The Inclusion of People with Intellectual Disability in Media and Communication Research: Insights and Contributions from Haraway

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Background

In research projects examining the usage of media as a strategy to foster empowerment and wellbeing in people with Intellectual Disability (ID), the critical reflection about such interventions and the limits for the involvement of the target audience emerged as crucial. Such relevancy is justified since people with ID are framed on a very specific part of the legal framework, considered mainly as unable to provide consent (Iacono & Murray, 2003). This means that laws tend to be developed assuming their lack of conditions, either natural or acquired, to self-determinate and defend their interests, even after reaching the legal majority/age of consent (Lennox et al., 2005).

Nevertheless, besides including the figure of a legal guardian/responsible person, profound reflection is needed to explore the ethical positioning of the researcher in this field, as well as the maintenance of the subjectsâ€™ self-determination through this process. Therefore, this essay intends to frame such critical reflection, emphasizing research involving people with ID in the scope of media studies, while exploring some philosophical assumptions, including insights from the text *A Manifesto for Cyborgs: Science, Technology, and Socialist Feminism in the 1980s* (Haraway, 1987). Moreover, the present essay has no pretension of being considered as a set of conclusions but can be better characterized as a range of questionings for further reflection.

Ethics and Research with People with Intellectual Disability

According to Carlson (2013), the inclusion of people with ID in empirical research must include the definition of risks, benefits, and competence of the researchers themselves. In this definition, researchers must assume and reflect on the fact that such a process involves normative judgments and represent values that might not be shared among all the stakeholders (including researchers, subjects, and the broader community). Moreover, stereotypes regarding people with ID and their presumed benefit, as well as the structural power relations inherent to clinical/therapeutic contexts must also be included in this reflection (Larsson & Jomfeldt, 2017). The issue with therapeutic contexts is further exponentiated if we consider adults with ID that live institutionalized in residential facilities. Therefore, and even if the United Nationâ€™s Convention on the Rights of Persons with Disabilities (CRPD) states the generic principles inherent to this process as full and effective equality, participation, and inclusion, respect for difference, and accessibility â€“ it is possible to highlight that this triggers more dilemmas and reflection spaces than certainties, linear actions, or objectivity.

Bigby, Frawley, & Ramcharan (2014) reflected on such questions by rethinking the concept of â€˜inclusive research,â€™ through two different paths: the inclusion of these subjects in the research team and the accessibility of scientific discovery to them. Then, by applying the traditional slogan *Nihil de nobis, sine nobis* (Nothing about us without us), they were able to characterize the inclusion of people with ID in research processes in four different modes: as subjects, as consultants in advisory boards, as the responsible person(s) for the study or project, or as participants in collaborative groups. However, while conducting research through these approaches, this Australian group of researchers also concluded that such reflections produce more questions than certainties, with several issues regarding the need for funding and the risks for the different stakeholders.

Cluley (2017) also explored the semantic shifts in the designation of these subjects, namely, the increasing usage of â€˜intellectual disabilityâ€™ over â€˜learning disabilityâ€™ or â€˜mental retardation,â€™ and the congruency of these shifts with changes in the intervention approaches in the field, including in research. The researcher discussed that, even if the core research in the field has been increasingly changing to meet more inclusive models, professionals nonetheless tend be skeptical in changing the adopted terminology in daily practice. This conclusion reinforces the need to consider power dynamics when reflecting on ethical questioning in this field. It is

important to note that the evolution of terminologies from â€˜mental retardationâ€™ to â€˜intellectual disabilityâ€™ is equivalent and complementary with the paradigm shift of intervention models from medical perspectives that center the problem on the subjectsâ€™ functional deficits to more ecological perspectives that center the problem in the environmentâ€™s inability to accommodate each subjectâ€™s needs (Parmenter, 2011).

A study developed by Crook, Tomlins, Bancrooft, & Ogi (2015), which included both professionals and people with ID, provides some relevant insights about the opportunities and constraints that potentially result from the process. It is highlighted that participants tend to perceive their inclusion in studies as relevant since they are exercising their right to participate and contribute to the building of knowledge about ID, which is crucial to reducing stigma and their daily obstacles. Nevertheless, people with ID also reported negative experiences while participating in research linked to a lack of measures designed to ensure confidentiality, as well as the bureaucratic challenges of obtaining consent. Depending on their specific country and/or cognitive specificities, this procedure must be dependent on a third party â€“ the legal guardian, as noted above.

Also, several studies report ethical concerns inherent to informed consent when there are legal guardians or similar figures. This type of power relation seems to stress the subjectivity of the perspectives on self-determination and participation costs/benefits, regardless of legal assumptions (Haines, 2017; Mietola, Miettinen, & Vehmas, 2017). Specifically, the constraints associated with the inclusion of subjects considered as having severe or profound ID have been inherent to their exclusion from research insights and conclusions, even in the field of disability studies. This is seen as conditioning the scientific progress in the interventions with this population, fostering their exclusion (McClimens & Allmark, 2011).

Especially in the field of media and communication research, there seems to be a scarcity of studies that clearly identify ethical concerns arising from this scientific context. Nevertheless, some studies approach the usage of images or multimedia narratives as relevant for the implementation of communication formats besides â€˜written wordsâ€™ (Boxall & Ralph, 2009; 2010). Such research designs could be even more relevant to ensure the existence of shared, appropriate, and effective communication modes in the research dynamics, providing answers to some of the previously approached ethical concerns (Carlson, 2013).

Debates, Dilemmas, and Assumptions

Since research with people with ID seems to result in more questions than provide closed answers, it is also relevant to frame some of the hitherto explored discussions with different established philosophical assumptions. Allan (2011), for example, proposed that some concepts of the so-called â€˜philosophers of differenceâ€™ â€“ Foucault, Derrida, Deleuze, and Guattariâ€“ provided an invitation to rethink the construction of the notion of disability, reframing research in this field. Therefore, the ideas of transgression from Foucault or rhizome from Deleuze and Guattari â€“ only a small part of the conceptual range that could be considered to this end â€“ allow the recognition of desire and resistance in individuals with disabilities, identifying their potential. Through the theoretical practices of deconstruction and rhizomatic analysis, the researcher can examine the politics and ideologies inherent to ID, interpreting and experimenting the â€˜worldâ€™ of ID and its inhabitants. Such theoretical contributions, allow research to be situated in an ethical perspective that intends to confront present inequities while being reoriented to human subjectivity.

Also, Donna Harawayâ€™s 1987 *A Manifesto for Cyborgs: Science, Technology, and Socialist Feminism in the 1980s* can be seen as a relevant contribution to rethink the way research with people with ID has been conducted in media studies that addresses its underlying ethical concerns. This manifesto, even if traditionally applied to the field of feminism and gender studies, can offer two dichotomic manners of rethinking disability. From one side, it reframes the limits between people with and without disability while exploring the intimate relationship individuals sustain with technology. From the other side, the cyborg discussion somehow assumes that both bodies and machines are fully functional entities (Goodley, 2010).

By reflecting on Harawayâ€™s (1987) work, Reeve (2012) highlights the hybridization of some disabled bodies, discussing the applicability of the notions presented by Haraway in the view of the relationship between people with disability and technologies such as wheelchairs and cochlear implants. Although this is a valid discussion, it is possible to emphasize that none of these technologies aim or allow for the extension of human intellectual capacity.

Considering the intersection between the question of extending/enhancing human cognition raised by the work of Haraway (1987) and the scarcity of specific ethical frameworks for ID and media studies, the premises mentioned by Goodley (2010) and Reeve (2012) lead to the emergence of at least three dilemmas:

1. If technology does not allow the extension of human cognition, and this pretension is replaced by the promotion of skills through media, then doesnâ€™t our current approach seem to treat media as mere assistive technologies?
2. If media as assistive technologies are presented to individuals with ID that have a passive role in research, how do we situate their self-determination?
3. If media are assistive technologies instead of an extension of the body for people with ID, how can these objects be studied also as cultural products?

These questions are broad but have in common a notion that the term â€˜assistive technologiesâ€™ is frequently operationalized in research in a manner that increases the individualsâ€™ passivity. Assuming that this assumption might not be true to every study or situation, it is possible to discuss that, when situated as assistive technologies, media are seen as a therapeutic resource instead of a form of expression, which decreases the centrality of self-determination and empowerment (Sousa, 2020).

A qualitative study developed by WÃ¤sterfors & Hansson (2017) with young adults who frequently play digital games seems to be a paradigmatic example of the raised hypothesis. If gaming for youth without disabilities is seen as a way of building alternative worlds to â€˜escape realityâ€™, then gaming appears as a â€˜reliefâ€™ for youth with disabilities from the obstacles imposed by their cognitive and/or physical impairments. Therefore, in the first scenario the subject is a builder of their own reality, and a passive element that receives a predefined â€˜treatmentâ€™ in the second scenario.

As a matter of fact, a simple search with the Boolean â€˜gaming AND disabilityâ€™ on Scopus illustrates this scenario. Moreover, most of the works that result from this search approach physical and/or cognitive rehabilitation in a way that neglects the experience of the players with disabilities as active subjects in the construction of their reality in various â€˜digital arenas.â€™

Given such hypotheses, it is possible to explore two aspects associated with research ethics. First, a mismatch in the perception of opportunities and benefits between researchers and people with ID. Second, a possible ethical positioning of the researcher as a promoter of scientific interest, rather than as an enabler of the self-determination of the subjects with ID. Therefore, emphasizing the historical positioning of technology in the field of disability studies, as associated with â€œnormalization,â€ â€œrehabilitation,â€ and â€œcure,â€ media tends to act as reinforcers of pathologizing perspectives of disability, seen as exceedable in futuristic views (Goodley, 2010; Reeve, 2012).

As a possible answer, the concept of self-determination should be understood in ways that contradict the strict sense assumed in most of the analyzed works, where it is operationalized merely through informed consent and other legal frameworks. An example could be involving individuals with ID in the decision and creative processes, with the potential to choose the type of competencies they would like to see promoted. With such paths to approach self-determination, it would be possible to situate research beyond the positioning of the academics as â€˜in chargeâ€™ of enunciating the priorities for this population, promoting the reorientation to human subjectivity discussed above in an empowering manner (Allan, 2011).

Final Remarks

Critical reflection about research including individuals with ID brings forth more questions than it produces certainties, especially if the dimension of the subjectsâ€™ cognitive limitations is addressed (Allan, 2011; Haines, 2017; McClimens & Allmark, 2011; Mietola, Miettinen, & Vehmas, 2017). The whole process of conceiving research and obtaining informed consent implies normative judgments that might not reflect values shared between the researcher and the subject (Carlson, 2013). And, even despite the evolution of practices and terminologies in this area, perceptions and attitudes towards this population do not seem to have fully evolved accordingly (Parmenter, 2011; Crook, Tomlins, Bancrooft, & Ogi, 2015).

With specific regard to media studies in the area of ID, the persistence of a pathologizing perspective can be better explained by some assumptions of Haraway (1987), also revisited by Goodley (2011) and Reeve (2012). The cyborg appears to reinforce the subjectâ€™s passivity in relation to media which, therefore, appears as assistive, even if aimed at the promotion of skills. This suggests a discrepancy between the subjectâ€™s self-determination and the scientistâ€™s interest. From a different point of view, the transgressive potential of cyborg theory could be reconstructed to represent a more disability-affirming approach to technologies that abandons the notion of fully functioning bodies to emphasize the practices that all different bodies produce, especially the more disruptive

ones. This premise is better explored by Kafer (2013) who investigates ID and stigma through the lens of a disruptive cyborg theory by emphasizing the fundamental differences between debates around physical and intellectual disabilities, criticizing the frequent connection of this condition with childhood and highlighting how the experience of ID can allow for new understandings of human experience in relation with the environment.

In the future, this critical reflection can frame the development of more comprehensive research modes that include individuals with ID as builders of their own reality through media that represents them and works as forms of cultural expression, regardless of any assistive potential.

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