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Exploring Independent Living Initiatives for people with Intellectual disabilities: Insights from the Spanish Case

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Exploring Independent Living Initiatives for people with Intellectual disabilities: Insights from the Spanish Case

Abstract:

In the past four decades, Independent Living (IL) has gained prominence in inspiring services for people with intellectual disabilities. Yet, its practical application faces challenges within a field still influenced by medical-rehabilitative and paternalistic perspectives. This study seeks to explore the fundamental characteristics that IL models assume within the field of intellectual disabilities, focusing on the Spanish experience, identifying pioneering projects, influential models, and their ripple effects. A comprehensive mapping of IL projects has been conducted, analyzing publicly available information on 86 identified cases. In seven significant cases, in-depth interviews were conducted with people responsible for their development. Our analysis sheds light on some emerging tensions, with a focus on what is identified as a family-centered approach, an emphasis on skills-oriented services, and an overreliance on housing accessibility. Finally, this paper offers recommendations to enhance these initiatives and foster the integration of IL in the intellectual disability context.

Points of interest:

- This study examines difficulties encountered when implementing independent living services for people with intellectual disabilities in Spain.
- The study shows that independent living for people with intellectual disabilities has the following characteristics: it is mostly oriented towards the families, it is focused on the development of personal skills, and it is strongly dependent on the possibility of housing access.
- We suggest the need to find ways to place people with intellectual disabilities at the center, while considering their social networks. It is also important to promote personal assistance, allowing support in tasks lead by the people themselves. And it is a fundamental responsibility of the administrations to ensure that everyone has access to housing.
- Independent living for individuals with intellectual disabilities should no longer be seen as something exceptional, but rather as the center of services provided in this field.

Keywords: intellectual disability, independent living, housing, transition, autonomy

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1-Introduction

Over the past 40 years, significant transformations have taken place in so-called Western countries regarding care for people with intellectual disabilities. These changes have often aimed at deinstitutionalization and ending exclusion (Altermark 2018) by promoting participation, self-determination, and independence (Clement and Bigby 2010). Inspired by the postulates of the independent living movement, smaller residential places have been created and notions such as assisted independent living or supported living have been promoted (Cocks et al. 2016; Baranowski et al. 2023), emphasizing that people with intellectual disabilities should have the right to live independently (Hooren et al. 2002).

The rise of the Independent Living Movement (ILM) started in the 1960-70s with several political, activist and academic initiatives, with the aim of allowing people who were discriminated against because of their disability to leave hospitals and institutions (Barnes and Bowl 2001), and achieve a life in the community. These movements demanded the closure of large institutions that were still mostly in operation during the 1970s (De Jong and Wenker 1979). During the early 1980s, more than three-quarters of these institutions were closed in the United States (Braddock and Heller 1985), and over time this model would spread internationally (Charlton 1998). In 2006, the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in its Article 19 recognizes the right of persons with disabilities 'to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community' (United Nations 2006). This has helped the expansion of a model of empowerment, equality, and the right to have control and to

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choose for people with disabilities, based on personal assistance, mutual support, and self-determination (Barnes and Mercer 2006).

In the field of intellectual disabilities, the IL model is generally built upon the delicate balance between fostering independence and ensuring safety within the support services for adults with intellectual disabilities (Petner-Arrey and Copeland 2014). Building on this, these approaches commonly entail ways in which individuals can make decisions collaboratively, fostering a sense of control and choice that resonates with their personal identities and needs (Williams and Porter 2015). This method advocates for strategies that respect and accommodate individual preferences and goals, while also emphasizing the importance of care-based support relationships in promoting autonomy (Petner-Arrey and Copeland 2014).

However, adapting the IL model to the field of intellectual disability has been challenging (Dowse 2001). On one hand, many organizations have faced significant hurdles in developing in practice these proposals. Challenges include a lack of suitable community-based services and support for individuals with intellectual disabilities (Dowrick 2004), inherent structural and financial issues within the community (Wilson et al. 2016), and difficulties in defining the role of professionals in promoting independent living (Pallisera et al. 2018). But moreover, this IL development in intellectual disabilities has been difficult due to the theoretical and structural difficulties faced by a group in which capacitism and stigma operate in an idiosyncratic way (Pinto et. al. 2023). Some authors have highlighted that the Independent Living Movement and its theoretical developement, has not adequately addressed the idiosyncratic elements that socially and structurally affect individuals with intellectual disabilities (Scior and Werner 2016). If we start from the social model of disability, closely intertwined in its

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development with the ILM (see Tarrant 2022), it emerges that there is a division between individuals with physical disabilities and those with intellectual disabilities, as the latter group's particular characteristics are often seen as inherent aspects of their impairment (Chappell, Goodley and Lawthom 2001). An almost ontological division that played a significant role in constraining the influence and opportunities that the development of IL could open up for people with intellectual disabilities, as their perceived as a 'natural' inability to make 'good decisions' has been a determining factor (Moyà-Köhler and Domènech 2022).

These difficulties and tensions are particularly interesting in terms of how IL has been, in practice, implemented by associations in the field. Firstly, because in the Spanish context there has been an exponential growth of these experiences over the last 25 years (see Rodríguez-Giralt et al. 2023), with particular emphasis in the field of intellectual disability (Puyalto and Pallisera 2020). And, secondly, because it involves an area where concerned individuals clearly prefer living according to IL models (Garcia Iriarte et al. 2014; Deguara et al. 2012).

Therefore, the objective of this paper is to examine the key characteristics of the arrival of IL in the context of intellectual disabilities. To accomplish this, the study focuses on a specific case—the incorporation of IL to the field of intellectual disabilities in Spain. By delving into its origins, influences, and key features, this paper examines the challenges faced in the practical implementation of Independent Living. Specifically, these challenges involve the family-centered approach, the habilitating nature of those IL services, and the excessive reliance on accessing suitable housing, particularly within a low-income population.

Ultimately, this research proposes three lines of action to further develop IL in the context of intellectual disabilities. While these suggestions are rooted in Spain, they

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can also serve as informative guidelines for similar developments and related fields of study in different environments.

2-Context and emergence of the independent living movement in Spain

To provide proper context for the emergence of IL for intellectual disabilities in Spain and in order to situate its particularities, it is essential to mention the historical background. In Spain, the development of support and services for people with disabilities occurred primarily through associations that were established during the dictatorship of General Franco and operated under the influence of the Catholic Church and the fascist regime (Maraña and Lobato 2003). Consequently, their ideology was predominantly rooted in religious discourse, emphasizing the acceptance of suffering and the need for penance. During this period, a direct correlation was drawn between disability and sin, resulting in cases of isolation, concealment, marginalization, and shame towards individuals with disabilities until the regime's downfall. These attitudes persisted well into the 1980s.

However, from that point onward, families of individuals with disabilities became key actors in constructing new care spaces for people with intellectual disabilities (Velázquez 2008). Spain witnessed a surge in family associations that focused on addressing the needs of individuals with disabilities, essentially stepping in as service providers in the absence of adequate state support (Guillén 1997). As a result, a semi-public system emerged, characterized by services managed by private entities yet funded through public subsidies. This presents a notably different context compared to the development of the model in Northern Europe (see Brennan and Traustadóttir 2020), and in Central and Eastern Europe (see Mladenov and Petri 2020). In Spain, this semi-public approach has led to increased professionalization and the formation of a

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complex network of associations, which predominantly embrace a medical-rehabilitative, familist, and institutionalizing approach (Maraña and Lobato 2003; Pié 2012).

In this Spanish context, the ILM emerged in the early 2000s through the Foro de Vida Independiente (FVI), a collective of disability activists who organized online (see Díaz-Alzate et al. 2020). Similarly to the European Independent Living philosophy and strongly influenced by it, the FVI aimed to challenge the prevailing medical model that influenced most organizations in the disability sector. This vernacular development aligns with the perspective of disability as a social construct, and also with a broad critique of the dangers arising from privatization and neoliberal austerity (see Mladenov and Petri, 2020). However, as described by Palacios and Romañach (2006), the model in Spain has a specific idiosyncrasy, especially through the emphasis on diversity as an inherent element of humanity, promoting the concept of 'functional diversity,' which has gained increasing acceptance. This model advocates for the right to a moral autonomy, distinguishing it from functional autonomy (Iáñez-Domínguez 2009) insofar as people with disabilities have the right to choose the support that they require to fulfill their wishes.

3-Methodology

The results presented in this paper are based on an inductive model allowing the elaboration of a corpus of data that enables the interpretative richness that is indispensable to obtain qualitatively new understandings (Alvesson and Sköldberg 2018). In alignment with the paper's objective to investigate the practical implementation of IL, we conducted a comprehensive mapping of IL initiatives undertaken by organizations in Spain. To gain deeper insights into the evolution of IL in

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the Spanish context, a series of interviews were conducted to delve into the core issues associated with these initiatives and explore the tensions that arose during their development. The study received approval from the Universitat Autònoma de Barcelona ethical committee.

Initiatives mapping

In order to account for the development of IL, an exhaustive search for independent living programs or projects in the intellectual field has been carried out. It is important to note that this mapping exercise does not aim to provide an exhaustive inventory of all existing cases but rather we focused on capturing initiatives that have been made visible.

To this end a systematized online search (Fielding et al. 2016) of entities that have developed a IL program or project for intellectual disabilities was carried out. The search strategy involved using combinations of keywords such as 'IL,' 'personal autonomy,' 'intellectual disability,' 'Spain' (or specific regions), 'project,' and 'service' on the Google search engine. Also through social networks (Twitter and Facebook). After the first phase and after analyzing the material collected, two more searches were carried out, in this case incorporating the direct search for initiatives that were referenced in the material collected in the first phase. The inclusion criterion for projects was that they explicitly mentioned IL as a central axis or practical principle in the title or explanation of the service. The search encompassed the period up until the beginning of 2023, resulting in the identification of a total of 86 projects distributed across different regions: Andalucía-14, Aragón-3, Illes Balears-1, Islas Canarias-5, Castilla la Mancha-2, Castilla y León-2, Catalunya-19, Extremadura-1, Galiza-3, Madrid-16, Murcia-4, Comunitat Valenciana-7, Euskadi (País Vasco) -8, Navarra-1.

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To systematize the collected data from each project, an Excel table was created, including the following details for each organization: 1-Name of the entity; 2-Title of the project; 3-Foundational genesis of the entity and the IL service (at this point providing information on other reference projects, if any); 4-Year of start of the IL project; 5-Summary of its functioning; 6-Type of support provided (e.g., habilitation, direct support or peer support); and, 7-Area of life for which IL is provided (e.g., leisure, housing, etc.). This last point includes whether they specifically have a service to facilitate IL in the user's own home or whether they mention housing as a purpose but do not have their own resources to facilitate this access.

Interviews

In addition, to enhance the understanding of the deployment of IL and to provide a deeper analysis, a series of interviews were conducted. The purpose of these interviews was to produce a narrative about the advent and development of IL, to find connections and to provide deeper insights and perspectives on how IL evolved. Thus, the selection of participants was not so much based on obtaining a broad heterogeneous sample, but rather on their relevance; those interviews were carried out with individuals who were directly responsible for the initiation of IL projects in organizations that were pioneering in the regions where IL began to develop at the turn of the century.

For this purpose, seven semi-structured in-depth interviews were conducted following the methodology described by Kallio et al. (2016). The interviews took place with entities located in Catalonia, Basque Country, and Murcia. Five of the interviews were conducted individually with professional staff from the associations, while the remaining two interviews were group interviews involving a professional and a member

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of the organizations' management. In both group interviews, the managers were also family relatives of a service user. The participants included a total of nine, seven professionals (five women and two men) aged between 35 and 55 years, as well as two organization managers (both women) aged over 65.

The interview structure revolved around three main topics: (1) the definition and characteristics of IL in the field of intellectual disabilities, (2) national and international inspirations for the project, and (3) the practical development of IL and the main challenges encountered. All interviews were audio recorded and subsequently transcribed and anonymized for analysis.

Data analysis

The data analysis employed an inductive approach, centering on relevant information extracted from the field. Initially, a thematic analysis was carried out independently, examining both the public data gathered during the mapping process and the transcripts of the seven interviews. This involved identifying and organizing key themes and patterns within the data, following the guidelines outlined by Braun and Clarke (2006).

Interviews were initially listened to gain a general understanding of their content and structure the themes accordingly. Subsequently, the interviews were partially transcribed, focusing on the elements relevant to the analysis. Thematic analysis was then applied to the transcriptions, resulting in the identification and assembly of categories. The analysis process was iterative, with the categories being refined and adjusted as more interviews were transcribed. For example, specific formulations such as "relationship with the Independent Living Movement" and "contacts with other models" were coded into more abstract themes such as "theoretical influences.". Finally, the themes were classified as: “formulation of the idea of IL”; “theoretical influences”;

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"concrete IL practices"; "types of support"; "actors involved and relationships"; "tensions emerged"; and "material resources involved".

Subsequently, the information of the two sources was cross-referenced, allowing for a comprehensive analysis and a more detailed understanding of the phenomenon under investigation. All the collected material has been analyzed by examining related codes and themes, enabling the creation of an interpretive and situated narrative. This process went beyond a purely descriptive approach, and instead focused on reflecting on the interactions and emerging meanings (Geertz 2008). Through this analysis, connections were established between the elements observed in the field and theoretical concepts, offering a comprehensive account that spans the temporal continuum of the emergence of Independent Living in the field of intellectual disability in Spain, as well as the specific aspects and tensions of its implementation.

4-The articulation of independent living for people with intellectual disabilities in Spain

The will at this point is to present the findings obtained throughout the study. To this end, we will first explain how the emergence of IL in intellectual disability in Spain took place, explaining two models that end up permeating most of the subsequent initiatives, and then go on to define the main characteristics and some of the tensions that run through these characteristics.

The emergence and expansion of two models

The first projects that we have identified in Spain emerged at the turn of the century, by means of two different projects that we will now explain. But first it is interesting to

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point out how this development took place, somewhat astonishingly, overlooking the momentum that, at the same time, was taking place in Spain due to the theoretical development and practical proposal of the FVI –introduced at the beginning of the text. We find very little direct cross-references between the political and practical development of the Foro and what happened in the field of intellectual disabilities. This can likely be attributed to the challenges the field of intellectual disabilities has faced in aligning with the IL paradigm, as one manager of an independent living project explains:

> The Foro de Vida Independiente has defended Personal Assistance in its most well-known essence, as a modality, or service... self-managed. Managed completely by the person themselves. And in the case of people with intellectual disabilities, we assume that this self-management may not be total. As I was saying before, because of the presumption of non-autonomy and freedom. (Profesional_EP1)

This starting point makes it even more interesting, if possible, to explore the various forms that IL has taken in Spain, paradoxically without any reference to the FVI and inspired by international models.

As mentioned at the beginning of this section, in Spain IL for intellectual disabilities appears to have been introduced through the application of two different models by two different organizations. In the region of Murcia in 1997 with the 'Escuelas de Vida' (EDV) model (Illán & Molina 2013), and in Catalonia in 1998 with the 'Me'n vaig a casa' (MVAC) service of the Fundació Catalana Síndrome de Down (Ruf 2007). These two pioneering initiatives embraced different international approaches for their development, diverging from the vernacular proposals of Independent Living in Spain.

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In the case of EDV the work of Nicola Cuomo, known for its strong pedagogical orientation, is a key reference. This approach aims to effectively intervene in the development of participants with intellectual disabilities, with the goal, as Cuomo himself states, of 'analyzing and intervening in the areas of the "potential development zone," which means being able to evaluate the effectiveness of intentional pedagogical-didactic intervention strategies' (Cuomo and Pellegrin 2005). In practice, this means that the EDV project primarily focuses on creating a learning space for decision-making, which ultimately enables individuals to live as autonomously and independently as possible (Illán 2013). To achieve this, EDV proposes three stages, with the first one being the 'Proyecto Amigo,' which serves as a learning space for acquiring skills. The next two phases, 'vivienda compartida' and 'vivienda entre amigos,' were planned for 2006, where housing and the option of moving out of the parental home would become central to the proposal.

The MVAC project differs significantly. It is directly associated with housing and draws inspiration from the concept of supported living (Hagner and Klein 2005), with references such as Peter Kinsella and his work in Liverpool (Ruf 2010), as well as deinstitutionalization approaches in the United States during the 1980s and 1990s, with Klein as a source of inspiration (see Klein 2000; Ruf 2007). This project is influenced by the principles of 'housing first' to seek more normalized housing solutions compared to residential settings (Vived Conte et al. 2013). In this case, there is no prior process of habilitation, and the focus is on empowering individuals with intellectual disabilities to make their own choices about with whom and how they want to live. The project promotes the provision of direct assistance to users to live in their own homes (which involves leaving the parental home), with funding provided by the regional government in Catalonia from the year 2000 onwards.

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These two models served as a reference for most of the projects we have identified, which, in one way or another, are based on these two approaches. In this study, we have documented several milestones where new initiatives emerged. Some of these initiatives started in Catalunya and Euskadi (Basque Country) in 2004 (see Fernández,2013); in 2005, they expanded to Andalucía, Aragón, Galiza, Madrid, and Navarra (see Matía and González 2016); in 2009, they began in Castilla y León; in 2012, in Extremadura and the Islas Canarias; and from 2013, in Castilla la Mancha.

Here, we can discern three distinct phases marking significant growth in the number of IL initiatives. The initial surge followed the emergence of the first two initiatives, from 2000 to 2005, witnessing the inception of 15 new cases. A second phase aligns with the post-2008 economic recovery, and is influenced by the legal reforms under the 'Ley de Promoción de la Autonomía Personal y Atención a las personas en situación de dependencia' [Law for the Promotion of Personal Autonomy and Attention to People in a situation of dependency] (see Planella, Moyano, and Balaguer 2012), from 2012 to 2017, with the creation of 28 additional initiatives. Since 2021, there has been a noticeable uptick with 11 new initiatives. This was probably in response to the new challenges introduced by the COVID-19 pandemic (see García-Santesmases et al., 2023) that intensified the model change initiated since Spain's ratification of the Convention on the Rights of Persons with Disabilities (2006) in 2008. These changes have gone hand in hand with the increased funding available through the NextGenerationEU fund plans (see Mi casa. Una vida en Comunidad n.d.).

Main characteristics

We have presented a concise summary of the introduction of IL in the field of intellectual disabilities in Spain, emphasizing two models that have influenced the

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development of new initiatives. These models differ in their approaches, with one emphasizing habilitation processes (EDV) and the other adopting a housing-first perspective (MVAC). However, despite these differences, we have identified several common characteristics among the IL initiatives in the field of intellectual disabilities. We highlight three key features that are shared by most projects to varying degrees:

Home focused

The first of the elements that emerges from the analysis is that most IL projects are articulated around housing, although there are some cases in which it is also linked to programs for access to the labor market (2) or leisure activities (3), among the 86 projects that we analyzed, 62 of them mention access to their own housing at some point in the process (in the form of rental, ownership, or transfer by the same organization or a public entity) as one of their direct purposes. Meanwhile, 21 work on the idea of preparing for this moment, although they do not have the resources to provide housing or direct housing support.

This trend is connected to two central elements within the sector, which seem to be interconnected. Firstly, it provides a space for individuals with intellectual disabilities to transition into adult life, fulfilling their desire to 'be and do like their brothers and sisters,' as expressed by one professional during an interview (Professional_EP6). Secondly, this opportunity is viewed as a means to overcome the tendency towards infantilization. As another professional expressed:

> intellectual disabilities subjects were traditionally incapacitated [today it is no longer legal in Spain, but it was the loss of the legal capacity to make one's own decisions, as ruled by a judge] at the age of 18... they are left without access to full citizenship. This clearly implies the perpetuation, whether you want or not, of a dependent and a non-

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> autonomous role... what we do is to give, with the housing... we also give a way out of this. It is not total, but it helps people with intellectual disabilities to access a space that was not possible before. (Professional_EP1)

This housing-centered approach, however, has encountered several challenges. Firstly, access to housing is highly unequal and heavily dependent on economic resources and the availability of public funds, which vary across different regions in Spain. In a population segment facing difficulties in accessing the labor market, the affordability of housing and, consequently, the ability to exercise the right to independent living, becomes contingent on familial financial disparities. This is further exacerbated by the lack of public support in facilitating such access, with a prevailing emphasis on more institutionalized options, thereby treating independent living as 'a mere anecdote within the realm of social benefits and services. For some, it has only been the "cherry on the cake," a superficial position that appears good but lacks substantial impact' (Trias and Ruf 2011).

Furthermore, it is important to acknowledge that some professionals problematize the association of independent living solely with housing. They argue that the right to independent living should extend beyond housing and be integrated into all stages of life and various aspects of well-being.

Skill oriented

After analyzing the collected data, another recurrent element that appears when addressing IL programs in the field of intellectual disabilities is that the development of independent living is linked to a strong enabling component—the acquisition of skills. Out of the 86 projects that we studied, 72 explicitly associated their programs with a process of skill acquisition for individuals with intellectual disabilities.

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Most of this process has been articulated through the so-called ‘pisos Puente’ (bridging apartments) or ‘pisos de entrenamiento’ (apartments for training). This approach to IL was already consubstantial for one of the two pioneering projects in the state, the Escuelas de Vida, which aimed to establish ‘a training model organized around a program with predetermined learning objectives, which can be evaluated through the Proyecto Amigo’ (Illán and Molina 2013, 34). This approach has not only influenced organizations directly dependent on the EDV model but also other projects; like Down Navarra, which emphasizes the pedagogical nature of their approach by providing ‘housing that offers support in the fundamental moments of the day and whose objective is learning and training in the skills necessary for an autonomous life in a real environment such as a shared apartment’ (Asociación Síndrome de Down de Navarra n.d.).

This emphasis on supporting skill acquisition is closely connected to the professionalization of the sector and the need for accountability regarding the sector's work. In this context, independence is assessed and can be enhanced through professional intervention. This is exemplified by the use of quality-of-life scales that largely measure one's ability to be independent, understood here as the capacity to identify and perform specific daily tasks (see Giné 2006).

Finally, these significant enabling approaches are viewed with suspicion by some professionals who state that ‘the training apartments and such, as transitory resources, raise the question in my mind of whether it is necessary to get a license to be able to live an independent life’ (Profesional_EP1). The fact is that certain enabling approaches end up linking the possibility of IL to sometimes almost indefinite processes of constant learning to which people whose ‘capacity’ is not in doubt are not subjected.

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Family centered

We have seen how families in Spain take a leading role in terms of articulating responses to the needs of people with disabilities, especially in the field of intellectual disability. If we look at the associations that promote some IL projects, 72 out of 86 trace their origins back to families who founded the associations at some point.

For example, the the Orobal Association from the Canary Islands stated on its website that it 'was founded by parents who had a child with a disability. As it grew and new families joined the project, the needs increased, and new resources were generated to cover them' (Orobal n.d.). This quote is paradigmatic and revealing. It not only shows the impulse of these families in the care of people with intellectual disabilities, but also the development that these associations have undergone over the years, in response to the changing needs and growth of their relatives. This element also explains the emergence of housing-related projects in the 2000s, following the reconversion witnessed in the previous section after the end of the dictatorship.

At a practical level, this highlights the significant role of families in the field, as they have established specific approaches to implementing IL projects. However, the perception of risk and responsibility is always present as a source of tension. As expressed by a family member who also served as the director of one of the associations under study, 'the limit of not allowing an incorrect decision is when that mistake causes significant harm. That's where the boundary lies, in terms of harm' (FamilyOrg_FP2). This tension, according to some professionals, carries the risk of overprotection, as exemplified in the following case:

> We must talk a lot with the families so that they let them live their lives (...) because the problem of the associations is that there is the cousin, the uncle... and they are not

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> objective, and are overcome by fears (...) The people with intellectual disabilities are manipulated. And we must work to control these families. (Professional_EP4)

Despite these tensions with some of the ideals of IL, most professionals recognize that IL is unthinkable without the support of families. They believe that involving families in the process of fostering independence is crucial because 'if we are not careful with the families, take care of them, everything goes down the drain... without them there is no option either. You must keep that in mind' (Professional_EP2). A negative attitude may not only slow down the process but also directly lead to the refusal of the person with intellectual disabilities.

5-Discussion

This work account for the exponential growth of IL in the field of intellectual disabilities in Spain over the last 20 years. A trend emerged later than in Anglo-Saxon and Scandinavian countries, but that has steadily gained momentum as the need for models that enable people with intellectual disabilities to live in environments aligned with the principles of IL became imperative (Carbonell 2019). Those models, influenced by pioneering proposals and shaped through different forms of articulation, have aimed at promoting less institutionalized life options (Ruf 2007). However, it is important to note that the IL approach in the field of intellectual disabilities presented elements that come up some tensions with some principles of IL.

What we have observed aligns with the findings of Hooren et al. (2002) in the field of intellectual disabilities, which highlights the progression from the 90s from segregation via normalization toward integration and autonomy. This connection between normalization and autonomy is particularly relevant, as it explains how in our

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case housing is established as a cornerstone for a normalized life, and as a tool to develop an adult social status (Carlsson and Adolfsson 2022), as well as the articulation of habilitation and skill-training approaches. Wolfensberger's work on normalization through Social Role Valorization (Peralta and Arellano 2014) and Wehmeyer's work on self-determination (1998) inspired the influential contributions of Schalock and Verdugo in the Spanish context, emphasizing the significance of personal development and empowering individuals with intellectual disabilities to have control over their own lives (Schalock and Verdugo 2007), ultimately leading to a better quality of life (van Loon 2009).

These postulates, widely present in the field of intellectual disability, have tried to generate a shift from the deficit model, which perceives individuals with disabilities as inherently lacking, to a model influenced by positive psychology that aims to enhance their social worth (Wolfensberger 2011). However, our findings have also raised concerns about potentially prolonging learning processes indefinitely and subjecting users to excessive pressure to conform to societal norms. This can result in inequality among users (Reynolds and Wieseler 2022), as IL may become contingent on merit rather than recognized as a fundamental right for all individuals under the CRPD.

Simultaneously, these ongoing learning processes and training apartments not only facilitate skill development but also provide reassurance and security for families, as observed in our research. Risk is a significant factor that creates tension in the field (see Moyà-Köhler and Domènech 2021), raising concerns about the implications of the right to decide and self-determination (Fyson and Kitson 2007).

In this regard our research provides further evidence of the significant role of families in the field of intellectual disabilities. This point has been a subject of criticism within the IL activism, as some activists argue that decision-making should solely rest

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with individuals with disabilities, and families are seen as potential obstacles to the empowerment process (Ratzka 1994). However, our findings suggest that, regardless of whether their presence is preferable or not based on a strict interpretation of IL, families play an essential role in the articulation of IL in the field. Their involvement is crucial within the complex relational network necessary for boosting IL –although it does not mean they should have the final say. The field of intellectual disabilities highlights the importance of recognizing the relational dimension in the articulation of independent living, which is often overlooked in strong interpretations of the model (Lydahl and Hansen 2020; Dowling et al. 2019).

Finally, with regards to the third element presented and its connection to the rhythms of associations and the life cycle of the users, 'home' plays a central role in IL (Martinez-Rivera and Benavent 2020). This link with housing is virtuous in a space where people with intellectual disabilities are often treated in an infantilizing manner (Mitchell and Snyder 2015; Gjermestad et al. 2017). The ability to live in a home independently enables the transition to what is understood as an adult life and allows individuals to be recognized as members of the community (see Klein 2000). However, the significance of housing in IL also poses challenges, as it links the prospects of a more autonomous life to the necessity of moving out of the parental home, in such a way that people who, for whatever reason, are unable to access their own home, are left out of the independent living scope. In Spain, this connection is even more critical due to the complex and under-financed legal and regulatory framework that governs IL (see Rodríguez-Giralt et al. 2023), leaving it as something exclusive, and non-essential—the 'cherry on top of the cake' mentioned in the previous point by people in charge of one of the pioneer projects.

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6-Final remarks

We have seen how three distinctive and strongly intertwined elements can be found in the field. The need to focus on housing, to facilitate training spaces and the central role of families. All of them being ambivalent aspects, since it is certainly difficult to consider IL without access to a space of one's own, it is difficult to imagine the family's approval without the security of a minimum number of basic skills on the part of the users, or an independent life is inconceivable if the family is not part of the network that encourages this possibility. In spite of this, due to the fact that these three elements are intrinsically and somehow vitally necessary, the concerns raised by these three elements with regard to IL should be taken into account for the possible futures of IL in the field of intellectual disabilities. With this objective in mind, we put forth the following three main lines of action.

(1) People with intellectual disabilities must be placed at the center, and efforts should be made to facilitate spaces for accompanying families.

The work allows us to enhance the commitment that many professionals and families have had with the right to IL, and their essential role in the field to achieve spaces that are increasingly aligned with the CRPD (see McCausland et al. 2019; Casey et al. 2023). Precisely for this reason, it is important to value the importance of self-management and the full participation of users in the development of these initiatives, and to assume that the person with intellectual disabilities themselves are the experts on what support should look like (Puyaltó and Pallisera 2020). This shift in perspective should aim to move away from a family-centered approach, which has been prevalent in associations due to their origins and evolution. Nevertheless, this transition should be

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supported by efforts to involve families, in situations where they are present, as they can sometimes hinder transitions to IL models. To address this, we must emphasize how IL spaces can provide safety and security—examples can be seen during emergency situations like the Covid-19 pandemic (e.g., Moyà-Köhler, García-Santesmases and Farré 2023)—and providing opportunities for families to feel valued and integral to the process. This redefinition of roles also holds the potential to enhance the concept of IL from a relational and ethics of care viewpoint (Tronto 2017), positioning it as a space where families, friends, or significant individuals can participate, if so desired by the person with an intellectual disability. Through this approach, this field and the present work have the potential to broaden the understanding of independent living and potentially benefit other groups facing questions about 'decision-making capacity'.

(2) It is necessary to explore new professional models that embody the ideals of personal assistance and are suitable for the field of IL.

The field of disability has traditionally been hesitant to question the conventional distribution of roles between users and professionals (Ratzka 2007). In many of the cases discussed in this paper, the transition to IL has not been accompanied by a reevaluation of the role and position of supports. Instead, this asymmetry persisted, subjecting individuals with intellectual disabilities to ongoing processes of habilitation and training. Recognizing that personalized support staff play a crucial role in the field (Meys et al. 2021; Zaagsma, et al. 2023), and that they are instrumental in enabling the rights of people with intellectual disabilities to be realized (Leif et al. 2023), it is essential to further explore ways to integrate the concept of the Personal Assistant—who serves as a vital tool for enhancing the autonomy of individuals with disabilities (Carbonell 2019). However, achieving this is challenging within a field where the

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Personal Assistant cannot simply act as a means for executing desired actions but also becomes part of the relational and emotional dimensions of the individual (Giesbers et al. 2019). Nonetheless, feminist perspectives have paved promising pathways for action in this area (see Garcia-Santesmases et al. 2023) and provide insights into how to deal complexity, allowing us to view autonomy as an interrelated process, rather than solely as individual processes of self-determination.

(3) Public administrations should provide the necessary resources to ensure that every person with intellectual disabilities has the right to access IL.

Finally, it is crucial for authorities to allocate the necessary resources to address the inequalities experienced by users. As we have seen, these disparities are often determined by factors such as geographic location or the economic capacity of families. Unfortunately, many individuals are unable to access IL services due to its lack of inclusion in the portfolios of most of the organizations in the field. This is further exacerbated by limited resources within these organizations, compounded by the constraints imposed by prevailing austerity measures, which hinder the development of ambitious projects aimed at upholding the right to IL (Yang 2014). This holds special significance in a context such as Spain, where funding for support services is granted to organizations, instead of directly to individuals with disabilities. From this standpoint, it becomes imperative for administrations to shift their perspective on IL, moving away from considering it as an optional addition, such as the 'cherry on top of the cake' (Trias and Ruf 2011), and instead recognizing it as the central pillar of the deinstitutionalization process advocated by the ILM and the CRPD. Therefore, it is essential to formulate a strategic plan at the public policy level to effectively implement IL (see Williams and Porter 2017). This plan should ensure continuity, not just the

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initiation of initiatives through one-time budgets or training models that lack long-term planning. Moreover, it should aim to subvert the post-institutional frameworks (see Altermark, 2019) that many of these initiatives continue to articulate.

These proposals aim to contribute to the ongoing transformation of assistentialist and institutionalizing models and promote the effective realization of the right to IL as outlined in the CRPD, particularly in its Article 19. It is essential to collaborate and continue working in a field where professionals, families, and most importantly, users, have already established strong foundations for the ambitious and intricate development of IL within the field of intellectual disabilities.

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