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“Tensions and escapes in independent living infrastructures for people with disabilities under Covid-19”

Authors:

Joan Moyà-Köhler – Universitat Autònoma de Barcelona – joan.moya@uab.cat

Andrea García-Santesmases - Universidad Nacional de Educación a Distancia - andrea.gsantesmases@der.uned.es

Lluvi Farré Montalà - Universitat Oberta de Catalunya - lfarremo@uoc.edu

Abstract

The COVID-19 pandemic highlighted the structural deficiencies of residential care homes. In this context, living arrangements based on the independent living paradigm emerged as more resilient care infrastructures in terms of preserving life. But what kind of lives have they preserved, and who has decided what forms those lives took? Drawing on an ethnographic study of two care infrastructures –one for people with physical and one for people with intellectual disabilities living independently in Barcelona–, the present study illustrates how the pandemic tensioned and unleashed escapes within these two services, revealing them as post-institutions working under logics of bureaucratization and hospitalization. This in-depth study allows us to delve deeper into the constraints that post-institutional models present, at the time that explores the possibilities these projects provide in continuing to work towards the promotion of self-organisation and full participation of people with disabilities in the becoming of their life projects.

Keywords: Disabilities, Learning Disabilities, Independent Living, Covid-19, STS, Care Infrastructures.

1. Introduction

Luis and Michel are two users of care infrastructures self-defined as independent living projects. Luís is part of the project *Anar a Casa* (AC), a service for people with learning disabilities in Catalonia. Michel is an inhabitant of City Living (CL), a project for people with physical disabilities in Barcelona. Both, Luis and Michel, were two of the 800,000 people denounced for breaking the rules imposed during the 14 March–2 May lockdown in Spain. According to support workers from both institutions, they “escaped”.

Luis “managed to go to meet a girl” in the middle of the lockdown “because he couldn’t stay at home anymore and he felt overwhelmed; he was going through a complicated time”, explained Anna, his support worker. Michel took advantage of the fact that he was allowed to go out to smoke at the front door of the facility and went down the main street with his automatic wheelchair one evening, shouting that they were “locked up like in Guantánamo”, according to several of the professionals interviewed. The CL director explained that Michel “had a psychotic breakdown, and that is why he is no longer in CL. He needs care that we cannot give him here”.

But, regardless of the specific motivations that drove both residents to break the confinement rules, we want to reflect on who defines what an escape is, and, above all, what underlies the idea of escape. It is usually understood that people escape from danger or enclosure. So, in projects based on promoting independent living, for which the idea of “living (as) at home” is essential, what do these escapes reveal? Under what conditions would someone escape from his or her home?

The present study takes the physical and intellectual disability services—two domains that are rarely researched and discussed together (Oliver & Barnes, 2012; Shakespeare, 2013)—to examine how these independent living projects reconfigured their daily care practice to adapt to the measures and restrictions imposed by the pandemic. These concrete adjustments, resulting from an exceptional period, help us to understand a deeper institutional dynamic in dealing with risk, vulnerability and autonomy. We know that

independent living infrastructures, as opposed to residential care homes and other large institutions, have been more successful in preserving life, but what kind of lives have they preserved, and who has decided what forms those lives took?

From here this paper introduces the Independent Living scenario in Spain and the challenge emerged with the Covid-19 pandemic. Thereafter, the theoretical and methodological starting point will be described, followed by a detailed explanation of how the pandemic has impacted on the two analysed care infrastructures. To conclude, the tensions, escapes and resistances faced by both services are discussed together.

2. Independent Living in Spain and the Covid-19 outbreak

The Independent Living Movement, which was born in the United States between the '60s and '70s, has been developing in Spain since the first decade of the current century under the influence of the approval in 2006 of the Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2006), and article 19 in particular. Thus, the *Foro de Vida Independiente y Diversidad* (FVID) was created, a community that advocates first-person participation, distanced from the protection of traditional disability organisations. One of the main commitments of this group is the theorisation of a new term: *functional diversity*¹. This seeks to underline the idea that all people have different "ways of functioning", but only some (i.e., those with disabilities) are defined and discriminated against because of their differences.

One of the political achievements of FVID was the creation of the first Center for Independent Living in Barcelona and Madrid, small spaces for the promotion and self-management of the Personal Assistance. Thereafter, with the advent of the Law for the Promotion of Personal Autonomy and Care for Dependent People in Spain in 2006, multiple initiatives that followed the principles of independent living began to appear, gaining special strength in new areas such as learning disabilities or autism and hybridising with other related fields, such as ageing or health. It should be noted that these bifurcations and openings have placed a strain on the more activist and self-managed ways of understanding

independent living, as Rodríguez-Giralt et al. (2023) has shown. The report's authors noted that the expansion of the concept of independent living has led to a lack of a mutually agreed upon definition and mechanisms to ensure the implementation of the concept (as laid down in the CRPD).

In this context, the outbreak of COVID-19 highlighted the importance to promote and consolidate these new care infrastructures based on independent living principles. The pandemic revealed structural deficiencies of traditional institutions, such as large residential institutions for older people and people with disabilities, and their role in sustaining their users' lives. Evidence can be found in the catastrophic mortality data during the first wave of the pandemic in Spain, with residential institutions being the sector in which the pandemic had the most devastating impact. In Barcelona, 17.7% of the population with disabilities living in residential centres were affected by COVID-19, according to the Municipal Institute for People with Disabilities (IMPD, 2020). The continuous data stream during the deadliest period of the pandemic pointed to particular individuals—"the oldest", "the sick", or "the disabled"—as being more likely to experience the severest symptoms of the virus.

This situation, and the accompanying health recommendations and readjustments introduced by care services, led to a greater social perception of certain groups' vulnerability and exposure to risk. In many cases, this was assumed and claimed by different actors in the disability field during the first wave of the pandemic, enabling the legitimisation of public health measures and configuring people with disabilities as more vulnerable and exposed to risk (García-Santesmases et al., 2022). This created a tension between the need to medicalise care for the sake of life defined in biological terms and with no attributes—the Agambian *nuda vida* (Agamben, 2004)—and the need to pursue a dignified life that maintained the social, rights, and practices of autonomy by people with disabilities.

Less institution-based models (e.g., certain living arrangements based on the independent living paradigm and aligned with the Convention on the Rights of Persons with Disabilities [United Nations, 2006]) proved to be more resilient care infrastructures than traditional nursing homes (Rodríguez et al., 2022). But, although the particularities of such

deinstitutionalising living arrangements appeared as more able to deal with the pandemic, the fact is that crisis has challenged these projects as well. This was witnessed in the way their spaces and programmes, conceived and designed in keeping with the principles of independent living, were unable to sustain autonomy as previously provided.

3. Theoretical Point of Departure

The intersection of disability studies with science and technology studies (STS; e.g., Moser, 2005; Moyà-Köhler & Domènech, 2021; Sánchez-Criado et al., 2016; Schillmeier, 2007; Winance, 2016) allowed to address the complex links between disability, autonomy, technology, and the environment, thus providing a further twist to the social turn characterised by the social model paradigm (Galis, 2011). People are always immersed in socio-technical networks, where we find prostheses, bodies, spaces, or gadgets, which allow the emergence of autonomous subjects. Thus, in the same way that agency turns to be the product of established connections between elements (Latour, 2001), disability should be studied in terms of social relations through which independent or dependent individuals emerge (Schillmeier, 2007). The present study aimed to analyse how care is articulated through the technologisation of interdependencies (Sánchez-Criado & López, 2009) and the modes of ordering (Law, 1994) that make it possible to sustain users' autonomy in the two services.

This approach brings together the materiality of space and care practices (Buse et al., 2018; Martin et al., 2015; Nord, 2011), and allow us to understand these spaces as care infrastructures (Danhold & Langstrump, 2012). Such an approach allows us to think beyond the limits of physical space and consider the inscription of those infrastructures on specific communities of practice, including practices, objects, skills, knowledge, spaces, or institutions, thus emphasising their situated and precarious nature (Law & Moser, 1999). We attend to the elements that enable and shape practice, making visible the constant task of

maintenance (Star & Bowker, 2006). Likewise, there can be no infrastructure without arrangements (López, 2015) or constant adjustments (Winance, 2006).

Finally, our analysis draws on the concept “post-institutionalisation” as proposed by Altermark (2018), who, rooted on Foucaults’ work on governmentality, problematises the use of both, technologies of inclusion and technologies of exclusion, as a way of governing the reason and autonomy of individuals. Within this framework, the paper analyses the different dynamics of control and discipline observed in both care infrastructures.

4. Methods and Materials

The present study is part of “Infrastructures for Independent Living: A Participatory Research Project for Rethinking Housing, Care, and Community in Times of Pandemic”, which was the recipient of a Barcelona City Council Urban Challenges Scientific Research Award (2020). The study is based on focused ethnographies (Knoblauch, 2005) in two different support services for people with disabilities. The first is an independent living project for people with learning disabilities that was inaugurated by a foundation for people with learning disabilities in Catalunya – the *Anar a Casa* service. The second, *City Living*, is an independent living project for people with physical disabilities. It was developed by a hospital. The names of both projects have been changed to protect the confidentiality of the people living there.

In the first context, AC, work was carried out during two periods. From March to June 2020, three online meetings between the service users were conducted and recorded in a field diary. Then, between July and November 2021, a series of interviews were conducted with 12 users and with 5 professionals. In the second space, CL, participant observation was carried out in the common areas of the facility from September 2021 to February 2022, and 34 semi-structured in-depth interviews were conducted with users (12), families (3), auxiliaries (12) and managers (7).

The interviews in both spaces were based on the same script and operationalised as follows: practices and strategies, care and community, space redefinitions, and material

elements. The script was carefully adapted to each of the spaces. The interviews were audio recorded and subsequently transcribed and anonymised.

These transcriptions were first analysed through a process of thematic analysis, where themes and categories emerged from the previous script. This process, together with the data obtained during the writing of the field diary, ended up forming what some authors have defined as *thick description* (Geertz, 2000). Thus, it was not a purely descriptive process but rather a reflective relationship on the interactions and meanings that have emerged in the field.

The present study was approved by the ethics committee at the Universitat Oberta de Catalunya (UOC) in 2021. The project has benefited from the advice of a group of co-experts, comprising formal experts, stakeholders, professionals, and scholars from various fields.

5. Rearticulating Independent Living Infrastructures Under COVID-19

5.1 Anar a Casa

Anar a Casa (the Catalan for “To go home”) started in 2000 as a pilot project. It was inspired by the principles of supported living, a model born in the 1980s in the United States (Hagner & Klein, 2005) as a reaction to the closure of total institutions (Smull & Danehey, 1994).

The unit, a pioneering one in Spain, now has almost 90 inhabitants and 20 support workers. The service is provided through a public subsidy that pays for 10 hours of personal support per week in the form of a grant from the regional government of Catalonia. Beneficiaries must be working or receiving a pension to access the programme, since they must be able to afford to pay the rent and day-to-day expenses. The service is not available in cases where the person lives with first-degree relatives, since it is understood that they already play the role of caregivers.

Principles and Functioning: Your Home, Your Choice

Moving out of the parents’ home and being able to decide “where, how, and with whom to live” (AC Website) is central to the AC project. Thus, the service builds independent

living around two main axes: on the one hand, by facilitating a certain possibility of “living in your own home” and, on the other hand, by placing users’ decision-making at the core of the service.

To this end, a series of meetings are held with a so-called “circle of trust”—people (generally family members) chosen by the users themselves to make decisions collectively—and one-on-one meetings between the service and the users. These take place on a regular basis (every 6 months), although at the beginning they are more frequent because they are used to draw up a personal attention plan, which serves as a guide for organising support and setting specific goals.

A good example of this way of articulating independent living can be found in a previous study we carried out at AC (see Moyà-Köhler, 2018), when Ramón and Xavi, two users who were getting ready to join the service, needed to decide about their apartment furniture so they could begin to make it their own home. As part of the decision-making process, the service first provided them with a space without their families in which they were able to think about what furnishings they needed and browse through catalogues and choose them. Deciding which sofa they wanted proved to be complicated, as Ramon and Xavi did not agree on the colour—they finally chose the red one—but they both agreed that it should be a sofa-bed so they could invite their friends to sleep over.

Then, a meeting with the family was arranged, in which the sofa topic was discussed extensively. Ramón and Xavi’s parents agreed that a non-convertible sofa was a better option because it would minimise the risk of strangers sleeping at their son’s home without them knowing it. The sofa was the materialisation of a dispute between Ramón and Xavi’s need to invite friends to sleep over and the preference of their families not to open the door to too many people. The service arranged informal encounters—meetings before or after some activity, during the weekend if Ramon or Xavi were visiting the family, or by a phone call asking for something else—where the support staff brought together the two sides. After this, in a last formal meeting, both parties agreed to buy a sofa-bed in exchange for a series of conditions that the users needed to follow when inviting friends to sleep over.

In short, the AC service sustains a socio-material assemblage by constantly adjusting, forming, and transforming a series of courses of action and possibilities. Sometimes, in formal situations (as we saw in the scheduled meetings), but mostly on the day to day, where the support worker is indispensable to maintain and keep the assemblage on going.

Towards a Bureaucratisation of the Service

In the middle of the pandemic, one staff member in charge of the service pointed out that what he feared most about COVID-19 was “the bureaucratisation” of the service, meaning that he felt “that everything is more difficult.” He explained “that they [the staff] must follow new protocols, that they have to constantly be asking the Foundation, or justify decisions.” (Fieldwork Notes, 2021). But, what did this mean in practice? To avoid perceived “risky situations,” the service started to draw up requirements that all users were expected to abide by. It was no longer possible to invite people or decide how to “hang out” in your own home. A good example of this was the imposition of sanitary masks. The service decided that, for all home visits by professionals, users had to wear a mask in their own homes. This was not agreed with on a case-by-case basis; users were simply told to wear a mask. This led to some tension with those who refused, and the service had to deal with it by establishing a single guideline: “It is mandatory, otherwise... ultimately the service would be suspended because we cannot put the rest at risk, right?” (Professional_Marina). The use of masks at home was ordered, and non-compliance jeopardised the continuity of the project. Users were not given an option and the rule prevailed uniformly; this meant that “the house” was just another space within the Foundation, where the same rules had to be followed as in other activities as part of the same bureaucratic order.

Probably the clearest example of the disarticulation of the network that allowed users to decide was when the AC no longer interceded, and it was the families themselves who decided that the people over whom they had guardianship should leave the service temporarily, or, as Albert, part of the support staff, said, “to return home” (Fieldwork Notes, 2021). This was the case for around 15 users, including Ramon and Xavi:

Interviewer: OK, perfect. And, who will decide that you will go to your parents' house?

Did you decide it yourself?

Ramon: The family.

Interviewer: The family decided...and in your case too?

Xavi: Yes, they decided also.

Interviewer: Would you have preferred to stay here [at your home]?

Ramon: Let's see, in principle, I wanted to stay with him here, but since there was a pandemic...

Xavi: But because of the pandemic, we can't stay together.

(User_Ramon & User_Xavi, September 2021)

Informal meetings no longer took place and the number of meetings, in general, was much smaller. The only space that counted were the inner circle meetings that placed the burden of decision-making on the family. For the support workers, there was a loss of intimacy and informality, the functioning became standardised: "Now it's not the same, we've lost the... we don't have informal spaces anymore, (...) We used to be able to work as we went along, with what came out. Now it's all just meetings." (Professional_Isaac)

All of this shows how the network of elements and practices that identified the user as "the one who decides" was truncated by a foldback process—or bureaucratisation—of the Foundation. In the wake of COVID-19, the service tended to rely on standardised processes and formalities that placed families and the service itself at the centre of the project, leaving little or no space for users to act (as we saw in the case of Ramón and Xavi, who had no option of whether to decide where to stay), thus reifying the asymmetries of power between users and the service or families.

5.2 City Living

City Living (CL) is a project associated with an internationally renowned institute in the treatment of spinal cord injuries, acquired brain damage, and other neurological disabilities. The institute has different social projects that go beyond medical treatment and the provision of hospital services. One of them is CL, an initiative "designed to promote the

autonomy and quality of life of people with disabilities who want to develop an independent life project in an active, inclusive way, and with their own lifestyle” (CL website).

It is a housing facility located in central Barcelona, adapted for people with physical disabilities who, mainly after being hospitalised because of an accident, are looking for an alternative to institutionalisation (i.e., a traditional residence) and familial care. It started in 2019. There are currently around 20 people living there. The facility has three floors with a series of small apartments and a coffee shop with a terrace on the ground level that is open to the public. It has a receptionist and a 24-hr security guard. The facility offers a 24-hr assistant service, the members of which work to meet the specific needs of the residents and carry out a wide range of tasks, such as hygiene, dressing, transfers, and feeding. The facility is adjacent to a clinic where advanced physical and neurological rehabilitation therapies are offered.

Principles and Functioning: Doing More and More Things

The CL project’s principal aim is not just to provide people with physical disabilities with an accessible place to stay and assist them during this time but also to promote their independent living. Therefore, functions as a training place to this end. Users are permitted a maximum stay period of 2 years, during which time they are expected to learn, or relearn, how to live independently. “Your goal for coming here, what is it? That you want to go to a house alone one hundred percent” (Professional_Miquel).

The CL independent living plan consists of individualised accompaniment for residents, collective empowerment and peer support sessions, and professional training. The facility’s coffee shop helps users to connect with the neighbourhood and promote their social inclusion as part of the project’s aim “to promote the participation of their residents in society in a community setting” (CL website). The project was intended to be different from a residential or medical centre; however, a lack of options meant that it was registered as a health centre. In addition, the workers, most of whom come from the residential sector, have a contract as residential assistants. Nevertheless, both the institution and the staff consider their work to be significantly different. They are trained to “promote the development of

personal autonomy.” This is based on a paradox: they have to attend to “whatever the person needs” if it is something specific and limited in time (the unwritten rule being no more than 20 min), but at the same time they are required to encourage “the person to do more everyday things by him/herself” (Professional_Nora).

Thus, we see how CL promotes an idea of independent living that is based on the user’s decisions but above all on the user *doing things* autonomously. The first director of the facility explained that “this is not for people who lay about all day in bed” (Fieldwork Notes, 2021). Although the service is based on the logic of being a temporary place with the aim of allowing users to “go home,” the space includes in its design elements that enable users to live there as if it was “their home.” So, everyone gets his/her own flat and interacts with the other users only if he/she wants to, as it is “in every neighbourhood community” (Professional_Maria Rosa). In addition, the service places the privacy of users at the centre, determining that they are the ones who request visits from the assistants or permit them to enter their home. In this way, they offer people who have just left hospital to recover a sense of intimacy and autonomy by living in a space that, in contrast to hospital care, allows for an individualised day-to-day existence.

Towards a Hospitalisation of the Service

The pandemic, which broke out when the project had been active for less than a year, meant that the specific independent living plan was not implemented; only an initial training of professionals was carried out. The stalling of the independent living project went hand in hand with the implementation of further restrictions and the incorporation of other changes. The use of many protective measures became extensive—such as shoe covers, single-use gloves, plastic face shields, masks, gel, and gowns—and after the vaccination campaign, the measures stabilised along two main axes: hand washing with hydroalcoholic gel at the entrance and during support times and the use of surgical masks by the support worker and user both in public spaces as well as in the users’ homes.

During the period of confinement, the two inhabitants who were born with a disability and were therefore there not for therapy but for independent living training “returned home”.

Many of those who stayed had been recently released from hospital, which probably made it easier for them to adapt to the restrictions. For those users who stayed, physical rehabilitation remained central; they were allowed to go out to work out in the common areas, and once the most difficult times were over, priority was given to getting them into rehabilitation as soon as possible. In fact, not only were the hospital's health protocols introduced but also its logic of space management.

First, the institution's mantra that the decision is in the hands of the user was suspended since, as a consequence of the restrictions, the assistants began to decide, with greater discretion than before, what was assisted and what was not, when, and for how long. This was a result of the implementation of the logic of the hospital in which care was reduced, protocolised, and minimised. As the director of CL—a former director of nursing at the hospital—explained, “I manage beds here.” There was a shift from managing “their homes” to managing beds as places of risk through exposure to infection (in a similar way as defined by Armstrong, 1998).

The idea that it was “their home” was also challenged. This assertion was already problematic because the apartments are different from a rented flat in several ways: the institution establishes a profile of potential residents, the price is agreed upon individually with the institution, users cannot change the furniture, make holes in the wall, or smoke, and an overnight visitor incurs an extra charge. It is made clear, in the words of the director of the facility, that you are “at your home” but “we [CL] are responsible.” Governmental restrictions on leaving the house were incorporated by the institution as a sign of compliance; instead of the individual responsibility of the residents, it became an institutional responsibility. Entry, exits, and visits were controlled. The boundaries between common–public spaces (e.g., corridors) and individual–private spaces (the flats) were blurred. One user told us that during this stage, the assistants “came in without knocking” (User_Marco) and he had to confront them to make them stop doing so.

In a service where “knock before entering” is a key element in recognising the autonomy of the users as well as a hallmark in promoting independent living, the fact that this procedure was challenged highlights the process of hospitalisation the service underwent. It represented on a material and symbolic level the logic of the hospital from which it derived – a logic based on the idea of risk (disability as a vulnerable body) and responsibility (where protection is in hands of the institution) led to a process of disabling that left the users, once again, as patients.

6. Tensions and Escapes

6.1 Tensions: Bureaucratisation and Hospitalisation

The discourses of vulnerability and risk mentioned in the introduction have caused people with disabilities to be considered especially vulnerable to COVID-19 (García-Santesmases et al., 2022). This, together with the configuration of the pandemic as a medical emergency that has assumed life without attributes (Agamben, 2004) as the only one to be saved has disarticulated some of the ways of sustaining users’ autonomy, as we have seen in both cases. Science and technology studies have shown how the capacity to act depends on heterogeneous networks that allow certain modes of individual agency (Callon, 2008). In the case of AC, this involves the articulation of a set of more or less formal meetings with families and users, the formulation of a personal care plan, the provision of formal and informal meeting spaces, the use of furniture catalogues, certain technologies, and so on (Moyà-Köhler & Domènech, 2022) that allow the person with learning disabilities to emerge as autonomous in the process of thinking (Law, 1999) and taking decisions. In the case of CL, it entails facilitating a non-hospital space, to develop individualised plans, the promotion of community activities, and the training of assistants in the promotion of independent living. Both care infrastructures articulate certain modes of “doing good care” (Lydahl & Hansen, 2020; Pols, 2003) to open up the possibility of users’ decision making—in the case of AC—, or on the capacity to do more and more things—in the case of CL—, enabling this way their independent lives.

But the underlying tension in both services between autonomy and risk, exacerbated by COVID-19, shifted the modes of doing good care to more security-oriented practices: Bureaucratisation in the case of AC and hospitalisation in the case of CL. Both services, in the face of an emergency, adopted less ductile forms to avoid risk and take refuge in spaces they considered safe, such as medical standardisation, protocols, and families. This led to greater standardisation, the loss of privacy, less decision-making on the part of users, asymmetries of power (what Mladenov and Dimitrova [2022] called “epistemic injustice”), and direct supervision and control modes.

Bureaucratisation and hospitalisation logics meant the loss of informal spaces in AC and a focus solely on physical rehabilitation in CL. The loss of those spaces for constant adjustment (Winance, 2006; López, 2015), the loss of ductility and adaptability, have largely disarticulated this set of discourses, socio-material elements and practices that sustained the possibility of autonomy. And so, paradoxically, what were spaces for promoting independent living and greater autonomy emerged as disabling spaces (Schillmeier, 2007, 2010). How exactly did this come to be?

6.2. Independent Living and Post-Institutionalisation

The present study opened by asking why anybody escapes from their own home. In the present context, if leaving home when it is not allowed is considered an escape, then it is not actually about their homes, but about the service itself. The resulting tension has led institutions to prioritise to work for their survival (Power, 2009). No one escapes from their own home if they feel at home in it – that is, if it is a safe space. What the present study has shown is how, despite years of deinstitutionalisation (Ericsson & Mansell, 1996), the projects that are articulated around the idea of independent living have remained institutions.

But what is of interest here is not so much whether they are total institutions—in fact, according to classic texts (e.g., Goffman 1972) the two approaches do not fulfil all the requirements—but rather how their rearticulation reveals elements of their functioning in a significant way. Post-institutionalisation (Altermark, 2017) would be a more appropriate term

in respect of what we have seen by the two services dealing with COVID-19. For Altermark, who drew on Foucault, post-institutionalisation is the operationalisation of two ways of governing people; on the one hand, governmentality—by creating self-ruling subjects who are allowed to be free in a particular way—and, on the other, discipline. It is the latter, by the use of technologies of discipline, that we have seen exacerbated during COVID, by those modes that follow logics of bureaucratisation and hospitalisation, giving rise to the provision of care using technologies of restriction and straightforward coercion that constrain the freedoms associated with citizenship (Foucault, 1976).

Thus, it is of interest to see how COVID-19 illuminates this line of continuity between total institutions, based on the articulation of technologies of discipline, and what are now presented as independent living services. In terms of STS, these institutions are inscribed (Ingelsböck & Schüßler, 2019) with ways of operating used by traditional residential care institutions for people with disabilities.

In the case of AC, the process has represented a foldback into ways of overprotecting and incapacitating people with learning disabilities that has been driven by infantilisation discourses and the adoption of paternalistic attitudes (Björnsdóttir et al., 2015). In the case of CL (which is associated with a benchmark hospital for the treatment of spinal cord injury), these inscriptions have reproduced the procedures of the traditional institution: the “latent function of the hospital is to adjust the disabled body-subject to the fact that both the decision-making and the execution of anything concerning their corporeality are in expert hands” (García-Santesmases & Sanmiquel-Molinero, 2022, pp. 391). In both examples, there was a backwards move towards the vestiges of the large institutionalising projects of the 20th century that constrained opportunities for independence and self-determination (Clement & Bigby, 2010).

6.3 Escapes and Resistances

As Altermark (2018) pointed out, “the very friction between inclusion and exclusion provides spaces for resistance” (p. 155) as we have seen in the example of Luís and Michel, and it is this notion to which we now return.

Both projects provide examples in which the users, during the full lockdown, decided to go out, subverting the regulations established by the government. We have discovered in our research that some users became recalcitrant (Akrich, 1992) in the face of the course of action imposed by service reorganisation. Winance (2016) argued that that “is this recalcitrance—which emerges in relationships—not the mark of the subject, of the person who resists what is offered in this relationship? For me, it is a form of what we could call ‘raw autonomy’” (p. 109).

What we can learn from the present examples is a manifestation of this alternative form of autonomy. For the services, the moment of escapism put the possibility of independent living at risk because it did not conform to the imposed framework and course of action; however, it is from the possibility of subversion that this *raw autonomy* can emerge. Although it may seem an oxymoron, it is precisely because of the same disposition of those services that these ways “against service” are able to occur, as it would be difficult to do so in a more institutionalised context. Although it is important to warn against steps that involve harsh forms of control and regulation of the subject, the point is relevant because it shows that the articulation of independent living projects has had a positive impact on the lives of people with disabilities (Altermark, 2017; Bigby et al., 2017). It is precisely in those spaces where the potential for new articulations of independent living become possible and new ways for autonomy emerge. Ways which until a few years ago were inconceivable in the field.

7. Conclusion: Towards Self-Organisation and Full Participation

The present study has shown how the pandemic, as a changing and uncertain scenario (Schillmeier, 2020) produced risk and vulnerability discourses regarding particular groups that tensioned independent living initiatives. It has paradoxically allowed spaces that were designed to promote greater autonomy for users to emerge as disabling spaces.

This tension implied a fold up towards disciplinary modes and illuminated a certain line of continuity between the independent living projects and the major institutions that

characterised the 20th century. Despite the establishment in recent years of many and diverse independent living projects (Rodríguez-Giralt et al., 2022), the pandemic has made it clear that deinstitutionalised models based on the principles of the Convention have been a fragile alternative and that the rights thus acquired are still perceived as dispensable in the event of major perceived risks. At the same time, what we have identified as escapes illustrate the potential of independent living infrastructures and the possibilities they can open up, even in foldback scenarios.

It is important to avoid a return to old ways and intensify the *politicisation* of such spaces by people with disabilities. The philosophy of independent living should not simply be complementary but a central part of the articulation of services, promoting self-organisation and the full participation of users in the becoming of their projects (Beresford, 2021; Mladenov, 2013). Failure should be permitted even in risky scenarios and resources should be made available for independent living, both for the development of infrastructures and for further research.

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ⁱ Although the most politicised and increasingly common terminology in our geographical and linguistic context is that of 'functional diversity', throughout this text we will use the term 'people with disabilities' as it is the term used by the CRPD.