

EMPOWERMENT AND OWNERSHIP IN INTELLECTUAL DISABILITY GAMING: REVIEW AND REFLECTIONS TOWARDS AN ABLE GAMING PERSPECTIVE (2010-2020)

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Abstract

As with other populations, the usage of games by people with Intellectual Disability (ID) has been increasingly approached by research. Notwithstanding, the role of games in the lives of people with disabilities tends to be studied through a categorical picture that emphasizes its therapeutic characteristics and neglects games as recreation and as a form of cultural expression. The present work aims to review the main research outcomes of the last 10 years in the field of gaming and ID. It presents an analysis of the main research objectives, and approaches to gaming adopted in the analysed studies, as a path to reflect on two specific concepts: empowerment and ownership. Therefore, a Systematic Literature Review (SLR) methodology, accompanied by statistical and content analysis procedures, was adopted to analyse a sample of 61 peer-reviewed research papers (2010-2020) in this field. The obtained results emphasize the passive role of individuals with ID in games research, with gaming mainly seen through therapeutic or game-based learning approaches. The presented reflection on inclusive research, through the parallelism between game studies and critical disability studies, also highlights that the access to games, as a cultural expression, for people with ID could foster the inclusion of these individuals in the public sphere, both in media and in the democratic civic structures. The produced insights intend to frame future approaches that situate the potential of games and their accessibility as strategies to decrease environmental barriers and hindrances that people with ID face in their specific contexts and foster inclusion.

Keywords: Intellectual Disability; Games; Empowerment; Ownership; Systematic Literature Review; Inclusion; Accessibility.

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Intellectual Disability (ID) is defined as a disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social and practical domains (APA, 2013). The social paradigms of approaching ID have been gradually changing, from social charity to social citizenship, through the inclusion - segregation - integration - inclusion path (Emygdio da Silva, 2009; Fontes, 2009). This change is in line with the centrality currently attributed to the context in defining the effective disability of people with ID. According to the World Health Organization (WHO), although ID is seen as an health condition, from which results a set of impairments in body functions and structures, activity limitations, and participation restrictions, all these factors can only be understood when considering their complex interactions with the contextual factors, that comprise both personal factors and environmental barriers and hindrances (WHO, 2001, p. 18). Therefore, it is relevant to distinguish between two concepts often misused, disability and impairment. The current conception, developed by WHO (2001, p. 18) as explained above and the recent advances in the field of critical disability studies clarify that impairment is a set of individual factors, while disability is the result of the way the contextual factors allow the individual to develop their daily live, despite such factors (Ellis & Kent, 2011, p. 3). In other words, this paradigm approximates contextual factors and human performance, considering these factors the most relevant determinant of disability. This also highlights the critical reflection about the risks of using the concept of disability in the public sphere, considering that this might neglects the solution of a problem that is not in the individual's body but in the environment (Martins & Cordeiro, 2015).

This framework might also open space to introduce new concepts, such as ableism, as an expectation of primacy of able bodies, or disableism, as the unwillingness to accommodate different needs, to the current research scenario. Such critical views of disability seek to emphasize the social, cultural, and political relevance of impairment to research, particularly in the context of digital technologies, seen as powerful tools to

eradicate socially constructed disability (Ellis & Kent, 2011, p. 3-4).

Another relevant concept to reflect on the inclusion of people with ID as full members of the gaming community is access, that in digital media frequently appears as tied to social equality and political participation (Ellcessor, 2016, p. 7). Access is, therefore, a necessary precursor to participation in media, as well as in democratic civic structures (Carpentier, 2011), that in disability might be tied to the "formation of a newly imagined and newly configured public sphere where full participation is not contingent on an able body" (McRuer, 2013, p. 374).

This new way of thinking the relationship between digital media, disability and, in particular, ID will only make sense if it accompanies changes in this field of research, regarding the adopted approaches and methods. According to Schwartz, Kramer, Cohn, & McDonald (2019), inclusive research with people with ID is about the inclusion of this individuals in the process as "co-researchers", fostering their meaningful collaboration in all its stages and the value of contextual factors. Such view involves the transformation of individuals, who otherwise would be research subjects, as instigators of ideas, by developing research problems that are owned by people with ID, giving them some control over the process. This also includes the conduction of research to further the interests and address relevant issues for people with ID, leading to improve their lives, through collaboration and by accessing and representing their views and experiences (Walmsley, 2001). Moreover, Cobigo, Ouellette-Kuntz, Lysaght, & Martin (2012) emphasize the importance of including subjective measures and forms of assessment that embrace personal experience to foster a paradigm directed towards the social inclusion of people with ID.

Consistent with the set of concerns discussed above, there is also a strong activist drive regarding the uniformly accepted terminology in this field, that emerged with the grassroots movement led by self-advocates and their families to

replace the stigmatising terms, such as mental retardation (Ford, Acosta, & Sutcliffe, 2013). This emerges from the social movement of self-advocacy that fosters the voice of people with ID and their ability to stand up for themselves, to address inequalities and discrimination. Self-advocacy is nowadays considered as crucial to empowerment, sense of belonging, self-identity, social identity, leadership, confidence, social connection, and meaningful occupation (Fenn & Scior, 2018).

Games and (Intellectual) Disability

It is possible to argue that it is in the centrality of the context and in the promotion of inclusion through improved access, that games can establish themselves as an important bridge for people with ID. Nevertheless, the contrast between the innovative assistive technologies built for mobile devices and the continued inaccessibility of cultural media expressions, such as games highlights the struggles of question the dominant ideologies of ability and digital media, and how the integration between disability and mainstream mobile cultures is limited (Ellcessor, 2016, p. 120).

This can be better illustrated by the apparent centrality of the notion of serious games in ID games research. According to a Systematic Literature Review (SLR) developed by Cano, García-Tejedor & Fernández-Manjón (2015, p.562), research in serious games for ID has been primarily focusing on three types of main aims: learning or skills promotion; the definition of methodologies for game design and game development; and the identification of patterns and behaviours in the use of video games by people with ID. However, such research perspectives tend to be mutually exclusive and neglect the centrality of the player's satisfaction and engagement in the process. In addition, the authors also underline the lack of empirical results, highlighting some methodological weaknesses of the existing studies (Cano, García-Tejedor & Fernández-Manjón, 2015; Jiménez, Pulina, & Lanfranchi, 2015).

Despite its potential in promoting skills, and at the social and recreational levels, it is important to emphasize that, given the impairments usually associated with ID, not all the currently existing games can be considered effectively playable by this individuals, highlighting the relevance of accessibility once again (Jiménez, Pulina, & Lanfranchi, 2015). In addition, people with ID frequently have other associated conditions, such as motor impairments (functional diversity) or deafness, raising even more questions regarding accessibility issues in the available games (Szykman, Gois & Brandão, 2015).

As previously said, the game studies universe tends to adhere to an instrumental vision of the person with disability, that is understood through a categorical picture, instead of being seen as an "artful game world member". This is reinforced by methodological questions, such as the dominance of experimental or quasi experimental research designs, in which the subjects frequently do not have choice of what they are going to play and/or in the way they are going to do it (Wästerfors & Hansson, 2017). Also according to the results of Wästerfors & Hansson (2017), the immersion of people with disability in gaming is categorized by specific paths, being one of them the view of games as a biographical or situational refuge, with games being treated as an allegorical and concrete site through which the individual defines and interprets his or her life. The individual's self-management of this path and the efforts to maintain immersion in the game, despite the inherent accessibility issues, foster the required competence in the individual to take ownership of gaming, becoming game world active agents (Wästerfors & Hansson, 2017). In the field of gaming and disability, self-advocacy as also emerged mainly through charities and activist movements. In the United States of America (USA) and United Kingdom (UK) respectively, Special Effect (<https://www.specialeffect.org.uk/>) and Able Gamers (<https://ablegamers.org/>) develop their work by providing individuals with accessibility devices for gaming. Nonetheless, it is important to point out that this work aims

mainly to overcome physical, and not intellectual/cognitive, impairments.

The present paper presents a path of critical analysis of the outcomes of a SLR about games and ID, as an effort to explore the role of these individuals in games research, the adopted methods, and existing efforts to foster inclusive research, and reflect on empowerment and ownership in disability gaming.

Methodology

Sample Selection

The SLR process started with a schematic database search, including Ebsco, PubMed, B-On (the largest database in Portugal, with most of the other ones associated with it), Academia.edu, and ResearchGate, by using the following terms and Boolean operators: [games AND (intellectual disability)]. Variations of this search formula included different forms of designating ID, such as "cognitive disability", "intellectual disabilities", among others. Academia.edu and ResearchGate were also used as data collection tools, to access Grey Literature, that is produced on all levels of government, academics, and business but is not controlled by commercial publishers. This process constitutes the Identification phase of the SLR.

The following phases were based in a set of inclusion criteria:

- Studies must be published in sources that include a peer-review process;
- Studies must have a publication date between January 2010, and February 2020 (the systematic search was developed in early March 2020);
- Studies must clearly approach games usage for ID and constitute empirical approaches.

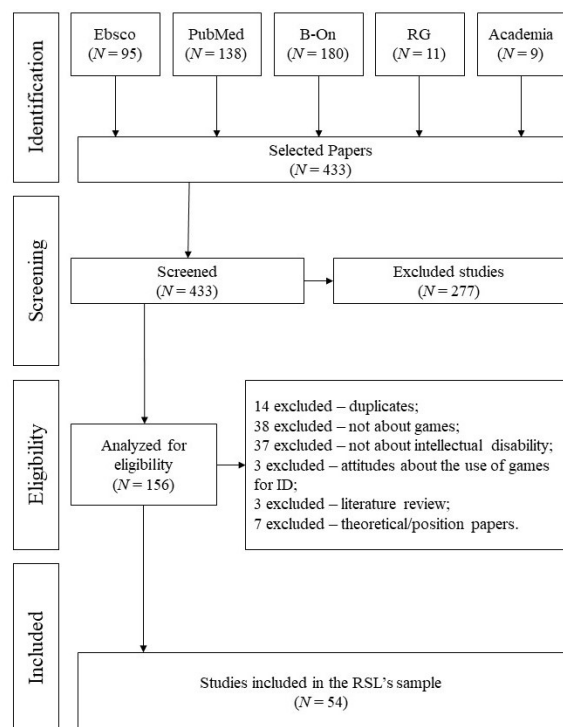


Fig. 1 Flowchart of the sample selection process

Studies approaching other disabilities, like learning disabilities, such as Attention Deficit Hyperactivity Disorder (ADHD), that are frequently confused in literature were also excluded. Using the above defined criteria, 54 scientific papers were obtained. The selection process throughout the final sample is represented in Figure 1. In the Screening phase, the criteria were applied at a superficial level, meaning that only titles, abstracts and general information were analysed. In the Eligibility phase the criteria was followed by thoroughly analysing each study, before select the final sample. Given the need to reference all studies included in the sample and the space limitations inherent to a journal, the final sample can be consulted through the link: <http://videojogos.ulusofona.pt/pdfs/EmpowermentAndOwnershipIntellectualDisabilityGaming.pdf>

Coding System and Data Analysis

The presented study is part of a broader RSL project and aims to reflect only on the components of such work that prompt the reflection about empowerment and ownership in gaming and ID. Therefore, the applied and now presented coding is part of a more complete list.

For this specific work, the SLR used the following coding system:

1. Main Research Objective
2. Sample
 - a. Size
 - b. Classification (1 - individuals with ID; 2 - individuals with ID and individuals without ID; 3 - individuals with intellectual and motor disabilities; 4 - individuals with associated psychological/developmental conditions)
 - c. Age Group (1 - adults; 2 - children and/or youth; 3 - adults and children/youth)
3. Terminology
 - a. with ID
 - b. Specific neurodevelopmental condition or syndrome
 - c. with Cognitive Disabilities
 - d. Intellectually Disabled
 - e. with Intellectual and Developmental Disabilities (ID/DD)
 - f. with developmental delay
4. Approach to gaming
 - a. Therapeutic (associated to assess, control or help control physical or psychological conditions, cognitive stimulation and rehabilitation)
 - b. Mainly recreational
 - c. Game-based learning (specifically for develop skills or acquire knowledge)
5. Role of the individual with ID
 - a. Role A (1 - consumer; 2 - creator)
 - b. Role B (1 - listen to in the research process, by means of participatory approaches, interviews, focus group, or other similar research techniques; 2 - only observed/systematically assessed by researchers; 3 - experts in the of ID were consulted; 4 - carers or trainers were consulted)
 - c. Role C (1 - listen to in the process of choosing game(s) to play; 2 - playing a game or games chosen by the research team)
6. Data gathering techniques
 - a. Standardized scales and measures
 - b. Usability surveys
 - c. Knowledge tests
 - d. Observation
 - e. 'Thinking Aloud' protocols
 - f. Focus groups
 - g. Tasks
 - h. Questionnaires (non-standardized)
 - i. Interviews
 - j. Performance data
 - k. Physiological measures
7. Did the study adopt a mixed-methods approach (more than one coded in data gathering techniques)?
 - a. Yes
 - b. No
8. Does the study clearly approach accessibility issues of games?
 - a. Yes
 - b. No

The coding system was developed through a bottom-up (considering the studies' manifest content) and top-down (considering the RSL specific objectives) process. After coding the 54 papers for each specific node and sub node, data was analysed

through descriptive statistical analysis (SPSS software, version 22) and through content analysis (NVIVO software, version 12).

Results

Sample and Terminology

The present study reviewed a sample of 54 studies, with a combined sample size of 1227 subjects, ranging between samples of two, and samples of 172 individuals ($M = 28,5$; $SD = 33,4$). In 87,0% of the studies ($N = 47$), the sample was only composed by individuals with ID. There were also studies: including individuals with ID and other associated psychological or developmental conditions, such as Autism Spectrum Disorder or Depression (7,4%; $N = 4$); including individuals with ID and associated motor disabilities (3,7%; $N = 2$); and including both individuals with ID and without ID (1,9%; $N = 1$). Most of the studies' samples were composed by children and/or youth (59,6%; $N = 31$), followed by studies with adults (32,7%; $N = 17$), and studies including both adults and children or youth (7,7%; $N = 4$). It is important to note that, for these data analysis, age groups were categorized as mentioned by each study's authors.

As terminology has been a constant concern for the community of people with ID and their families, that can be seen as one of the biggest areas of struggle in the scope of self-advocacy (Ford, Acosta, & Sutcliffe, 2013), it was important to specifically analyse the terms adopted by the researchers in each study. Most of the studies used the terminology "with Intellectual Disability" (70,4%; $N = 38$), the one also used in this review, followed by 11 studies (20,4%) that characterized the sample with the name of a specific neurodevelopmental condition etiologically linked to ID, such as Down Syndrome. Five studies adopted other terminologies to describe the sample, particularly "Intellectual and Developmental Disabilities" (3,7%; $N = 2$), "with cognitive disabilities" (1,9%; $N = 1$), "with developmental delay" (1,9%; $N = 1$), and "intellectually disabled" (1,9%; $N = 1$).

Approaches to Gaming and Games Research

A total of 49 studies provided clear information on the adopted data collection techniques, which is important to further reflect on the most used research methods and approaches to analyse the complex processed inherent to gaming. Since some studies used more than one technique, a total of 66 references to data collection techniques was analysed. Standardized/validated scales and measures were most used technique (22,7%; $N = 15$), followed by observation (18,2%; $N = 12$), and non-standardized questionnaires (12,1%; $N = 8$). Remaining results were ordered as follows: interviews (10,6%; $N = 7$); tasks (10,6%; $N = 7$); game performance data (7,6%; $N = 5$); knowledge tests (6,1%; $N = 4$); usability surveys (6,1%; $N = 4$); focus groups (3,0%; $N = 2$); physiological measures (1,5%; $N = 1$); and 'thinking aloud' protocols (1,5%; $N = 1$).

Given the above, and considering the sample of studies, it is possible to note that most of the studies adopted only one data collection technique (65,3%; $N = 32$), while the others (34,7%; $N = 17$) adopted a mixed-methods approach, triangulating the results obtained through more than one technique. Five studies did not provide enough information regarding data collection techniques to be categorized as single or mixed-methods and were excluded in this analysis.

Regarding the approaches to gaming adopted by each study, categorized as explained above, it is possible to note that most of the studies focused Game-Based Learning (56,6%; $N = 30$), followed by therapeutic approaches (37,7%; $N = 20$). Only three (5,7%) approached gaming for people with ID focusing mainly on its recreational elements. The main research aims of the three studies (as mentioned by researchers) were:

- To investigate the effectiveness of Stomp, a tangible user interface designed to provide new participatory experiences for people with ID (Wyeth, Summerville, & Adkins, 2011);
- To teach three adults diagnosed with mild ID to use an iPad in the context of playing the video game Angry Birds (Chan, Lambdin, Graham, Fragale, & Davis, 2014);

- To create roleplay games for children with mild ID, their caregivers, and their peers, who promote their social inclusion, through a kit (Vives et al., 2016).

In 94,4% ($N = 51$) of the studies the individuals with ID were positioned as game consumers, this is as subjects without any role in the game creation process, that play a game chosen and presented to them in its final version. In the remaining 5,6% ($N = 3$), individuals with ID were framed in the study as creators or co-creators. The strategies adopted in each study to operationalize the participation of the individuals with ID in the creation process were the following:

- Through the development of a game creation kit (MoJi) for children with mild ID, their caretakers, and peers (Vives et al., 2016);
- Through the adoption of a participatory design approach, where "children were consulted at the beginning of the project regarding their preferences and abilities regarding existing games", involved in usability tests, and consulted after the development phase, through collaborative processes (Robb, Waller, & Woodcock, 2019);
- "Children with intellectual disabilities were invited to participate in designing the technology at the outset and valued as experts in living successfully with disabilities. They contributed in the process of developing and validating the technology" (Kang, Chen, Miaou, & Chang, 2020).

In 77,8% ($N = 42$) of the studies the individuals with ID were only observed or systematically assessed by the research team, without being actively consulted, like for instance through an interview or a participative design procedure. On the other hand, in 16,7% ($N = 9$) of the studies, individuals with ID were listened to during the research process. There were also cases of studies where other individuals were consulted about the possible opinion or performance of the individuals with ID, particularly experts in the field of ID (1,9%; $N = 1$) and carers (3,7%; $N = 2$). Accordingly, and regarding the role of the individual with ID in the research process, it is possible

to categorize this role as passive in 83,7% of the studies ($N = 45$), and as active in the remaining 16,7% ($N = 9$).

In 83,3% of the studies ($N = 45$), the sample's subjects played a game presented to them and chosen by the research team. In contrast, in the remaining 16,7% of the studies ($N = 9$) individuals were somehow included in this choice, either directly, through strategies to collect their interests or needs, or through participatory design procedures. A total of 24 studies (44,4%) approached accessibility issues, although in the context of a game specifically developed for that study and not approaching the adaptation of existing or mainstream games. Most of the studies (55,6%; $N = 30$) did not approach accessibility issues.

Discussion

The present study aimed to develop a SLR about games and ID, as path for the discussion of empowerment and ownership of the individuals in this field.

A larger interest of research in games specifically for children/youth with ID was reported, although it is in the area of adult intervention that seems to exist greater difficulties in terms of significant occupation, especially after the end of compulsory education. Regarding the adopted terminology in the field of games for ID research, the most frequent is exactly "people with Intellectual Disability", what is in line with the claimed by self-advocates as the most dignifying term (Ford, Acosta, & Sutcliffe, 2013).

The review about methods and, specifically, data collection techniques adopted in each study's research design highlighted that, in this field, the comprehensive and detailed inclusion of people with ID's feedback is not prioritized, nor their empowerment in the research process. Such finding counters the postulated of meaningful collaboration in inclusive research (Shwartz et al., 2019), and the need to embrace the personal experience of people with ID as a form

of social inclusion (Cobigo et al., 2012). This is reinforced by the passive role of the individual with ID in the research process, that also counters the notion of “co-researchers”, explored by Shwartz et al. (2019). Likewise, the minority of research approaches that adopt more than one type of method strengthens the dominance of mutually exclusive views in this field, already mentioned by Cano, García-Tejedor & Fernández-Manjón (2015).

The view of games as a biographical or situational refuge (Wästerfors & Hansson, 2017), that implies that the person with disability takes ownership of gaming, only seems to be possible with changes in the field of game studies, that focus the issues of accessibility, through a broader adoption of inclusive research.

Most of the studies approach games through a therapeutic or game-based learning lens and, although it cannot or should not be totally dissociated from the recreational aspect, do not have recreation as the main focus. This supports Wästerfors & Hansson (2017) findings, regarding the exclusion of people with disability, although not specifically ID, as “artful game world members”, placing the research focus on their therapeutic needs, instead of prioritizing these individuals’ empowerment or need to take ownership of the gaming process. Moreover, this highlights the need to transform the view of people with disability and, particularly with ID, to become active game world agents. This can also include the conjugation of the concept of individuals’ empowerment, as brought by the fields of self-advocacy and social inclusion, and the views of empowerment through participatory culture and the engagement in significant media creation practices, such as postulated by Knobel and Lank-shear (2010) for the field of education. It is also important to point that in a relatively large sample of studies ($N = 54$), only one developed efforts to democratize a commercial game for people with ID with exclusive recreational goals, in this specific case Angry Birds (Chan et al., 2014), which illustrates the previously discussed.

The results also emphasize that the way people with ID are approached in research as gamers, considering their roles in the process, is crucial to somehow merge the field of critical disability studies and the field of game studies. Similarly, making games, not only as a therapy or educational tool, but as a cultural expression accessible for people with ID could foster the inclusion of these individuals in the public sphere, considering the notion of access as a necessary precursor to participation, both in media and in the democratic civic structures (Carpentier, 2011). This becomes even more relevant if we mention that the studies that address the issues of accessibility of games for people with ID are not yet a majority.

Considering the explored sample, people with ID are mainly positioned only as game consumers that play games chosen by others, namely researchers. This result is even more interesting if we note that most of the efforts to include people with ID in the games’ creation processes are based in participatory design strategies. There is only one mention to a study that effectively aims to democratize game creation tools for children with ID (Vives et al., 2016).

Such finding frames a reflection regarding media creation as a possible path for media participation and social inclusion of people with ID, and how self-advocacy can be crucial also in this field.

Limitations and Future Directions

It is important to clarify that this study does not intend to establish an utopic framework for the relationship of gaming and intellectual disability research. The above explored critical reflections are made with full notion of the complex challenges that research in ID poses and the inherent practical challenges (Coons & Watson, 2013). Moreover, the present study may not represent a complete view of the games and disability research landscape, since it is limited in a time frame (2010-2020), and cannot guarantee the inclusion of all the studies produced during such period, with a conscience

that several empirical works are also unpublished or somehow inaccessible.

The insights produced in this study aim to frame future approaches that situate the potential of games and their accessibility to foster the decrease of the environmental barriers and hindrances that people with ID face in their specific contexts, by establishing an able gaming research framework. Therefore, it is significant to clarify that neither this study, nor future ones, should confuse an able gaming perspective with an ableist gaming perspective, based on the primacy of able bodies.

The obtained results also emphasize the crucial importance of increasing the centrality of accessibility, not only of the games specifically developed in the context of research projects, but also of mainstream games, as a way to foster cultural inclusion and broaden the daily recreational experiences of people with ID. Future studies should focus the increasing need to critically reflect on the concept and the idea of assistive technology in the field of games, as it seems to be framed in approaches mainly based on medical models instead on a sociocultural view of digital media.

As a conclusion, the above presented and discussed results intend to provide some sustainability for the development of an able gaming perspective for games research, that truly applies the classic notion of “nothing about us without us” to this field.

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