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APPLICATION OF ADVANCE DIRECTIVES IN PATIENTS WITH INTELLECTUAL DISABILITIES

APLICAÇÃO DAS DIRETIVAS ANTECIPADAS DE VONTADE EM PACIENTES COM DEFICIÊNCIA INTELECTUAL

APLICACIÓN DE LAS DIRECTIVAS ANTICIPADAS EN PACIENTES CON DISCAPACIDAD INTELECTUAL

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ABSTRACT

Advance Directives (ADs) represent a fundamental ethical and legal instrument to ensure the autonomy of patients with intellectual disabilities in health decisions. However, their application in people with intellectual disabilities is still permeated by practical, ethical, and legal barriers. The objective of this study was to analyze, through a systematic literature review, the main challenges in the application of ADs in patients with intellectual disabilities. The search was conducted in the PubMed, SciELO, BVS, and Google Scholar databases, encompassing articles between 2012 and 2025. Studies in Portuguese and English that addressed ADs in patients with intellectual disabilities were included. Of the 68 articles identified, 22 met the inclusion criteria. The results highlight three central axes: 1) practical difficulties in culture and communication; 2) the need to use ADs adapted to individuals with disabilities; 3) the adoption of Advance Care Planning (ACP) to promote early dialogue, according to international experience. It is concluded that the effectiveness of advanced driving techniques (ADs) for people with intellectual disabilities depends on cultural change, professional training, adoption of the Pacing Action Plan (PAC), and the use of specific protocols adapted to the Brazilian health system.

Keywords: Autonomy. Person with Disabilities. Advance Directives. Support for Decision-Making.

RESUMO

As Diretivas Antecipadas de Vontade (DAVs) representam um instrumento ético e jurídico fundamental para assegurar a autonomia do paciente portador de deficiência intelectual em decisões de saúde. Contudo, sua aplicação em pessoas com deficiência intelectual ainda é permeada por barreiras práticas, éticas e legais. O objetivo deste estudo foi analisar, por meio de revisão sistemática da literatura, os principais desafios na aplicação das DAVs em pacientes com deficiência intelectual. A busca foi realizada nas bases PubMed, SciELO, BVS e Google Acadêmico, abrangendo artigos entre 2012 e 2025. Foram incluídos estudos em

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português e inglês que abordaram DAVs em pacientes com deficiência intelectual. Dos 68 artigos identificados, 22 atenderam aos critérios de inclusão. Os resultados evidenciam três eixos centrais: 1) dificuldades práticas de cultura e comunicação; 2) necessidade de utilização de DAVs adaptadas aos indivíduos com deficiência; 3) adoção do Planejamento Antecipado de Cuidados (PAC) para favorecer o diálogo precoce, conforme experiência internacional. Conclui-se que a efetividade das DAVs para pessoas com deficiência intelectual depende de mudança cultural, capacitação profissional, adoção do PAC e do uso de protocolos específicos adaptados ao sistema de saúde brasileiro.

Palavras-chave: Autonomia. Pessoa com Deficiência. Diretivas Antecipadas de Vontade. Apoio à Tomada de Decisão.

RESUMEN

Las directivas anticipadas (DA) representan un instrumento ético y legal fundamental para garantizar la autonomía de los pacientes con discapacidad intelectual en las decisiones de salud. Sin embargo, su aplicación en personas con discapacidad intelectual aún está permeada por barreras prácticas, éticas y legales. El objetivo de este estudio fue analizar, a través de una revisión sistemática de la literatura, los principales desafíos en la aplicación de las DA en pacientes con discapacidad intelectual. La búsqueda se realizó en las bases de datos PubMed, SciELO, BVS y Google Scholar, abarcando artículos entre 2012 y 2025. Se incluyeron estudios en portugués e inglés que abordaron las DA en pacientes con discapacidad intelectual. De los 68 artículos identificados, 22 cumplieron con los criterios de inclusión. Los resultados destacan tres ejes centrales: 1) dificultades prácticas en la cultura y la comunicación; 2) la necesidad de utilizar DA adaptadas a las personas con discapacidad; 3) la adopción de la Planificación Anticipada de la Atención (PAA) para promover el diálogo temprano, de acuerdo con la experiencia internacional. Se concluye que la efectividad de las técnicas avanzadas de conducción (EAC) para personas con discapacidad intelectual depende del cambio cultural, la capacitación profesional, la adopción del Plan de Acción de Estimulación (PAC) y el uso de protocolos específicos adaptados al sistema de salud brasileño.

Palabras clave: Autonomía. Persona con Discapacidad. Voluntades Anticipadas. Apoyo a la Toma de Decisiones.

1 INTRODUCTION

Advance Directives (AVDs) emerge as one of the most relevant instruments in the contemporary debate on autonomy, dignity and decision-making in health. They allow the individual, while having full cognitive and legal capacity, to register his preferences regarding medical treatments and future care, including situations of terminal life or inability to manifest will. Internationally, VADs are associated with the strengthening of the principle of patient autonomy, consolidated from the second half of the twentieth century as a response to criticism of medical paternalism and the centralization of clinical decision-making in health professionals (Beauchamp; Childress, 2019).

In Brazil, the regulatory framework occurred with Resolution No. 1,995/2012 of the Federal Council of Medicine (CFM), which recognized the ethical and legal validity of AVDs, consolidating their application as a legitimate means of recording the patient's will (Federal Council of Medicine, 2012). In parallel, legislation such as the Brazilian Law for the Inclusion of Persons with Disabilities (Brazil, 2015) reinforce that disability, in itself, does not reduce civil capacity, reaffirming the need for equal access to legal and health instruments.

However, the effectiveness of AVDs faces obstacles. Adherence is still limited, both due to the lack of knowledge of the general population and the difficulty of communication between health professionals, patients and family members (Barbosa; Lisbon; Vilaça, 2023; Pepes *et al.*, 2023). In vulnerable populations, there is resistance, misinformation, and difficulties in understanding the purpose of directives (Vanzella *et al.*, 2023).

In this scenario, the discussion about AVDs in patients with intellectual disabilities presents even greater complexities. Intellectual disability is defined by significant limitations in intellectual functioning and adaptive behavior, affecting conceptual, social, and practical areas to varying degrees of severity (American Psychiatric Association, 2013; First *et al.*, 2022; Toth *et al.*, 2021). Historically, these people have been subjected to civil interdiction and guardianship processes, which has resulted in exclusion from rights and decisions about their own lives (Alencar; Assis; Musse, 2016).

With the enactment of the International Convention on the Rights of Persons with Disabilities and its internalization in Brazil by Law No. 13,146/2015, the full civil capacity of this group was reinforced, including with regard to health-related choices (Brazil, 2015).

However, the ethical and legal challenges are evident. On the one hand, there is a risk of neglecting the autonomy of patients with intellectual disabilities, reducing them to a state of permanent disability. On the other hand, there is a concern about the real understanding of these individuals about the severity of treatments or the terminality of life. Thus, there is a need for complementary mechanisms, such as supported decision-making, provided for in article 1,783-A of the Civil Code (Brazil., 2002), which makes it possible to choose trusted people to assist in the decision-making process without replacing the individual's will.

Despite the relevance of the topic, there is a significant gap in scientific production: while VADs are widely discussed in contexts such as palliative care, chronic diseases, and geriatrics, there is a lack of research focused on their application in people with intellectual disabilities. This absence limits the formulation of inclusive public policies and compromises the effectiveness of current legislation, perpetuating inequalities in the exercise of self-determination (Lima *et al.*, 2022).

In addition, the lack of adapted protocols and training of health professionals to address these situations intensifies the practical challenges and increases the vulnerability of this group. In view of this panorama, it is justified to carry out studies that promote a critical reflection on how to ensure the autonomy and dignity of people with intellectual disabilities in the context of AVDs, reconciling individual rights with bioethical principles and legal requirements.

Thus, the general objective of this study was to analyze, through a systematic review of the literature, the application of advance directives in patients with intellectual disabilities, identifying the main ethical, legal and practical challenges related to the theme.

2 METHODOLOGY

This is a descriptive and exploratory Systematic Review of the Literature, whose objective was to analyze and synthesize the available scientific evidence on the application of advance directives in patients with intellectual disabilities.

Data collection was carried out between August and September 2025, through a systematic search in the electronic databases PubMed, VHL (Virtual Health Library), SciELO, and Google Scholar. To this end, a structured search was carried out using the Boolean strategy with logical operators to expand and refine the results. The combinations applied were: ("intellectual disability" OR "developmental disability" OR "cognitive impairment") AND ("advance directives" OR "living will" OR "advance care planning" OR "end-of-life decisions") AND ("ethical issues" OR "legal issues" OR "practical challenges" OR "implementation difficulties").

The sample consisted of indexed scientific articles, published between 2012 and 2025, in Portuguese and/or English, available for download, which specifically addressed the application of advance directives in individuals with intellectual disabilities. Duplicate articles, abstracts, works with an exclusive focus on other populations, and publications that did not directly address the topic were excluded. The results obtained were organized in electronic spreadsheets for screening and subsequent analysis. The screening of articles was conducted independently by two reviewers, with divergences resolved by consensus.

After the final selection of the articles, the relevant data were extracted and systematized, including information such as authors, year of publication, country, methodological design, objectives, main findings and conclusions. The analysis was conducted through the Content Analysis technique, according to the proposal of Bardin (2015), developed in three stages: pre-analysis, characterized by the floating reading and initial organization of the material; exploration of the material, with coding, categorization and classification of emerging contents; and treatment of the results, inference and interpretation, with the elaboration of a qualitative synthesis of the findings. This approach allowed us to identify recurring themes, knowledge gaps and different perspectives presented by the literature. Due to the heterogeneity of the included studies, quantitative statistical analysis was not performed.

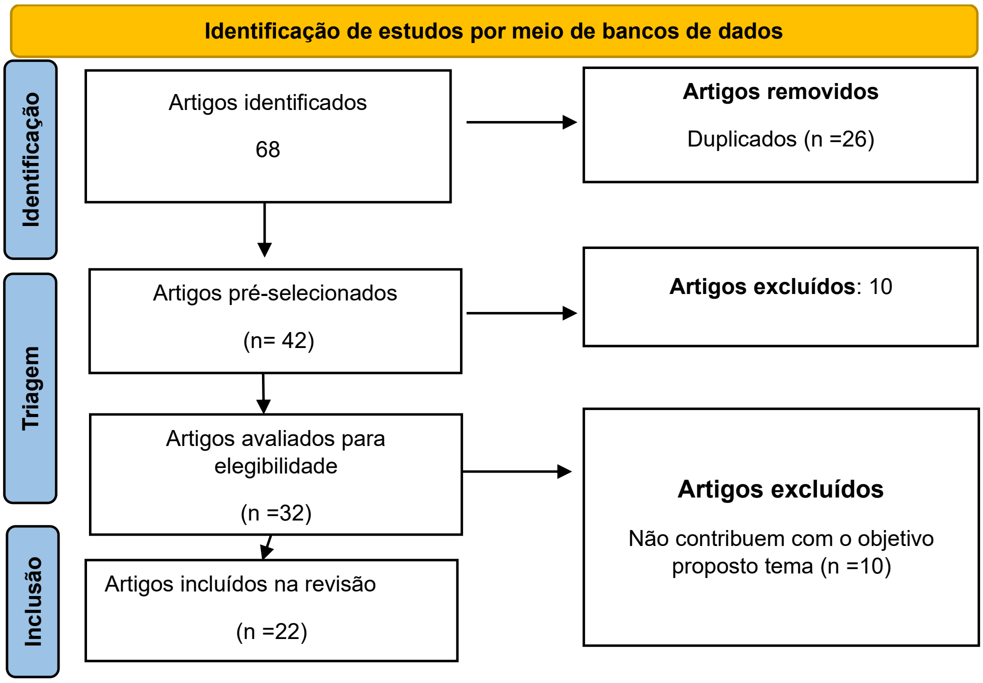
This study consisted of a secondary bibliographic research, not involving primary data collection with human beings or animals, so the need for submission to the Research Ethics Committee was not applied. Even so, fundamental ethical principles were observed, such as respect for the copyright of the works consulted, the proper citation of the sources used, the commitment to reliability, integrity and scientific impartiality in the selection, analysis and discussion of studies, in addition to methodological transparency, ensuring the reproducibility of the research.

3 RESULTS

From the selection process, 68 articles related to the application of Advance Directives of Will (DAVs) in people with intellectual disabilities and in groups with cognitive impairment were identified. After the removal of duplicates, 42 articles remained for screening. In the screening stage, the abstracts of these articles were analyzed, resulting in the exclusion of 10 studies that did not meet the inclusion criteria. The remaining 32 articles were evaluated in full for eligibility, and 10 more articles that did not directly contribute to the objective of the study were excluded. Thus, 22 articles were included in the final review, all of which were considered relevant to compose the discussion. All the steps described above can be seen in the PRISMA Flowchart (Figure 1).

Figure 1

PRISMA flowchart



Source: Prepared by the authors.

The 22 selected articles were published between 2017 and 2025, mostly in international journals, with a predominant language in English. Regarding the type of study, systematic and narrative reviews were identified, including international analyses of VADs in intellectual disability and cognitive impairment, empirical studies with original data, practical and longitudinal intervention studies, including analysis of perceptions of patients, family members, and health professionals, as well as studies on consensus documents or proposals for tools and protocols for the implementation of VADs.

From the content analysis, recurrent units of meaning were identified among the articles, which were organized into three main categories, aligned with the specific objectives of the study: 1) Practical difficulties in approaching the AVDs; 2) Ethical and legal challenges involved; and 3) International recommendations and models.

Table 1 presents articles from the first category, referring to the practical difficulties in approaching AVDs, pointing out that the effectiveness of AVDs is compromised by communication and cognitive barriers that hinder dialogue between patients, professionals and family members. Cultural and family resistance to the inclusion of these individuals in end-of-life decisions reinforces paternalism and perpetuates exclusion. To overcome such obstacles, it is recommended the creation of practical tools and standardized protocols that guide the performance of health professionals, associated with continuous training and the use of visual and digital resources that favor the understanding and expression of the patient's will. The collaborative participation of family members and caregivers is equally emphasized as an essential component of the decision-making process.

Table 1

Propositions in the category "Practical difficulties in approaching AVDs"

Author, Year	Propositions	Condensation of propositions
Bruun *et al.* (2024)	Collaboration between support staff, people with intellectual disabilities, and health professionals contributes to the success of care planning.	Overcoming cultural and communicational barriers between family members, caregivers, patients and professionals through dialogue and accessible language.
Bruun *et al.* (2025)	Promotion of dialogue about death and dying, favors the overcoming of cultural barriers and family resistance to patient participation.	
McKenzie *et al.* (2024)	The use of accessible models, with visual materials and simple language, facilitates the realization of the PAC and obtaining the DAVs.	
Nicholas *et al.* (2023)	Understanding cognitive limitations and their implications for communicating about early decisions.	
Tilley *et al.* (2024)	Creation of practical tools (toolkits) to support professionals in communicating with people with intellectual disabilities.	Use of practical and digital tools that support professionals and encourage the participation of people with disabilities.
Kotwal *et al.* (2021)	Implementation of digital tools to stimulate the participation of cognitively compromised people.	
Huang *et al.* (2022)	Involvement of family members in end-of-life decisions in cases of cognitive decline favors subsequent decision-making.	Encouragement of dialogue for the collaborative involvement of family members and caregivers in the decision.
Shepherd-Banigan *et al.* (2022)	Strengthening the dialogue in the patient-caregiver dyads, integrating advance planning, favors subsequent decision-making.	

Source: prepared by the authors.

Table 2 presents articles referring to the second category referring to the "Ethical and legal challenges involved", showing that tensions between protection and autonomy persist, aggravated by normative gaps. Decision-making using AVDs is a strategy to ensure autonomy and respect for the dignity of patients with intellectual disabilities.

Table 2

Propositions in the category "Ethical and legal challenges involved"

Author, Year	Propositions	Condensation of propositions
Angeluci; Bongardi (2020)	Adoption of DAVs and social inclusion as an expression of citizenship.	The use of social inclusion, DAVs and Informed Consent ensure the exercise of autonomy, while respecting and protecting the dignity of individuals with intellectual disabilities.
Souza (2020)	Adoption of DAVs to ensure respect for the autonomy and dignity of people with intellectual disabilities.	
Teixeira; Ribeiro (2021)	Use of Informed Consent to address attitudinal barriers.	
Martins *et al.* (2023)	Integrate bioethical and legal principles through the application of AVDs.	
Kalil *et al.* (2023)	Fill regulatory gaps and define ethical and legal responsibilities of professionals through DAVs.	

Source: prepared by the authors.

Finally, the articles in the third category are presented in Table 3, where international experiences show that collaborative practices, especially the use of pre-formulated models of AVDs, sending of an Introductory Letter, use of accessible protocols and consensual guidelines, strengthen the autonomy and inclusion of patients with intellectual disabilities. The adaptation of these strategies to the Brazilian context is seen as an essential way to make AVDs effective.

Table 3

Propositions in the category "International recommendations and models"

Author, Year	Propositions	Condensation of propositions
Pozón *et al.* (2024)	Recommendation to health professionals to dialogue with patients and family members for the implementation of Advance Care Planning.	Conversations with family members and patients about CAP and VAD, which can start before the progression of cognitive impairment or worsening of the clinical condition, favor subsequent decision-making that is more aligned with the person's preferences
Voss *et al.* (2017)	The adoption of Advance Care Planning (PAC) improves the quality of life of people with intellectual disabilities.	
Kirkendall; Linton; Farris (2017)	Conversations prior to the onset of the disease favor decision-making during the end of life of people with intellectual disabilities	
McCallion *et al.* (2017)	International protocol recommends enabling CAP and DAVs before significant progression of dementia	
Bélanger *et al.* (2022)	The finding of an amyloid PET test in a patient is a motivation for the adoption of early AVDs, although the person's preference may suffer later variations.	The use of an International Protocol and an introductory letter on the wishes of patients and family members, especially for people with amyloid PET, favors the adoption of CAP and the elaboration of VADs before the most severe manifestation of the disease.
Wolff *et al.* (2021)	Sending an introductory letter inviting patients and families to share their information about their wishes for future care facilitates Advance Care Planning actions.	

McCallion *et al.* (2017)	An International Protocol (International Summit on Intellectual Disability and Dementia) recommends performing PAC and obtaining DAVs before significant progression of dementia	
Jongsma *et al.* (2020)	Health professionals need to be trained to meet the needs of patients with intellectual disabilities. A standardized, partially pre-formulated model of DAVs for early application would be adequate, but such models are not yet available.	Obtaining Advance Directives early contributes to guiding health professionals on decisions during the end of life of people with intellectual disabilities.
Meirelles (2019)	The elaboration of DAVs by people with intellectual disabilities, obtained early, guides the decision about the care and treatments that the patient wishes or does not wish to undergo in the future.	

Source: prepared by the authors.

In general, the results reveal convergence on three central points: 1) the need to overcome communication barriers through collaborative dialogue and accessible language; 2) the adoption of the DAVs supported by Informed Consent to overcome ethical and legal barriers; and 3) sending correspondence to family members, using an International Protocol and pre-formulated models to obtain VADs, before phases of greater cognitive impairment or at times of greater functional and communicational stability.

4 DISCUSSION

The systematic review of the literature allowed us to identify different perspectives on the application of Advance Directives (AVDs) in patients with intellectual disabilities, grouping national and international studies that address ethical, legal and practical aspects related to the theme.

The results presented in Tables 1, 2 and 3 showed that the application of Advance Directives (AVDs) in people with intellectual disabilities is still a field permeated by ethical, legal and practical challenges. Although Brazilian legislation, especially the Brazilian Law for the Inclusion of Persons with Disabilities (Law No. 13,146/2015), recognizes the full civil capacity of these people, the realization of this right in the context of health remains limited, especially in decisions related to the end of life (Meirelles, 2019; Souza, 2020; Teixeira; Ribeiro, 2021).

The analysis of the articles in the first category, presented in Table 1, showed that the effectiveness of AVDs is significantly compromised by communication and cognitive barriers, hindering dialogue between patients, professionals and family members. Recent studies indicate that technical language and the absence of accessible materials disadvantage the understanding and participation of people with intellectual disabilities (Bruun *et al.*, 2024;

McKenzie *et al.*, 2024; Nicholas *et al.*, 2023). In addition, cultural factors and family resistance to the inclusion of the patient in end-of-life decisions reinforce paternalistic practices and perpetuate exclusion (Bruun *et al.*, 2025).

To overcome these difficulties, some authors recommend the creation of practical tools and standardized protocols that guide the work of health professionals, combined with continuous training and the use of visual and digital resources (Kotwal *et al.*, 2021; Tilley *et al.*, 2024). The collaborative participation of family members and caregivers also stands out as essential for the decision-making process, strengthening the dialogue in the patient-caregiver dyads and promoting advance planning (Huang *et al.*, 2022; Shepherd-Banigan *et al.*, 2022). These findings reinforce the need for structured interventions that are sensitive to cognitive limitations to ensure that AVDs are effectively implemented.

The second category, presented in Table 2, addresses the ethical and legal challenges of the tensions between protection and autonomy that are intensified by normative gaps and paternalistic attitudes. Several studies emphasize the importance of ensuring the exercise of autonomy and the protection of the dignity of people with intellectual disabilities through DAVs, as an ethical and legal foundation, and social inclusion as an expression of citizenship (Angeluci; Bongardi, 2020; Souza, 2020).

Attitudinal barriers that compromise the informed consent of people with disabilities are a recurring challenge, requiring strategies to reduce paternalistic practices and ensure free and informed decisions (Teixeira; Ribeiro, 2021). The integration of bioethical and legal principles emerges as a solution to harmonize ethics and legislation in the context of AVDs, filling normative gaps and defining responsibilities of professionals (Kalil *et al.*, 2023; Martins *et al.*, 2023; Pozón *et al.*, 2024). These studies highlighted that, even in the face of regulatory advances, the absence of specific regulation limits the practical implementation of AVDs in Brazil.

The third category, described in Table 3, focuses on international experiences, evidencing good collaborative practices, accessible protocols, and consensual guidelines that strengthen autonomy and inclusion. Research carried out in countries such as the United Kingdom, Canada, and Australia indicates the importance of adopting Advance Care Planning (CAP) and international protocols, using the advances of international experience to facilitate their adaptation to the Brazilian context (Kirkendall; Linton; Farris, 2017; McCallion *et al.*, 2017; Voss *et al.*, 2017).

In the international scenario, studies such as those of Kirkendall; Linton; Farris (2017), Voss *et al.* (2017) and McCallion *et al.* (2017) They present reviews and consensus on end-of-life decision-making for people with intellectual disabilities, pointing out recurrent challenges: communication difficulties, family resistance, and lack of adapted protocols. These authors also describe concrete experiences, such as the use of supported decision-making models, such as "Person-Centred Dementia Care", the adoption of checklists, and structured family meetings to ensure the active participation of people with intellectual disabilities.

Recent studies, such as Wolff *et al.* (2021), with the *SHARING Choices*, and Bélanger *et al.* (2022), with the participatory family planning model, also reinforce the need for operational instruments and periodic reviews of advance directives. Other initiatives, the accessible "My Plan for a Good Life" protocol (McKenzie *et al.*, 2024) and the collaborative process described by (Tilley *et al.*, 2024), facilitate and reinforce the value of clear communication, simplified language and multi-professional engagement as core elements of supported autonomy.

Therefore, valuing cultural diversity and application contexts is emphasized when comparing perceptions of patients and caregivers in different countries (Bélanger *et al.*, 2022). The integration of family members and multidisciplinary teams in the decision-making process increases adherence to AVDs and promotes the effectiveness of interventions (Jongsma *et al.*, 2020; Wolff *et al.*, 2021). And the promotion of the integration of ethical and practical guidelines, as well as the recognition of supported decision-making as an instrument of legal inclusion, are pointed out as fundamental paths for Brazil (Meirelles, 2019).

It should be noted that studies with original data included information from different international contexts, such as the United Kingdom (Bruun *et al.*, 2024, 2025)United States (Kotwal *et al.*, 2021; Nicholas *et al.*, 2023; Shepherd-Banigan *et al.*, 2022; Wolff *et al.*, 2021) Denmark (Jongsma *et al.*, 2020)Australia (McKenzie *et al.*, 2024) and Canada (Bélanger *et al.*, 2022). On the other hand, no original study with Brazilian samples was identified, and the national data are restricted to the legal, bioethical and theoretical discussion on the application of AVDs in people with intellectual disabilities.

The results showed that Brazilian scientific production is still incipient, as in the works of Souza (2020), Meirelles (2019) and Teixeira; Ribeiro (2021), which highlight the autonomy of people with disabilities and the difficulties in implementing informed consent. Authors such as Martins *et al.* (2023) and Kalil *et al.* (2023) reinforce that, despite the normative advance with the Brazilian Inclusion Law, the absence of specific regulation for AVDs limits their practical implementation.

5 CONCLUSION

It is concluded that obtaining AVDs from people with intellectual disabilities faces three important challenges. First, the cultural and communicational barriers that can be overcome through professional training, dialogue with accessible language and the active participation of family members and caregivers in the decision-making process are highlighted.

Regarding ethical and legal challenges, the use of DAVs is recommended. The difficulty in obtaining AVDs can be overcome by performing them early, even before the progression of the disease, creating an environment conducive to the exercise of autonomy and the preservation of the dignity of people with intellectual disabilities with greater ethical and legal security.

Finally, regarding the international experience, the need to use the PAC was evident, which involves dialogue between family members, patients and health professionals. Sending explanatory correspondence to family members and adapting international protocols can favor the process.

As a limitation of the study, this review predominantly identified the use of DAVS and CAP, practices that are still incipient in Brazil, as recommendations to ensure the autonomy of patients with intellectual disabilities. Thus, it is suggested that future studies prioritize the development of guidelines and practical tools adapted to the national reality, with a view to facilitating their routine adoption by health professionals in the near future.

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