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Research paper

Care in the (critical) making. Open prototyping, or the radicalisation of independent-living politics



Le care dans le faire (critique). Prototypage ouvert ou la radicalisation des politiques de la vie indépendante

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ABSTRACT

In this paper, we reflect empirically on some collective attempts at intervening the ways in which care for and by disabled people is being devised and carried out in Spain in austerity times. We highlight the novelties and challenges of the way in which these projects seek to tackle the current crisis of care through different forms of self-fabrication of “open” and “low cost” technical aids. We analyse them as forms of “critical making” expanding the repertoire of independent-living and disabled people’s rights politics to the experimentation with technological production. Through the deployment of an empirical example of the prototyping process by the Barcelona-based activist design collective *En torno a la silla*, we show how open prototyping constitutes a major challenge for the radicalisation of the independent-living movement’s precepts of control and choice, displaying the matter of care arrangements and making available its transformation.

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Dans cet article, nous réfléchissons empiriquement sur certaines tentatives collectives d'intervention dans le *care* pour et par les personnes handicapées en période d'austérité en Espagne. Nous mettons en évidence les nouveautés et les défis de la manière dont ces projets visent à aborder la crise du *care* grâce à l'auto-fabrication d'aides techniques « ouvertes » et « low cost ». Nous les analysons comme des formes de « fabrication critique » élargissant le répertoire des politiques de la vie indépendante et des droits des personnes handicapées à travers l'expérimentation de la production technologique. En montrant l'exemple d'un processus de prototypage du collectif *En torno a la silla* à Barcelone, nous essayons de décrire comment le prototypage ouvert constitue un défi majeur pour la radicalisation des principes du mouvement de la vie indépendante – le contrôle et le choix –, en déployant la matérialité des arrangements du *care* et en permettant sa transformation.

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1. Introduction: developing independent-living advocacy in Spain

The independent-living movement developed recently in Spain. In 2001, a lively small group of activists created a mailing list to promote the right of disabled people to independent living in the country. Their challenge was to intervene an institutional and political context dominated by Christian charity and the medical-individual model of care, organised around huge sectorial disability associations managed on the most by relatives or professionals (Maraña and Lobato, 2003). Contrary to that, the Independent Living Forum (*Foro de Vida Independiente*) as it was originally named sought to create a virtual community organised around the values of direct participation, self-management, experience-based knowledge, as well as the promotion of disabled people's rights through practices of empowerment and the fight against discrimination. Translating the motto and the philosophy of “nothing about us without us”, this small but hugely influential group was responsible for the creation in 2006 of the first Independent-Living Offices, pilot projects funded by municipal or regional administrations, to self-manage personal assistance in Barcelona and Madrid – the notion of “centre” in Spanish resonates with residential homes and was thus avoided –. They also succeeded in claiming the right to personal assistance in the debates surrounding the *Law 39/2006 for the Promotion of Autonomy and the Assistance of Dependent People*, a legal enactment they fiercely countered because of its “ableist” groundings. And, more importantly, they managed to create a new conceptual framework around what they call the “diversity model” (Palacios and Romañach, 2006; Palacios et al., 2012; Romañach, 2009).

In contrast to the social model of disability (Oliver, 2013), the *diversity model*¹ does not revolve around “dis/ability” but stresses the dignity of all human diversity (Rodríguez-Picavea, 2013). This shift is underpinned by the concept of *diversidad funcional* (functional diversity), coined in 2005 as

¹ This model has been developed by Spanish activists as a result of online debates about the experience of disability, and has entailed the production of a vernacular form of *Disability Studies* in the country. According to Javier Romañach (2010), one of its most prominent authors and activists, the *diversity model* is an extension or evolution of the social model of disability (Oliver, 1981). Drawing on a humanist approach, the model of diversity poses “functional diversity” as another form of “human diversity” and, hence, its advocates defend that all diverse human lives should be treated according to the same legal, moral and bioethical values (Lafaye and Romañach, 2010).

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