FROM TOKENISM TO SELF-DETERMINATION

Ethical Considerations in Research with People with Intellectual Disabilities

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List of Abbreviations

APA - American Psychiatric Association
CRPD - Convention on the Rights of Persons with Disabilities
ID - Intellectual Disabilities
FCT - Foundation for Science and Technology
GameIN - Games Inclusion Lab: Participatory Media Creation Processes for Accessibility
UN - United Nations
OPP - Portuguese Psychologists Association
PwD - People with Disabilities
PwID - People with Intellectual Disabilities
WMA - World Medical Association

PREFACE

The Convention on the Rights of People with Disabilities reaffirmed the human dignity of People with Disabilities in a social context that knows how to include them without any restraints or discriminations, and in which they are afforded control over their own decisions, making their own choices and accomplishing their dreams, inside a desired and self-realized life project. However, intellectual disabilities is where one will find the greatest challenges to accomplishing the measures emanated from this Convention. Their invisibility, for the most cases, the lack of empathy it generates in the common citizen, and the great challenges they face in integrating into a world that is increasingly digital, and that privileges each individual's intellectual capacities, are some of the specificities that harm the prospects of their total inclusion. Besides this, one of the main characteristics of people with ID is their difficulty to coherently and consistently express themselves, which, in the most severe cases, is manifested as an absence of orality. Therefore, integrating people with intellectual disabilities in scientific research processes that must be inclusive, consented, and participative naturally emerges as a daunting challenge that we must tackle.

This work consists in the presentation of a conceptual model that systematizes the results, concepts, and values evidenced by a great number of papers published in international journals about this subject, in the several septs of a research project featuring this population, and consequently in the definition of a set of guiding principles that crystalize scientific search that is integrated in the greater respect for autonomy, consent, and self-representation of the involved people with intellectual disabilities. This document aims to, in a necessarily succinct manner, define the essential concepts and foster reflection and discussion about this topic, that should constitute a concern of the scientific community. The qualitative research methodology used by the authors allows them to formulate patterns from the different perspectives and the constructionist paradigm that it stands for, and strengthens the voice of people with intellectual disabilities as an important part of the research's success. Therefore, this work constitutes a valuable document for understanding the ethical and empirical challenges of scientific research that involves people with intellectual disabilities. With a consistent view of the fundamental rights and liberties inherent to any human being, the authors approach this question holistically, in the scope of the Social and Human Rights models that are so upheld nowadays. Although this work emerged in the context of the Games Inclusion Lab: Participatory Media Creation Processes for Accessibility (GameIN) project, co-financed by the Foundation for Science and Technology (FCT) – in which HUMANITAS, Federação para a Deficiência Mental, acted as a partner, its national and international applicability greatly transcend it, constituting a must-read for everyone who produces science with/about the population with intellectual disabilities, particularly in the academic field.

Helena Albuquerque
The President of Humanitas Federation and APPACDM Coimbra

SUMMARY

Throughout history, several moments guided the creation of ethical principles to combat abuses in scientific research with human beings. Starting in 1947, the Nuremberg Code was developed as an answer to the atrocities committed by nazi doctors during the Second World War and had the intention of protecting the autonomy and voluntary consent of the individual. The Declaration of Helsinki was developed in 1964 by the World Medical Association after they identified flaws in the Nuremberg Code and established basic principles related to clinical research, professional care, and non-therapeutic clinical research. The Declaration adds, among others, the introduction of consent via a third party, with legal faculties to authorize the participation of someone in a process of scientific research. During the following revisions to this Declaration, some points have been added regarding vulnerable groups and/or individuals, ethical committees, privacy, and confidentiality, among others.

When looking at the context of disability, in addition to the aforementioned ethical documentation, the assumptions of the "United Nations Convention on the Rights of Persons with Disabilities" have necessarily been taken into account since 2008. In particular, it postulates that the idea of "universal design" should guide the conceptualization of research processes and the creation of new products or technologies.

However, the application of these premisses to the specific context of People with Intellectual disabilities (PwID) appears to still clash with socially stigmatizing views, strongly set on a medical model of disability, that tend to take no notice of their participation and the value their contribution can have for the scientific research as ethical imperatives.

In this sense, this document presents a conceptual model from which proposals for ethical guidelines in research with PwID are devised.

The conceptual model, presented in Part II, consists of seven groups: (1) accessibility during the research process, where topics such as reasonable adaptations, feasibility, diversity and representation, good practices, and barriers are presented; (2) power imbalances, namely with regards to asymmetric power, tokenism, and gatekeeping; (3) vulnerability, both as a form of exclusion and power, along with the risks associated to it; (4) self-determination in scientific research, collaborative groups, and consulting sessions; (5) (in)capacity to consent, specifically concerning ethical dilemmas, fluctuating ability, risk perception and assessing the ability to consent; (6) informed consent, especially to proximity, adaptations, and barriers; and, lastly, (7) methodological approaches, about ethical challenges posed by it and the opportunities it brings.

After a detailed description of the thematics inherent to each group, in Part III of the document, it is possible to find, summarily, the proposed guidelines, written to facilitate operationalization in planning a research design.

It is important to mention that the proposed guidelines were converted to accessible language and empirically validated in partnership with portuguese PwID. In these sense, the validation was only done for the portuguese version of the guidelines.

PART I

Context

According to the American Psychiatric Association (APA), Intellectual disabilities (ID) is a neurodevelopmental disorder defined by significant impacts both to intellectual functioning and adaptive behaviour. Generally, these impacts become evident before the age of 18 and can manifest in an ample spectrum of severity. PwID may need different levels of support throughout their lives, with particular emphasis on their social, practical, and conceptual capabilities (APA, 2023).

How society perceives and interacts with PwID has evolved significantly throughout the years, in great part due to different models of disability. These models shaped societies' attitudes, policies, and practices, deeply affecting the lives of PwID (Emydgio da Silva, 2009).

> *" (...) [the Social Model] shifted the focus from a person's disability towards the societal attitudes and barriers that prevented them from participating (...)."*

Historically, the Medical Model interpreted disability as a medical condition or an incapacity that required diagnosis, treatment, or a cure. It often emphasized the individual's deficits or incapabilities, which led to stigmatization and institutionalization. PwID were seen as someone that required "fixing", instead of an individual whose necessities were addressed to be included in society (Donoghue, 2003).

The Charity Model, on the other hand, portrayed PwID as objects of mercy, being dependent on charity or kindness for support. This model perpetuated stereotypes of dependence, reinforcing a feeling of "otherness" and emphasizing the aspect of mercy rather than equity (Fontes, 2009).

The appearance of the Social Model brought with it a significant shift in perspective. It shifted the focus from a person's disability towards the social attitudes and barriers that prevented them from participating, underlining that disability results from a misalignment between the environment and the specific needs of the individual. This change paved the way for PwID's rights movements, promoting inclusion, equal access, and the elimination of physical and social barriers (Barnes, 2020).

In line with the Social Model, the Human Rights Model further emphasized disability as a matter of rights, focusing on the dignity of PwID. Aligning itself with international accords, particularly with the United Nations Convention on the Rights of People with Disabilities (CRPD), this model led to legal changes, anti-discrimination laws, and greater awareness of the rights of PwID, emphasizing the importance of equal opportunities and choices (Degener, 2017).

Considering the last two models mentioned – as well as the legal framing of many PwID, while stripped of decision-making power in different contexts, including in scientific research – this work aims to establish priority areas for their inclusion in research, setting the goal of developing more inclusive guidelines that promote their self-determination.

This study is under the scope of the research project Games Inclusion Lab: Participatory Media Creation Processes for Accessibility (GameIN), being an important step in the phase of contextual analysis of PwID, namely the identification and definition of ethical procedures inherent to inclusive research. This study is funded by national funds through the FCT - Foundation for Science and Technology, I.P., under project GameIN (2022.07939.PTDC) – available at https://doi.org/10.54499/2022.07939.PTDC.

Methodological Approach

In response to the need to develop guidelines for scientific research with PwID, taking into account the state of the art and existing evidence, a literature review methodology was adopted, which is described below.

To this end, besides searching for scientific articles about the described theme, this secondary research adopted a qualitative approach to the systematization of the evidence collected in this process - namely, a thematic analysis, based on the postulates of Braun and Clarke (2006; 2014). Through this analysis, it was possible to develop a conceptual base model that collects the main concepts and ethical concerns inherent to scientific research involving PwID while also aligning itself with the premises of the Social and Human Rights Models of Disability, as previously explained.

The next phase, in turn, was a summarization of the narrative context from the themes and subthemes of this conceptual model, derived from the analyzed articles, and a subsequent rewriting in the form of guidelines. These themes were renamed or merged, originating a set of supporting guidelines for scientific research with PwID, to be considered along with the already existing norms and documentation, which will be briefly explored in the "Additional Guidelines and Documents for Consultation" section.

The adopted methodological approach is, first and foremost, a work in progress, since it constitutes a first step before the validation of the guidelines' accessible formats with self-representatives, and their dissemination to civilians and activist organizations.

PART II

Thematic Analysis

Thematic Analysis is a qualitative method that allows for a flexible approach to data, and for the identification and analysis of intrinsic patterns (Braun & Clarke, 2006).

Attride-Stirling (2001) conceptualizes thematic networks, featuring some principles from Toulmin's Argumentation Theory (1958) and identifying six phases:

1. The coding of the material, consisting of the development of a coding structure and the separation of the text into different segments - based on the previously established structure;
2. The identification of themes, which in the first phase consists of the segments' abstract themes and then their refinement;
3. The construction of thematic networks, which requires an organization according to themes, followed by the selection of the base themes (or basic) and then a reorganization for deducing the global themes;
4. The description of the network and its exploration;
5. The synthesis of the thematic networks;
6. The interpretation of the verified patterns.

On another hand, Tuckett (2005) approaches thematic analysis with systematic processes common to Grounded Theory - conceptualizing that the organization of data is the basis on which the codification, writing, theory, and reading occur, given their simultaneousness. In this sense, the organization of data begins with its codification, which requires the creation of codes so that the analysis and comparison are more efficient.

With this in mind, the author divides the thematic analysis into four steps: (1) the literature review and analysis of the interviews verbatim; (2) the reading and theorization; (3) the codification, writing, and theorization; and (4) the development of the theme. Additionally, to avoid having the literature review influence the process of analysis, the author recommends performing the triangulation of data - investigator triangulation - and that the analysis of the verbatim is validated by the participants.

Another view on thematic analysis is Braun and Clarke's (2006), which dictates that, before starting the analysis, the research team must define the method, whether the analysis is inductive or theoretical, and what is the level of identification of the analysis' themes.

> *"(...) thematic analysis can be a method that works both to reflect reality and to unpick or unravel the surface of 'reality'."*

The analysis can be an essentialist/realist method, constructionist, or contextualist. It is essentialist/realist if it reports on experiments, meanings, and the reality of those involved in the research. Whereas, if it refers to the effects discourse has inside a society through events, realities, meanings, and experiences it is constructionist; or, if it has characteristics of the two previously mentioned methods, it is contextualist and is based on theories such as Critical Realism. In this sense, "thematic analysis can be a method that works both to reflect reality and to unpick or unravel the surface of 'reality'" (Braun & Clarke, 2006, p. 81).

Regarding the identification of the themes, thematic analysis can be inductive or theoretical: in the former, the themes of the analysis are related to the data itself, while in the latter it is motivated by the theoretical or analytical interest of the researcher.

As for the level of identification of the analysis themes, these can be identified on the semantic/explicit or the latent/interpretative level. At the semantic/explicit level, the themes are superficially identified and no further search is conducted beyond what was said or written. In this case, the data is organized in a way that allows for the development of patterns at the semantic level so they can then be summarized for interpretation to create theories with regards to the meaning of the patterns, and their wider meanings and implications, frequently related to the theory. Although, the latent level identifies implicit ideas, concepts, and ideologies that are formulated as moulds or information of the semantic content.

Following the definition of these three aspects of thematic analysis, it is possible to start the actual analysis, by dividing the thematic analysis into six distinct levels (Braun & Clarke, 2006): (1) the familiarization with the data, based on a repeated reading to identify patterns and ideas; (2) the creation of initial codes, referring to the organization of the data into significant groups; (3) the identification of themes inherent to the data; (4) the review of the themes, through the clarification and reflection with regards to the data and the cohesive patterns, or not, with which they form; (5) the definition and naming of themes, based on the re-reading of the information in each theme to summarize it and denote the potential existence of subthemes; and (6) the writing of the report based on the collected data and the developed thematic model.

Considering the three mentioned perspectives, Braun and Clarke's criteria (2006; 2014) will be the main reference for the present thematic analysis, since they are understood to be the most adequate considering the goals of the current research.

In this sense, the method of thematic analysis corresponds to a constructivism paradigm since it recognizes the active role of the researcher in the construction of meanings from qualitative data, recognizes the subjectivity of the interpretation, and values multiple perspectives and contextual factors that influence the construction of themes. Through this, it aligns with constructivism epistemology, which argues that knowledge is social and individually constructed, instead of being constituted by objective and external truth (Braun & Clarke, 2014). With this in mind, the analysis will be conducted to gather information regarding the practices that are implemented in research featuring PwD, specifically research with PwID. Through this, and because we intend to propose research guidelines from our analyses of the scientific articles, the identification of themes is inductive. Lastly, the themes' level of identification corresponds to a middle path between the explicit semantic content featured in the several articles included in this study, paired with an interpretative lens, which is concerned with the signification of different power structures that explain the oppression of PwD in contemporary society (Charlton, 2006).

Study Description

Before starting the actual thematic analysis it was necessary to select the papers to be featured in it. With this in mind, the initial search of papers was conducted by the five members of the team, having gathered a total of 111 papers. However, after reviewing their titles, eight duplicates were identified, leading to their exclusion. Lastly, after reviewing the abstracts, five additional papers were excluded given their flimsy connection to the investigation in question.

Before the full-text review of the papers, the relevant information was selected for analysis inside three wide categories, namely:

1. Main guidelines/concerns to have in studies featuring the participation of PwID;
2. Main constraints/limitations in studies featuring the participation of PwID;
3. Good practices/guidelines/concepts about ethics in general.

Having concluded this "pre-analysis", understood as familiarization and reorganization, the thematic analysis was started.

Level 1: Familiarization with the data

To optimize the research team's familiarization with the data, a full-text reading of 98 papers was conducted. However, after this task, it was concluded that 15 of them were not related to this investigation – and one other was not accessible, leading to 82 articles being considered for the second level of analysis.

Level 2: Creating the initial codes

After the familiarization with the data, five initial codes were identified: informed consent, (in) capacity to consent, self-determination, vulnerability, and gatekeeping.

Level 3: Identifying themes

For this step, and to validate the themes, it was determined that three members of the team had to, autonomously, read all the previously selected content and identify the themes that they considered to be relevant to the investigation. This was also considered to be a manner of triangulation and consequent diminishing of the risks of biases. With this in mind, the results are as follows:

- Team member 1 identified six themes: gatekeeping, vulnerability, self-determination, (in) capacity to consent, informed consent, and criticism of academic studies;
- Team member 2 identified seven themes: power imbalances, vulnerability, self-determination, (in)capacity to consent, informed consent, accessibility to the research process, and methodological approaches;
- Team member 3 identified eight themes: gatekeeping, vulnerability, self-determination, (in) capacity to consent, informed consent, involvement in research, ethics of care, and research.

Level 4: Reviewing the themes

In this phase, the team conducted a discussion about the semantic content of the themes identified during level 3. After a critical evaluation of these meanings, it was determined that, despite using distinct labels for each category, the team indicated similar semantic content in the identified themes. With this in mind, the most intermediate model (team member 2) was selected, given its relative simplicity concerning central aspects such as accessibility for PwID in the research process.

Level 5: Defining and naming themes

This phase started by defining each theme, along with the sub-themes that integrated it. Through this process, it was determined that the sub-themes of asymmetrical power, tokenism, and gatekeeping would be integrated into the theme related to power imbalances. As for "vulnerability", the sub-themes would be associated with exclusion, power and the associated risks; and the theme of self-determination would encompass inclusive research, collaborative groups, and consultancy. Concerning the (in)capacity to consent, it would include the ethical dilemmas associated with severe and profound disability, fluctuations in the capacity to consent, risk perception, and the assessment of the capacity to consent. On the topic of informed consent, the attainment of consent via someone who is not the participant, the adaptations to informed consent, and the barriers that may arise from this process were included. For the accessibility of the research process, the team considered the use of reasonable accommodations, the feasibility of the inclusive research, the functional diversity and representativity, to the good practices and barriers. Lastly, concerning the methodological approaches, the topics included were the ethical challenges that may arise according to the adopted methodological approach - and the opportunities that may come with them.

> **"It is important to highlight that there is no hierarchical organization between these themes, but only some cross-cutting nature of "Accessibility of the research project" (...), it is also possible to hypothesize that all the themes intersect and intertwine to illustrate the complex reality of the participation of PwID in scientific research processes."**

Level 6: Writing the report

This is the last phase and corresponds to the present report. It consists of the elaboration of guideline proposals for the accessible participation of PwID in scientific research, which will be elaborated based on the conceptual model that arises from the thematic analysis presented here.

CONCEPTUAL MODEL

The conceptual model developed is shown in Figure 1 and is composed of seven main themes, to which different sub-themes are added. Regardless of its visual aspect, it is important to highlight that there is no hierarchical organization between these themes, but only some cross-cutting nature of the "Accessibility of the research project", which is inherent to all the others. However, given the lack of empirical validation, it is also possible to hypothesize that all the themes intersect and intertwine to illustrate the complex reality of the participation of PwID in scientific research processes.

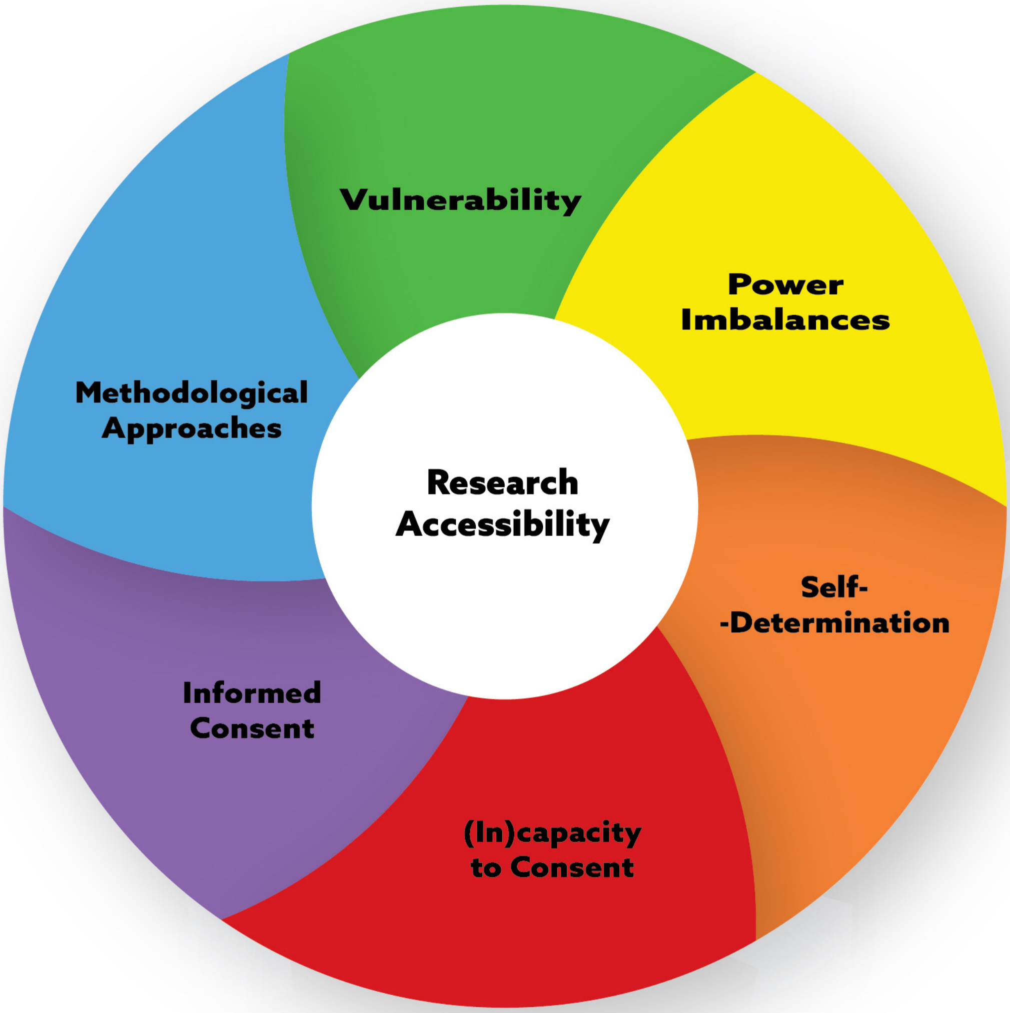

Figure 1. Proposed conceptual model (simplified version)

Figure 2. Proposed conceptual model (detailed version)

In short, the proposed conceptual model (Figure 1) is composed of the themes and subthemes listed below and, subsequently, described through a narrative and critical review of the papers that were analyzed.

Considering the detailed graphic representation of Figure 2, and the themes resulting from the analysis, the conceptual structure was organized, presenting as is below.

- Research accessibility
    - Reasonable accommodations within the research
    - Feasibility
    - Functional diversity and representativity
    - Good practices
    - Identified barriers
- Power imbalances
    - Asymmetrical power (acting on behalf of)
    - Tokenism
    - Gatekeeping
- Vulnerability
    - Vulnerability as exclusion
    - Vulnerability as power
    - Risks associated with vulnerability
- Self-determination
    - Operationalized through inclusive research
    - Operationalized through collaborative groups
    - Operationalized through consultancy
- (In)capacity to consent
    - Ethical dilemmas associated with profound and severe ID
    - Fluctuations in the capacity to consent
    - Perceived risk
    - Assessment of capacity to consent

- Informed consent
    - Proxy consent
    - Informed consent adaptations
    - Barriers to informed consent
- Methodological approach
    - Ethical challenges posed by the methodological approach
    - Opportunities posed by the methodological approach

Research Accessibility

According to the final conceptual model, resulting from the thematic analysis described, it was possible to identify a set of five sub-dimensions, which make up the **Research Accessibility** dimension:

- Reasonable accommodations within the research
- Feasibility
- Functional diversity and representativity
- Good practices
- Identified barriers

As a whole, this dimension concerns the degree to which the processes, procedures, and results of a research process are both planned and executed in such a way as to guarantee the full participation of all the people involved, taking into account their different backgrounds, skills, and characteristics.

Regarding the **reasonable accommodations within research**, the model capitalizes, above all, on 20 of the works included in the final sample of this literature review, namely: Adams et al. (2010), Bigby et al. (2014), Boxall and Ralph (2009), Cithambaram (2019), Coons and Watson (2013), Drozd et al. (2021), Goldsmith and Skirton (2015); Hall (2013), Hamilton et al. (2017), Herron et al. (2015), Ho et al. (2018), Northway et al. (2015), MacDonald (2020), McDonald et al. (2016;

2022; 2022), St John et al. (2022), Skarsaune (2023), Taylor and Baladin (2020), and Thomson et al. (2014). This sub-dimension concerns the work of identifying a set of reasonable adaptations implemented in the context of scientific research, to accommodate specific characteristics of individuals, systematizing the rationale that underlies them, implementation experiences identified in the literature, and possible threats to the validity of the processes arising from this.

> *"This sub-dimension concerns the work of identifying a set of reasonable adaptations implemented in the context of scientific research, to accommodate specific characteristics of individuals (...)."*

According to Bigby et al. (2014), the significance of participation in a research process depends on the effectiveness of support strategies to ensure that participating people understand the decisions being made, the issues debated, and the relevant materials. In this sense, a more inclusive look at the knowledge production process should emphasize what can "prevent" or "limit" the participation of people with ID, and eliminate or reduce any barriers – instead of considering them "incapable" of participating in a meaningful way. This is, according to Northway et al. (2015), an "ethical imperative", which allows us to rethink the inclusion of people with ID in society, in a broader sense.

Specifically, **reasonable adaptations** that promote better support for the needs of PwID in the scientific research process may include:

a) Adoption of visual and/or image-based approaches (Boxall & Ralph, 2009; McDonald et al., 2016; McDonald, 2021);

b) Consideration of augmentative and alternative communication technologies from the research design and onwards (Boxall & Ralph, 2009; Herron et al., 2015; Taylor & Baladin, 2020);

c) Developing accessible formats for informed consent, which can include accessible language and writing, for example: pictograms or easy-to-read formats (Boxall & Ralph, 2009; Drozd et al. 2021; Goldsmith & Skirton, 2015; Northway et al., 2014; St. John et al., 2022; Thomson et al., 2015);

d) Ensuring that PwID have access to their daily support during the research process, as well as individualized support (McDonald et al., 2016);

e) Reading aloud of questions in the research protocols, or the use of text-to-voice/voice-to-text technologies (McDonald, 2022; St. John et al., 2022);

f) Including systematic forms of assessing capacity to consent in research (McDonald, 2022);

g) Ensuring that research protocols are tested with representatives with ID before the formal investigation begins (Drozd et al., 2021);

h) Research design protocols with the priority of reducing research fatigue (McDonald, 2021).

"(...) the significance of participation in a research process depends on the effectiveness of support strategies (...)."

In turn, these adaptations seem to raise some **concerns related to the validity of the process** itself, as it is considered that they may result in some threats, biases, and/or parasitic variables arising from them, which include:

a) Complex regulations on the use of images and visual content, adopted by most ethics committees in the social sciences field (Boxall & Ralph, 2009);

b) Threats to validity associated with the inclusion of people who have no command of verbal communication tend to promote the invisibility of an audience already marginalized by scientific research, particularly people with profound ID (Boxall & Ralph, 2009);

c) Mitigate concerns about deviations from the protocol, inclusive and accessibility-promoting adaptations should be included in the protocol, right from the conceptualization phase (McDonald, 2022).

About the **feasibility of inclusive research**, in this specific context, this refers to the possibility of PwID becoming full participants in scientific research processes. It should be noted that of the papers collected, only Bigby et al. (2014), Tilley et al. (2021), and Walmsley et al. (2018) address this issue.

> *"(...) these adaptations seem to raise some concerns related to the validity of the process itself (...)."*

Inclusive research is one of the several approaches that can be adopted to understand difficulties, as well as promote the participation of PwID in research. However, this method is expensive and requires a lot of time from the researchers, as continuous monitoring is required throughout the entire process (Tilley et al., 2021; Walmsley et al., 2018). Furthermore, for research to be truly inclusive, PwID must be considered co-investigators, having the same level of control as researchers without ID. However, seems to be some reservations regarding their ability to conduct research (Bigby et al., 2014).

It is also important to note that in inclusive and participatory research it is essential that there is maximum **functional diversity and representativity** among PwID to ensure that the research results can benefit as many people as possible.

Regarding this sub-dimension, the conceptual model is based on 10 of the 82 articles included in the final sample of the literature review, namely on the work of Bigby et al. (2014), Boxall and Ralph (2009, 2011), Dee-Price (2020), Feudtner and Brosco (2011), Goldsmith and Skirton (2015), Maes et al. (2021), Marshall and Tilley (2013), McDonald and Kidney (2012), and Thomson et al. (2014).

One of the obligations of the scientific community is to ensure that the use of research methods that include rather than exclude is encouraged, as well as the need to have participants with different levels of disability (mild, moderate, severe, or profound) in studies, and what the underlying implications are when this is not allowed (Boxall & Ralph, 2009).

> *"(...) PwID must be considered co-investigators, having the same level of control as researchers without ID."*

That being said when structuring research with PwID, it is necessary to consider these factors and have as diverse a group of participants as possible, not only to provide the best possible results but also to be more representative. Even when the research is related to a specific group of people, for example, people with Fragile X Syndrome, it is necessary to consider each person in their individuality and specific characteristics, since these characteristics translate into different life experiences, which will influence the results obtained.

It is important to highlight that one of the barriers to the participation of people with profound ID is the perception that they need greater protection. According to Feudtner and Brosco (2011), such is not necessarily true since the protections that are currently in place for all people are also suitable for groups considered to be more vulnerable, and no additional barriers are needed.

> *"(...) it is necessary to consider each person in their individuality and specific characteristics."*

Through the thematic analysis carried out, it was possible to draw up a compilation of the existing **good practices regarding the participation of PwID in scientific research**, with several papers addressing this issue, particularly those by: Boxall and Ralph (2009), Burns et al. (2008), Cameron and Murphy (2007), Crook et al. (2016), Coons and Watson (2013) Drozd et al. (2021), Ellem et al. (2008), Haines (2017), Hart et al. (2020), Herron et al. (2015), Jacobs et al. (2021), Jepson (2015), Lotan and Ells (2010), Maes et al. (2021), McDonald et al. (2016; 2017; 2022), Meierer et al. (2022), Mietola et al. (2017), Muir and Coe (2023), Okyere et al. (2021), St. John et al. (2022) Tilley et al. (2021), Van Goidsenhoven and De Schauwer (2022), and Zaagsma et al. (2022). Overall, good practices were identified in 23 of the papers included in this study.

Lotan and Ells (2010) identified five steps to support the decision-making process of PwID, which are: (1) goals identification; (2) the investigation of factors that promote participation during decision-making; (3) the preparation of conversations with participants; (4) the scheduling of decision-making meetings; and (5) follow-ups with participants and team.

> *"(...) the protections that are currently in place for all people are also suitable for groups considered to be more vulnerable (...)."*

On the other hand, Tilley et al. (2013) made six recommendations for working inclusively with people from marginalized groups when it comes to data analysis, primarily:

1. Obtain the resources that the collection phase may need in advance;
2. Collect data so that it can be analyzed inclusively;
3. Present the data in a way so that members with ID can participate in the interpretation process;
4. Select the data to work with the members with ID;
5. Recognize that each person contributes uniquely to the team and research;
6. Promote moments of reflection about the process.

Before starting the research, it is important that the research team identifies the potential harms and consequences of the investigation, aiming to minimize them (McDonald et al., 2017) and prevent potential communication problems (Herron et al., 2015). In addition, it is essential that the team studies which expressions, terms, and designations are most widely accepted by individuals - which in contemporary times can include aspects related to neurodiversity, for example - promoting respect and self-determination through the language adopted (Meierer et al., 2022).

It is also essential to guarantee, in a justified manner, when presenting to ethics committees or similar bodies, that the research presented effectively contributes to the knowledge about the living conditions of PwID and, consequently, to their well-being (Jepson, 2015).

During the research, the good practices identified include:

a) The use of photos of each member of the research team to accompany the name, as an accessible resource (Herron et al., 2015);
b) An explanation of the purpose of the study and respective conditions at the beginning and throughout the process, giving the participants the option of having someone they trust to support them at key moments (Gjertsen, 2019);
c) Treating the person as an adult and not as a label or condition (McDonald, Conroy, Kim, et al., 2016; McDonald et al., 2017);

> *"(...) it is essential that the team studies which expressions, terms, and designations are most widely accepted by individuals (...) promoting respect and self-determination through the language adopted."*

d) The view that both the person and the appropriate obtaining of consent must be considered according to personal characteristics (Coons & Watson, 2013; McDonald et al., 2017; McDonald, Schwartz, et al., 2022);
e) The guarantee of confidentiality, specifically considering that there may be people who are providing support to the participant. However, if they must have access to the data, it is advisable to sign a confidentiality contract/agreement (McDonald, Conroy, Kim, et al., 2016; McDonald et al., 2017);
f) Promoting decision-making by the participant (Burns et al., 2008; Gjertsen, 2019; McDonald, Conroy, Kim, et al., 2016; McDonald et al., 2017);
g) Ensuring the scientific basis of exclusion criteria (McDonald, Schwartz, et al., 2022);
h) Providing different dates and times for participation, so that the investigation does not interfere with other activities (Drozd et al., 2021);
i) The inclusion in the process of people trusted by PwID who can help in the interpretation of

non-verbal cues, in particular those that confirm, or do not, their willingness to participate (Mietola et al., 2017);

j) Promote clarification regarding the temporary nature of contact between the research team and PwID, minimizing the possible impacts of the abrupt end of the relationship created (Haines, 2017).

At the end of the fieldwork process, associated with more direct contact with PwID, it was also identified good practices to consider, namely:

a) Review interviews carried out with the participants, as well as reports or articles that emerged from them to assess how all parties feel about their dissemination (Van Goidsenhoven & De Schauwer, 2022; Zaagsma et al., 2022);

b) Make investigation summaries available in accessible formats, allowing PwID to also have access to their conclusions (Boxall & Ralph, 2009);

c) Use various media and strategies in the process of disseminating study results, promoting accessibility to results for non-academic audiences. Here, newsletters, videos, and social media, among others can be included (St. John et al., 2022);

d) Give PwID credit for their contributions to the research (Crook et al., 2016).

The last subdimension relates to the **several barriers identified in the inclusion of PwID in research processes** which, as opposed to good practices, tend to condition it negatively, perpetuating the exclusion of their voices and narratives.

Regarding references on the topic, it was possible to identify that it was present in 16 of the articles collected, namely: Avery (2019), Carlson (2013), Goldsmith and Skirton (2015), Hall (2013), Leighton (2009), Martino and Schormans (2018), McAllister et al.(2013), McDonald et al. (2009), Morgan et al.(2014), Northway et al. (2015), St. John et al (2022), Taylor and Balandin (2020), Tilley et al. (2021), Tuffrey-Wijne et al. (2008), Walmsley et al. (2018), and Watchman et al. (2019).

According to Northway et al. (2015), during the process of obtaining ethics approval, the research team must fill out a form about the possible barriers to inclusion. However, the form itself is a barrier to inclusion, considering that the way it is formatted and the language used tends to be not accessible to PwID (Northway et al., 2015). Furthermore, the level of detail required in a study protocol makes the document very long and of little use to these people as co-investigators (Northway et al., 2015).

More systematically, the barriers identified include:

a) Lack of knowledge or specific skills on the part of the research team (St. John et al., 2022);
b) Environment inaccessibility (St. John et al., 2022);
c) Communication barriers (Leighton, 2009; St. John et al., 2022);
d) Inaccessible language and documents (St. John et al., 2022);
e) Use of offensive or outdated language in research policies and associated documents (St. John et al., 2022);
f) Difficulty in recruiting diverse people among the group, which includes the possibility of coercion from caregivers, family members and/or legal guardians (Goldsmith & Skirton, 2015; St. John et al., 2022; Tuffrey-Wijne et al., 2008);
g) Difficulty in obtaining consent (McAllister et al., 2013; St. John et al., 2022);
h) Systematic exclusion related to participation (St. John et al., 2022);
i) Protection of ethics boards (McAllister et al., 2013; Watchman et al., 2019);
j) A high probability that it will be necessary to request an extension of time, which implies a restriction on costs (McAllister et al., 2013);
k) Possibility of gatekeeping by associations/organizations, caregivers, family members and legal guardians (Tuffrey-Wijne et al., 2008);
l) Lack of privacy that PwID may be subject to from caregivers (Hall, 2013);
m) Lack of knowledge, on the part of ethics councils, about capabilities, needs, correct

> ***"(...) the form itself [for ethical approval] is a barrier to inclusion (...)."***

language to be used, and necessary adaptations, among others (Martino & Schormans, 2018; Watchman et al., 2019).

The pressure associated with publishing articles and scientific production also presents itself as a fundamental barrier to the creation of more inclusive research teams (Tilley et al., 2021).

Power Imbalances

The **power imbalances** dimension is composed of three subdimensions, according to the conceptual model concluded by the thematic analysis described:

- Asymmetrical power
- Tokenism
- Gatekeeping

In general, this dimension concerns how relationships between PwID, neurotypical people, and other institutions give rise, in the context of an ableist society (Goodley, 2014), to power imbalances that impact, at different levels, the process of scientific research.

Directly, the subdimension called **asymmetric power** emphasizes the paternalistic tendency of these imbalances, which tends to protect PwID, creating direct or indirect barriers and constraints to their significant contribution. For this conceptualization, 10 of the articles included in the review process were taken as a basis, in particular: Boahen (2015), Hall (2013), Leighton (2009), Mataityte-Dirziene et al. (2023), McDonald et al. (2016; 2017), Mietola et al. (2017), Morgan et al. (2014), Munford et al. (2008) e Van Goidsenhoven e De Schauwer (2022).

According to Hall (2013) this protection of a paternalistic nature, although it may emerge from a desire to avoid risk or harm, can lead to conservative views of scientific research, fostering non-inclusive or even discriminatory decisions about the participation of people with ID. It should also be noted that power asymmetries tend to be more prominent when decisions are made by a person legally responsible for making them, other than the participants themselves - such as under the Regime of the Accompanied Adult (Law no. 49/2018, of August 14 - Regime do Maior Acompanhado in the original Portuguese formulation), in the Portuguese context. In this sense, the research team may encounter the following situations:

a) The carers attempt to make decisions on behalf of the participant rather than the court-appointed person (Munford et al., 2008), being the team tasked with avoiding such conflicts of interest (Leighton, 2009);
b) Problems can arise around confidentiality (McDonald et al., 2017);
c) Situations of asymmetric reciprocity may emerge, associated with the inability of the person without disability to effectively put themselves in the place of the PwID and resulting biases (Mietola et al., 2017; Young, 1997).

In this sense, the research team must also ensure that, concerning their participation in the study, the (potential) research participants are the first to be contacted, not their family members and/or carers, as otherwise this could be seen as paternalistic gatekeeping (McDonald et al., 2016).

> *"(...) can lead to conservative views of scientific research, fostering non-inclusive or even discriminatory decisions about the participation of people with ID."*

Regarding the **tokenism** subdimension, it aims to emphasize practices in which individuals from underrepresented groups, particularly those with ID, are included in research projects solely for symbolic representation, as opposed to meaningful and genuine inclusion. Thus, it refers to the superficial inclusion of individuals to give the illusion of diversity, without addressing underlying power imbalances or providing opportunities for meaningful participation. In this context, the works of Bigby et al. (2014) and Schwartz and Durkin (2020) were identified as most relevant.

Tokenism, which is often discussed concerning inclusion, raises concerns about participation superficiality and the emphasis on appearances rather than real partnership with co-researchers. Some examples of the promotion of this superficiality in the context of ID research include: the team's lack of support to self-representatives and/or co-researchers; the inability to adapt meetings to their needs; and the difficulty in adapting the project calendars to their needs (Bigby et al., 2014). In contrast, methodological choices are very relevant for collaborative research, with the training of co-researchers in specific academic aspects being the subject of discussion. This is because it is also considered that inhibiting the authentic participation of people with ID, filtering it through the common and rigid canons of scientific research, can result in a form of superficial involvement and tokenism (Schwartz & Durkin, 2020).

> *"Tokenism (...) raises concerns about participation superficiality and the emphasis on appearances rather than real partnership with co-researchers."*

The **gatekeeping** subdimension refers, in the context of research involving PwID, to the control or restriction of access to participation in research or decision-making processes by people or entities in positions of authority or power. Furthermore, through this subdimension, the aim is to encourage a reflective view of the potential impact of gatekeeping phenomena on the diversity of perspectives, innovation, the perpetuation of existing power structures, and the progress of scientific knowledge. Only seven articles address this issue, namely: Crook et al. (2016), Ellem et al. (2008), Goldsmith & Skirton (2015), Jepson (2015), Strickler and Havercamp (2023), Taylor and Baladin (2020), and Van Goidsenhoven and De Schauwer (2022).

Several constraints can emerge when it comes to the participation of PwID in research, one of them relates to the fact that gatekeepers can prevent them from participating or affect recruitment processes in various ways. Institutions in the field of disability, the people who work in them, families, and the ethics councils themselves are some of the gatekeepers to consider, and it is important to demonstrate the ability of PwID to participate with the different stakeholders (Ellem et al., 2008).

One of the main impacts of gatekeepers is on informed consent processes, which can become inappropriate or coercive, affecting the participation of many PwID in research (McDonald, Schwartz, et al., 2022; Strickler & Havercamp, 2023). Other factors that may prevent this population from participating in research include the lack of recognition of their autonomy or, conversely, the pressure they may be under from carers, family members, or legal representatives to participate (Ellem et al., 2008; Goldsmith & Skirton, 2015; Taylor & Balandin, 2020).

In turn, about the recruitment of participants, by relying on gatekeepers to do the recruitment, it is necessary to remember that:

a) They will be the ones who will decide who can participate and who the research might be of interest to (even without discussing it with them first), while the preconceived ideas that the recruiters might have about the study, as well as the degree of conservatism of the ethics board, will also affect the risk of excluding participants (Taylor & Balandin, 2020; Van Goidsenhoven & De Schauwer, 2022);

b) By relying on someone else to recruit, there may be some delay and possibly exclusion of potential participants (Goldsmith & Skirton, 2015);

c) Gatekeepers usually have a protective attitude towards PwID, so they may prevent certain people from participating, something that also happens when the recruiter's agenda is not the same as the research team's (Goldsmith & Skirton, 2015; Taylor & Balandin, 2020).

In this sense, if the research team can control the recruitment process, the risk associated with the exclusion of participants decreases substantially (Crook et al., 2016; Goldsmith & Skirton, 2015).

> *"One of the main impacts of gatekeepers is on informed consent processes (...)."*

Vulnerability

Vulnerability, in a research context, is usually associated with the reduced capacity to resist abuse and exploitation (Morgan et al., 2014; Snipstad, 2022). In this sense, and still having into consideration the abuse and exploitation to which PwD were subjected in the name of science in past contexts, this group – which includes PwID – tends to be seen as vulnerable and in need of specific protection (Snipstad, 2022). In this dimension of the thematic analysis, insights regarding the impacts of considering PwID as vulnerable in their full and effective inclusion in scientific research were considered. Within this context, recognizing the complexity of this dimension, it was possible to subdivide it throughout the thematic analysis, into three subdimensions, which are:

- Vulnerability as exclusion
- Vulnerability as power
- Risks associated with the vulnerability of PwID

As mentioned, PwID are considered to be vulnerable and in need of protection, which ends up meaning that they are often excluded from participating in research for this very reason (Northway et al., 2015). In the opposite direction, this tends to increase their vulnerability, which is a form of discrimination and social exclusion, namely because it removes their voices from the potential resolution of their daily problems. This dimension therefore addresses the notion of **vulnerability as a form of exclusion.**

Some articles address this issue, namely 15 of all those selected: Carlson (2013), Cithambaram et al. (2019), Dakic (2018), Evans (2022), McClimens and Allmark (2011), McDonald et al. (2016; 2009, 2015), McDonald and Patka (2012), Mietola et al. (2017), Northway et al. (2015), Okyere et al. (2021), St. John et al. (2022), Strickler and Havercamp (2023), and Watchman et al. (2019).

When the topic of vulnerable groups is approached, it usually refers to individuals within that group and not to the group as a whole, that is, by labelling all profound PwID as being vulnerable, it is understood that all these people are subject to a greater risk to participate in studies. However, when naming a group of people as vulnerable, we are only considering their shared characteristics and are not considering the ethical and social relationships of the people who are part of that group (Evans, 2022).

Several studies mention that people considered to be vulnerable, particularly PwID, are often excluded from participating in investigations, sometimes based on the presumption that they are not capable of giving consent (Carlson, 2013; Cithambaram et al., 2019; Dakic, 2018; McDonald, Conroy, Kim, et al., 2016; McDonald et al., 2015; Northway et al., 2015; Okyere et al., 2021; St. John et al., 2022). Additionally, other factors that also contribute to the exclusion of these people are related to the time that the entire ethical approval process takes and the inherent requirements (Cithambaram et al., 2019; Okyere et al., 2021).

"Is a form of discrimination and social exclusion, namely because it removes their voices from the potential resolution of their daily problems."

This is because, being more vulnerable, they are more likely to suffer harm. However, this vulnerability also makes them susceptible to exclusion, which can further exacerbate their vulnerability, since only PwID can answer certain questions about their lives and issues that affect them. This exclusion is considered a form of marginalization and discrimination, raising ethical and validity issues in research (Carlson, 2013; Cithambaram et al., 2019; McDonald et al., 2009; Mietola et al., 2017; Northway et al., 2015; Strickler & Havercamp, 2023).

One of the ways to combat exclusion associated with people's perceived vulnerability is through the adoption of an emancipatory research model, in which those in control of the study are PwD, reducing the risk of exploitation and exclusion (McClimens & Allmark, 2011).

On the other hand, **vulnerability can also bring a connotation of power**, in the sense that inclusive and participatory research aims to empower the people participating and investigating, who typically belong to underrepresented groups. In these cases, all research is carried out to suit their specific personal characteristics, and if they do not agree with any aspect, they have the power to change it.

Few articles address this topic, notwithstanding six mentioned this issue, namely the works of Cameron and Murphy (2007), Karmiris (2022), McDonald and Patka (2012), Morgan et al. (2014), Snipstad (2022), and Van Goidsenhoven and De Schauwer (2022).

> *"This exclusion is considered a form of marginalization and discrimination, raising ethical and validity issues in research."*

When doing research with PwID it is imperative that everyone involved empowers, protects, and recognizes their needs and vulnerabilities to minimize the risks and cognitive load that the process represents (Morgan et al., 2014). One way to empower is through respect and mutual trust, which can be promoted by modifying inappropriate approaches to ones that strengthen understanding on the part of PwID. This includes the sensitivity of the research team to issues associated with coercion and paternalism during the consent process (McDonald & Patka, 2012). In addition, another tool for empowering PwID is inclusive research itself. This research is based on research "with" PwD and not "about" PwD, which is based on the mantra "Nothing About Us Without Us", associated with activism for the civil rights of this population (Snipstad, 2022).

> *"(...) inclusive and participatory research aims to empower the people participating and investigating (...)."*

At the same time, it is also important to note that PwID tend to be subject to persuasion by carers and family members, so, fundamentally, the team should question internally what their level of decision control will be (Cameron & Murphy, 2007). Some self-reflective questions for research teams, proposed by Karmiris (2022), include:

a) What are safeguarding practices?

b) Who is part of the group of people who need to be safeguarded?

c) Among the gatekeepers, who have knowledge related to protection?

The last subdimension, **risks associated with the vulnerability of PwID**, relates to the factors that researchers, ethics committees, and gatekeepers have to consider when involving this group in research, such as whether they have sufficient information about their involvement and/or the study (Strickler & Havercamp, 2023).

> *"One way to empower is through respect and mutual trust (...)."*

Of all the articles included in the thematic analysis, only two address this issue, Carlson (2013) and Strickler and Havercamp (2023).

Researchers who carry out research with PwID regularly face ethical negotiations between the risks inherent in including this population in their studies and the necessary protections. Since people belonging to groups considered vulnerable have not had their rights protected in several past situations, ethics councils may tend to impose obstacles to the inclusion of PwID in scientific research processes. This impediment may contribute to their exclusion from society, further promoting the risk of erroneous extrapolation of results (Strickler & Havercamp, 2023).

> *"Due to the fact that people belonging to groups considered vulnerable have not had their rights protected in several past situations, ethics councils may tend to impose obstacles to the inclusion of PwIDs in scientific research processes."*

In summary, four main risks must be taken into consideration when researching people with ID, these are (Carlson, 2013; Strickler & Havercamp, 2023):

a) Excluding people from research that may be beneficial to them;

b) The inclusion of people who did not understand or are not sufficiently informed about the study;

c) Treating adults with ID as children by obtaining proxy consent;

d) Excessive dependence on external decision-makers.

Self-determination

Everyone has the right to self-determination however, such right does not always apply to PwD (Skarsaune, 2023). Self-determination, in research, concerns the person's free decision regarding their participation in the study or the research team.

That said, in research processes, and according to the thematic analysis prepared, self-determination can be promoted through:

- Inclusive research
- Collaborative groups
- Consultancy

Regarding the **promotion of self-determination** through scientific research, this is related to the inclusion of the voices and experiences of PwID in the process and can occur, mainly, at three levels, such as consultants, research leaders, or even collaborators in specific studies (Bigby et al., 2014).

Among the articles included in the thematic analysis, seven address this topic, namely: Bigby et al. (2014), Boxall and Ralph (2009), Gjertsen (2019), Hart et al. (2020), Kuri and Schormans (2022), Schwartz and Durkin (2020), and Walmsley et al. (2018).

The main aim of **inclusive research** is to give control of the research to PwD so that they have power over it and it relates to topics that are relevant to them. This type of investigation uses the action-research approach, and participatory and emancipatory methodologies, aiming to promote awareness-raising actions about structural factors (Bigby et al., 2014).

For Bigby et al. (2014) and Kuri and Schormans (2022), inclusive research can be divided into three different approaches related to the participation of PwD:

1. **Consultancy**, in which people provide support to research teams, the government, and organizations on various issues, with a less active role in controlling the process than in the following approaches;
2. **Research leadership or control**, which includes an active role in all aspects, including funding, and research design, among others;
3. **Collaboration**, in which PwD and people without disabilities work as a team, and where PwD are considered co-researchers.

> *The* **promotion of self-determination** *(...) is related*
> *to the inclusion of the voices and experiences of PwID*
> *in the process (...).”*

Throughout the development of the conceptual model, it was possible to identify advantages, disadvantages, and recommendations related to inclusive research, which:

- The direct involvement of PwID in the study means that the results obtained will be better, resulting in better benefits for this population (Boxall & Ralph, 2009);
- The collection of different perspectives and the certainty that the subject of the study and the results are relevant to this population (Walmsley et al., 2018);
- Support in recruiting people, making it easier to reach groups that are normally inaccessible (Walmsley et al., 2018);
- Support or control of the process of dissemination and application of knowledge (Walmsley et al., 2018);
- Empowering PwID to participate, potentially promoting policies that generate change (Walmsley et al., 2018);

- Support in the appropriate creation of informed consent and interview questions in accessible and easy-to-read formats (Gjertsen, 2019; Walmsley et al., 2018).

> *"The main aim of* **inclusive research** *is to give control of the research to PwD so that they have power over it (...)."*

Nevertheless, the disadvantages are mainly related to the higher cost of this type of research, as it involves more people, adaptations, and hiring translators and/or interpreters, among others. Also related to cost is the increased time of inclusive research processes, as it is necessary to guarantee equal participation and understanding from each team member, which may involve several iterations (Walmsley et al., 2018). Furthermore, inclusive research also involves concern with financial compensation models for PwID (Bigby et al., 2014).

Self-determination through collaborative groups is explored by Bigby et al. (2014), mentioning that groups are characterized by being made up of academics or others without ID and people with ID, with the participation of all people being crucial to generating new knowledge. In this sense, the value given to each person's contributions must be similar, as they represent particular and distinct points of view and experiences.

> *"The direct involvement of PwID in the study means that the results obtained will be better (...)."*

Another way of participating in studies is through **consultancy**, which in the case of PwID can promote their self-determination, as they give their opinion on a certain topic or on the direction the study is taking. The role of consultants is crucial in topics such as research design, recruitment strategies, or data collection (Bigby et al., 2014).

In the thematic analysis, four articles were identified referring to this topic, namely those written by Bigby et al. (2014), Haines (2017), McDonald et al. (2015), and Munford et al. (2008). PwID are considered consultants par excellence or "experts by experience" (Bigby et al., 2014, p. 5), who must be recruited to support prioritizing, designing, advising, and disseminating. To this end, they must have, as much as the context allows, control over the elements of the study.

"Collaboration with people with ID [supports] the scientific community's awareness of the capabilities of this population, which is often excluded or underrepresented."

Collaboration with people with ID in research can help in the development of policies and practices relevant to them, in addition to supporting the scientific community's awareness of the capabilities of this population, which is often excluded or underrepresented (McDonald et al., 2015). Thus, McDonald et al. (2015) mention the need to create guidelines that help the research team maintain confidentiality, exploring new models of supported decision-making that reinforce capacity and self-determination.

(In)capacity to Consent

Considering the final conceptual model obtained, regarding **(in)capacity to consent**, it was possible to group the results into four distinct themes that relate to:

- Ethical dilemmas associated with profound and severe ID
- Fluctuations in the capacity to consent
- Perceived risk
- Assessment of capacity to consent

This theme concerns the capacity to understand and retain relevant information so that PwID can, voluntarily, make an informed decision (Calveley, 2012). Although PwID commonly have difficulties understanding and retaining information, this need for support can be alleviated through the use of accessible communication and assistive technologies, for example (Strickler & Havercamp, 2023).

Concerning the **ethical dilemmas associated with severe and profound ID**, these are related to a complex set of aspects, associated with the implementation of inclusive research with people whose support needs are very high.

In total, nine articles address this issue, namely those by Bigby et al. (2014), Boxall and Ralph (2009), Crook et al. (2016), Haines (2017), Martino and Schormans (2018), McClimens and Allmark (2011), McDonald and Kidney (2012), Skarsaune (2023), and Tuffrey-Wijne et al. (2008).

In line with what was mentioned in the previous category, although self-determination is a right that is explicit in the CRPD, in the case of people with profound dependence, this right is often not respected (Skarsaune, 2023). This is due to the need to implement rigorous ethical processes to ensure that consent is informed and voluntary. This implies the adaptation of resources and more support that enables proximity consent, which may dissuade research with this group of people (Crook et al., 2016; McDonald & Kidney, 2012).

> *"(...) people who least fit into normative capacity parameters also tend to be less recruited for studies, strengthening the underrepresentation of their voices and perspectives."*

This last statement is in line with what was mentioned by Martino and Schormans (2018), who state that people who least fit into normative capacity parameters also tend to be less recruited for studies, strengthening the underrepresentation of their voices and perspectives. This arises from the emergence of obstacles, given the increased care and protection of ethics committees for people with profound disabilities, or those with multiple disabilities in studies (Haines, 2017; Martino & Schormans, 2018).

Other ethical dilemmas that arise concerning the participation of people with severe and profound

ID are related to the difficulty in understanding the aims of the study. Both Boxall and Ralph (2009) and Haines (2017) state that this group of people is less likely to understand the aims and their potential collaboration, which makes the entire process challenging and can lead to their exclusion (McClimens & Allmark, 2011).

However, some recommendations emerge in this context:

1. Research the needs of each person, to justify to the ethics committees that the greatest number of risks were minimized and that the remainder are proportional to the benefits (Haines, 2017);
2. Be aware of each person's strengths and vulnerabilities, as the capacity to consent may become greater if the information is particularly relevant to the person (McDonald & Kidney, 2012).

The second theme concerns **fluctuations in the capacity to consent**, that is, changes that may occur in a person's understanding of the study in question, potentially affecting their willingness to participate or disclose information (Ellem et al., 2008). These concerns were expressed in four studies, namely those of Carlson (2013), Ellem et al. (2008), McDonald and Kidney (2012), and Strickler e Havercamp (2023).

> ***"(...) heterogeneity, fluidity, the context of concepts, as well as the particularities of each person must always be considered."***

A PwID's capacity to consent can vary throughout the investigation (Ellem et al., 2008; Strickler & Havercamp, 2023). In this sense, and considering that this capacity is not something static, the team must take into account all the needs to support informed decision-making (Strickler & Havercamp, 2023). However, PwID may have difficulties in making informed decisions in certain areas of their life and not in others, so heterogeneity, fluidity, the context of concepts, as well as the particularities of each person must always be considered (Carlson, 2013; Ellem et al., 2008).

Perceived risk is addressed in the conceptual model according to the studies carried out by McDonald et al. (2016; 2017). According to them, PwID have a different perception of risk than other people, having a moderate interest in participating in studies with greater associated risks. This may happen due to their desire to be included in community life and return for a significant societal contribution. On the other hand, they do not show the same interest when the research may involve "negative social exchanges, decreased agency, and a loss of confidentiality" (McDonald et al., 2017, p. 89).

> *"(...) the assessment [of the capacity to consent] should be made according to the context (...)."*

The issue of the **assessment of capacity to consent** is based on the lack of agreement in the scientific community about this process, with various perspectives being highlighted (Carlson, 2013). For example, Fisher (2003) and Meierer et al. (2022) indicate that the assessment should be made according to the context, rather than just considering the person's capacity and understanding of the study, stressing the need to design informed consent according to the needs of each person. Nine studies addressed this issue, namely: Carlson (2013), Cithambaram et al. (2019), Dee-Price (2020), Goldsmith and Skirton (2015), Hamilton et al. (2017), McDonald (2022), McDonald and Patka (2012), Meierer et al. (2022), and St. John et al. (2022).

The assessment of capacity to consent inherently has some problems associated with the exclusion of people with ID, including the assumption that people are not competent, so the assessment is not carried out at all, or the overestimation of the ability to read and write (McDonald et al., 2022).

More specifically, St. John et al. (2022) identified three steps for assessing the capacity to consent:

1. Assess only the understanding that is relevant to the study;
2. Confirm, through questions, the person's understanding of the study and informed consent;
3. Avoid using standardized measurement scales.

Complementing this view, Hamilton et al. (2017) concluded that decision-making and visual aids, as well as obtaining new consent after data collection and using person-centred approaches are important for informed consent and capacity decision-making.

Nonetheless, according to Carlson (2013), there is still no consensus on the best way to assess and who should do it, although several authors point out that people should be assessed individually according to the context of the decision and the study, considering the time when the assessment was made and not the diagnosis they were given (Goldsmith & Skirton, 2015; McDonald, Schwartz, et al., 2022; McDonald & Patka, 2012; Meierer et al., 2022).

Informed Consent

Informed consent is an essential ethical component for any research, promoting the autonomy and the right to self-determination of the individuals participating in the study (Andre-Barron et al., 2008; Thomson et al., 2014). Therefore, the information contained in it must be relevant and appropriate to the conceptual and comprehension skills of potential participants (Andre-Barron et al., 2008).

It is crucial that during the process of obtaining informed consent, the participant has:

- Knowledge of the purpose, methods, risks, and benefits of the research;
- Capacity to decide if they intend to participate or not, without any type of coercion;
- Free and voluntary participation during the study (Andre-Barron et al., 2008; Ghosh, 2013; Thomson et al., 2014).

When developing this topic for the conceptual model, it was possible to identify three main subthemes:

- Proxy consent
- Informed consent adaptations
- Barriers to informed consent

Proxy consent occurs when the person with whom the research might be conducted does not have the capacity to make this decision, based on a court decision. When that happens, it is up to the research team to present the informed consent and request the participation of the PwID to the individual's representative, not excluding the necessity to present the study, methods, risks, and benefits in the best way possible to the participant (Black et al., 2010; Meierer et al., 2022).

> *"(...) even though the judicial system understands they are being represented by the legal representative, it is important that their will and decisions are considered of higher priority (...)."*

Several studies tackle proxy consent, particularly: Boxall e Ralph (2009), Haines (2017), Hart et al. (2020), Iacono and Carling-Jenkins (2012), McDonald and Kidney (2012), McDonald and Patka (2012), McDonald et al. (2016; 2017; 2022), Morgan et al. (2014), St. John et al. (2022), Thomson et al. (2014), and Watchman et al. (2019). It is still important to highlight the importance of continuously assessing the participant's desire to participate, not resorting exclusively to the act of obtaining informed consent (Hall, 2013; Hart et al., 2020; Jepson, 2015; Tuffrey-Wijne et al., 2008).

Several authors raise some concerns about the use of consent by proximity, among them:

- The attribution of a child's role to the adult with ID (Hart et al., 2020; McDonald et al., 2009);
- A greater risk of coercion (McDonald & Kidney, 2012);
- Failure to recognize the right to self-determination (McDonald et al., 2009);
- The risk of someone making a decision based on their interests instead of the PwID's (Boxall & Ralph, 2009; McDonald et al., 2009; McDonald & Kidney, 2012).

Besides this, the study by McDonald et al. (2017) concludes that having someone make decisions for the PwID can cause damage, possibly resulting in "denying the dignity of risk and self-determination and preventing learning" (McDonald & Kidney, 2012, p. 35). This means that, even though the judicial system understands they are being represented by the legal representative, it is important that their will and decisions are considered of a higher priority since consent by proximity does not necessarily include the PwID (McDonald et al., 2017; McDonald & Kidney, 2012).

> *"(...) the communication needs of each person should be based on their expressed desire (...)."*

When conducting a study with individuals who may have specific communication needs, including PwID, it is fundamental that **adaptations to the informed consent** are done so they fully understand what is on it. There are various possible adaptations, such as changing the whole material by accessible communication, that is, having the written consent in an easy-to-read format (Ellem et al., 2008; Haines, 2017), sign language, audio description, and, if possible, in braille. Additionally, another adaptation would be to allow for the presence of someone close to the participant - who may know them well - so that they may inform the team, through their observations and previous knowledge, if there is interest in participating (Marshall & Tilley, 2013). Another necessity has to do with giving more time for the individual to read and understand the information providing explanations and support (Cameron & Murphy, 2007; Hall, 2013). It is important to note that the communication needs of each person should be based on their expressed desire as much as possible.

Several of the analysed studies reflect on the possible adaptations that can be done to informed consent when research features PwID, particularly the following: Adams and Boyd (2010), Cameron and Murphy (2007), Cithambaram et al. (2019), Ellem et al. (2008), Haines (2017), Hall (2013), Hart et al. (2020), Jepson (2015), Karmiris (2022), Marshall and Tilley (2013), McDonald et al. (2009, 2015; 2022), Meierer et al. (2022), Munford et al. (2008), St. John et al. (2022), Skarsaune (2023), Strickler and Havercamp (2023), Taylor and Baladin (2020), and Tuffrey-Wijne et al. (2008).

On the other hand, research teams have faced several challenges when aiming to accommodate the participation of PwID, which condition their participation, considering them **barriers to informed consent**. Ten studies mentioned here tackle this topic: Cameron and Murphy (2007), Ellem et al. (2008), Hamilton et al. (2017), Hart et al. (2020), McClimens e Allmark (2011), McDonald et al. (2017), Meierer et al. (2022), Mietola et al. (2017), Strickler and Havercamp (2023) and Taylor and Baladin (2020).

There are several possible barriers to the process of getting the informed consent, namely:

- The demands of the ethical committee;
- The time it takes to receive it;
- The language used in the consent;
- The lack of involvement from the individuals that have a legal representative or similar;
- The lack of confidence from prospecting participants in the scientific research;
- The fear of disrespectful treatment;
- Communication barriers (Ellem et al., 2008; McDonald et al., 2017; Meierer et al., 2022; Strickler & Havercamp, 2023).

Scientific processes are, typically, submitted to and evaluated by ethical commissions or councils. However, such stipulations may cause roadblocks to the project, given the frequent challenge of determining all the procedures a priori when PwID are part of it.

> *"(...) stipulations [by ethics committees] may cause roadblocks to the project, given the frequent challenge of determining all the procedures a priori when PwID are part of it."*

Methodological Approaches

According to Parr (2015), the methodological approaches that are adopted in research should answer the need to place the knowledge and experience of the participants at its centre, particularly when their narratives of reality tend to be devalued, at the societal level. From this concept and the analyzed material, the component of **methodological approaches** emerges, consisting of the identification of ethical challenges and opportunities that research designs present to the full participation of PwID. Here, two aspects of analysis are included:

- Ethical challenges posed by the methodological approach;
- Opportunities posed by the methodological approach.

At the level of the **ethical challenges posed by the methodological approach**, insights from 10 studies featured in the performed review were analyzed, namely: Boxall and Ralph (2009), Clement and Bigby (2013), Drozd et al. (2021), Ellem et al. (2008), Haines (2017), Mietola et al. (2017), Northway et al. (2015), Taylor and Baladin (2020), Tuffrey-Wijne et al. (2008), and Van Der Weele and Bredwold (2021).

Several methodological approaches can be adopted in research featuring PwID, such as the participatory approach, with each having its challenges. For the participatory approach specifically, these challenges can be the wait time for ethical approval, the potential need to change the initial request, and the need for a vast volume of information a priori (Boxall & Ralph, 2009; Ellem et al., 2008; Haines, 2017; Northway et al., 2015).

"These opportunities appear to be valued by PwID, as it allows them to express themselves and make decisions through research that is not only participative but also emancipatory."

Concerning the **opportunities that arise from the adopted methodological approach**, eight articles were included for the conceptual elaboration of the theme, particularly: Boxall and Ralph (2009), Conroy et al. (2021), Coons and Watson (2013), Hall (2013), Herron et al. (2015), Maes et al. (2021), Morgan et al. (2014), and Riggs et al. (2022).

This theme refers to the advantages that the most participative and/or horizontal methodological approaches – with how they perceive the role of PwID – provide to the very research process. This includes the increased access of PwID to the research and its results, providing more supportive processes for decision-making (Boxall & Ralph, 2009), greater representation of the heterogeneity of the target audience (Maes et al., 2021), and stronger partnerships between universities and the community, based on open communication, shared goals, and mutual trust (Riggs et al., 2022).

Generally, the opportunities that emerge from the described methodological approaches are, mainly, opportunities for PwID to participate; where the researcher's 'dominant' role fades away as the motto of "Nothing About Us, Without Us" is incorporated into the process. These opportunities appear to be valued by PwID, as it allows them to express themselves and make decisions through research that is not only participative but also emancipatory (Conroy et al., 2021; Coons & Watson, 2013; Hall, 2013; Herron et al., 2015; Morgan et al., 2014).

PART III

Proposed Guidelines for Scientific Research with PwID

Taking into account the developed conceptual model and the inherent themes identified, some proposals for guidelines were developed to prioritize the self-determination and effective inclusion of PwID's voices in the scientific research processes.

At the level of **accessibility in the research process**, the following guidelines are proposed for operationalization:

1. Reasonable adaptations in the aim of the scientific research
    a. Before starting the research, every reasonable adaptation necessary to accommodate the specific characteristics of participating PwID should be identified, taking into consideration recommendations from literature such as visual approaches, augmented communication technologies, and accessible formats for informed consent, among others.
    b. The proposed adaptations should always be tested with self-representatives, that is, PwID, before formally starting the empiric research.
    c. A systematic evaluation of prospecting participants' capacity to consent should be included in the design of the research.

2. Achievability of the inclusive research
    a. The necessary resources to conduct inclusive research should be evaluated, both time and financing, along with considering specific necessities for continuous support throughout the process.
    b. The inclusion of PwID as co-researchers should be considered, providing them with a level of control that is equivalent to the other members of the research team.

3. Functional and representative diversity
    a. Stigmatizing labels associated with disability should be avoided, elaborating research designs that recognize the individuality of each PwID and take into consideration their distinct life experiences.
    b. When allowed by the research goal, the sample should be diversified concerning the level of support to the included PwID, or other contextual factors that characterize them.

4. Other aspects to consider about accessibility in scientific research
    a. Providing support to the PwID's decision-making, through clear information regarding the study and giving them the option to have someone they trust present when they consider it necessary.
    b. The research results should be made available in an accessible manner, including summaries in accessible formats and using different media to reach non-academic audiences.
    c. Physical and communication barriers in the research environment should be considered and, if possible, eliminated.
    d. An accessible language should be adopted in the documents referring to the research projects, avoiding outdated or stigmatizing terms.

With regards to **preventing power imbalances in the context of scientific research**, the following guidelines are suggested:

5. Promoting horizontal power dynamics in the aims of scientific research
    a. The design of the investigation and respective planning should recognize the importance of PwID's self-determination in every phase, excluding paternalistic decisions that may limit their significant participation.
    b. When possible, direct communication with PwID should be prioritized, instead of resorting to family members or any other intermediaries that may function as

gatekeepers and reinforce paternalistic dynamics.

6. Preventing tokenism
   a. The research should promote the effective inclusion of PwID in all its aspects, guaranteeing that their contribution is valued and not only symbolic.
   b. The methodological approaches should be adapted to the necessities of PwID, guaranteeing their ability to fully participate.
   c. The PwID should be provided with adequate training so they can be co-researchers, if they so desire, giving them the specific academic competencies necessary for research.

The **consideration for vulnerability in the context of inclusive research** also originated the following set of guidelines:

7. Prevention of exclusion due to perceived vulnerability
   a. The research should actively promote the inclusion of PwID, recognizing that their perceived vulnerability should not be a motive for exclusion, including the avoidance of stigmatizing beliefs over their ability to consent.
   b. The research teams and/or researchers should work in direct collaboration with the ethical commissions or equivalent organisms to speed up the process of ethical approval, guaranteeing that the importance of conducting inclusive research and its potential benefits to PwID is considered.
   c. The research teams and/or researchers should consider adopting emancipatory research models where PwID have significant control over the process, reducing the risk of exploitation and exclusion.
   d. The research planning should be sensitive to the ethical concerns raised concerning coercion and paternalism during the process of consent, promoting autonomous decision-making by PwID.

8. Preventing risks associated with PwID's vulnerabilities
   a. Risks associated with the participation of PwID in research processes should be

assessed systematically, considering the exclusion of potential benefits, the potential lack of understanding of the study and the excessive dependence on external decision-makers.

b. Open and transparent communication with ethical commissions or equivalent organisms should be promoted, highlighting the importance of inclusive research and the risks of unwarranted exclusion.

c. Research teams involved in studies featuring PwID should be given adequate training, giving them the ability to adopt an ethical and inclusive attitude towards the process.

Regardless of the eventual legal barrier to consent procedures - tackled in greater detail in the general guidelines 10 and 11 - some measures that concern **the consideration towards PwID's capacity to consent** are proposed, these are:

9. Considerations for PwID's capacity to consent
    a. Recognising self-determination in the context of scientific research should also be considered - and even emphasized - in the case of people with severe or profound ID, always adapting the consent strategies if possible to do so.
    b. The use of assistive technology should be promoted, when necessary, to support the PwID's comprehension and retention of relevant information.
    c. Constant reflections from the teams regarding the processes of consent should be promoted, including the notion that the capacity to consent might vary depending on the context, specific information, and during the research.
    d. The capacity to consent should be contextual and centred on the PwID as much as possible.
    e. The adoption of pattern evaluations as measures of the capacity to consent should be avoided, as well as other types of generalizations centred on the diagnosis or aetiology of the ID.

Formally, the processes of **informed consent** in the context of research with PwID could be guided by the following guidelines:

10. Informed Consent
    a. The research team should make sure that all information included in the informed consent is relevant and appropriate to the conceptual competencies of potential participants.
    b. It should be guaranteed that PwID are aware of the goal, methods, risks and benefits of the research, allowing them to make an informed decision without coercion.
    c. The informed consent should be adapted to the specific communication needs of the PwID, including the creation of easy-to-read material, sign language, audio narration, braille, or others, as appropriate.
    d. The adaptations should be based on the specific communication needs of each participant, considering as much as possible their expressed desires.
    e. Besides the initial consent, the PwID's will to participate should be continuously verified whenever possible.

11. Proxy Consent
    a. When applying consent by proximity, besides the involvement of the representative, the will and decision of the PwID should be held at a higher priority.
    b. The representative should be presented with all the relevant information regarding the goal, methods, risks, and benefits of the research.
    c. The research team should be conscious of the associated concerns about consent by proximity, with its possible risk of infantilizing adults with ID and leading to coercion, taking the necessary measures to avoid these risks.

At last, it is still important to highlight that the **chosen methodological approach** should also obey a set of ethical concerns that support concerns towards inclusion and self-determination, substantiated by the following guidelines:

12. Choosing the methodological approach

a. When planning the design of the research, different levels of participation from the PwID should be considered, including consulting, leadership, or collaboration, depending on the desired and/or achievable degree of engagement.
b. The adoption of participatory and emancipatory approaches that place the knowledge and experience of PwID in the centre of the production of knowledge should be considered.
c. The contributions of all participants should be equally considered, whether they are academic, PwID or others, recognizing that each represents a singular perspective or experience.
d. The research teams should promote continuous ethical or methodological revisions throughout the process of investigation, considering their challenges and opportunities for continuous improvement.

Additional Guidelines and Documentation for Consultation

The proposed guidelines are constituted by a set of statements - based on the collected scientific evidence - that aim to complement the existing ethical norms in operation, either being transversal or specific for each research team or researcher. In this context, it becomes relevant to systemise the documents that may be relevant for this phase.

In the international scope, the World Medical Association's (WMA) Declaration of Helsinki, for example, is understood as relevant for research with PwID, as it is also for any other research that involves human beings, given the established ethical standards and principles of integrity for medical and clinical research it provides (WMA, 2013). Similarly, the Ethical Principles of Psychologists and Code of Conduct of the American Psychological Association (APA) are fundamental for research with PwID, since they provide a set of ethical guidelines that guide the studies, safeguarding the rights and wellbeing of these people, that are understood to be more vulnerable (APA, 2017).

Aligning itself with the previously mentioned documents, though specifically contextualized to

Portugal, the Deontological Code of the Order of Portuguese Psychologists (OPP) aims to guarantee the well-being of the people who participate in scientific research processes, independently of their condition of disability, defining the obligations of the professionals in Psychology (OPP, 2020).

As previously mentioned, these are examples of relevant documentation regarding ethical guidance in scientific research, highlighting the individuality and contextual variance of its inherent procedures.

CONCLUSIONS

Conclusions

The current work set out to support the definition of ethical procedures inherent to the inclusive research in the GameIN research project (2022.07939.PTDC), through an evidence-based approach for the definition of guidelines to support the participation of PwID, in this context.

Through a thematic analysis, focused on 82 scientific articles, it was possible to organize a conceptual structure featuring seven main themes, namely: accessibility in the research process; power imbalances; vulnerability; self-determination; (in)capacity to consent; informed consent; and methodological approach.

After a theoretical exploration of these themes, respective subthemes, critical analysis, reorganization and resignification, a proposal composed of 12 groups of guidelines for scientific research with PwID was devised, to complement the already existing contextual norms to regulate the activity.

The conceptual model and the obtained guidelines seem to substantiate operational models of the motto “Nothing About Us, Without Us”, of the social and human rights models of disabilitys, in the context of scientific research.

However, the use of these guidelines, their achievability and the possible resistance from the different actors of the processes still need to be assessed, particularly through the empiric documentation of their implementation.

In the future, following the guidelines that resulted from this study, accessible formats of these guidelines should be created, testing their format and content with PwID.

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Throughout history, several moments guided the creation of ethical principles in an effort to combat abuses in scientific research with human beings.

When looking at the context of disability, the assumptions of the "United Nations Convention on the Rights of Persons with Disabilities" have necessarily been taken into account since 2008. In particular, it postulates that the idea of "universal design" should guide the conceptualization of research processes and the creation of new products or technologies.

This document presents a conceptual model from which proposals for ethical guidelines in research with People with Intellectual disabilities are devised.

After a detailed description of the thematics inherent to each group, in this research it is possible to find, summarily, the proposed guidelines, written to facilitate operationalization in planning a research design.

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