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## **DESIGN FOR PEOPLE'S AUTONOMY. RIGHTS TO INDEPENDENT LIVING**

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## EDITORIAL

# Design for People Autonomy

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In the last years the debate related to people autonomy has been investigated in different fields of research and experimentation, starting from the relationship between personal autonomy and well-being, the ability to make decisions freely, the affirmation of one's right of choice, (the right to political participation, access to justice or the right to have a family) for the self-determination development (i.e. legal capacity), but at the same time "autonomy" can be interpreted as a complex result of human relationships, strengthening interaction and opportunity. This is valid for everyone, regardless of their health condition or functional limitations; in fact, no human being can be considered completely "autonomous" since everyone acts in a condition of interdependence with others to varying degrees.<sup>1</sup> This last aspect is particularly significant for people with disabilities, because it affects their active involvement in the life of the

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<sup>1</sup> Ruth Northway, "Ethical Issues," in *Learning Disabilities-E-Book: Towards Inclusion*, ed. Helen Atherton and Debbie Crickmore (Churchill Livingstone: Elsevier Health Sciences, 2011), 75–88.

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community in which they live, and their ability to lead an independent life. The concept of independent living was introduced in the Article 19 of the Convention on the Rights of Persons with Disabilities (CRPD) and it is therefore closely connected to the citizen's rights of disabled persons.<sup>2,3</sup> The World Bank (WB) and the World Health Organization (WHO) estimate that a billion disabled people in the world face some barriers in the inclusion in many vital sectors, such as mobility, job, education, or simply in being socially or politically involved during their everyday life. However, the right to actively participate in the public life and reduce disparities are core elements of a stable democracy. Accessibility is intended as empowerment, meaning the individual and collective awareness of the right to access goods or services within one's own community.

Some important milestones have been reached: in the 2006 with the United Nations *Convention on the Rights of Persons with Disabilities*, the adoption of *The European Disability strategy 2010-2020*; the 2011 biopsychosocial model of disability principles by WHO & WB; the adoption in 2019 of the Agenda 2030 by European Union in which "people with disabilities" are specifically mentioned 11 times, especially in the parts related to education, growth and employment, inequality, accessibility of human settlements, as well as data collection and monitoring of SDGs.<sup>4</sup> This progressive process towards the recognition of the rights of people with disabilities helps a paradigm shift necessary to ensure independent living.

Two main concepts emerged and offered new perspective of innovation and development of strategies and measures for the Design for People Autonomy: the deconstruction of the concept of disability as a social category, considering also that the limit between ability and disability is subject to temporal and environmental variables: the increasing incidence of people with disabilities, also as a consequence of diagnostic and therapeutic progress in the medical field, the relationships between chronic diseases and disabilities, the increase in risk factors related to unexpected and sudden phenomena (e.g. climatic disasters, COVID 19) and that can affect the entire population; the need to apply instead of special policies, universal policies,<sup>5</sup> in all areas of society.

Accessibility, autonomy and inclusion are such cross-cutting societal issues that the biggest impact is achieved if they can be mainstreamed and implemented in programmes such as youth, gender, education,

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2 Raffaello Belli, *Vivere eguali. Disabili e compartecipazione al costo delle prestazioni* (FrancoAngeli, 2014).

3 ENIL (European Network on Independent Living), CIL (Centre for Independent Living) Sofia and Rusihak, *Independent Living Manual*, December 2015. <http://www.enil.eu/wp-content/uploads/2012/06/Independent-Living-Manual-FINAL.pdf>

4 United Nations and Department of Economic and Social Affairs, *Disability and Development Report: Realizing the Sustainable Development Goals by, for and with Persons with Disabilities: 2018, 2019*.

5 Irving Kenneth Zola, "Toward the Necessary Universalizing of a Disability Policy," *The Milbank Quarterly* 83, no. 4 (2005). <https://doi.org/10.1111/j.1468-0009.2005.00436.x>

employment, education and public and private service, thus safeguarding the “no one is left behind” principle.

Re-reading the principle: “Disability is part of the human condition because almost everyone, at some point in their lives will experience temporary or permanent disabilities”<sup>6</sup> in the light of the COVID 19 Pandemic experiences and the post-pandemic perspectives, highlights how overcoming cognitive, communication and physical isolation barriers is a necessity for the whole population. The opportunity to intercept needs related to large segments of the population then becomes a boost to the definition of responsible measures to counter the effects of the epidemic on a social and economic scale. For example, work-from-home policies to ensure that all workers (with disabilities and not) have appropriate adjustments at home; the need to provide the non-expert public with tools for their reading and interpretation of information and data, possibly free from prejudices and stereotypes; the physical distancing in public spaces that adopts new lengths to facilitate movements and flows also for people with disabilities, the digitalization of services and the use of enabling technologies to foster the fruition of health, culture, education contents remotely, etc.

An enlarged definition of “universal accessibility” implies the adoption of an integrated design approach involving the public realm of the city avoiding a use strictly linked with population groups while supporting a more inclusive mixed-use strategy.

The researches and the practices presented in this issue of CPCL describe accessibility and autonomy topics through the lens of fields of investigation and experiences in different environments, giving examples of theoretical and practical work. The contributes explores the concept of accessibility as a design tool, capable of translating individual and collective instances, needs and topics into design elements for new services, products, use of the spaces.<sup>7</sup> An approach that goes beyond the logic of a simple cause-and-effect sequence to take into account the complexity, leaving precise metrics to accept a development by successive approximations placing the user (the citizen) at the core of social life and public realm definition.

Some contributes narrate the progressive implementation of accessible community-based services (transport, healthcare, culture, leisure), adequate for the needs of the disabled but also for the needs of all

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6 World Health Organization, *World Report on Disability* (Geneva: World Health Organization, 2011).

7 Marilyns Christofi, “Trade Union Education Management Disability Movement: Accessibility and Disability,” (Athens: 2013). Available at: <http://www.esamea.gr/Publications/Books-Studies/496-Ekpaideytiko-Egxeiridio-No-4-Prosbasimotita-Kai-Anapiria-Tis-Marilys-Xristofi>.

citizens,<sup>8,9,10,11</sup> removing in many cases “dedicated” structures and segregated services, for a barrier-free environment suitable for satisfying the citizen’s well-being in an equitable manner and in mainstream settings.

Part of the academic papers focus on social and physical factors that influence the independent living of vulnerable people (autistic adults, elderly). In the first case, the contribution of KU Leuven research group investigates the role of the housing environment in the life setting and real experiences of people on the autism spectrum and the design of possible solutions.

The integration of enabling technologies, digital devices and automation, and the relation between the autonomy goal and the rethinking of private houses, are presented both in the paper written by the contribution of Adolfo Baratta, Antonio Magarò and Fabrizio Finucci which presents an integrated house device system low cost and open source to support elderly in their daily practices, and also in the contribution of the University of Ferrara research group. In this case the paper describes the potential of IoT application in commonly used objects, not only to facilitate their usage, but also for monitoring elderly movements, preventing domestic accidents or difficulties in use.

Enabling technologies’ role in the improvement of vulnerable people’s life experiences is also the object of the Information Technologies Institute in Greece research group: in this case the integration of AI powered systems especially in the identification of people and objects facilitate the use of spaces and facilities by visually impaired people.

The “Practices” area of this CPCL edition is a collection of research-actions’ results in which the processes designed have the same importance of the achieved results. All these cases are designed and realized in collaboration with different vulnerable groups of people, but they have an accessibility impact on the whole target groups of museums, historic city’s areas, marginalized neighborhoods, cultural facilities at urban scale. All these practices offer the opportunity to explore, with a prototyping approach, the translation of needs, requirements, individual and collective arguments, experiences, gathered in any case adopting collaborative approaches with the communities, into new services, products and new uses related to the city, to Cultural Heritage, to cultural contents, etc.

For example, the experiences in Bologna and Barcelona represent the opportunity to extend the “right to the city” and to its contents to all citizens,

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8 Adolf Ratzka, “Independent Living for People with Disabilities: From Patient to Citizen and Customer,” *GLADNET Collection*, 2007.

9 Antonio Lauria, *I piani per l’accessibilità. Una sfida per promuovere l’autonomia dei cittadini e valorizzare i luoghi dell’abitare*. (Roma: Gangemi, 2012).

10 ENIL (European Network on Independent Living), *Myth buster. Independent living*, December 2015.

11 ENIL (European Network on Independent Living), CIL (Centre for Independent Living) Sofia and Rusihak, *Independent Living Manual*, December 2015.

starting from fragile people inclusive design, putting in evidence the necessity to foster culture democracy, autonomy and self-determination.

In the case of Bologna, the practice described by Foundation of Urban Innovation group focuses on the development path started as pilot collaborative labs and service prototyping that led to the candidacy of Bologna to the Access City Award 2020. While in the case of Barcelona the accessibility design promoted by in a marginalized neighborhood is the occasion to remove physical and social barriers among the local communities.

The Architect Fornasari in his paper renders the paradigm shift from the disability of the person to the disability of the environment, highlighting how favorable contexts and responsible solutions can mitigate the social exclusion of fragile people to the fruition of museums and cultural spaces.

The necessity to consider culture intellectually, culturally and socially accessible is the core theme of Cecile Houpert and Anthony Colclough article. The specific focus is on the relevance of cultural offer for the culturally diverse groups that coexist within a city, through the adoption of multiple languages, different forms of communication and dissemination, adjusting the offer itself, enriching for instance the museum experiences for every visitor.

Furthermore, cultural accessibility and the importance to promote an accessibility training for art and culture sectors are the main topics of CRT Foundation of Turin, which narrates the building of a training program for museum operators promoted adopting peer-coaching, learning labs, born as an initiative under the European Year of Cultural Heritage of 2018 and currently applied in the whole museum system of the city. The training program supports the transition from the right to cultural enjoyment to the right of cultural production.

In all the issue the concept of accessibility as a design tool has been explored, transforming specific instances in universal services and solutions to foster a collective fruition of common goods, to reaffirm the right to an independent life by vulnerable groups of people, and to experiment new tools (technologies, digital devices) as enabling elements of life setting and self-experiences.

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