

# **We Are Here to Transform. We Want Everything. We Demand Desire.**

**Antonio Centeno Ortiz**

*“Do you imagine what it would be like to include in the hitherto narrow territories of desire and pleasure all bodies, all forms of moving, feeling and understanding? Here seems to be a pending revolution. We speak about revolution because it dynamites the hetero-patriarchy that hijacks our bodies and desires at the service of capitalist reproduction; a revolution because it claims pleasure for the abject bodies, the same bodies that are unproductive for that capitalist system.”*

*The documentary Yes, we fuck! by the filmmakers Antonio Centeno Ortiz and Raúl de la Morena captures six stories about the sexuality of people with functional diversity that challenges how we build relationships with our own bodies and with others through desires and pleasures in a scenario of capacitive and sexist oppression.*

*In the following text, originally presented during the “Parliament of Bodies” at Bergen Assembly 2019, Antonio Centeno Ortiz takes a closer look at the cost of ableism, political failures, the situation in Spain, and the Politics of Desire that his filmmaking is reflecting on. As he puts it: “The representation of sexuality is important not so much because it shows a reality but because it builds it.”*

Those of us with functional diversity know very well that the parliamentary system does not work, and it is high time that everyone knew. In Spain, along with other instances of daily violence, hundreds of thousands of people remain locked up in institutions, and nobody is held accountable for this permanent breach of the law: there are no judicial or political consequences. How is this possible? What is failing with the apparently irrefutable logic of representative democracy? What solutions are there? I would like us to discuss the possible causes for the failure of the system and its alternatives.

Firstly, the lack of material support for living, such as personal assistance, universal accessibility, and inclusive schooling, keeps people with functional diversity living in a parallel universe, confined to residencies, special schools, centers of special employment, occupational centers, et cetera. Good intentions, prejudices, and social inertia isolate us and transform us into extraterrestrials for the majority of the population, who have practically no interaction at all with functional diversity. This general situation of segregation generates a politics of “everything about us but without us.” The political participation of people with functional diversity is prevented and those who claim to represent us lack the vital experience of any aspect of our reality. It is not surprising that they want to believe that the issue of functional diversity is a purely technical one. Yet what is the use of putting ramps in every nightclub if no one wants to dance with us? We have to understand that we are facing a general situation of discrimination and oppression; we need to value the slogan of the Independent Living Movement, “Nothing about us without us.” From this perspective, locking us up in institutions or supporting our families so that we become dependent on them is not a part of the solution—it is a part of the problem.

Ableism is expensive, and those who pay for it are primarily those of us with functional diversity. However, the rest of society also foots the bill. We know that including difference in any field is an engine of social transformation that improves life for everyone, while exclusion implies a great loss of opportunities to live better lives. The clearest examples of this are schools, which have better pedagogical tools for all students;

transportation, which is safer and more comfortable for everyone; and architecture and urbanism, which have become more user-friendly for the population as a whole. Given the seriousness of letting this opportunity slip, especially considering the fact that we are living longer and surviving increasingly more diseases and accidents, it should be noted that we pay the highest price in terms of gender. The entire disability and dependency industry functions on the basis of mandatory care by women in the family. The lives of this army of slaves have no value. Meanwhile, the spreadsheets of the public authorities say this work is free. As soon as we understand, as [the Spanish poet] Antonio Machado once said, that “it is foolish to confuse value and price,” then we will realize that ableism is unsustainably expensive.

## *We need to reclaim our bodies and our lives for ourselves*

That is why the independent living model is so interesting. Because it proposes participation and cooperative living. “Independence” is a historical term, which refers not to doing things for ourselves without support, but rather to having the responsibility and freedom to manage the necessary support, thus avoiding situations of dependency. That is, there is a shift in decision-making from the family members and professionals to the person with functional diversity. This means recognizing one’s own autonomy as a result of interaction with others in similar conditions of responsibility and freedom, without relations of domination. Ultimately, we are talking about “interdependence,” although for historical reasons we maintain the word “independence.” It is through this interdependence that both direct participation in politics and cooperative living are possible. We need to reclaim our bodies and our lives for ourselves and stop being extraterrestrials to everyone else.

Often, attempts are made to discredit the independent living paradigm as elitist and economically unsustainable. It must be said that seeing oneself as oppressed



Antonio Centeno Ortiz and Raül de la Morena, Filmstills from *Yes, We Fuck*, 2015



and claiming one's freedom entails a process of empowerment that calls for a certain level of "passing" as "valid"—something that almost always has to do with capacity, class, race, and gender privileges. Nothing new under the sun, the same has always happened across liberation movements. The point is that from this awareness of having privileges, a political process can be articulated—one that is for everyone and is coherent in theory and viable in practice. In this sense, it is important to understand that people with intellectual or mental diversity make decisions in their own ways, with the necessary support. Usually, in collaboration with their guarantor and circle of support, they define a map of decision-making: what they can decide for themselves, what they decide with the support of their assistants, and what they decide through interpretations of their will. Thus, when we talk about deciding, it is implied that we mean that everybody does it in their own way: the independent living model is also for people with intellectual or mental diversity. With respect to the economic issue, all of the experiments and studies indicate that locking us up in institutions is far more expensive than supporting us in our communities with the necessary personal assistance. They don't lock us up for the money; they do it because of their principles.

Indeed, if the laws emanating from parliament, albeit deficient, formally recognize the right to independent living for people with functional diversity, and if the pilot experiments and studies certify that this is possible to implement in a socially and economically sustainable manner, then why do they keep confining us to institutions?

Because there are other more powerful laws, unwritten laws, those that through culture, art, and the media inform us of what the world is like and how we should behave. In addition, these unwritten laws are reinforced without the counterweight of a cooperative living context. The story that is told about functional diversity has been distorted and stereotyped through "everything about us but without us." Only the "absolutely miserable" are represented (in Spain, the film that won the most Goya awards is *The Sea Inside* [2004]). On the other hand, we have "the heroes who surpasses themselves and become inspiring, thanks

to the help of 'normal' people" (in Spain, the last winner of the Goya award for best film was *Champions* [2018]). The first justifies restricting personal freedom, which is what occurs when they lock us up in institutions. Meanwhile, the second blames the person with functional diversity for their situation: if they are suffering, it is not because of discrimination but because they haven't been trying hard enough.

This biased, stereotyping, and polarizing cultural representation of functional diversity also incorporates a permanently infantilizing and asexualizing gaze. And of course, if we are seen as children, then we will be treated as such. An idea is constructed around us that our families are responsible for us and that this dependency is natural. That is why it is necessary to sexualize functional diversity, in order to repoliticize it. The more we become visible as sexed and sexual beings, as desiring and desirable bodies, the more difficult it will be to keep treating us like children, and if we are not children, then it is not natural for us to depend on our families. These situations of dependence are a political question regarding how we organize ourselves collectively to make possible all forms of autonomy, including that which consists in doing daily tasks and making decisions with the hands of another person. This kind of autonomy requires figures of support, such as personal assistance and sexual assistance. The latter, defined as support in sexually accessing one's own body, is key in the process of sexualizing functional diversity. Not because this is our way of experiencing sexuality, but because establishing a relationship with one's own body through desire and pleasure is essential for constructing links of all kinds with others.

It is common now to hear about the debate on whether sexual assistance is a right or not. Those who are against it argue, among other things, that it is not a right as it does not respond to a need. "You can live without sexual pleasure," they say. This is a conception of rights that is disturbing at the very least. My father, who was born poor into the period of fascism, never went to school. So yes, you can live without education. But do we want to live without education? This seems to me the key question: Do we do politics from the perspective of "what I need" or "what I

want”? The politics of need responds only to fear, as in “I cannot live without this thing,” and it removes responsibility by presenting this need as a natural law that exists externally to the person. Perhaps it is time to activate a politics of desire—“What do I want?”—as a means of creating responsibility and forming personal and social commitments.

This kind of politics of desire requires an ethical commitment around one’s own desire. First we must ensure that our desires are definitely our own. Do we want to accumulate capital or do we want to live with dignity? It is essential to build an erotics of dignity, placing it at the center of any desire we construct. On the other hand, we should question our experience of desire. Sometimes, it might seem that the only sense of desire rests on its becoming pleasure, which we might achieve by applying a series of techniques each time. But this would be a dead and repetitive form of desire, unable to move everything necessary to face the complexity of living. We need the feeling of desire to become a form of pleasure, so that the disjointed segments that place desire and pleasure at opposite

ends become virtuous circles wherein desire and pleasure feed each other, keeping each other as alive as everything they answer to.

Finally, we need to know who we are, and who we can count on to open up experiences across this politics of pleasure. From the outset, there are many of us who share vital experiences of having been crushed by the politics of fear and its normalizing mythologies. Women, the LGBTQ+ community, the fat, the mad, the racialized, the people with functional diversity, et cetera. Those who have lived the brief reverie of normality will wake up abruptly when age, illness, or other circumstances expel them from this plastic paradise. So the alliance is open to anyone. Our differences have been pathologized and stigmatized, with a small section of society reserved for us where we are “tolerated,” as a final destination. But we know that nothing but desire is enough. Everything that is not desiring us is assimilationism.

**We are here to transform. We want everything. We demand desire.**

