Without doubt, design today has to respond to the growing need of the elderly population and specifically those with dementia. Central to this is the question on how to include the person with dementia, their family and caregivers in the design process. Designing for and together with persons with dementia poses challenges for design educators, designers and researchers as traditional design approaches are sometimes not appropriate and may need adjustment. The Dementia Lab 2016 at Folkwang University of the Arts offered a perfect setting to discuss this. Rita Maldonado Branco took part....
Dementia Lab – The Role of Design. Reflections on Design Education, Research and Practice. Rita Maldonado Branco

Last month I had the pleasure of having been invited to speak at a two-day event about design and dementia. The common interest in what design can do for people with dementia and how to involve them in the design process brought together several design practitioners, researchers, educators and design students to the two-day event Dementia Lab: The Role of Design. Organised by Niels Hendriks and Andrea Wilkinson, from LUCA School of Arts, Belgium, and supported by the Robert Bosch Stiftung, the event was hosted by the Folkwang University of the Arts, in Essen, Germany, on the 14th and 15th September 2016. The two days balanced lectures from a varied range of speakers and case-study presentations in the morning with small workshops in the afternoon, to listen, share and discuss the challenges outlined in the call for participation: the involvement of people with dementia in the design process, design education focusing on designing for (and with) people with dementia and the reflection on the personal and professional impact of working for and with people living with this condition.

Lectures
The event opened with a presentation by the organisers of the event, Andrea Wilkinson and Niels Hendriks, about some of the challenges and their approach to involving people with dementia in the design process, based on four years of experience in working and guiding students to design for and with people with dementia. In their vivid talk, Wilkinson and Hendriks shared their way of working through clear key learnings, illustrating them with several anecdotes of what went right or wrong. In their approach, the person with dementia is central. There is an effort on developing an empathic, personal connection with the person, trying to step into the person’s reality, and to respond to it. This requires the acceptance that results are unpredictable, and therefore a flexibility to change one’s role, the project scope and set up, so that is possible to find
ways to involve the person with dementia, where objects and actions are crucial to communicate. Although focusing on the individual living with dementia, they have also stressed importance of considering and involving the ones around them (family and formal caregivers), and to make design happen in the context of care.

Helma van Rijn introduced the idea of creative understanding – the information, empathy and inspiration – which emerges from the direct encounters with people. Although empathy can be generated indirectly through literature or other references and imagination, the direct contact with people is more meaningful and allows collaboration to happen with non-designers. She reflected on the value of enjoying and getting inspired by the context of care, being open to what emerges from it, from funny mismatches or unexpected reactions, but also the importance of demonstrating the potential of design and the experiences it is able to provide in a context of care. According to van Rijn, it is essential to allow time to get familiar in the context, to observe and generate empathy, which also ensures ethics in practice.

John Vines’ lecture focused on the work with communities of care. Through the presentation of three projects that involved different communities of care, Vines discussed the role of the researcher in these project, both as a facilitator to trigger discussion within a community, as well as a resource that brings expertise and support on producing something that can enable necessary actions in a community. No toolkits or methods apply when working in these scenarios. The effort should be put in finding and building relationships with partners, engaging and taking the most out of the encounters with others, respecting their pace, as well as to think of the sustainability beyond the project.

The potential of objects as things to speak through was highlighted in Jayne Wallace’s talk. In her Personhood Project, probes became opportunities to enable participants to reflect, share their stories and their views, namely to the person with dementia. Inversely, objects or activities can be also important to allow participants to remain silent when needed. The very personal engagement with the participants made them feel at ease not only to respond to the exercises but to also comment on and evaluate them. This effort to give voice to people with dementia and their carers was also implicit in Wallace’s presentation, where several quotes from participants appeared to illustrate the projects.

Tommy Dykkes spoke about his ongoing PhD project and reflected on the role of befriending when designing for dementia. He shared his experience about his personal engagement with Jim, and how trying to take people with dementia out of their ‘loops of thought’ can become moments of meaning in their day. The use of artefacts can also have this ability to generate meaning for people with dementia in a context of care, which Dykkes demonstrated with two of his digital
artefacts—the *Paper Street View* and the *Digital Scrabble*. His work brought questions about the impact of these experiences for a designer both professionally and personally, as well as the value that design can bring to contexts of care, suggesting that designers could be embedded in these settings.

**Case Study presentations**

Workshops conducted by Andrea Wilkinson and Niels Hendriks, on working for and with people with dementia, in three German design schools, were presented as case studies. Nina Pillen (Folkwang University of the Arts), Stefanie Schwartz (Staatliche Akademie der Bildenden Künste Stuttgart) introduced their design education context, interests and approaches practiced in their schools, and how engaging in such workshop enriched and opened what they can offer to students. They highlighted the importance the input of Hendriks and Wilkinson. Their personal stories and guidance were crucial lower the fear and inspire the students. Pillen and Schwartz have also exposed some of the challenges of embedding this kind of projects in a more traditional design curriculum: the complexity and extra time of organising these projects, finding, dealing, meeting with partners and participants; the difficulty to guide students and specifically of working and teaching towards and open-ended outcome, since the commonly the format is given up-front in the design brief (for instance, students need to design a poster). Schwartz also pointed out that, mainly in more tradi-
"Why/How we design for and together with persons with dementia“, Andrea Wilkinson & Niels Hendriks (Social Spaces, LUCA School of Arts, KULeuven, Belgium)
tional design schools, there is a general lack of awareness of what design can do in the context of dementia, and other contexts of healthcare or social design, which hinders the engagement in such topics. These kind of projects could be better communicated and shared, so they can be examples and inspiration for new designers to work on these topics.

In addition to these accounts, it was very interesting to hear from Lasse Rosenfeld, a student at the BTK University of Art and Design, who spoke about his own experience in participating in this project, the initial fear of being ‘dropped’ at the institution, what triggered his attention to inspire and influence design ideation and how his idea evolved into a prototype, the results and reactions from trying them at the care institution and possibilities of being further developed into a product.

Workshops

In both afternoons, we were invited to participate in brief workshops that addressed issues of design education such as what characteristics should future designers have to respond to social topics such as dementia or what the design course of the future would be. In here, it was curious to see a focus on the human qualities and values, whereas more traditional design skills were slightly overlooked. Another workshop, as well as a funny ‘speed-dating’ activity, revolved around personal stories. These moments represented an important space to learn and bond with other participants, through sharing experiences and anecdotes of working with people with dementia. The last exercise proposed was to look at the sustainability of these projects that seem to happen frequently in academic contexts, where results and outcomes rarely evolve to become accessible, distributed or used. During a short-time, we had to think of how a business plan could work in this context, considering all the elements for its success (money, partners, resources, distribution, costumer segments and relationships, etc.) – which are left out of research projects concerns.
„The Designer of the Future / What does the designer of the future need to respond to real-world-relevant (social design) topics such as designing for and together with persons with dementia?“ (Workshop)
Round table

To finish the event, Catherine Stones moderated a round table with all the speakers. Catherine made a thought-provoking summary of what have been discussed on these two days: we spoke a lot of empowerment, play, conversation, stimulation, we brought our personal stories out, we mentioned the possibilities of generalisation and reproducibility, as well as the idea of personalisation, but we did not touch on more specific questions related to these like cost, durability, hygiene, etc. She drew attention to the need of rigour, and questioned about measurement and evaluation, and impact. This specific aspect generated an interesting discussion about the use of quantitative and qualitative evaluation. On the one hand, looking at these projects quantitatively will not reveal the richness of the work, the interactions, the meaning, thus a qualitative analysis, through elaborated case studies for instance, seems to be more appropriate for these cases. On the other hand, this makes it challenging to communicate and to make these projects sustainable and accessible to people. It seems to be a delicate balance, and we should find suitable ways to evaluate and reveal the value of our work and, in this way, have an impact.

"The Sustainable Future / What kind of system enables the designer of the future to work in a sustainable context?" (Workshop)
Going back to the main points for reflection of Dementia Lab, design education focusing on designing for (and with) people with dementia was discussed by Niels Hendriks and Andrea Wilkinson who presented their approach, but mostly during the case study presentations, where the values and challenges of engaging students in such projects were highlighted, and in the two of the workshops, where the designer and the design course of the future were brought to debate.

The challenge to involve people with dementia, as well as their communities of care, was primarily addressed by the speakers, mostly from a design research perspective. Although a wide variety of approaches, methods and results from several projects were presented, the respectful and open attitude, the emphasis on empathy and personal engagement, the effort to find ways to communicate through the use of objects and activities seem common aspects in the different ways of working.

Many of the speakers also reflected on the professional and personal impact of working with and for people with dementia, but this was also the common theme of informal conversations during breaks, through sharing impressions, stories, projects, which was one of the most interesting aspects of Dementia Lab. This brings me to reflect on the fact that this event was so specific. Usually, in design research, but also in more commercial contexts, we attend conferences that are within our field, but still quite broad. In this case, participants were committed, had plenty to share, common views and approaches. The specificity of Dementia Lab permitted this rapport to happen.

A publication about Dementia Lab is expected to be published in early 2017 and more information about the event can be found at www.dementialab.com

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