Synopsis

INTEGRATIVE SOCIETIES AND DISABILITY:
OPEN AND SMART CITIES FROM SOCIAL SCIENCES

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ON DISABILITY: RIGHTS IN OPEN, SMART CITIES

According to the World Health Organization, more than 1 billion people (15% of the global population) have some sort of disability, 150 million of which have serious difficulties.

A disability isn’t defined as solely a physical limitation, but more broadly as a restriction to participating in society. In this complex landscape of often unmet needs, evolving cities and emerging technology offer up new opportunities for integration, but also difficulties that are hard to identify and overcome. People with disabilities are seeking empowerment to reclaim the rights they are due.

To discuss the current panorama and future challenges and opportunities, national and international experts and representatives called together by Institut Guttmann and the Institute of Government and Public Policy (IGOP-UAB) met for a session of B-Debate—an initiative of Biocat and the “la Caixa” Foundation to promote scientific debate—, on the conference ‘Integrative Societies and Disability: Open and Smart cities from social sciences’.

CONCLUSIONS

- Disability is a social construct that encompasses a certain symbolic violence and barriers that are often invisible.
- People with disabilities are seeking empowerment to ensure their rights are respected, without the need for third-party paternalism.
- Technology can help overcome physical and social barriers, but it must target specific problems.
- Smart cities are an opportunity for inclusion, although they also run the risk of widening the digital gap.
“Disability is a social construct,” explained Leonor Lidón, professor at the Valencia Catholic University. This is because, beyond injury, it encompasses barriers. And these may be direct or indirect, physical or mental.

“There is often a symbolic violence in the disability,” she added. “When we look at the Venus de Milo—an armless statue—we see a work of art. But when we see a swimmer with no legs or arms, our attention is immediately drawn to what is missing.” Symbolic violence and indirect barriers can sometimes lead to a false sensation of inclusion.

“For the needs of people with disabilities to have an equivalent in reality, it is key to ask them, understand first-hand what they need,” explained Facundo Chávez, advisor to the Office of the United Nations High Commissioner for Human Rights. “Cities are being redesigned and will end up being home to more than 80% of the global population. But how can we integrate all the people with disabilities?”

One of the possibilities lies in the concept of “universal design”, a way of developing environments that allows for the greatest accessibility for the greatest number of people. “But there is a problem with this sort of design,” Chávez added, “because you can lose sight of the individual, of each person’s specific needs.” This is why Chávez advocates for a reasonable adjustment to correct for the possibility of ending up with a magnanimous design, with the best possible intentions, that doesn’t actually work when applied in real situations. A bit like Churchill’s response when asked what he thought of the French, as Director of the European Connected Health Alliance Joan Cornet mentioned: “I can’t say, I don’t know them all.”

Other players involved were also mentioned. Technology is a basic tool for meeting the needs of people with disabilities, “and States are the ones that mobilize resources. We need them to act, and for technology companies to respond to this need,” said Chávez.

“We’re talking about rights, industry, individual care, etc.,” said Sara Rodríguez, president of Federación Provincial de Asociaciones de Personas con Discapacidad Física y Orgánica de Córdoba (FEPAMIC). “It seems like we all agree, and we’re just thinking about how to reformulate the message so it arrives, so it makes it through the wall.”

“Speaking has an impact,” stressed Karen Heinicke, senior advisor at CBM.
“People with disabilities should empower ourselves to make sure our rights are respected, and I'm not sure we've done that,” said Josep María Solé, lawyer and head of Foundation Girona Guardianship. “On many occasions, people with disabilities don't have a voice. Those around us speak on our behalf, with the best intentions but often misguided paternalism. It's partially our fault, because we aren’t aware of our rights so we can’t exercise them.”

Solé stressed the tendency towards care that turns to institutionalization instead of individual action in the community. For example, “a mental patient in Catalonia gets €500 if they live at home but €2,000 if they are in a care center.” Fernando Fantova, an independent social-services consultant in Bilbao, believes the pyramid of social protection is changing. Before, social services were the end goal, with no importance given to any of the other elements of the system, and people with disabilities had to make do with finding a place there. Now, ”They want to be full citizens with all their rights. They demand to break free from a state whose social services took those with disabilities from cradle to grave and move towards one that is more inclusive and transversal in terms of diversity.” As explained Margarita León, of the Institute of Government and Public Policy (IGOP-UAB), “It’s too easy to just talk about healthcare. It’s complex and must all be interconnected.”

Gary Bourlet is the co-founder of the Learning Disabilities England initiative and has been working to defend the rights of people with learning disabilities for more than thirty years now. After often being rejected by society, as he explained in an interview in The Guardian (in which he remembers how he was kept away from other children for fear they would catch his epilepsy), “We want people to speak for themselves on the topics that concern them. We want to have the same rights to be seen, to vote, to be included, to have the same opportunities in social life, in education and in employment as everyone else.”

Some of these opportunities come from technology, which “has revolutionized communication and participation,” but it also has a negative side. Among other things, because “many people with disabilities can’t afford it or don’t have the support to be able to use it, and because technology isn’t a substitute for human contact.”
3. TECHNOLOGY: ACCESSIBILITY, APPLICATIONS AND SMART CITIES

Technology is an essential tool for inclusion. It is everywhere these days and its design and implementation can and should be geared towards breaking down social and physical barriers of all sorts. And it is the basis of smart cities, a hope for integration that is not without its own risks.

Tomás Sánchez, researcher at the Munich Center for Technology in Society, presented one of the projects from the group “En torno a la silla” (Around the chair). It is a series of do-it-yourself co-creation workshops that allow people with disabilities to make their own low-cost, personalized solutions, while also giving them a place to interact. The question is how to implement the initiative on a larger scale. “Probably one option would be to get support from the Fab Labs,” commented Sánchez. “And an additional challenge is to bring designers into the specific problems of each of these people,” he added. Because as mentioned Nicolás Barbieri, researcher at the Institute of Government and Public Policy, paraphrasing Leonard Cohen in a video from the same group: “Any system you contrive without us will be brought down.”

Other ways of applying technology to benefit people with disabilities come from using their own medical records. This is the aim of the QVIDLAB project at Instituto Guttmann, presented by Joan Saurí. By collecting and analyzing large amounts of information on health and quality of life from patients undergoing neuro-rehabilitation, they aim to generate data that can be applied to clinical care and social innovation.

“I don't know if introducing information technology in our lives is exactly progress,” said Jordi Tolrà, head of mSocial. “The debate lies in how to use it to make sure it is.” Tolrà presented several mobile apps designed to boost inclusion. One was developed by the Arrels foundation for the homeless so people can send a notification when they see someone sleeping rough. “The challenge is to empower the homeless. Many of them have mobiles and could easily access information and services and decide what to do on their own.” Another is the Vincles project for the elderly who live alone, giving them a way to contact others in their personalized circle of contacts, who they choose and trust.

There are also apps that help read instructions for medicines on a mobile when the writing is too small, as explained David Zanoletty, manager of the ONCE Foundation
Department of Accessible Technology. Even “meta-technology” projects, which aim to identify the best model of mobile for people with specific needs.

The generalization of technology is the basis of smart cities, understood as sustainable cities that use information technology and connected structures to address the needs of institutions and residents. **Barcelona aspires to become a “digital city”,** as commented Anna Majó, technical director of Digital Innovation at Barcelona Activa, citing projects like **Decidim Barcelona**, which aims to improve the quality of democracy and municipalism.

These concept cities offer many opportunities, as explained Giorgia Nesti, professor at the University of Padua. They should, in principle, foster business development, sustainability and participation. And they would allow for an approach to urban policy that includes fostering inclusion. **But they aren’t free of risks.** “They could widen the digital gap, foster an excessively neoliberal ideology and lead to fragmentation,” she warned. This is why we must adopt “a paradigm of cooperation among the parties involved, encouraging their participation, voice and responsibilities.”

The goal should be no less than full inclusion, said Luz Zelderloo, secretary general of the European Association of Service Providers for Persons with Disabilities (EASPD). “When we speak of a target of 95% accessibility, I like to say it would be like building 1,000 kilometers of roads with 5 kilometers of interruptions.”