to use the Lorm Alphabet ("Lorm", for short) for communication. Lorm, developed in the 19th century by deaf-blind inventor Hieronymus Lorm, is a tactile hand-touch alphabet, in which every character is assigned to a certain area of the hand. The "speaker" touches the palm of the "reader's" hand and draws Lorm Alphabet Signs onto it by tracing lines and shapes.

This requires both interlocutors to be familiar with Lorm. Physical contact is indispensable. These preconditions often lead the deaf-blind into social isolation and dependence on information relayed by people around them. Both on- and offline social networking, as well as independent information access are difficult, and are often hardly possible.

The research project *Interaktiv Inklusiv* addressed these issues with a sustainable impact in mind: with an ageing population also the role of technology design changes. The raising of awareness towards accessible design and technology is also related to the global demographic development and the associated certainty that an increasingly ageing population will be confronted with a growing number of physical limitations, such as age-related visual or hearing impairments.

In a collaborative research and design process⁹, we developed the *Lorm Hand*. Users can write the Lorm Alphabet signs on the *Lorm Hand* as if they were *lorming* to another individual, holding the hand shortly to signal the end of each word (a white space character). The hand will vibrate slightly whenever a character is recognized and more deeply when the end of a word is signalled. The user may post

GJSS Vol. 12, Issue 2



Image 1: The *Lorm Hand* gives access to various kind of digital information and social networks.

the message online by holding the Lorm Hand for a few seconds, and it will vibrate in a crescendo to confirm the operation is completed. An application performs the recognition of Lorm gestures based on sensor data, displays the resulting message on a screen (especially helpful for non-deaf-blind learners) and handles the posting of messages on the Twitter account @LormHand and a connect-

ed Facebook page. A small tactile push button was included, located in the wrist, that disables the capacitive sensing in order to allow blind users to get a feel of the hand's shape and position before or in-between actually *lorming*. Another button was added to the pedestal surface which deletes a single character or, when pressed for a few seconds, the whole message.

This hand-shaped device is based on conclusions drawn from previous work on a wearable interface¹⁰ for translating the tactile Lorm alphabet for the deaf-blind into text and vice-versa (Bieling/Gollner/Joost 2012). The Lorm alphabet maps letters to gestures signed on the palm of the hand, making it easy to translate textual content into a haptic language. Both approaches are part of the research project *Speechless*, focusing on the difficulty of access for visually or hearing impaired people to information channels and communication systems; all the while based on the assumption that this development also brings an added value to a variety



Image 2: The Lorm Hand at the Protest March.

of other users (Bieling/Sametinger/ Joost 2014).

The *Lorm Hand* was originally devised as a public installation in the context of the deaf-blind protest march *Aktion Taubblind – Taubblinde in Isolationshaft*, ¹¹ which took place on October 4 of 2013 in Berlin, culminating at Potsdamer Platz.

The installation would allow deafblind individuals acquainted with the Lorm Alphabet to post their thoughts on the social networks Twitter and Facebook, where they might potentially reach others around the world, raising awareness towards their situation. This created the opportunity for the deaf-blind and other attendants to share their thoughts and opinions with a wider audience, creating awareness towards the core topic of the protest, i.e. the experience of isolation that often accompanies the deaf-blind condition, while at the same time working against it.

Additionally, the *Lorm Hand* would provide the opportunity for





Image 3 + 4: A participant tries the *Lorm Hand* in different orientations.

participants and passers-by to become acquainted with the Lorm Alphabet as a method of communication with deaf-blind individuals, creating awareness towards this form of communication and the possibilities it offers. The *Lorm Hand* installation allowed the research group to approach the issue of accessibility to digital media for deaf-blind individuals from a different angle: using a tangible interface with a natural shape. This in turn prompted experimentation with other crafting methods and sensor technologies.

The first prototype versions of the *Lorm Hand* have been ideated, produced, tested and exhibited collaboratively. Both the further development of the *Lorm Hand* and its display in several public exhibitions have been actively accompanied by a group of deaf-blind individuals and institutions. These were mainly represented by members of the ABSV (Allgemeiner Blinden- und Sehbehindertenverein Berlin)¹² and the Oberlinhaus Babelsberg¹³. The outcome: an interactive installation with a natural shape as its central feature, embodying a concept of inclusion and accessibility, its presence felt both physically and online. As such, it quickly gathered attention, especially on online social networks and related media and

102 GJSS Vol. 12, Issue 2

became publicly perceived as a project aiming at empowering deaf-blind people to engage with a broader spectrum of people and gain access to a broader range of information, thus enhancing their independence.

Through its presence in events as public installation and in online social networks, the *Lorm Hand* has proven itself as medium for raising awareness towards accessibility issues in new technologies (and the role that technology can play in avoiding isolation) as well as an educational tool to introduce the Lorm Alphabet and demystify communication possibilities with deaf-blind individuals.

Discussion

The Lorm Hand has been frequently tested by deaf-blind users and Lorm experts during development; and provided observations of a qualitative nature during public events. These observations have guided further efforts in improving the prototypes and simultaneously raise awareness – both towards the deaf-blind cause and to the possibilities afforded by design and technology in the service of accessibility, social Media and social transformation in general.

Particularly with regard to social transformation, Tobin Siebers (Siebers/Bieling 2013 47–48) points up the (potential) role of disability:

The disability community has the ability to drive social transformation, and it depends [...] on at least two factors [...]. First, disabled people have emerged as knowledge producers; [...] This new knowledge of society frees people with disabilities from oppressive stereotypes because they understand that it provides a better explanation than existing ideas of their social location. The justifications for the oppression of disabled people no longer hold water, and once they realize this fact, they begin to gather together to fight oppression and to transform their society into one that will not only accommodate them, but accept their contributions as valuable. Second, [...] identity politics and political action groups hold the key to leading disabled people to full citizenship. [...] use [...] political action to advance their goals. Disabled people have to hit the streets.

Thus "raising a voice" is a key tool to trigger social transformation. Design can intervene in cases, where certain voices hardly get heard, by offering tools again.

And peoples who are supposed to use these tools can also play a key role in (co-)developing them.

Conclusion

This case study addresses and discusses the issue around the cultural constructions of normalcy and the processes of social exclusion/inclusion raised by technology, opening up important questions in regard to the politics of design, research and technology development.

One of which is to clarify the positions design and design research can have in the social sphere and its construction, and thus in structuring of society. One approach is to more fully integrate disadvantaged, disregarded or marginalized groups through the design process – and in this sense, design also means the determination of decisions, situations and processes or participation.

Developed in the context of deaf-blind communication, interaction and empowerment, the collaborations between developers of technologies, their end-users and the devices themselves should play a central role in future investigations. It will be particularly interesting to understand the political implications of modes of collaborations in the processes of development, especially when reflected on how these practices of working together tie into their technological materialisation.

In the coming years it will be an important task to more firmly entrench such questions in the design discourse and to problematize them in design education. Thus the critical reflection of one's responsibility as a designer should play a more integral role in education in order to both understand and operate the social and political aims of the technology itself as it attempts to break down barriers. This includes to discuss the role-shift of the designer towards more participatory approaches, in which the user becomes an essential partner in innovation development. This implies new forms of bodily appropriation, the challenging of stereotypes of "normalcy".

Acknowledgements

The project "speechless" was funded by the BMBF – Bundesministerium für Bildung und Forschung (Federal Ministry of Education and Research). The project

"Interaktiv Inklusiv" was supported by the Hochschulwettbewerb (German University Competion), as an initiative within the Year of the Science "Wissenschaftsjahr 2014 – Die digitale Gesellschaft".

Video link

https://www.youtube.com/watch?v=TW2FoVVrkEg

Endnotes

- 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.
- 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, emphasizing to identify and critique the processes and effects of institutionalized oppression, social inequality or dominant group privileges. As Bessing and Lukoshat (Bessing and Lukoschat 2013) indicate, diversity has increasingly been discussed and shown to contribute to the field of "Innovation".
- Lennard Davis indicates how the term "normal" coincides with the birth of statistics and eugenics in the mid 19th 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 31; Wendell 1996, 55) has established a basis towards a "shift form the ideology of normalcy to a vision of the body as changeable, unperfectable". (Davis 2005)
- 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.
- Throughout the paper, the terms Disability/disabled and Impairment/impaired are used to illustrate (at least) two different perspectives: Especially in the academic field of *Disability Studies* "Disability" has been discussed as a social construct, whereas "Impairment" is often meant to describe certain physical or cognitive conditions of a human's body or mind. Based on this distinction, (at least) two opponent models of disability have been discussed: The "social model" and the "medical model" of Disability. (Bick-

- enbach et al., 1999) The further tends to identify disability from a clinical perspective, which corresponds to a concept of "curing" and "healing" a specific "illness" and refers to an understanding of norm and accordingly conforming with normative values. The latter identifies society and systemic barriers or exclusive practices as a main contributor towards disability.
- More concrete, the question could be, whether the impairment or the techno-cultural settings are to blame for misfits, problems, etc.
- According to the Inclusive Design Toolkit, developed at the University of Cambrigde (UK), »Inclusive design emphasizes the contribution that understanding user diversity makes to informing these decisions. User diversity covers variation in capabilities, needs, and aspirations.« http://www.inclusivedesigntoolkit.com/betterdesign2/whatis/whatis.html
- ⁸ English: Interactive Inclusive.
- In an iterative process throughout regularly meetings the participants have been participating in all project phases, starting from the first explorations (regarding everyday-life-challenges in a deaf-blind person's life or specifics of deaf-blind communication); jointly formulating hypotheses and research questions; ideating and conceiving (regarding potential design approaches/solutions); and evaluating (process, methods and outcome).
- The *Lorm Glove*, also developed at the Design Research Lab, is a wearable interface/device. It uses sensitive areas located on the palm of the glove to detect the wearer's touch and thus identify Lorm alphabet signs, composing a message to be wirelessly relayed to a mobile device, such as a smartphone or tablet. Conversely, messages received through the mobile device are wirelessly relayed to the *Lorm Glove*; and played back as simulated Lorm alphabet signs through haptic actuators, located on the glove. Thus communication goes both ways and enables the user to both send and receive messages.
- ¹¹ English: Mission Deaf-blind Deaf-blind People in Isolation (Isolated imprisonment).
- Public Association of the Blind and Sight Impaired, Berlin
- The Oberlinhaus (Oberlin House), named after Pastor Johann Friedrich Oberlin (1871), is an institution focusing on care and education for people with disabilities, based in Potsdam-Babelsberg near Berlin.

References

Bessing, Nina, and Lukoschat, Helga (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, Tom. 2010. "Dynamic Perspectives: Looking forward to a better past"; Sustainability in Design: Now! – Challenges and Opportunities for Design Research, Education and Practice in de XXI Century; Edited by Fabrizio Ceschin, Carlo Vezzoli and

- Jun Zhang; Proceedings of the LeNS Conference, 29th September to 1st October 2010; Bangalore India; Sheffield: Greenleaf Publishing, 98–106.
- Bieling, Tom, Gollner, Ulrike and Joost, Gesche. 2012. "Schnittstelle Hand Kommunikation mit Gefühl | Feeling communication The hand as an interface." *i-com Zeitschrift für interaktive und kooperative Medien*, August 2012, Vol. 11, No. 2, pg(s) München: Oldenbourg Wissenschaftsverlag, 32–36.
- Bieling, Tom, Sametinger, Florian, Joost, Gesche. 2014. "Die soziale Dimension des Designs" (The Social Dimension of Design) In *Die Geschichte des nachhaltigen Designs* (The History of Sustainable Design), edited by Karin-Simone Fuhs, Davide Brocchi, Michael Maxein, and Bernd Draser, 218–229. Bad Homburg: VAS.
- Bickenbach, Jerome E., Chatterji, Somnath, Badley, Elizabeth and Üstün, Bedirhan T. 1999. "Models of disablement, universalism and the international classification of impairments, disabilities and handicaps" *Social Science & Medicine* 48 (9): 1173–1187.
- Davis, Lennard J. 2005. "The Tyranny of Normalcy" Diverse Ability *SGI Quaterly*, http://www.sgiquarterly.org/feature2005Jly-2.html, Accessed May 7, 2015.
- Davis, Lennard J. 1995. Enforcing Normalcy: Disability, Deafness, and the Body. New York: Verso.
- Erlandson, Robert F. 2008. Universal and Accessible Design for Products, Services and Proceses. Boca Raton: CRC Press.
- Fuad-Luke, Alastair. 2009. Design activism: beautiful strangeness for a sustainable world. London: Earthscan.
- Heidkamp, Philipp, KISD Köln International School of Design 2010. Learning from Nairobi Mobility A Cultural Library Project. Cologne: KISDedition.
- Herwig, O.: Universal Design: Lösungen für einen barrierefreien Alltag (Solutions for an accessible Everyday Life). Birkhäuser Verlag, Basel 2008.
- Imrie, Rob, Hall, Peter. 2001. Inclusive Design: Designing and Developing Accessible Environments. London: Spon Press.
- Joost, Gesche, Chow, Rosan. 2010. "Design Research in University-Industry Collaborative Innovation: Experiences and Perspectives" In *Applied Technology and Innovation Management*, edited by Heinrich Arnold, Michael Erner, Peter Möckel, and Christopher Schläffer, 157–167. Berlin Heidelberg: Springer.
- Latour, Bruno. 2001. Das Parlament der Dinge Für eine politische Ökologie (The Parliament of Things Towards a political Ecology). Frankfurt: Suhrkamp.

- Lund, Cornelia, Lund, Holger (Ed.). 2014. Design der Zukunft (Design of the Future). Stuttgart: AVedition.
- Mace, R.L. / Hardie, G. J. / Plaice, J.P. 1991. "Accessible Environments. Towards Universal Design." In *Design Inverventions. Towards a more Human Architecture*, edited by Wolfgang Preiser, Jacqueline Vischer, and Edward White. New York: Routledge.
- Manzini, Ezio. 1997. "Leapfrog designing sustainability." *Domus* 01/1997 43–51.
- Mitrasinovic, Miodrag. 2008. "Universal Design" In *Design Dictionary: Perspectives on Design Terminology*, edited by Michael Erlhoff and Tim Marshall. Basel: Birkhäuser.
- Moser, Ingunn and Law, John. 1999. "Good passages, bad passages" In *Actor Network Theory and After*, edited by John Law and John Hassard. 196–219. Oxford: The Sociological Review and Blackwell.
- Papanek, Victor. 1971. Design for the Real World: Human Ecology and Social Change.

 New York: Pantheon.
- Shakespeare, Tom. 2008. "Opportunities and threats in Disability Studies" Paper presented at Life-Science-Governance Lectures, Universität Wien, Vienna, May 9.
- Siebers, Tobin and Bieling, Tom. 2013. "Disability Representation and the political Dimension of Art." *Baltic Horizons, No 21 (118), II. Social, ethical and political Aspects of Research in Design; October 2013.* Tallinn: Euroakadeemia EuroAcademy Series Art & Design 45–48.
- Wendell, Susan. 1996. *The Rejected Body: Feminist Philosophical Reflections on Disability*. New York: Routledge.
- Winance, Myriam. 2006. "Trying out the Wheelchair." *Science, Technology & Human Values 31(1)*, 52–72.
- Yelavich, Susan and Adams, Barbara (Ed.). 2014. *Design as Future-Making*. New York: Bloombsburry.