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Advanced technologies for people with intellectual and multiple profound disabilities: state of the art, challenges and future prospects
Tecnologie avanzate per persone con disabilità intellettiva e multipla profonda: stato dell'arte, sfide e prospettive future

Call

This article analyzes the role of advanced assistive technologies in improving the Quality of Life of people with profound intellectual and multiple disabilities (PIMD). A systematic review of the most recent scientific literature explores current applications of these technologies, such as interactive devices, Alternative and Augmentative Communication tools, and sensor-based systems. In addition, emerging frontiers are deepened, focusing on integrating innovative technologies such as Machine Learning and Virtual Reality, which open new horizons in personalized interaction and daily support. The article also addresses the ethical and pedagogical challenges of implementing such technologies, highlighting the importance of a person-centred approach and appropriate training for practitioners. The goal is to provide an overview of the opportunities and critical issues that advanced assistive technologies present in the context of people with intellectual and multiple profound disabilities while offering insights for further research and the development of sustainable operational practices.

Keywords: PIMD; Assistive Technologies; Machine Learning; Virtual Reality; person-centred approach.

Questo articolo analizza il ruolo delle tecnologie assistive avanzate nel migliorare la qualità della vita delle persone con disabilità intellettiva profonda e multipla (PIMD). Una revisione sistematica della letteratura scientifica più recente esplora le attuali applicazioni di queste tecnologie, come i dispositivi interattivi, gli strumenti di comunicazione alternativa e aumentativa e i sistemi basati su sensori. Inoltre, vengono approfondite le frontiere emergenti, concentrandosi sull'integrazione di tecnologie innovative come il Machine Learning e la Realtà Virtuale, che aprono nuovi orizzonti nell'interazione personalizzata e nel supporto quotidiano. L'articolo affronta anche le sfide etiche e pedagogiche dell'implementazione di tali tecnologie, sottolineando l'importanza di un approccio centrato sulla persona e di una formazione adeguata per gli operatori. L'obiettivo è fornire una panoramica delle opportunità e delle criticità che le tecnologie assistive avanzate presentano nel contesto delle persone con disabilità intellettiva e multipla profonda, offrendo al contempo spunti per ulteriori ricerche e per lo sviluppo di pratiche operative sostenibili.

Parole chiave: PIMD; Tecnologie assistive; Machine Learning; Realtà Virtuale, approccio centrato sulla persona.

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1. Introduction

People with profound intellectual and multiple disabilities (PIMD) face complex and multidimensional challenges in communicating, interacting in the environment, and performing daily activities, requiring specialized support (Blain-Moraes & Chau, 2012; Lancioni et al., 2021; Munde & Vlaskamp, 2019; van der Putten et al., 2017) and making the exploration of innovative approaches to improve the Quality of Life of these people crucial (Nakken & Vlaskamp, 2007).

In this complex scenario, the advent of cutting-edge assistive technologies is emerging as a potential catalyst for significantly improving the Quality of Life of people with PIMD, offering unprecedented opportunities to enhance their resources and promote social participation (Nota et al., 2007; Maes et al., 2021; Munde & Vlaskamp, 2015). Integrating these technologies into daily support represents a paradigm shift in the approach to care and assistance, shifting the focus from limitations to the unexpressed potential of these individuals (Lancioni et al., 2013).

The relevance of using assistive technologies is particularly significant for people with PIMD because they communicate predominantly at a pre-symbolic level through facial expressions, vocalizations, movements, and body postures (Nijs & Maes, 2014). This way of communication, which is often complex and idiosyncratic, poses significant challenges in interpretation and appropriate response by operators and caregivers (Hostyn & Maes, 2009). In this direction, assistive technologies can act as an interpretive bridge, facilitating understanding of these idiosyncratic and contextual cues and enabling more significant interaction with the surrounding environment (Van Delden et al., 2020; Maes et al., 2021).

This role of technological mediation amplifies the communicative abilities of people with PIMD and can radically transform their everyday experience, opening up new possibilities for expression, choice, and environmental control (Stasolla et al., 2015). Moreover, as we will explore in this paper, integrating emerging technologies such as Artificial Intelligence (AI), the Internet of Things (IoT), and Augmented Reality (AR) systems opens new horizons in supporting people with PIMD. These cutting-edge tools promise to revolutionize skill development, facilitate the expression of preferences and needs, and promote active participation in daily activities and social relationships.

Applying Machine Learning techniques, for example, allows the creation of adaptive systems that learn and refine over time, increasingly personalizing the support offered according to a person's specific needs (Lancioni et al., 2020). Similarly, IoT can create intelligent environments that proactively respond to a person's needs, increasing their sense of control and autonomy (Domingo, 2012).

However, it is crucial to emphasize at the outset that the effectiveness of these technologies depends mainly on the presence of a highly skilled support staff capable of mediating their accessibility and optimal use (Iacono & Bigby, 2016; Nijs et al., 2019). This aspect highlights the importance of a holistic approach that integrates technological innovation within the person's Individualized Plan and accompanying continuing education for caregivers to maximize benefits for people with PIMD (McNaughton & Light, 2013).

This paper aims to provide an overview of the state-of-the-art assistive technologies for people with PIMD, highlighting their transformative potential and the challenges and ethical considerations accompanying their development and implementation. In detail, we will explore the role of assistive technologies in supporting people with PIMD, analyze the available scientific evidence, present current challenges and prospects, and highlight the latest frontiers of research in this field, including applications derived from Machine Learning. This analysis will extend to the technical and functional aspects of the technologies and their impact on the quality of social interactions, decision-making autonomy, and overall Quality of Life of people with PIMD (Simplican et al., 2015). Finally, we will discuss the pedagogical implications of using these technologies, considering crucial issues such as equity of access, personalization, and impact on self-determination, autonomy, and privacy.

These aspects are key to ensuring that the implementation of assistive technologies respects the dignity and rights of people with PIMD and avoids potential risks of stigmatization or excessive technological dependence (Deveau & Leitch, 2018).

2. Research on assistive technologies for people with PIMD

The scientific literature has highlighted the significant potential of assistive technologies in improving the Quality of Life of people with disabilities, including people with complex disabilities (Engelhardt, Kosiedowski & Duszyńska, 2020; Kosiedowki et al., 2020; Lancioni et al., 2024). By leveraging various assistive devices, communication aids, and adaptive technologies, people with PIMD can gain greater autonomy, improve their social interactions, and access previously unattainable educational and recreational opportunities.

One of the most promising research areas concerns using assistive technologies to increase people's communication skills with PIMD. Because these people often communicate through unconventional and highly individualized means (Nijs & Maes, 2014), assistive technologies can be crucial in interpreting and translating these communicative signals. For example, several studies (Cavadini, Courbois & Gentaz, 2022; Okamoto et al., 2022; Kochanowicz & Pawłowski, 2024) have explored the use of eye-tracking systems and eye-controlled devices to enable people with complex disabilities to communicate and interact with their surroundings. Along these lines, Borgestig and colleagues (2016) conducted a longitudinal study of children with PIMD, demonstrating that consistent eye-tracking technologies can significantly improve communication skills and autonomy. Study participants showed an increase in the frequency and variety of communicative interactions, as well as an increased ability to express preferences and needs. Similarly, Karlsson and collaborators (2019) showed how the introduction of eye-controlled devices can facilitate the participation of people with complex disabilities in educational and recreational activities. The study found a significant increase in participant engagement and motivation during structured activities, suggesting that these technologies can open up new opportunities for learning and development.

Other research (Rensfeld Flink et al., 2024; Hanley et al., 2024) has focused on using Augmentative and Alternative Communication (AAC) devices specifically designed for people with PIMD. These devices can range from simple buttons with pre-recorded messages to more complex tablet- or computer-based systems that offer a wider range of communication options. Along these lines, Stasolla and collaborators (2015) conducted a study on the effectiveness of a microswitch-based AAC system. Results showed a significant increase in adaptive responses and a decrease in stereotypical behaviours in participants, suggesting that the appropriate use of AAC technologies can improve communication and the overall well-being of people with PIMD. Desideri and collaborators (2020) examined the impact of a tablet-based AAC system for children with complex disabilities in school settings. The study found increased positive social interactions and participation in educational activities, highlighting the potential of AAC technologies in promoting school inclusion.

Another strand of research, which can be traced in the literature (Engelhardt, Kosiedowski & Duszyńska, 2020; Keeley & Bernasconi, 2023), relates to the impact of assistive technologies on the social participation of people with PIMD. Studies have shown how appropriate technologies can facilitate peer interaction and group activity participation (Lancioni et al., 2017). These findings suggest that assistive technologies can be crucial in overcoming barriers to social participation for people with PIMD. In addition, Nijs et al. (2016) examined the role of caregivers in implementing assistive technologies to promote social participation. The study highlighted the importance of training and ongoing support for caregivers, emphasizing that their ability to use assistive technologies effectively is critical to the success of the intervention.

Research (Skarsaune, 2023; Kuld et al., 2023) has also highlighted the role of assistive technologies in supporting the autonomy and self-determination of people with PIMD. Through adapted and personalized devices, these people may have more opportunities to make choices and exercise control over their environment, which are fundamental to their well-being and Quality of Life (Nota et al., 2007; Giaconi, 2015). Within this framework is the study conducted by Stasolla and collaborators (2018) to examine the impact of a choice system based on assistive technology. The results showed a significant increase in the frequency of autonomous choice for people with complex disabilities participating in the study, suggesting that using assistive technology can promote self-determination and help improve Quality of Life. Similarly,

Lancioni and colleagues (2019) investigated the effectiveness of technological systems in supporting autonomy in daily activities for people with PIMD. The study showed that audiovisual prompts and sensory feedback can significantly increase independence in performing basic tasks, contributing to greater self-efficacy and well-being.

Another emerging area of research concerns using assistive technologies to support learning and cognitive development in people with PIMD (Engelhardt, Kosiedowski & Duszyńska, 2020; Munde & Zentel, 2020). Despite significant challenges, recent studies (Munde & Zentel, 2020) suggest that targeted interventions using assistive technologies can promote the development of cognitive and adaptive skills. Among these, we mention research (Ten Brug et al., 2015; Ten Brug et al., 2018; Desideri et al., 2020; Engelhardt, Kosiedowski & Duszyńska, 2020; Munde & Zentel, 2020) that highlights the role of multimedia and multisensory stories, which complemented by assistive technologies become helpful for learning and participation in educational settings. Such research shows a significant increase in attention spans and responses, which are found to be appropriate to the context of the narrative, by people with PIMD (Ten Brug et al., 2015; Ten Brug et al., 2018; Desideri et al., 2020). In detail, integrating assistive technology devices seems likely to improve the accessibility and interactivity of such narrative experiences significantly. These technologies not only facilitate attention and comprehension, as noted by Ten Brug et al. (2015), but also offer new opportunities to personalize the learning experience, monitor progress, and promote autonomy in the enjoyment of multimedia content.

In the same vein, Lancioni et al. (2020) conducted a groundbreaking study on the impact of technological interventions focused on leisure and communication activities for people with PIMD. The results revealed significant improvements in participants' problem-solving skills and working memory. These advances were concretely manifested in people's ability to navigate more complex interfaces, select tasks independently, and use more elaborate sequences of actions. Implementing advanced technologies, such as tablets with specialized software, motion sensors, and audio-visual output devices, has created highly personalized learning environments. A particularly relevant aspect is the generalization of learning beyond the specific context of the intervention, with some participants demonstrating the ability to transfer learned skills to new situations.

3. Exploring open questions

Even in light of the aforementioned significant findings, researchers (Boot et al., 2018; Kosiedowski et al., 2020) agree that one of the main challenges concerns the accessibility and personalization of assistive technologies.

Recent studies, such as those conducted by Nijs and colleagues (2019) and Iacono and collaborators (2016), emphasize that the effectiveness of these technologies depends not only on their sophistication but, to a large extent, on the ability of operators to implement them and, adapt them to the individual needs of people with disabilities. Importantly, research agrees that the effectiveness of assistive technologies depends mainly on the quality of the support provided and the operators' skills. In this direction, the literature (Vlaskamp, Hiemstra & Wiersma, 2007; Maes et al., 2007; Nijs, Vlaskamp & Maes, 2018; Giaconi et al., 2022; Ware et al., 2024) emphasizes the importance of adequate training for support staff so that they can effectively use these technologies and mediate their accessibility for people with PIMD. This training should cover the technical aspects of using technologies and strategies for personalizing interventions and interpreting the unconventional responses of people with complex disabilities. For example, McNaughton and Light (2013) pointed out that training for practitioners should include skills in assessing individual communication needs and dynamically adapting technologies according to their responses. In addition, studies (Skarsaune, 2023; Traina et al., 2024) have shown that well-trained practitioners can act as "technology mediators," facilitating access to and effective use of assistive technologies for people with PIMD. This mediating role is crucial given the complexity of the disabilities and the need for ongoing, individualized support. The literature on the topic (Maes et al., 2007; Giaconi et al., 2022;

Ware et al., 2024) also suggests that practitioner training should be an ongoing process, given the rapid evolution of assistive technologies. Regular refresher programs and ongoing technical support are essential to ensure that staff remain proficient in using the latest technologies and implementation best practices.

In summary, while assistive technologies offer significant potential to improve the Quality of Life of people with PIMD, their effectiveness is intrinsically linked to the quality of support provided. Investing in the training and professional development of practitioners is therefore critical to maximizing the benefits of these technologies and ensuring that they are genuinely accessible and helpful to people with complex disabilities.

These reflections are even more central concerning the potential that opens up in the integration of assistive technologies with Machine Learning systems, as we will explore in the following section.

4. The most recent innovative advancements

Technological developments have led to a rethinking of the application areas of assistive technologies in multiple directions. Among these, we will consider the leading frontiers of development attributable to both the areas of Machine Learning (ML) and those proper to Virtual Reality (VR) concerning the new opportunities they may offer for people with PIMD.

Regarding Machine Learning, preliminary studies (Cigale et al., 2018; Tredup, 2019; Engelhardt, Kosiedowski & Duszyńska, 2020) suggest that machine learning algorithms can significantly improve the accuracy and personalization of assistive communication systems, adapting to the unique needs of each person with complex disabilities. In the same vein, some recent studies (Dovgan et al., 2021; Campomanes-Álvarez & Campomanes-Álvarez, 2021; Gaya-Morey et al., 2024) have developed AI-based facial expression and body movement recognition systems that can help interpret the nonverbal communicative signals of people with PIMD. In addition, advanced voice assistants, which can understand and respond to simplified voice commands or unconventional sounds, may expand interaction possibilities for people with Complex Communicative Needs soon.

Adding to these frontiers is the need for prediction and anticipation systems developed using Machine Learning technologies. These systems can analyze behavioural and physiological patterns to proactively predict and respond to the needs of people with PIMD (Herbuela et al., 2021; Mochida et al., 2024).

Potential hardware applications that can integrate Machine Learning technologies are wearable devices emerging as promising tools for health monitoring and autonomy support for people with PIMD. Recent research (Engelhardt, Kosiedowski & Duszyńska, 2020; Jęśko, 2021; Herbuela et al., 2022; Zentel et al., 2024), has demonstrated the potential of these devices in detecting and preventing seizures (Herbuela et al., 2022), significantly improving the safety and Quality of Life of such people. Using sensors that monitor physiological parameters and Machine Learning algorithms, these systems can predict seizures with more than 80% accuracy. In addition to epilepsy monitoring, wearable technologies show potential in other crucial areas, such as sleep monitoring, physical activity, and communication. These developments are particularly interesting for health management, providing real-time data for more informed care decisions.

Research is exploring the latest technological frontiers of Virtual Reality and its role in creating personalized learning environments and sensory stimulation for people with PIMD. VR can offer unique benefits such as customised environments, safe learning, and rich multisensory stimulation.

Pilot studies, such as the one conducted by Lancioni and colleagues (2021), explored virtual environments, using adapted VR viewers and customized software to promote learning and social participation in people with complex disabilities. Results showed increased attention, spatial orientation and object categorization improvement, and potential for simulating social interactions in controlled environments. In addition, some participants showed a transfer of skills acquired in VR to real-world situations, suggesting possibilities for generalization.

Despite the promising results, further research on a larger scale and over the long term is needed to fully evaluate the effectiveness of these immersive technologies in supporting people with PIMD, opening new perspectives for improving their Quality of Life, stimulating their personal development, and fostering opportunities for social inclusion.

Future application prospects coming from Machine Learning and Virtual Reality are, therefore, promising and range from the use of machine learning algorithms (to continuously adapt the interface and functionality of devices based on the person's preferences and abilities, allowing for improved adaptability and personalization of devices) to greater integration between different forms of assistive technologies (such as combining eye-tracking systems with Augmentative and Alternative Communication devices) to create more comprehensive and practical solutions.

In addition, advances in human-machine interfaces could open up new possibilities for communication and interaction for people with PIMD, allowing direct control of devices through brain activity. Solutions that shortly could dialogue with "smart" living environments that is, with interconnected sensors and devices that can automatically adapt to the needs of people with PIMD, improving their autonomy and safety (Engelhardt, Kosiedowski & Duszyńska, 2020).

However, implementing these technologies raises fundamental ethical and practical issues. Privacy in the collection and use of personal data and appropriate training for caregivers require further research to fully explore the potential of such technological frontiers in the context of people with PIMD.

5. Exploring pedagogical challenges in the integration of advanced technology for people with PIMD

Technologies such as Machine Learning and Virtual Reality open new frontiers in caring for and supporting people with PIMD. However, implementing such technologies raises several pedagogical issues that require careful consideration and thorough debate.

One of the main concerns concerns the privacy and protection of data collected and used through the new technologies. As emerged in the preceding paragraphs from a pedagogical perspective, using this data offers significant benefits for personalizing learning and care opportunities. However, balancing these benefits with the need to protect the person's privacy is critical. Educators and caregivers must maintain an active role in the personalization process and be trained on how to handle this sensitive data responsibly and how to effectively communicate with people with PIMD and their families about the use of their data. As highlighted earlier, there is a need to develop comprehensive training programs that not only cover the technical aspects of using the latest frontiers of technology but also address the associated ethical and pedagogical issues. Indeed, educators must be able to critically assess the appropriateness of these technologies for each person, recognize their potential risks and opportunities, and respect their dignity and autonomous learning.

This aspect is central to the autonomy and self-determination of people with PIMD since, on the one hand, these technologies can significantly enhance people's communication and interaction skills, increasing their independence. On the other hand, they can create overdependence on technology or unintentionally foster limitations in opportunities for personal choice.

Studies (Herbuela et al., 2022) examined the impact of ML-based decision support systems for people with PIMD. Their findings suggest that, if designed properly, these systems can effectively promote self-determination by providing personalized support in everyday decisions. However, the authors warn of the risk of "algorithmic paternalism", in which algorithmic decisions could overwhelm individual preferences. It is therefore essential that the use of ML and VR be integrated into an educational approach expressly geared toward empowering self-determination, framing the technology within broader pathways. Wehmeyer and Shogren (2016) emphasize the importance of explicitly teaching self-determination skills to people with intellectual disabilities.

Alongside these reflections, it is also crucial to consider the impact of new technologies on the social and emotional development of people with PIMD.

Ensuring that these technologies do not reduce opportunities for real social interaction is essential. In this sense, professionals should ensure that educational interventions use technologies as tools to facilitate and enhance social interactions, not to replace them.

In conclusion, the use of new technologies in the caregiving of people with PIMD offers unique opportunities to develop more inclusive pedagogical approaches, where these technologies must be integrated into a sound, person-centred pedagogical framework.

6. Conclusions, implications and future prospects

Advanced assistive technologies are emerging as essential tools for improving the Quality of Life of people with PIMD, providing them unprecedented opportunities to develop autonomy, express preferences, interact with their surroundings, and actively participate in social life (Lancioni et al., 2017). The review highlights that emerging applications, such as those based on Machine Learning and Virtual Reality, can open up new perspectives in daily support and skill development due to their ability to tailor interventions and respond dynamically to individual needs (Shih et al., 2019).

The effectiveness of these tools is highly dependent on adopting a person-centred approach and the ability of practitioners to use the technologies appropriately and purposefully (Nijs & Maes, 2014). Therefore, investment in staff training is an imperative priority to ensure the proper implementation of technologies and address fundamental ethical issues, such as privacy protection, respect for self-determination, and equity of access to these innovations (Brosnan et al., 2019).

In this context, developing continuing education programs that integrate technical, pedagogical, and ethical skills is crucial, enabling practitioners to adapt quickly to technological evolution and use tools critically and responsibly (McNaughton & Light, 2013).

In parallel, it is essential to adopt a pedagogical vision that integrates assistive technologies within targeted educational interventions, avoiding the risk of technological isolation and instead promoting use that fosters social interactions and inclusion (Stasolla et al., 2015). This approach requires careful planning of interventions, considering the technological potential and the relational dynamics and life contexts of people with PIMD. Integration between different technological systems, such as eye-tracking devices, Augmentative and Alternative Communication, and advanced interfaces, represents one of the most promising frontiers to ensure comprehensive interventions adaptable to the specific needs of people with PIMD (Lancioni et al., 2019).

The future of assistive technologies requires interdisciplinary collaboration between researchers, designers, practitioners, caregivers, and families to overcome remaining structural and cultural barriers (Brosnan et al., 2019).

This collaboration should aim to develop new technologies and create supportive ecosystems that facilitate the adoption and effective use of these tools in daily life. Technological solutions that dialogue with innovative environments, wearable devices, and machine learning systems could transform everyday support and redefine the concept of participation and inclusion for people with PIMD (Lancioni et al., 2020).

A crucial aspect to consider is the affordability of these advanced technologies. Policies and strategies need to be developed to ensure equitable access to innovations, preventing socioeconomic disparities from resulting in further forms of exclusion (Boot et al., 2018). This could include public funding initiatives, collaborations with the private sector, and the development of open-source solutions that can be cost-effectively adapted and implemented.

In addition, future research should focus not only on the development of new technologies but also on longitudinal evaluation of their impact on the Quality of Life of people with PIMD. Long-term studies could provide valuable information on the sustained effectiveness of these interventions and any changes

needed over time (Maes et al., 2021). In parallel, it is essential to explore how assistive technologies can be optimally integrated with other forms of support and therapy, creating holistic approaches that address the multiple dimensions of well-being for people with PIMD.

Standardization and interoperability of technology systems are critical areas for the future. The development of common protocols and standards could facilitate the integration of different technologies and improve the portability of solutions across different living and care settings (Scherer, 2019). This approach could also facilitate greater personalization of interventions, allowing different technologies to be combined and adapted according to the specific needs of each individual.

Despite the remaining challenges, it is clear that the potential of these technologies can only be fully realized through a comprehensive and sustainable approach that places the person at the centre and promotes his or her dignity, autonomy, and social participation (Simplican et al., 2015). This vision represents a goal that is not only technological but also ethical and social, to be pursued with collective commitment and continuous updating of knowledge.

Achieving this goal will require ongoing dialogue among all stakeholders, including policymakers, to ensure that principles of inclusion, equity, and respect for human diversity guide the development and implementation of assistive technologies.

In conclusion, while advanced assistive technologies offer unprecedented opportunities to improve the Quality of Life for people with PIMD, their effectiveness will depend on the ability to meaningfully integrate them into daily care, education, and support practices. Only through a holistic, ethical, and person-centred approach will we be able to harness the full potential of these innovations to promote a more inclusive and accessible society for all.

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