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Enhancing Participatory Research with Neurodiverse Individuals: The Potential Role of Assistive Technologies in Facilitating Informed Consent

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Abstract

The following chapter aims to address the potential that assistive technologies can have in facilitating the participation of neurodivergent individuals in participatory research. Considering that their participation can help them to have meaningful participation in society, equal opportunities, advocate for their rights, show their point of view, and be valued as important and active members of society, it is crucial to have their presence when research impacts them directly. When recruiting this specific group of people is crucial to respect their self-determination and have accessibility as the front and center of the research. The use of assistive technologies can prove to be a great resource to facilitate interpersonal communication between the researchers, the consultants, and the participants, as well as to obtain informed consent or assent. Although there is some research developed about the barriers faced before, during, and after the whole research timeline, there is not enough when it comes to the role that assistive technologies can have in mitigating these barriers.

Keywords: Participatory Research; Neurodiversity; Assistive Technologies; Informed Consent; Accessibility and Inclusivity.

The term 'Neurodiverse People' emerged from the autism rights movement in 1998 (Kapp, 2020) and although is not yet well defined (Russell, 2020) it is usually used to refer to autistic people, as the neurodiversity movement is led by autistic people (Hughes, 2016; Kapp, 2020). Notwithstanding, Hughes (2016) defines 'Neurodiversity' as an umbrella term that includes the diverse variations of neurocognitive functioning, such as autism and intellectual disability, a vision shared by Dwyer (2022). This perspective embraces a more empowering notion in scientific discourse (Dwyer, 2022) including both neurodivergent people and neurotypical people (for more detailed information see Kapp, 2020 and Hughes, 2016). While using the term 'Neurodiverse People', we are distancing ourselves from the medical model of disability that frames disability as something that needs to be prevented, cured, and, overall, changed (Marks, 1997).

The Convention on the Rights of Persons with Disabilities was adopted in December 13th, 2006 and according to the last data available has been signed by 193 countries, of which: 186 are state parties, 8 are signatories and 4 took no action (for more details go here) (Office of the High Commissioner for Human Rights, 2006, 2023). In the article 3 of the Convention is possible to find its eight general principles of which we decided to highlight six, not intending to devalue the importance of the remaining two:

1) Respect for inherent dignity, one's self-determination and independence;
2) Non-discrimination;
3) Full and meaningful participation and inclusion in society;
4) Value diversity and embrace individuals with disabilities as integral parts of humanity;
5) Equality of opportunity;
6) Accessibility.

Why participating in research matters?

Having the opportunity to participate in studies can help them: have a meaningful participation in society, have equal opportunities, advocate for their rights, show their point of view and to be valued as important and active members of society that have different characteristics that need to be met. Accordingly, when research needs to have Neurodiverse people participating and/or supporting it is essential that while recruiting

to: not discriminate based on their need for support, respect their self-determination, needs and opinions, and have accessibility as front and center of the research.

One type of research where Neurodiverse People participate on equal grounds in research is participatory research. This method of research is commonly used when doing inclusive research with People with Neurodiversity, since its ideology is of a collaborative process of partnership that values equality and transparency. In this approach the person takes the role of co-researcher that contributes continually in the various phases of research process, for that it is necessary to disclose, clarify and inform the co-researchers of the complete process, which in turn will ensure that their experiences and knowledge are taken into account giving them the opportunity to be heard, having has a ending result better research (Boxall & Ralph, 2009; Morgan et al., 2014).

Moreover, for Participatory Research with Neurodiverse People to be successful it might be needed to use assistive technologies to facilitate interpersonal communication between the research, the consultants, and the participants. Assistive technologies (ATs) are any objects, either in physical form or digital, that support the well-being of individuals by helping them to increase, maintain or improve their functioning in normal life activities (Assistive Technology Industry Association, 2015; Austin & Holloway, 2022). Usually, this technology is used by people who have difficulties "speaking, typing, writing, remembering, pointing, seeing, hearing, learning, walking, and many other things" (Assistive Technology Industry Association, 2015) which includes not only people with disabilities but also older adults that due their longevity have difficulties in their day-to-day life. Addicionally, because ATs facilitate day to life activities they end up being used by everyone.

In this sense ATs can be (Assistive Technology Industry Association, 2015):

- Low technology, for example, communication boards;
- High technology, for instance, computers designed for specific purposes;
- Hardware, for instance, prosthetics;
- Computer hardware such as, specialized keyboards, mice and controllers;
- Computer software, such as, voice-to-write programs or screen reading software;

- Learning materials and curriculum aids, for instance, books written in braille;
- Specialized curriculum software, for example, enCORE (TeachTown, n.d.);
- Other types of objects, for example, eye-gaze and head trackers.

Regarding the participation of Neurodiverse People in research, some of the assistive technologies that might be used in order to facilitate their participation, understanding and communication are (Assistive Technology for Education, n.d.): communication and visual boards/augmentative and alternative communication; memory aids; mind mapping, brainstorming, and graphic organizers; among others.

Inquiring the potential role of assistive technology

Neurodiverse People are seen as vulnerable, as they belong to the group of people that are more subjected to harm, abuse, and exploitation (McDonald et al., 2017; Morgan et al., 2014; Scully, 2013). Due to the several protections implemented that were put in place to prevent them from exploitation, abuse and harm they encounter several barriers that prevent them participating in research (Hall, 2013; McClimens & Allmark, 2011; St. John et al., 2022).

Accordingly, when we are intending to or are carrying out research with People with Neurodiversity it is necessary to have several considerations, mainly when it comes to their willingness and interest in participating in research. One tool for verifying that is through informed consent or, if a guardian is needed to sign the informed consent, through assent. Both of these tools are extremely important for the study to have ethical approval and is allowed to commence, notwithstanding, it is in this crucial stage that most of the barriers occur (St. John et al., 2022; Strickler & Havercamp, 2023).

Concerning the obtaining of the informed consent the problem lays, mainly, in the lengthy process and words used in it can lead to difficulties in understanding what is written, which in itself can lead to frustration and need for help of others, something that can hinder their autonomy and self-determination (Strickler & Havercamp, 2023). Additionally, the worry about potential harm, abuse, exploitation and coercion are also present (Goldsmith & Skirton, 2015).

Finally, regarding the process to obtain assent from the participants, this

is where the assistive technologies can become a great ally to both the potential member of the team with Neurodiversity and the rest of the team. Assent is when the person who will participate in the study did not sign the informed consent and when asked if they want to participate answers affirmatively to the question, if they respond negatively then is dissent (Meierer et al., 2022). Neurodiverse People and Neutotypical People may have difficulty communicating between them if they do not know each other beforehand, and during the assent and dissent process it is fundamental that both parties understand what is being communicated. As such, using assistive technology that facilitates interpersonal communication both ways can be instrumental to their participation.

Summarizing, one way of promoting the autonomy of People with Neurodiversity could be through the use of assistive technology during (but not limited to) the informed consent/assent/dissent process.

With this being said, in order to understand if People with Neurodiversity feel the need to use assistive technologies, while being part of a participatory research, we will be conducting two different studies that intertwine with each other. The first is related to the development of a PhD thesis, developed on the scope of the GameIN project (2022.07939.PTDC), where we will work alongside Neurodiverse People. In the PhD thesis, we propose to develop guidelines to help create accessible game rulebooks for Persons with Neurodiversity, as a strategy to foster their autonomous engagement in playing analog games. The GameIN project, on the other hand, has as its aim to create a game toolkit to be enjoyed by everyone, including Persons with Neurodiversity.

In both cases, Participatory Research will be implemented as the involvement of Neurodiverse Persons is fundamental for its success and implementation. Therefore, it is important to understand what's the best strategy to eliminate the barriers associated with consent and/or the (in) capacity to consent, either by the use of assistive technology or another method.

The research will be divided into three main parts to have a better understanding of the barriers that Neurodiverse People face while being part of Participatory Research regarding informed consent and/or the (in) capacity to consent, of which (Figure 1):

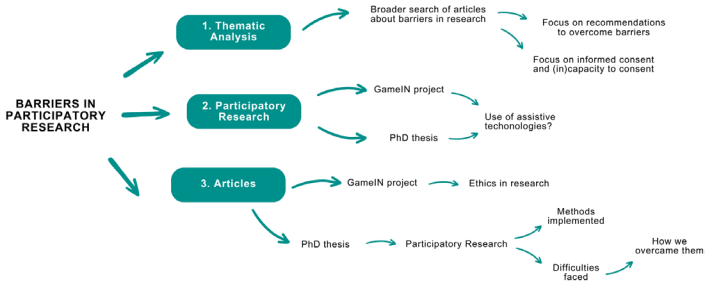

Figure 1 - Mind-map of the research methodology

For the first part of our research, we are doing a thematic analysis based on the parameters established by Braun and Clarke (2006). For this analysis, we searched for articles that mention the several barriers that People with Neurodiversity face while participating in research and came upon five main dimensions:

1) Research accessibility
2) Power imbalances
3) Vulnerability
4) Self-Determination
5) (Un)ability to consent
6) Informed Consent
7) Methodological approaches

After the first phase, and based on the information collected, we will be doing several Participatory Researches in the GameIN project and in the thesis, where assistive technologies can be used to facilitate the communication among and between the team, the participants and the consultants.

The last phase will consist on the elaboration of two articles: one about ethics in research that has the participation of Persons with Neurodiversity, which will be done under the scope of the GameIN project, and the other, which will be related to the PhD thesis, will consist on describing the methods that were implemented in the Participatory Research to minimize, as much as possible, the barriers faced by the group, as well as the difficulties that we faced and what we did to overcome them in the research.

At the time of the writing of this chapter we are on the first part of this proposal, very close to finalizing the report.

There is still a lot more work to be done

Although there is some research developed about the process of obtaining informed consent with People with Disabilities and the several barriers faced during that period (McDonald et al. (2009, 2017), McDonald and Kidney (2012), Mietola et al. (2017), Munford et al. (2008), St. John et al. (2022), Strickler and Havercamp (2023), Van Goidsenhoven and De Schauwer (2022), to name a few), there are not enough when it comes to studying the possibilities that assistive technology can have on promoting a safe, autonomous and self-determination research.

The same is valid when it comes to the barriers faced before, during and after the whole research timeline, including but not limited to the ethics committee approval, the recruitment of Neurodiverse People, working with this group in research and the dissemination of results. It is also important to acknowledge that there is a lack of awareness in ethics committees about the capabilities of this group and what can be done to overcome obstacles to the participation of People with Neurodiversity, which can be the fruition of the lack of research and training, as maintain by Boxall and Ralph (2009, 2011), Dee-Price (2020), Martino and Schormans (2018), and Northway et al. (2015).

Also, there are some similarities between the approaches that are done when recruiting and developing research with People with Disabilities and children. So I end this chapter with the following question: Do these similarities happen by chance and are nonetheless valid and correct or do they occur because people without disabilities view People with Disabilities as 'eternal' children?

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