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## Personal assistance, independent living, and people with disabilities: An international systematic review (2013–2023)

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## ABSTRACT

**Background:** The article discusses the contribution of personal assistance for the independent living of people with disabilities. This right is evolving at different speeds internationally, presents controversial aspects, and is under continuous debate.

**Objective:** To synthesize the evidence relating to the promotion of self-determination and independent living through personal assistance.

**Methods:** A systematic review was conducted following Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines. A search for relevant literature published was conducted during March 2023 across nine databases. The findings of the included studies were coded and analyzed via inductive content analysis.

**Results:** 26 articles were included, mostly qualitative, from four different continents. The analysis revealed six different key themes. The social framework highlighted the influence of international agreements and disability activism on cultural shifts in understanding disability. Secondly, healthy relationships and life or service expectations were emphasized. Key agents included users, personal assistants, family members, service providers, and other professionals. Personal assistants' work context explored ethical dilemmas, training, and working rights. Decision-making about personal assistance involved factors like lack of information, access requirements, and funding. Lastly, the implications underscored the positive impact of personal assistance on independent living, while identifying threats, and best practices for improvement.

**Conclusions:** This systematic review was the first to explore the promotion of independent living of people with disabilities through personal assistance schemes and highlights the need for governments to prioritize and coordinate efforts to ensure access for all, emphasizing the ethical imperative to progress toward social justice.

### 1. Introduction

Personal assistance (PA) is an essential support for people with disabilities to live autonomously and independently.<sup>1–15</sup> It also helps to reduce the inequalities they face in comparison to people without disabilities, because people with disabilities have traditionally been marginalized and discriminated.<sup>16–19</sup>

The understanding of disability has evolved throughout history.<sup>18–25</sup> The *charity model*, hegemonic in Antiquity, placed disability in external

causes, such as divine punishments. The prevalence of mutilations after the world wars of the 20th century, and the need to reintegrate these people into the labor market, inaugurated the rapidly expanding *medical-rehabilitation model*. The self-organization of people with disabilities under the Independent Living Movement made possible the emergence of the *social model* in the 1960s. Currently, the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD)<sup>26</sup> seeks to consolidate the *rights-based model* around the world with many countries changing and renewing their disability regulation.

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According to UNCRPD<sup>26</sup> people with disabilities do not have access to or enjoy the Universal Declaration of Human Rights (UDHR),<sup>27</sup> so it urges governments to establish real and effective guarantees. Consequently, supranational organizations are promoting broad agreements that favor the recognition, respect, and guarantee of all the rights of people with disabilities, and laws and regulations are being reformed internationally.

PA is the paradigm of the rights-based model; it facilitates the support that a person with a disability needs. It consists of a support Fig. 13 who helps another person (usually a person with a disability) to develop their life,<sup>4</sup> a professional service<sup>15</sup> with an employment contract<sup>13</sup> directed by the user<sup>22</sup> to promote and encourage personal autonomy, independent living and social participation based on knowledge of the user, their situation, needs, lifestyle and preferences, without providing more support than is strictly necessary.<sup>9</sup> PA can be materialized in different ways, like a personal budget or like a public service, among others. It allows him/her to decide what, when, how, or from whom to receive support to develop his/her independent living project.

Currently, PA is in the process of expansion in the public policies of different regions, such as countries from Latin America and the Caribbean.<sup>28,29</sup> However, it is a figure under constant debate due to its formal complexity, with multiple legislative forms depending on the country.<sup>30-32</sup> In addition, countries with a long tradition of this service are beginning to debate the economic resources allocated to this type of service.<sup>33,34</sup>

Different aspects arouse special interest in the literature. On the one hand, the respect that PAs should have for the will, beliefs, wishes, and decisions of the person with disabilities and his/her life project, can generate conflicts and ethical problems.<sup>1,10,35-37</sup> On the other hand, PA is not specifically regulated in many countries and this can lead to confusion with other jobs based on more traditional care. This is generating a great deal of debate about training for PA work.<sup>9,15,38-41</sup>

## 2. Objective

The evolution of the rights-based model makes PA a strategic service to promote the independent living of people with disabilities making this work useful and necessary. The main objectives are: (1) to systematically review the evidence on PA, independent living, and people with disabilities; and (2) to summarize the literature, and analyze the evidence related to the promotion of self-determination and independent living through PA schemes.

## 3. Method

### 3.1. Design

In order to respond to the objectives formulated, a synthesis of qualitative evidence was carried out through a systematic review. There are, at least, three types of standards for conducting systematic reviews.<sup>42</sup> In this study, the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA)<sup>43,44</sup> was used for the reporting standards. As regards methodological standards, the Cochrane guidelines and criteria<sup>45</sup> have been taken as a reference; however, since the data are essentially qualitative and from the field of social sciences, we have relied on the specific considerations for systematic reviews in this branch of knowledge.<sup>46</sup> The review protocol was registered in PROSPERO International Prospective Register of Systematic Reviews (CRD42023404211).

### 3.2. Search strategy

The Population, Intervention, Comparison, Outcome, and Context statement<sup>46</sup> was used to facilitate the literature search and to develop the inclusion criteria.

Population: people with disabilities, their families, and their PAs.

Intervention: PA, including it as a service or as a direct payment.

Comparison: people with disabilities and family situations when are users of PA compared to people with disabilities and family situations when are not users of PA.

Outcomes: promotion of self-determination, personal autonomy, and independent living for people with disabilities, and their family environment.

Context: any geographic setting.

The review team searched nine databases: Web of Science, Scopus, PsycINFO, PubMed, ERIC, Teacher Reference Center, Cochrane, Dialnet Plus, and ÍNDICES CSIC. Our keywords were based mainly on the Medical Subject Heading (MeSH), although some terms were used because of their common use in this topic (see [Appendix A](#)). Searches in each database were done during March 2023.

### 3.3. Criteria for study selection

As is recommended in most systematic reviews,<sup>42</sup> we opted for broad inclusion of study design. Thus, all articles with empirical results were included.

All the studies had to meet the following criteria: (a) studies published both in English or Spanish, the most common languages in research in Europe and with the highest number of speakers globally<sup>47</sup>; (b) studies published in peer-reviewed journals; (c) studies indexed in the Journal Citation Reports (JCR), Journal Citations Indicator (JCI) or Scopus using Scimago Journal and Country Rank quartiles and impact factors as the reference; (d) studies from the last decade, between 2013 and 2023, until the final search date; and (e) studies where the relationships between PA, independent living, and people with disabilities were on the main goals.

On the other hand, exclusion criteria were: (a) studies in other languages different from English or Spanish; (b) communications, theses, reviews, books, book chapters, or grey literature; (c) studies not indexed in JCR, JCI or Scopus; (d) studies published before 2013; and (e) studies about PA, independent living, and people with disabilities on a really specific way or aspect, like only legal framework, or only general comparisons without a deep analysis on the implications of these relationships; also excluded are items where the main service does not correspond to personal assistance, for example, home care services or services in specific contexts.

### 3.4. Data extraction and analysis

A flowchart to provide clear information on the included studies' selection process was used.<sup>42,43</sup> [Fig. 1](#) shows the procedure for the review process and data extraction, which was carried out in duplicate. EndNote 21<sup>48</sup> and Microsoft Excel version 2305<sup>49</sup> were used to identify duplicate studies and to develop the inclusion criteria and the screening process of the paper review. First, Author and Author independently reviewed titles and abstracts before achieving consensus about whether to include each study. Both resolved conflicts about inclusion in weekly online meetings and when there was no consensus, another author, Author, broke the deadlock. The same procedure was used for the full-text screening.

This step allowed the identification of 976 studies. Between them, 399 duplicate studies were eliminated. Abstracts and titles of the rest of the studies were read, removing 493 which did not connect to the purpose of the review. After this, 84 studies were selected for full reading, but 61 were discarded because did not meet the inclusion criteria. Finally, 23 studies were selected. A list with the excluded studies at the full text level is shown in [Appendix B](#).

ATLAS.ti Windows (Version 22.0.7.0)<sup>50</sup> was used to code the data and produce the themes and sub-themes from our analysis.

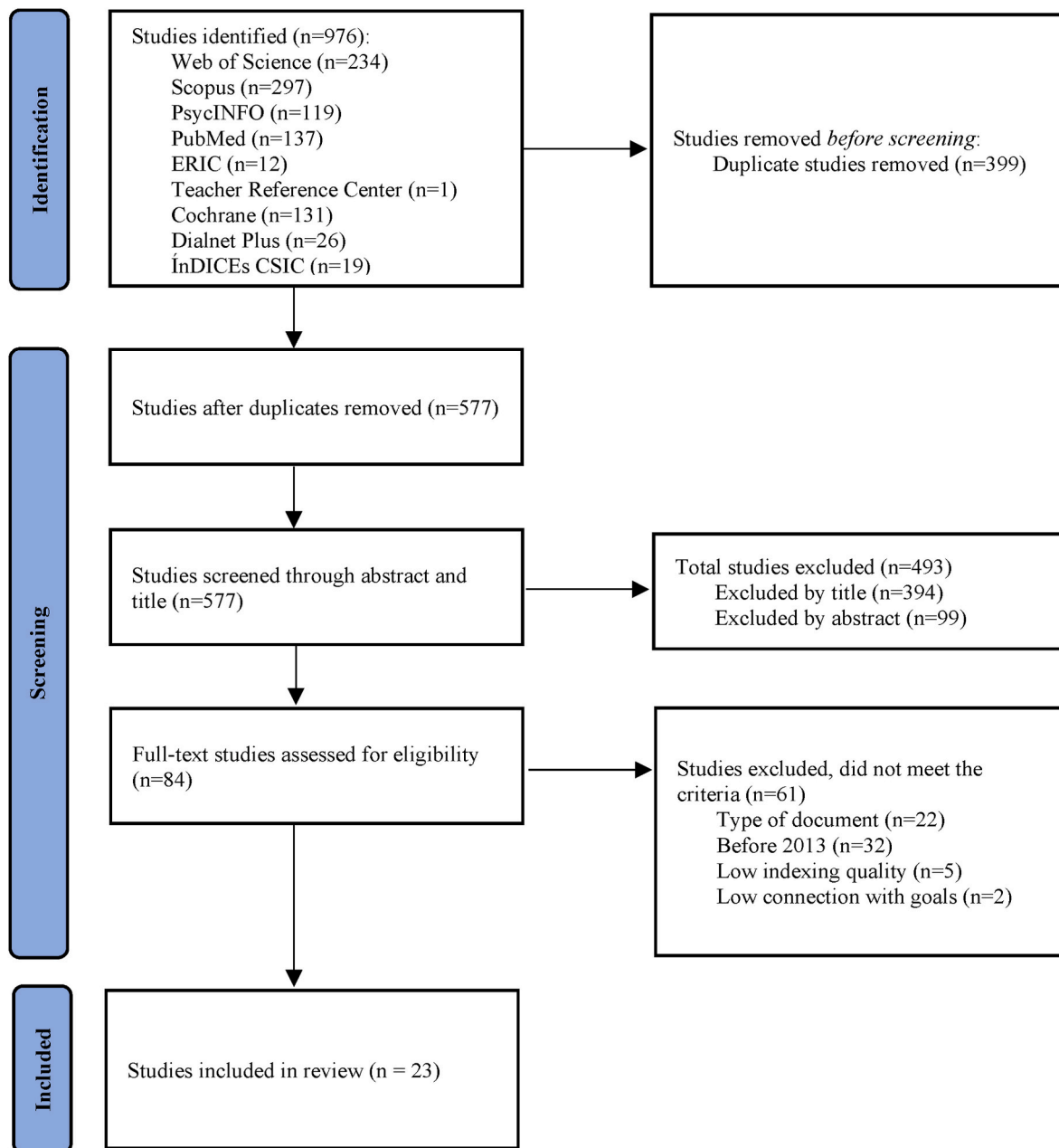


Fig. 1. PRISMA flow diagram.

### 3.5. Quality assessment

The McGill University's mixed method appraisal tool (MMAT)<sup>51,52</sup> was used to critically assess the methodological quality of the studies. First, the studies were appraised using the screening questions, and then by the type of design, as the MMAT is valid<sup>53</sup> and reliable<sup>54</sup> for the assessment of qualitative, quantitative, and mixed-method research.

## 4. Results

### 4.1. Study selection

The stages of the study selection have been presented in Fig. 1. A total of 23 studies were included. A summary of each study has been presented in Table 1. There was total agreement between Author and Author at the full-text stage.

### 4.2. Quality assessment

An overview of the quality assessment has been provided in Appendix C.

### 4.3. Study characteristics

Of the 23 included studies, 17 were qualitative, including one case study; 3 were quantitative, with one longitudinal study; and the last 3 were mixed methods approaches. The largest number of studies were published in the years 2022 (n = 5), 2020 (n = 4), 2019 and 2018 (both n = 3) showing the emergence of interest in PA. The main subject area of the journals where the studies were published was Social Sciences (n = 16), followed by Health Professions (n = 10), and Medicine (n = 9). Regarding the area of analysis, the European continent is in the majority, with three areas standing out: Scandinavia (n = 6), Spain (n = 5), and the United Kingdom (n = 5). In addition, the European area (n = 2),

**Table 1**  
Description and main overview of the studies included in the review.

N	Author/s (Year)	Region	Type research and sample	Scales and instruments	Subject area	MMAT quality check	Results/Findings	Conclusions/Proposals
1	Romer and Walker, 2013 <sup>55</sup>	USA	Qualitative 16 PA	Appreciative inquiries	Health professions Public Health, environmental and occupational health Social Psychology	4/5	There are critical factors involved in successfully providing person-centered support. It acknowledges the importance of developing and recruiting PAs with the desired relational characteristics, focusing on creating meaningful relationships in the context of supported living agencies.	It emphasizes the importance of person-centered support for people with disabilities, stressing the need for meaningful relationships between service seekers and providers. It highlights the shift towards person-centered cultures in organizations and the importance of an organic, relationship-focused approach to help people with disabilities lead inclusive lives in the community.
2	Graham, 2015 <sup>56</sup>	England	Qualitative 8U/7 PA/6 F/3 S	Unstructured interviews	Health professions Social Sciences	5/5	It explores the multifaceted nature of PA relationships within a financial exchange framework, highlighting their value beyond practical assistance to include emotional aspects. It also underlines direct payments in England, particularly in the context of employers with learning difficulties, and emphasizes the complexity of PA roles and their impact on relationships and expectations.	It emphasizes a shift away from the strictly market-driven concept of empowerment to a more informal, valued exchange rooted in personal and emotional aspects. It raises questions about the future of PA, especially in the context of potential regulation and the need to recognize the social and collective aspects of these relationships.
3	Roulstone and Hwang, 2015 <sup>57</sup>	England, Sweden, and Wales	Qualitative Case Study (n = 3)	Literature and Practice Review Interviews	Health professions Social Sciences	5/5	It explores the growing engagement of disabled people in cooperatives for social care support and underscores the significance of active participation in decision-making and collective dynamics. Challenges include limited awareness of cooperative models, inadequate government backing, and policy hurdles. It advocates for viewing cooperatives as supplements to well-funded public services, not replacements.	It underscores the close link between cooperative principles, direct payments, and disabled people's organizations, focusing on shared ownership, user control, and trust in individuals' expertise in their lives. It presents effective cooperative models and recommends that the United Kingdom explore cooperative principles more extensively, with proper funding and support, while addressing opposition and funding issues.
4	Brennan et al., 2016 <sup>58</sup>	Iceland, Norway, and Sweden	Qualitative 17F <sup>a</sup>	In-depth semi-structured interviews	Health professions Social Sciences	5/5	It examines parental advocacy for personalized support services for their disabled children, leading to legal changes for equal PA access. It addresses the principles of independence and choice from parental perspectives, as well as the challenges they encountered in promoting their children's well-being and independence within the PA scheme.	It argues that emphasizing independence, choice, and individual autonomy alone is insufficient for comprehending PA schemes where someone manages on behalf of the user. It introduces the idea of "supported PA" to differentiate from user-led PA, recognizing the significance of social and community support and promoting equality and a comprehensive understanding of various PA models.
5	Von Granitz et al., 2017 <sup>59</sup>	Sweden	Quantitative 10,201U	Questionnaire	Medicine	5/5	It raises concerns about unequal terms for participation, possibly due to shifts in the user profile and unclear demarcation between PA and medical attention. The results suggest a significant focus on Health	It reveals a notable disparity between the anticipated and actual results of PA in Sweden. It suggests a shift in focus from a citizenship-oriented approach to a more medical model, potentially impeding the goal of

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Table 1 (continued)

N	Author/s (Year)	Region	Type research and sample	Scales and instruments	Subject area	MMAT quality check	Results/Findings	Conclusions/Proposals
							and Care, raising questions about whether the policy intentions of the LSS Act are being met, especially regarding the promotion of participation for people with disabilities.	enabling full community participation for people with disabilities and hindering the realization of disability rights per the UNCRPD Article 19.
6	Dunér and Olin, 2018 <sup>60</sup>	Sweden	Qualitative 17U <sup>b</sup>	Open-ended, semi-structured interviews	Health professions Social Sciences	5/5	It explores the experiences of people who receive PA from family members who are employed as PAs. It identifies three themes: the ambivalence of family relationships, challenges in distinguishing formal and informal roles, and complex dynamics of dependence and independence. Using family members as PAs can both enhance and constrain recipients' autonomy and well-being.	It highlights the pros and cons of family-based assistance, urging a balanced approach. It questions the shift of responsibilities from the welfare state to individuals and their families, which could return to traditional family care. It emphasizes the need for flexibility and collaboration among support actors and institutions for freedom, equality, and justice in modern welfare societies.
7	Jenhaug and Askheim, 2018 <sup>61</sup>	Norway	Qualitative 11F	Semi-structured interviews	Health professions Medicine Social Sciences	5/5	It explores parental experiences with PA for disabled children and emphasizes the positive impact on family life and parents' ability to work, their managerial role in PA arrangements, and its significance for children. Challenges include navigating the municipal allocation process, the need for predictability, and the role of parental advocacy in varying municipal contexts.	It delves into the positive parental experiences with PA for their disabled children, highlighting its role in enabling a more normal life. Parents usually take on managerial roles, with some experiencing stress. Challenges in dealings with municipal offices affect parental empowerment, stressing the importance of co-production and trust with caseworkers and the need for improved PA delivery for families with disabled children.
8	Shakespeare et al., 2018 <sup>62</sup>	England	Qualitative 30U/28 PA	Semi-structured interviews	Medicine Social Sciences	5/5	It analyses metaphors describing PA relationships between disabled people and their PAs, showing the influence of cultural context and the diversity of PA models. It highlights the role of reciprocity, particularly the concept of "paid friendship," in empowering disabled individuals, emphasizing the need for a flexible approach to meet diverse needs while respecting privacy and autonomy.	It explores diverse metaphors used to describe PA relationships, including "staff," "extension," "family," and "friendship." It stresses the importance of clear expectations and role definition to avoid conflicts. Training and support for both disabled people and PAs are essential for maintaining satisfactory relationships while acknowledging potential challenges in unregulated PA arrangements
9	Olin and Dunér, 2019 <sup>63</sup>	Sweden	Qualitative 17U/23 PA <sup>c</sup>	Open-ended, semi-structured interviews	Medicine Social Sciences	5/5	It delves into the cultural and individualistic contexts influencing family-based PA. Emotional involvement is central, yielding both positive and negative aspects. It underscores structural conditions' role in shaping PA opportunities and stresses the importance of context-specific approaches in PA policies and services.	It presents three approaches to family assistance: "family as a substitute," "as a complement," and "family first." While "family as complement" can be empowering, the "family as substitute" approach may lead to negative consequences and marginalization. The "family first" approach heavily relying on family assistance may limit opportunities for independent living for both assistants and users.
10	Prieto et al., 2019 <sup>11</sup>	Spain	Qualitative a 4U/6 PA/5 F/12 S	a. Semi-structured interviews	Rehabilitation	5/5	PA services receive acclaim for their positive effects on people with intellectual	PA services offer innovative support for people with intellectual disabilities and

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Table 1 (continued)

N	Author/s (Year)	Region	Type research and sample	Scales and instruments	Subject area	MMAT quality check	Results/Findings	Conclusions/Proposals
			b 3U/5 PA/1 F/9 S	b. Four discussion groups			disabilities and severe mental illness, promoting autonomy, well-being, and social inclusion, while also benefiting their families. Challenges include limited awareness of social services, decision-making difficulties, and funding concerns. PAs face issues like job recognition, compensation, stress, and work-life balance, underscoring the nascent stage and potential challenges of the service.	severe mental illness, enhancing autonomy and well-being. However, implementation is intricate, and hampered by personal, family, cultural, and organizational hurdles. Overcoming these challenges necessitates support from organizations, training for PAs, and effective regulation to ensure access and quality, ultimately working towards genuine independent living.
11	Ruiz et al., 2019 <sup>54</sup>	Spain	Mixed: 1. Quantitative 120U/147F 2. Qualitative Case Study (n = 4)	1.a. Persons with ID (QPID) 1.b. Parents or guardians of persons with ID (QF) 2.a. Semi-structured interviews 2.b. Participant observation 2.c. Field journals	Medicine Psychology Social Sciences	5/5	It explores the implementation of PA for people with intellectual disabilities. It identifies relationships between PA and variables like a child's need for assistance with showering and participation in occupational programs. Case studies demonstrate how PA positively impacts users, enhancing self-care, personal image, financial management, personal planning, and organization. These interventions involve collaboration with family members, peers, and professionals to ensure success.	It underscores the importance of considering the viewpoints of service users and their families in supporting people with intellectual disabilities in their journey toward independent living. It stresses the need for PA programs to foster autonomy and coordination of support. It also advocates for evidence-based interventions, discusses obstacles like parental involvement and behavioral challenges, and outlines ten essential competencies for PAs.
12	López-Pérez and Álvarez-Nieto, 2020 <sup>6</sup>	Spain	Mixed: 1. Quantitative 74U/29 S 2. Qualitative 1PA/7 S	1.a. Users <i>ad hoc</i> questionnaire 1.b. Coordinators' <i>ad hoc</i> questionnaire 2. Semi-structured interviews	Social Work	5/5	It emphasizes that PA is a relatively new and underrepresented concept in Spain, with limited awareness and access to PA services. It points out that the lack of political commitment and unfamiliarity with the PA profession are key factors hindering the establishment of specific regulations, and that PA primarily employs female, immigrant, and student workers.	It underscores the lack of awareness and understanding of PA for people with disabilities in Spain. It emphasizes the need for better information, improved PA access, and comprehensive regulations to address labor challenges. The positive impact of PA on personal autonomy and empowerment is highlighted, concluding that PA is a crucial resource for achieving independence and equality for individuals with disabilities.
13	Minoletti et al., 2020 <sup>55</sup>	Chile	Qualitative	Scoping review Expert panel Focus group interviews with experts by expertise Focus group interview with potential users	Medicine Psychology Social Sciences	5/5	The review highlights the "Person-Centered Planning" model as a key approach for people with intellectual disabilities. Experts stress individualized support and family involvement in the transition to adulthood. The proposed "Brief PA Model" combines PCP and Critical Time Intervention over 9 months to enhance self-determination and community inclusion.	Proposal of a brief PA model for people with intellectual disabilities based on both evidence and experiences in recent literature, along with expert opinions. This PA model aims to increase between 3 and 5 items over 9 different items during critical periods of development and for a limited time
14	Mladenov, 2020 <sup>7</sup>	Europe	Quantitative 35U/15NU	Questionnaire PA Inventory	Health professions Social Sciences	3/5	It examines factors affecting choice and control in PA. Key enablers involve user autonomy and assistant safety, while barriers include scheme limitations and ideological issues. Non-consensual aspects reveal	It pinpoints enablers for PA, emphasizing choice, needs assessment, and timing control. These insights shape EU disability policies. Areas of PA requiring further study include creating an evaluation checklist,

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Table 1 (continued)

N	Author/s (Year)	Region	Type research and sample	Scales and instruments	Subject area	MMAT quality check	Results/Findings	Conclusions/Proposals
							conflicts within the disabled community and independent living philosophy.	overcoming limitations, and seeking input from a wider range of PA users for improved relevance in fostering independent living and social inclusion.
15	Porter et al., 2020 <sup>10</sup>	United Kingdom	Qualitative 30U/28 PA	Semi-structured interviews	Medicine Social Sciences	5/5	PA relationships blend personal and professional elements, with informality, affection, and collaboration promoting independence but also raising potential risks. Both employers and PAs must recognize these dynamics and address them, emphasizing asymmetrical disclosure to maintain genuinely empowering and sustainable support for disabled individuals.	PA challenges conventional relationship boundaries, with disabled employers and PAs often having different perspectives. They require support to consider the nature of their desired relationships and their consequences, promoting an empowering and sustainable experience of this support model for more disabled people.
16	Chou et al., 2021 <sup>66</sup>	Taiwan	Qualitative 33U/12 S	Open-ended, semi-structured interviews	Health professions Social Sciences	5/5	In Taiwan, the nascent PA system differs from Western models, lacks user control, and is constrained by Confucian cultural influences. It falls short of empowering disabled people for independent living due to government decision-making rather than user influence, limited funding, and a lack of substantial policy changes toward community-based care.	PA for disabled people is commonly government-controlled and supplementary, not an alternative due to insufficient public funding and a lack of alignment with independent living principles in East Asian contexts. To address this, there's a need to shift authority and funding to community-based services, improving PA for disabled people.
17	Alario, 2022 <sup>67</sup>	Spain	Qualitative (n = 45) a. 4U/6 PA/5 F/12 S b. 3U/5 PA/1 F/9 S	a. Semi-structured interviews b. Four discussion groups	Rehabilitation	5/5	PA empowers individuals with mental health issues, enabling autonomy and choice. It supports emotional, behavioral, and physical recovery, helps achieve life goals, and facilitates social participation. PA aids in staying in familiar environments, improving overall quality of life, and is essential for individuals' well-being and recovery.	PA is effective in reducing social and employment exclusion for those with mental health issues. It provides personalized support, aiding recovery and community participation while reducing stigma. The main challenge is the lack of national regulation, including accreditation and economic support, with ongoing efforts to resolve these issues.
18	Biziewska and Palattiyil, 2022 <sup>68</sup>	Scotland	Qualitative 9 S	Semi-structured interviews	Health professions Social Sciences	5/5	The implementation of Self-Directed Support (SDS) in Scotland faces challenges. While it raises awareness of service users' rights, practitioners struggle to guide informed choices due to complex processes and limited information. Resource control sometimes overshadows human rights, and the absence of advocacy groups hinders service users' rights, showing a gap between SDS ideals and economic realities.	It found a disconnect between the human rights rhetoric of SDS and its practical implementation. The study suggests that addressing this disconnect requires empowering practitioners with knowledge of local SDS implementations and allocating sufficient resources to prioritize human rights over budget constraints in social work departments.
19	Nally et al., 2022 <sup>69</sup>	Europe	Qualitative	Scoping review	Health professions Social Sciences	5/5	It underscores the necessity for strong legislation, more funding, streamlined processes, and better governance to enhance the quality and effectiveness of PA programs. It also highlights the pandemic's impact on PA schemes and	Governments have often favored cost-cutting over human rights in PA programs, not fully complying with UNCRPD Article 19. It advocates for user-led PA models, sufficient funding, and policies aligned with the social model of disability. Co-designing

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Table 1 (continued)

N	Author/s (Year)	Region	Type research and sample	Scales and instruments	Subject area	MMAT quality check	Results/Findings	Conclusions/Proposals
							stresses the importance of recognizing their value.	legislation and prioritizing long-term social inclusion over short-term savings is essential for human rights. It discusses challenges in PA relationships, emphasizing their informal nature. Differences in expectations and values can lead to conflicts, requiring flexible strategies, training, and support for disabled employers and PAs. Accessible, well-funded support is crucial to make independent living achievable for all.
20	Porter et al., 2022 <sup>70</sup>	United Kingdom	Qualitative 30U/28 PA	Semi-structured interviews	Business, Management and Accounting Economics, Econometrics and Finance Social Sciences	5/5	It identifies three trouble categories in PA relationships: practical, personal, and proximal. These issues can lead to conflicts and deviations, affecting disabled employers and PAs. Problems vary from practical task and management issues to deeper personal and value conflicts, and socio-spatial organization challenges, potentially harming trust, and safety in these relationships.	
21	von Granitz et al., 2022 <sup>71</sup>	Sweden	Quantitative, longitudinal, 2010 10,201U 2015 2,612U	Questionnaire	Medicine	5/5	The findings indicate a shift towards health and care-related PA, raising concerns about a transition to a more medical model and the risk of social exclusion due to fewer activities outside the home. It emphasizes the importance of monitoring and individualized planning of PA to ensure improved participation in line with the LSS Act's intentions.	Increasing PA by 16 h per week doesn't boost participation in external activities, showing limited benefits. Instead, there's a trend towards home-based activities and technology reliance, raising concerns about social isolation, particularly for women, older people, and those with special needs. This emphasizes the need to monitor PA content for improved societal inclusion, in line with UNCRPD Article 19.
22	Pino-Morán et al., 2023 <sup>72</sup>	World	Qualitative	Integrative literature review	Environmental Science Medicine	5/5	It explores the role of PAs in promoting independence for people with disabilities. It expresses concerns about the medicalization of PA, touches on ethical aspects, and discusses the tension between Independent Living and Feminist Movements. The legal and contractual dimensions of this care are also examined.	It explores the ongoing debate surrounding PA for people with disabilities, shaped by the historical context of two identity-based movements. This debate often oversimplifies complex issues. It advocates for a collective, context-specific, and inclusive approach that promotes interdependence, and autonomy and respects diverse life experiences and projects.
23	Riobóo-Lois et al., 2023 <sup>40</sup>	Spain	Mixed 49 PA	Open-ended <i>ad hoc</i> questionnaire	Psychology Social Sciences	5/5	It presents data of Spanish PAs, with 75.5 % being women aged 23–34, and 55.1 % having a university education. It underscores the necessity for enhanced PA training, particularly in emotional management and psychology, due to current training gaps. Continuous education and specialization in PA fields are recommended.	It emphasizes the pivotal role of PA in the independent living philosophy for people with disabilities. It highlights the ongoing marginalization due to insufficient support and a lack of resources. It advocates for university-level training in PA that includes human rights, ethics, and gender equality to provide quality care and support.

Note: JCR, JCI, and SJR were extracted from the year 2022 classifications. Key for Table 1: U – users of personal assistance. PA – personal assistants. F – family members or supporters. S – staff, including CEOs of service providers, third sector staff, coordinators of PA services, etc. NU – non-users of personal assistance. More information about the MMAT research quality check on [Appendix C](#).

<sup>a</sup> Parents of children with disabilities who are managing their PA services.

<sup>b</sup> PA provided by family members of the users.

<sup>c</sup> Family members working as PAs.



and the conjunction of Scandinavia and the UK (n = 1) complete the studies from the old continent. To these are added Chile in South America (n = 1), the USA in North America (n = 1), Taiwan in Asia (n = 1), and the World area (n = 1) so without representation from Africa and Oceania, the socio-demographic variety of the studies analyzed is limited. The scarce presence of North American studies contrasts with the emergence, in this territory, of the independent living philosophy.

#### 4.4. Findings

Table 2 displays the themes and sub-themes generated after the inductive analysis of the studies and more supportive quotations for both are presented in Appendix D.

#### 4.5. Social framework theme

The social framework influences the implementation and development of PA. Broad international agreements and the activism of people with disabilities have led to a cultural change in the understanding of disability. Three sub-themes were identified: (a) social construction, and the UNCRPD, (b) disability movements, and (c) cultural shift.

#### 4.6. Social construction, and the UNCRPD sub-theme

The sociopolitical and sociocultural context can favor or restrict the consolidation of the philosophy of independent living. The literature is concerned with the need to move towards more inclusive and accessible societies<sup>6,7,11,40,55-61,63-69,71,72</sup> in line with the UNCRPD<sup>26</sup> because “welfare arrangements were often characterized by a lack of attention to the intentions and agency of disabled people, who were assumed to be incapable of controlling their own lives”.<sup>60</sup> The UNCRPD has promoted regulatory changes, favored the implementation of PA schemes and contributed to the expansion of the philosophy of independent living in the face of inequalities in access and the exercise of rights by people with disabilities<sup>6,7,40,58-60,63,65-67,69</sup>. All of this, in societies where there is “no social recognition to caring for people with disabilities”.<sup>72</sup>

#### 4.7. Disability movements sub-theme

Self-organization has been key to achieving new rights and guarantees for their real and effective exercise. The disability movement has lobbied national governments and international institutions for greater recognition of their needs.<sup>7,57,58,61,62,64,66,68,72</sup> “PA is a result of initiatives and struggles among disabled people to achieve empowerment,

independence and the right to participate in society on equal terms”<sup>61</sup> and “the UNCRPD is a milestone for the international independent living movement”.<sup>58</sup>

#### 4.8. Cultural shift sub-theme

Between the disability movement and broad international agreements, a cultural shift in the understanding of disability has been initiated and consolidated<sup>6,7,57,58,61,62,64,68</sup> where “PA is opposed to traditional forms of care”.<sup>10</sup> This shift is intended to be global, although the philosophy of independent living is based on Western values that are not universal<sup>7,66,72</sup> because “different historical, ideological and cultural factors, it is clear, have helped shape the roll out and interpretation of independent living in each country”.<sup>57</sup>

#### 4.9. Relationships theme

Relationships are one of the main aspects involved in PA. Especially important is the relationship between the users and his/her PAs. Two sub-themes were identified: (a) healthy relationships and (b) life or service expectations.

#### 4.10. Healthy relationship's sub-theme

It is essential to establish a healthy and respectful relationship between the different parties involved, especially the person with a disability and his or her PA<sup>7,10,11,55-58,60-64,69,70,72</sup> because “how these relationships emerge and are supported is of critical importance”.<sup>56</sup> Although there are underlying difficulties in creating and maintaining these bonds over time,<sup>6,10,56,57,62-64,70</sup> as well as the influence, positive or negative, of other agents on these relationships<sup>7,60-62,64,65,70</sup> because “no reasonable person would argue that people with disabilities only need relationships with their PAs”.<sup>55</sup>

#### 4.11. Life or service expectation's sub-theme

What is expected of people with disabilities can have a pernicious influence,<sup>6,40,58-60,62-64,66,70,72</sup> as well as the expectations placed on the PA, a sign of lack of knowledge about this service or confusion with other types of support or care.<sup>6,56,59,61,62,68,70,71</sup> In addition, “different disabled people had different ways of approaching the employment and management of their workers. This reflects personality characteristics, as well as the life goals”.<sup>62</sup>

#### 4.12. Key agents theme

Different actors emerge around the PA that play an important role at certain moments. Five sub-themes were identified: (a) users, (b) PAs, (c) family members, (d) service providers, and (e) other professionals.

#### 4.13. Users sub-theme

People with disabilities are the main character of the PA and can play different roles: from manager or employer to service receiver.<sup>6,7,10,11,40,55-57,59-63,66-70,72</sup> One user recognized that “now that I have PA for such help, I do not feel I owe somebody for giving me a favor”.<sup>66</sup>

#### 4.14. Personal assistants' sub-theme

PAs assume the responsibility of providing the support they require in different areas of their lives.<sup>6,7,10,11,40,55,58,60-64,67,70,72</sup> To do so, they must have innate qualities and develop different skills to be able to play multiple roles depending on the different situations<sup>6,11,40,55,64,67</sup> because “its actual effect usually depends on how direct services workers go about doing their job”.<sup>55</sup>

**Table 2**

Themes and sub-themes from the promotion of self-determination and independent living through PA.

Themes	Sub-themes
Social framework	Social construction and the UNCRPD Disability Movement Cultural shift
Relationships	Healthy relationships Life or service expectations
Key agents	Users PAs Family members Service providers Other professionals
PAs work context	Ethical dilemmas Training Worker rights
Decision-making about PA	Lack of information and local authorities Access requirements Funding
Implications and best practices	Independent living, empowerment, choice Risks or threats Best practices

#### 4.15. Family members sub-theme

Their work in the promotion of rights is recognized, as well as the undervaluation of their contribution to the care of people with disabilities.<sup>60,64,67</sup> Most of them “care for and live with them, and they are in most cases the sole caregivers”.<sup>67</sup> Depending on the socio-political context, they can exercise PA,<sup>10,60,63,71</sup> manage the service<sup>58,61–63</sup> or complement it at certain times.<sup>6,11,56,57,60,63,65,66,69–71</sup>

#### 4.16. Service-providers' sub-theme

Disability organizations act as a link between people with disabilities and their families, and administrations, facilitating the management and/or provision of PA.<sup>6,11,55–57,61,64–66,68–70</sup> For their part, private companies exploit the underlying individualism of the philosophy of independent living and generate conflicting positions. On the one hand, the possibility of greater personalization of the service is favored<sup>57,63</sup> while, on the other hand, there are calls for a review of the quality of the PA they provide.<sup>56,57,67,69</sup> In addition, “the consumerist assumption of rational, well-informed and competent consumers has to be problematized, taking into account the diversity of disabled people”.<sup>63</sup>

#### 4.17. Other professionals' sub-theme

All professionals involved in the access, provision, and monitoring of PA should be trained in the philosophy of independent living to be aware of and act against the barriers present in the assessment process, as well as institutional restrictions.<sup>11,57,58,61,64,66,68</sup> It is needed to make “a shift from a person-centered model of care to a person-planned model of care”.<sup>11</sup>

#### 4.18. Personal assistants' work context theme

The PA is based on a very close interpersonal relationship due to the nature of its functions. The working conditions are very particular and variable, in response to the highly personalized nature of the functions performed by the PA. Three sub-themes were identified: (a) ethical dilemmas, (b) training, and (c) working rights.

#### 4.19. Ethical dilemma's sub-theme

PAs face different ethical issues due to the relational nature of their work and seek to make the best possible decision. However, the confluence and/or divergence of positions between them, the person with a disability, and other people close to them can generate conflicts.<sup>10,11,40,55,56,58–63,67,70,72</sup> In fact, “all of our participants reported having experienced conflict over PA at some point”<sup>62</sup> or “relationship boundaries involve issues of power, influence and control”.<sup>10</sup>

#### 4.20. Training sub-theme

There is agreement on the characteristics and interpersonal skills needed to practice PA.<sup>6,11,40,55,64,67,72</sup> However, there is debate as to whether there is a need for more professional training. The disability organizations suggest that there should be no specific training,<sup>6,7,11,56–58,65</sup> while, on the other hand, there is support for expanding and improving different aspects of current training<sup>11,40,55,56,62,64–66,68,70</sup> because “two to 10 h of ethics training (...) is very scarce (...) must play a central role and, consequently, be one of the pillars of training in PA”.<sup>40</sup>

#### 4.21. Working Right's sub-theme

The flexibility of working conditions to adjust to the needs of people with disabilities is positively valued.<sup>6,61,62,72</sup> At the same time, “one fundamental care problem is the lack of recognition for it as a paid job

activity”<sup>72</sup> so there is a warning about the possible consequences and the need for PA to have greater social consideration and decent working conditions.<sup>6,7,10,11,40,55,56,60,62,66,69,70,72</sup> Currently, PAs have “low wages and poor conditions reflecting the value attached to all involved”.<sup>56</sup>

#### 4.22. Decision-making about PA theme

The design and implementation of independent living policies, such as PA, depends on socio-cultural and socio-economic factors. Three sub-themes were identified: (a) lack of information and local authorities, (b) access requirements, and (c) funding.

#### 4.23. Lack of information sub-theme

There is still a widespread lack of knowledge about PA among people with disabilities, their families, the general public, and even local authorities and their professionals.<sup>6,7,11,59,61,66–68</sup> Besides, “transparency was identified very early as one of the conditions necessary for enabling service users to make informed decisions”.<sup>68</sup>

#### 4.24. Access requirement's sub-theme

Requirements such as age, type of disability, or service management capability among others, restrict access to PA under the terms of the UNCRPD<sup>5,11,40,59,61,66,68,69</sup> and people with “intellectual disabilities are among the most excluded”.<sup>40</sup> In addition, there are internal inequalities in different territories within the same country.<sup>40,59,61,67–69</sup>

#### 4.25. Funding sub-theme

PA is often underfunded or offers limited coverage of the needs of people with disabilities.<sup>6,7,11,40,56,57,60,61,63,64,66,68–70,72</sup> Besides, “austerity policies (...) are impeding the injection of more and better resources”.<sup>72</sup> Despite the low investment in PA in many countries, some studies report a high social return.<sup>11,56,65</sup>

#### 4.26. Implications and best practices theme

PA favors the independent living of people with disabilities. At the same time, some threats deserve attention and elements that can constitute good practices in its management and provision. Three sub-themes were identified: (a) independent living, empowerment, and choice; (b) risks or threats; and (c) best practices.

#### 4.27. Independent living, empowerment, and choice sub-theme

There is a positive and decisive impact on the independent living of people with disabilities, their families and environments, and society as a whole.<sup>6,7,10,11,40,55–72</sup> “The user can perform any activities with the support of an assistant in order to live an independent life like others, thus eliminating limitations to participation in society”<sup>71</sup> and “allows them to learn and develop social and relational skills, as well as real opportunities to meet other people, network and establish new relationships”.<sup>67</sup>

#### 4.28. Threats sub-theme

Some threats are identified as poorly managed interpersonal conflicts, insufficient funding, access requirements and restrictive regulations, territorial inequalities, poor training, or negative interference by some agents, among others.<sup>6,7,10,11,40,56–66,68–72</sup> On the other hand, “there is a shift to a medical model and a risk of social exclusion due to fewer activities outside the home”.<sup>71</sup>

#### 4.29. Best practices sub-theme

Aspects are identified that can contribute to improving the quality of the service and, consequently, the quality of life and well-being of people with disabilities, their families, and environments. These aspects may constitute possible good practices.<sup>7,11,40,57,58,63–65,67–69</sup> For example, regarding PA training, it should “be shared with all actors, starting with the users themselves, who must also be trained in the philosophy of independent living, as well as their families and, ideally, their environment”.<sup>40</sup> That “would be a useful foundation for good PA”<sup>7</sup> because “there is a vast difference between finding people to fill out schedules and seeking people to enter into a relationship of equality and at the same time to realize you are there to offer yourself in service”.<sup>55</sup>

## 5. Discussion

This systematic review explored the implications of PA schemes to promote personal autonomy and independent living of disabled people. Findings revealed six relevant themes: (1) social framework, (2) relationships, (3) key agents, (4) personal assistants’ work context, (5) decision-making about personal assistance, (6) implications and best practices.

### 5.1. Social framework

The literature points out the traditional situation of vulnerability of people with disabilities.<sup>16–19,73,74</sup> Besides, women face situations of greater discrimination and vulnerability than men.<sup>59,60,65,71,75,76</sup> The construction of contemporary societies has been built on discrimination and barriers, slowing down the cultural change necessary for the expansion of new paradigms and approaches,<sup>7,11,40,55–61,63–69,71,72,77,78</sup> supported by the UDHR<sup>27</sup> and the UNCRPD.<sup>26</sup> After its ratification in many countries,<sup>79</sup> continues to demand its compliance. Its activism has achieved important international agreements and has favored the expansion of the philosophy of independent living,<sup>28,29,65,66,80–82</sup> despite its marked link to the Global North.<sup>7,66,72</sup> However, these agreements are not breaking down the physical, communicational, and, especially, attitudinal barriers in many societies. PA remains in the background or is not contemplated, among the social policies aimed at people with disabilities.<sup>37,40,83</sup>

### 5.2. Relationships

The relationship between the person with a disability and his or her PA acquires crucial importance. As it is constant work for very long periods and in the closest proximity, it provokes the need to manage different situations that may compromise that bond.<sup>1,6,7,10,11,55–58,60–64,69,70,72,84</sup> Consequently, a healthy relationship based on respect and consideration for the other is needed. However, as human and social beings, there may be differences that lead to the deterioration and even rupture of these relationships.<sup>6,10,56,57,62–64,70</sup> Besides, the possibility of suffering mistreatment or negligent service is greater in private settings and is usually carried out by people very close to the individual.<sup>62,70,85–87</sup> For all these reasons, the influence that other people involved in the process may have on the relationship established between the person with a disability and his or her PA is also important. This influence can favor a healthier relationship or increase tension and mistrust between the parties involved.<sup>7,60–65,70</sup> At the same time, these relationships are mediated by different expectations. When a person with a disability is a user of the PA, especially if we are talking about minors, families may encourage overly demanding expectations.<sup>6,40,58–60,62–64,66,70,72</sup> Likewise, people with disabilities themselves may have expectations regarding their PAs.<sup>6,56,59,61,62,68,70,71</sup> that are not in keeping with the reality of a low-skilled job, with very little training.<sup>40,66,88</sup> In addition, there is a high level of ignorance regarding what PA and the philosophy of independent living imply,

which leads to confusion between PA with other figures linked to traditional care.<sup>6,56,59,61,62,68,70</sup> and not to equal care.<sup>36,89</sup>

### 5.3. Key agents

PA involves different people around them such as users, PAs, family members, service providers, and other professionals. The active main character of the service is the person with a disability, who can assume the management of the employment relationship or be the service receiver of PA that is managed by a third party.<sup>6,7,10,11,40,55–57,59–63,66–70,72,77,84,90</sup> It is even suggested that they may provide PA as peer support.<sup>67</sup> PAs are mostly women, whether they are family members or PA professionals.<sup>6,7,10,17,37,40,58,60–63,70,72,91,92</sup> In some cases, they have university training in the social or social-health care field, although it is not required for their services.<sup>37,40,84</sup> They must be multi-faceted and multi-situational, so they must have a high sense of adaptability.<sup>64,77,93,94</sup> On the other hand, families have been undervalued<sup>60,64,67</sup> as they have historically led struggles for the recognition of the rights of people with disabilities. Regarding PA, depending on the sociopolitical context, they can exercise PA,<sup>10,60,63,71</sup> which constitutes a form of *hybridization*<sup>63,72</sup>; they can manage PA for their children<sup>58,61–63</sup>; or they can act as a complement to the service.<sup>6,11,56,57,60,63,65,66,69–71,77,78</sup> The different agents involved in PA do not reach a consensus on the best course of action about the family’s role: their proximity to and knowledge of the support needs of people with disabilities are valued,<sup>60,61,63</sup> while highlighting the ethical connotations and consequences for personal autonomy and independent living due to possible over-protection.<sup>37,58,60,64,65,67,70,95–97</sup> The service providers can be summarized in two options: disability organizations, sometimes in the form of cooperatives or co-production mechanisms; and the market.<sup>11,55–57,63,69,77,84</sup> Disability organizations constantly lobby public authorities intending to implement, expand, and improve policies for people with disabilities, such as the PA.<sup>62,68,77,96</sup> They have taken over part of the management of the service by supporting people with disabilities or facilitating direct hiring with pools of PAs at their disposal or other strategies,<sup>57</sup> although there is a warning that this may imply weakness to continue fighting for improvements.<sup>77</sup> In the face of the trend towards the commercialization of care,<sup>98</sup> the philosophy of independent living has revealed a new market niche, even if it does not coincide with neoliberal self-sufficiency.<sup>99</sup> Traditional care provider companies must update their principles to facilitate good PA,<sup>10,11,67,70</sup> although there is no consensus on their role. It is claimed that they allow access to a more personalized service, transforming people with disabilities into consumers who choose what they want.<sup>57,77</sup> On the other hand, other voices argue that attention should be paid to the quality of the PA provided and point out that the existence of a private offer does not mean that people with disabilities are in a better position to decide on the care they need and want.<sup>56,57,63,68,69,77</sup> The cultural shift initiated must be extended among the professionals of the different welfare systems. To this end, training in the philosophy of independent living is essential to favor less medical-rehabilitative actions and assessment processes based on the social model with a rights-based approach.<sup>6,11,40,56–58,61,64,66,68,77,90,100</sup>

### 5.4. Personal assistants’ work context

The main, but not the only, work center of the PA is the home of the person with a disability. This, together with the characteristics of the PA’s functions, creates a unique and particular work context that is not free of conflicts.<sup>1,10,11,13,15,35–37,56,57,60,62,63,70,72,84,101–103</sup> Among them, ethical problems arise from the systematic, consensual violation of the privacy and intimacy of people with disabilities. However, this consent is not a *carte blanche* for PAs in the development of their functions. Its exercise must be based on respect for the dignity of the person, adopting the best decisions in situations where privacy, intimacy, or confidentiality are threatened.<sup>10,37,55,59,61,62,70,84,104</sup>

Consequently, to have an ethical or axiological code of PA,<sup>37,56,59,81</sup> as well as more ethical training,<sup>37,40,62,84,105</sup> seem to be appropriate strategies to reduce the occurrence of these conflicts. At the same time, interference from people close to the relationship established between the person with a disability and the PA can influence it. The development of social, interpersonal, and emotional management skills favors the management of these influences and reflective and less impulsive decision-making.<sup>40,56</sup> The disability movement advocates that people with disabilities should train their PAs because they do not consider specific formal training necessary.<sup>6,7,9,38,39,56–58,84</sup> and, so far, this is the norm in the countries that provide this service. Interpersonal skills are highly valued,<sup>6,11,40,55,64,67</sup> however only a small number of the PAs have developed them.<sup>55,77</sup> Thus, it seems that more in-depth training would be necessary, emphasizing aspects such as the philosophy of independent living, ethical problem solving, emotional management and self-management, mobilization and transfer techniques, alternative communication systems, use of information and communication technologies or first aid, among others.<sup>6,9,11,15,38–41,61,63,65,67,69,70,75,106</sup> In this way, the needs identified by both parties would be met,<sup>11,37,40,64,83</sup> the quality of service would be increased and would result in an improvement in the quality of life and a reduction in the risk of abusive practices.<sup>6,56,62,68,70,86,107</sup> It is even proposed to carry out training practices to evaluate the necessary skills and attitudes,<sup>40</sup> following the UNCRPD Committee.<sup>108</sup> Work within the care system, such as PA, is invisible and socially and politically undervalued,<sup>6,11,22,40,56,66,84,109</sup> which results in much-improved working conditions, for example, having to perform tasks that do not correspond to them; although, such flexibility is highly valued by people with disabilities, as it better suits their needs.<sup>6,91,62,72,77</sup> However, PAs must have decent working conditions.<sup>6,7,10,11,40,55,56,60,62,66,69,70,72,84,106,110</sup> It does not seem to enable independent living on the exploitation and poor working conditions of other people, also in vulnerable situations,<sup>6,7,10,40,66,70,72,91,92</sup> is an acceptable ethical and social justice option, regardless of the historical discrimination to which it has subjected people with disabilities.

### 5.5. Decision-making about PA

Care policies are connected to political, economic, and cultural interests,<sup>111</sup> factors influencing independent living policies. The widespread ignorance of society and public administrations about the implications of PA as a paradigmatic tool of these policies favors restrictive regulations and access procedures.<sup>6,7,11,59,60,66,67</sup> This is in addition to the differences depending on the territory of residence, with requirements that are sometimes even opposite.<sup>11,30–32,40,59,61,67–69</sup> Some regulations establish age, type of disability, or the ability to make decisions without support as essential requirements, which denies a PA for all people with disabilities.<sup>6,9,15,26,30–32,40,59,61,68,69,89,112</sup> This is compounded by poor funding, with low amounts for accessing the service or insufficient coverage of the hours required for real and effective independent living.<sup>6,7,11,40,56,57,60,61,63,64,66,68–70,78,113,114</sup> As if that were not enough, some governments take on the capitalist argument<sup>99,115,116</sup> and reduce their investment in PA or establish more restrictive requirements as a policy of austerity and expenditure control,<sup>7,33,34,40,69,72,110</sup> when different studies reveal its social return.<sup>4,11,56,65,106,117–119</sup> On the other hand, proposals are emerging that propose that PA can be an occasional complement for any person in situations such as hospital recovery, among others.<sup>65,83</sup>

### 5.6. Implications and best practices

PA contributes decisively to improving the inclusion, self-determination, and independent living of people with disabilities; it facilitates their empowerment, participation, and labor insertion, as well as improving their quality of life and that of their families and the closest environment.<sup>1–15,37,40,55–72,74,77,78,83,84,99,100,106,114,117,120</sup> However, some risks may threaten the quality of the service: weak ethical training,

insufficient skills to manage emotions, territorial inequality, restrictive interpretations of the service or negative interference of family members and/or professionals in the development of the service.<sup>1,6,7,10,11,40,56–66,68–72,77,100,121,122</sup> PA was incorporated into the UNCRDP<sup>26</sup> to ensure that people with disabilities could access and enjoy the same rights as other people. However, some studies reveal that more hours of PA do not necessarily mean a more independent life.<sup>71,72,123</sup> Thus, it seems necessary to strengthen the training of PAs and link it to the philosophy of independent living and the UNCRPD, as well as to train people with disabilities and their immediate environment in these principles.<sup>6,40,56,124</sup> Possible good practices emerge, such as: making environmental barriers visible and raising awareness of the rights of people with disabilities<sup>11,125</sup>; favoring the design and implementation of policies that guarantee a perspective of independent living<sup>40,57,65,69,77,126–130</sup>; coordinating the agents involved and the environment where the person lives<sup>11,63</sup>; hold regular team meetings when different PAs provide the service<sup>58</sup>; not only to support but also to encourage and favor the development of skills and competencies that favor greater autonomy and independence<sup>64,115,131,132</sup>; to promote the exercise of PA by persons with disabilities, as peer-to-peer support<sup>63,67</sup>; provide and transmit information clearly about the processes and their consequences<sup>7,68,128,133,134</sup> and to simplify them<sup>69</sup>; or, among others, guaranteeing good working conditions for PAs.<sup>7,40,106,135</sup>

### 5.7. Limitations

This systematic review was novel in synthesizing the literature about the promotion of independent living and self-determination through PA schemes. Rigorous methods were used in all steps, including several information sources, until nine different databases. One potential limitation was focusing only on English and Spanish literature, some relevant international studies may have still been missed, which could enable another limitation: the poor socio-demographic diversity of the areas that could be included in the analysis. Finally, the need to group the different key actors into more homogenous groups, especially the Staff one, to be able to analyze the information, may have obscured relevant information from a particular perspective.

### 5.8. Implications

This review offers a worthwhile contribution to implementation science in disability research, with a focus on independent living. It synthesizes the literature of the last ten years by identifying the different aspects of concern about the provision of PA for people with disabilities. In addition, it identifies several possible good practices that can contribute to improving the quality of the service and thus the quality of life of people with disabilities. The findings formed the basis of a few recommendations to optimize research and the delivery of PA services for people with disabilities (see Table 3).

## 6. Conclusions

Findings suggest the value of PA to promote independent living and self-determination of disabled people. However, many governments are not strongly committed to PA and the human rights of people with disabilities cannot depend on sufficient funding or living in one place or another to access the service. Today's political decisions determine the future of societies, which is still far from being inclusive. Therefore, the results show the need for greater guarantees of access to PA for people with disabilities and this could be materialized through structural changes in disability care policies. The agents involved, users, families, PAs, service providers, and professionals must internalize the philosophy of independent living and coordinate among themselves and with their respective environments. PA is not a mere provision of support; it must be aimed at enhancing people's autonomy and independent living. Further research is needed to address the challenges identified and to

**Table 3**  
Summary of supported practices to enhance research and policy.

Recommended suggestions	Description
<b>Policy suggestions</b>	1. Integrate an independent living perspective Policies aimed at people with disabilities should move away from a biomedical perspective and be based on an independent living perspective that recognizes the influence of barriers in the social, economic, cultural, and political environment that may impact lifestyle behaviors. An independent living perspective must be mainstreamed across all policy decision-making. <sup>6,7,11,59,60,66,67</sup>
	2. Co-design policies for independent living People with disabilities should have an active role in the design of policies. They should guide and orient their implementation to ensure they are truly accessible and be part of the evaluation and improvement processes of these policies. <sup>62,68</sup>
	3. Ensure equal access and adequate funding Universal access to PA must be guaranteed for all people who need it, regardless of place of residence, age, gender, type of disability, or any other personal characteristic. In addition, 24/7 access to the service should be guaranteed for all those who need it. <sup>6,7,11,40,56,57,60,61,63,64,66,68-70</sup>
	4. Integrate universal design into PA information Access to information in easy-to-read format and including pictograms, when necessary, should be guaranteed to facilitate and transmit information on PA more clearly. People with disabilities should be able to adequately know the information on the processes for accessing the service, as well as its different consequences. <sup>7,68,69</sup>
	5. Enhance PA in the educational system Promoting access to PA at an early age and allowing its use in educational centers can increase the independent living of people with disabilities in the future. Furthermore, it would make environmental barriers visible, raise awareness among future generations about the rights of people with disabilities, and favor the construction of more inclusive societies. <sup>11</sup>
	6. Improve the working conditions of the PAs The working conditions of PAs must be improved; the independent lives of people with disabilities cannot be built on the exploitation of other people, many of whom are in vulnerable situations. Equalizing the labor rights of PAs to those of other jobs and professions can also help to increase their social value. <sup>7,40</sup>
<b>Research suggestions</b>	1. Deepen the real impact of PA on personal autonomy According to longitudinal studies, increasing the number of hours of PA may not have an impact on increased social participation. Comparative studies, randomized controlled trials, and effectiveness reviews on the social participation of people with disabilities who are users and non-users of PA may provide more information. <sup>71,72</sup>
	2. Co-construct a PA Code of Ethics PAs are in permanent relationships with people with disabilities even violating, in a consensual way, their intimacy and privacy. It is necessary to work on the co-construction of a code of ethics for the PA like that of other professions and jobs that work with constant interaction with people in moments or situations that may involve great vulnerability. <sup>56,59</sup>
	3. Design and test broader training programs Poor training of PAs in ethical problem-solving and other training deficiencies can affect respect for the self-determination of people with disabilities and pose a risk of potentially abusive practices. Regulating, designing, implementing, and evaluating the necessary training of PAs is crucial to ensure that PA has the desired impact on promoting independent living. <sup>46,9,11,40,62</sup>
	4. Explore the possibility of temporary PA pilot projects. All people are interdependent because we need support to be autonomous and independent at different times in our lives. Exploring the possibility of temporary PA services for prolonged recovery processes can favor better recovery, reduce readmissions, and promote personal autonomy. <sup>65</sup>

determine best practices among those proposed.

### Disclosures and disclaimer

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### Availability of data and material

Data sharing does not apply to this article as no new data were created or analyzed in this study. Requests for the data reported by the studies included in this systematic review should be directed to their corresponding authors.

### CRedit authorship contribution statement

**Breogán Riobóo-Lois:** Writing – review & editing, Writing – original draft, Visualization, Validation, Methodology, Formal analysis, Conceptualization. **Paula Friero:** Writing – review & editing, Resources, Methodology, Formal analysis. **Rubén González-Rodríguez:** Writing – review & editing, Validation, Project administration, Methodology. **Carmen Verde-Diego:** Writing – review & editing, Visualization, Supervision.

### Declaration of competing interest

The authors report that there are no competing interests to declare.

### Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.dhjo.2024.101630>.

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- References identified with \* at the beginning of the reference are part of the systematic review results.
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