

Higher Education and Inclusion through the Lens of Students with Intellectual and Developmental Disabilities: A Case Study at the University of Aveiro Portugal

Mariana A. Dantas¹, Paula Coelho dos Santos², Oksana Tymoshchuk³

¹ *PHD Student and Member of CIDTFF*

² *Associate Professor and Member of CIDTFF*

³ *Researcher and Member of DigiMedia*

Abstract:- The present article aims to report the experience of the Individual Multidisciplinary Studies Program (PIEM) at the University of Aveiro, highlighting the challenges, potential and achievements related to using an adapted Photovoice and the contribution of photography as a resource to understand how students with Intellectual and Developmental Disabilities (IDD) experience inclusion in Higher Education (HE). The PIEM Program, launched in 2021, is a pioneering course in Portugal and is based on full inclusion, encompassing interactions with peers without intellectual disabilities. The paramount idea was making students the protagonists of their entire journey through a Person-Centered Planning approach and the choice of the curriculum units they would be willing to attend. The study was anchored in the exploratory paradigm, following a qualitative methodology using the case study method. For data collection, the techniques of inquiry were employed through interviews with visual support, specifically the adapted use of Photovoice. A group of six students and one mentor participated in the study. The study's contribution lies in the importance of understanding students' perceptions and views on inclusion in HE considering that, even though they are the main actors in the process, they are often not heard. Consequently, they are frequently represented by mentors, families, or even professors. The main findings are related to different perspectives provided by students on objects and places around the campus that are often overlooked but seemed to be important and meaningful to most of them in the realm of the university. After the implementation of Photovoice, the students decided to organize a photo exhibition, which turned out to be an enlightening outcome. Interestingly, their impression on the photographs demonstrated a sense of belonging and participation in campus life and in the academic area. Photovoice, in addition to being a methodological intervention strategy for the researcher, also served as a formative tool for the students involved in this process. Furthermore, the participation of mentors was identified as one of the pillars of inclusion and well-being for students in the context of HE. Results show that the mentorship, reflected in the improvement of relationships among peers and contributed to the integration of students with disabilities into the social and academic environment with increased capacity for participation and self-determination. This impact was also reflected in the development of the student mentors themselves. The research provided a significant contribution regarding recommendations for the course and the university. Additionally, it contributed to the personal development of the students with IDD in digital literacy.

Keywords: *Inclusion in Higher Education, Intellectual and Developmental Disabilities (IDD), Photovoice.*

1. Introduction

The perception regarding students with intellectual and developmental difficulties (IDD) has undergone significant transformations in recent years. As highlighted by Santos and Morato (2012), substantial progress and

achievements regarding fundamental rights can be observed due to a paradigm shift in the assessment and characterization of IDD. In this new scenario, it becomes feasible to consolidate victories such as the right to compulsory education and access to higher education (HE). O'Brien et al. (2019) also emphasize a shift from a deficit-focused model, centered on the difficulties faced by individuals in general, to a perspective focused on full citizenship, with a primary emphasis on participating fully in society without any exclusion.

Access to higher education provides an additional opportunity to develop skills for adult life and independent living, as well as for exercising citizenship. According to Biesta (2020) being part of the academic community offers a range for personal and professional development possibilities. Reflecting on inclusive HE is crucial, but the key stakeholders should not be excluded from this process.

Therefore, the voices of students with IDD are fundamental at every stage of policy and structure development. Thus, building on the slogan of "A transnational/European framework for the development of an inclusive flexible and student-centered HE curriculum for young adults with IDD" (HiLives, 2022), "Nothing about us without us!" guides this research.

In this context, it is possible to observe the emergence of a potential for full inclusion in HE in Portugal through the Individual Multidisciplinary Studies Program (PIEM). This program provides students who wish to continue their studies with an additional opportunity and an additional space to participate in the academic community at a Portuguese university. With this opportunity comes the possibility of focusing on HE through the perspective of students with IDD.

Anchored in this scenario of changes and discussions of public policies that support the access and permanence of students with IDD in HE institutions, the objective of this study is to document the experience of the PIEM, emphasizing the challenges, potentials, and accomplishments related to the utilization of adapted Photovoice. Additionally, it explores the role of photography as a resource in comprehending the experiences of inclusion in HE for students with IDD.

2. Background

Intellectual and developmental disabilities (IDD) are classified by Shalock and Bradley (2010), and defined as difficulties associated with significant limitations in the intellectual sphere and in adaptive behavior, manifesting themselves from conceptual capacities (numerical, spatial, verbal, etc.), social (interpersonal relationships, problem solving, following rules, among others) and practices (everyday issues such as hygiene, health, leisure, etc.)

Since the 1970s, the inclusion of students with IDD has been implemented in countries such as the United States of America and Canada. However, it does not yet have a representative expression in Portugal, which until now has only one program at the Polytechnic Institute of Santarém - Higher School of Education. According to Machado, Santos and Espe-Sherwindt (2019), in an analysis of the world panorama and programs for students with IDD, only in the USA 270 programs are offered for this population, varying between different models. In the European context, one of the first courses implemented in Spain at the Universidad Autónoma de Madrid and the Prodis Foundation in 2004. Since then, the number of programs in European universities has been growing, with Ireland being the first European country with a fully inclusive program.

In Portugal, the PIEM is as a pioneering course in inclusion models. The program aims for the full inclusion of students with IDD, enabling their active participation in regular classrooms, where they learn meaningfully and receive support tailored to their needs as identified by the students themselves, the organization, professors, or the administration.

The two-year course, comprising four semesters and incorporating extracurricular internships to enhance students' employability, features a curriculum structure with ten optional Curricular Units (CUs) aligned with Person-Centered Planning (PCP) and each student's chosen academic and professional trajectory. Person-centered planning, as outlined by Pereira (2017), is recognized as a set of strategies aimed at assisting individuals in

planning their lives and determining the necessary support. This approach is commonly employed to empower individuals with disabilities, fostering an increase in their self-determination and autonomy.

Delivered by different university departments, the CUs are taught by faculty members who have expressed interest in the project. The course also promotes the Polybat (FPDD, s.d.), sports activity adapted for individuals with various conditions such as muscular dystrophy, cerebral palsy, spinal cord injuries, traumatic brain injury and intellectual disabilities, fostering integration and interaction among students.

Student support is based on the Student Support Circles model developed by Griffin et al. (2016), with student mentors supported by the course tutor. Specific mentor functions range from academic support to daily activities, aiming to enhance the well-being and integration of students.

The mentoring model is implemented each semester, involving identifying students' needs, the course dynamics to mentors, and recruiting mentors. Mentor functions include curricular support, daily activities on campus, and literacy support.

The course tutor plays a central role in coordinating the program, ensuring tutorial support, organizing meetings, and collaborating with various university sectors. PIEM's success is reflected in students' autonomy and growth throughout the course, emphasizing the importance of personalized and inclusive support.

The PIEM began in 2019, with the first cohort comprising six students. Mentors play a crucial role providing tailored support to the individual needs of students with intellectual difficulties. Feedback reveals that initially, mentors have apprehensions regarding how they could talk to the students, which words to use and how to address the issue of intellectual disability in a general manner, but end up realizing that the experience is enriching and that the experience contributes to a more positive perception of inclusion.

Throughout the course, students with IDD request support in areas such as digital literacy, academic learning, socialization, and exploring the campus. With the acquired autonomy while taking part of the program, they have also expressed interest in disseminating their experience through a memory album, aiming to inspire other young individuals to succeed as well as to contribute to the academic community as a whole.

Based on the students' needs and the request for the use of photovoice (Wang & Burris, 1997), it emerged as a powerful tool and tangible possibility to supply the need to listen to the students' voices.

Photovoice is a data collection technique focused on participant engagement and empowerment that employs photography as a means of expression (Wang & Burris, 1997). Through this method, participants are encouraged to capture images that depict their experiences, perspectives, and challenges related to a specific theme or social issue. These photographs are then discussed in group settings, allowing participants to share their stories and interpretations (Wang & Burris, 1997). Photovoice is frequently utilized in community-based research projects, empowering marginalized groups, and promoting social change (Wang & Burris, 1997).

This study focused on the students' at the University of Aveiro, and on the opportunity of sharing that perspective. Therefore, all outcomes are based on the voice of students with IDD. Rather than choosing a methodology and theoretical foundation to understand the vision of students, the primary focus of this research is to empower students through the method recognized as Photovoice (Wang & Burris, 1997), aiming at an active process of participation and social representation.

3. Motivation

The motivation for undertaking this investigation primarily stemmed from the need to hear the main protagonist's voice in the entire inclusion process. According to Kubiak (2017), the majority of studies are conducted based on the opinions of other participants in most processes of inclusion, such as mentors, parents, and teachers. Listening to the students' voices is a significant differentiator, and the support of Photovoice was crucial for the perspectives to be perceived and acknowledged as a valuable contribution. Additionally, according to the *Diário da República*, 2nd Series, Part E, No. 140, dated July 21, 2021, "pp. 97. PIEM has as its main purpose "...to provide meaningful (inclusive and supported) opportunities for HE for individuals with IDD through participation in the academic and social life of the university". Consequently, requests for interventions on this theme were initiated by the

students themselves, along with the desire to share their experiences in HE with other individuals and family members.

4. Objective

The present study aims to report the experience of the Individual Multidisciplinary Studies Program (PIEM), highlighting the challenges, potentials and achievements regarding the use of an adapted photovoice and the contribution of photography as a resource to understanding how students with IDD experience inclusion in HE.

5. Collective Statement of contribution

In this collaborative research endeavor, each team member played a distinctive role that collectively contributed to understanding how students with IDD experienced HE. Our combined efforts aimed to integrate diverse skills and expertise, ensuring the success and richness of the study.

The specific role of each team member enriched the project and underscored the importance of collaborative efforts in addressing complex research questions.

6. Methods

Based on the study's purpose and research objective, it is grounded in the exploratory paradigm and possesses a qualitative nature. The methodology is structurally designed to describe the contributions of using adapted Photovoice and photography to understand how students with IDDs experience inclusion in HE.

This study was conducted within the framework of the Individual Multidisciplinary Studies Program (first edition) at the University of Aveiro, specifically within the Digital Literacy tutoring. This tutoring process contributes to students' inclusion in the university context and academic matters. It was developed in a workshop format, addressing needs identified by the students for integration. The workshop was led by the responsible tutor/coordinator, with the support of one of the course mentors with expertise in marketing and photography. All students in the course were invited to participate, and they all expressed interest, as it addressed a topic they sought significant assistance with.

The development of activities (organization, implementation, and analysis) was structured into five important phases.

The first phase involved initial planning for activities related to photography. During this session, various functionalities of the digital camera were explored to enhance the quality of digital photos. Features such as lighting, motion capture, and focus were explained and tested by the students. Mobile phones were also utilized, considering that the pictures around the campus could be captured using both cell phones and cameras. In addition to these technical aspects, ethical considerations related to the right to image were addressed. Students were instructed to always seek permission before taking photographs of individuals and to ensure that in open environments, they were not capturing individuals and faces without consent.

The second phase was categorized as the composition phase. During this stage, students worked on the composition and focus of their photographs. Issues such as the intentionality of the photo, the message conveyed by the photo, and what they wanted to communicate through the image were discussed to guide their compositional decisions.

The third phase was the recognition phase. During this stage, students visited a place called "Place of Affections," which dealt with symbolism and emotions through thematic spaces with games or messages. This visit aimed to demonstrate how ideas could be developed and how figures and messages were conveyed. The visit to this location was also initiated by the students themselves.

The fourth phase involved organizing the material. After taking photos and learning various aspects of photography and how to use it to express their experience at the university, students decided how to handle the collected material. At this point, they chose to organize a photography exhibition to inform other university students about the course they were attending. Additionally, the exhibition aimed to show other students with intellectual difficulties that attending university is possible.

The fifth phase was the execution phase. During this stage, students prepared and presented the exhibition to the university. They selected the photos they wished to showcase based on a script. The guiding questions were: "What did I like most about my/the university? Why? What would I like to share with others from this experience? How will the course contribute to my life? What was the biggest challenge during my experience at the university?"

Data Collection Techniques

Following the methodological approach based on the study's objective and guided by the classifications outlined by Coutinho (2011), data collection techniques employed included surveys and observation. The data collection instruments utilized were semi-structured interviews with the aid of photography as a supporting tool, content analysis (Bardin, 1979), the investigator's diary, and reflections on the sessions as the basis for analyzing survey collections. For each outlined phase, five photographs were individually and collectively analyzed.

7. Results

The primary findings highlight diverse perspectives from students about often overlooked objects and spaces on campus, which they deemed significant within the university context.

Regarding the chosen photographs concerning the campus experience, it was possible to observe that students selected individuals whom they deemed relevant both within the academic community and among peers and fellow course mates. Art on campus also emerged as one of the elements depicted in photographs across various departments. Students who utilized public transportation also signaled, through photography, bus stops and train stations. In one photograph related to a bus stop, a student captured a personal perspective. To comprehend the symbolism of the photograph, multiple inquiries were necessary, as the student took the picture from where most students typically waited for transportation, providing insight into their perspective while awaiting the bus.

Other photographs showcased campus activities, such as participation in academic parades with peers without intellectual difficulties. In one of the photos, a student explained their future aspirations upon completing the course, emphasizing their sense of belonging to the university by participating in the parade. The students' captured images also revealed various activities, including picnics, coursework-related projects, and insights into campus accessibility. Students specifically highlighted departments they have attended for some classes. One student even took photos of the route from campus to their residence.

Following the implementation of Photovoice, the students in the program opted to curate a photo exhibition, yielding an enlightening outcome.

The exhibition took place at the culmination of the entire process of collecting photographs and was initiated by the students themselves. During a group discussion, the students named the exhibition "Inclusion through Images: Students' Perspectives on the Spaces They Inhabit." They also crafted the exhibition description, and the final text read, "We put our creativity into practice to show, through our lenses: What we think, what we feel, the places where we share our experiences with new friends and colleagues, as well as with teachers, mentors, and tutors. These photos reveal our well-being here at the University of Aveiro, like a second home. It's a place where we can get help for what we need. We are a family and support each other, as if it were a second home with warmth." The text and the title themselves reflect the students' profound feelings toward the course, the university, and the group and individual experiences lived on campus.

Notably, their response to the photographs conveyed a sense of belonging and active participation in campus life and the academic sphere. Besides serving as a methodological intervention strategy for the researcher, Photovoice also functioned as a formative tool for the students engaged in the process. Through learning to use Photovoice, students acquired knowledge in the field of photography, which, according to them, can contribute to the context of social media, for instance. This initiative demonstrates that the knowledge gained extended beyond an effort to learn about digital literacy at the university and became a part of the students' lives outside/beyond the university. The phrases in which students characterized the university as an extension of home or family indicate that they

feel a part of the academic community to which they belong. Statements regarding collaborative work with peers in academic units also illustrate integration concerning academic matters.

Some remarks, contextualized with the students' developmental stage, may characterize how the university contributes beyond academic matters. An example of this is a student's choice of photograph featuring a train station. At that stage of her life, independence in public transportation was significant and extended beyond university activities. Consequently, the student chose to capture a photograph of this process, expressing her fondness for the Aveiro station, especially as it was the place she went to for university.

Moreover, the involvement of mentors emerged as a crucial element fostering inclusion and well-being for students in the higher education setting. Results indicate that mentorship, evident in the enhanced peer relationships, played a pivotal role in integrating students with disabilities into the social and academic fabric, fostering greater participation and self-determination. This impact also manifested in the personal growth of the student mentors themselves. All students revealed that mentors played a crucial role in the context of inclusion, both academically and personally. The students' primary desire in the exhibition was to showcase their peers in photographs taken together during university moments.

However, it was not possible to publish or present photos of people, or characterizations of people in the exhibition, due to data protection rules. Despite the impossibility to present these photos, students took pictures with mentors for personal keepsakes. The mentor involved in the exhibition pointed out that, in addition to personal growth, she also observed professional development. As a photographer, she was capturing different perspectives and learning how to adapt the teaching of these photography techniques to individuals with IDD.

The research contributes significantly to course and university recommendations, while also playing a role in the personal development of students with IDD in the realm of digital literacy. The digital literacy workshop contributed to understanding the students' needs in the university context and the organization of the course. From this experience, the course coordinators recognized the need to address digital literacy to prevent exclusion on campus and foster relationships in the university setting. Additionally, based on this experience, a new perspective for students was created in the program's second edition—the course newsletter's development. In this new phase of digital literacy training, capturing photos and content will not be the sole focus.

Through the newsletter, the academic community will have more access to the students' desires, aspirations, learnings, and most importantly, knowledge regarding the reality of individuals with IDD.

8. Discussion

According to the research objectives, it is evident that the achieved results favored the understanding of what students identify in their own experience within the process of inclusion in higher education, and the contributions were relevant to the organization of the course and the new version of digital literacy in the second edition of PIEM.

The main findings relate to the sense of belonging and participation on campus, as well as the very important role of mentors in inclusion. These results confirm the conviction presented by O'Brien (2019) that full inclusion is ideal for students with intellectual difficulties and that a non-segregated environment fosters the growth of all involved.

The results also support what Biesta (2020) asserts regarding the additional gains that the experience in higher education provides, particularly concerning the personal aspects of students with intellectual difficulties. It is noteworthy that in the case of this investigation, mentors also benefit from this experience.

Based on what was identified and listed by the students, the proposal of the Multidisciplinary Individual Study Program manages to correspond to what was outlined in its regulations and promotes a sense of belonging and participation. Students attend higher education and feel part of a "family."

The study gives students a voice throughout the research and decision-making process, demonstrating innovation and differentiation from similar studies in the field. The study's contribution fills the gaps in the student's voice as a protagonist in the decision-making and suggestion process.

The limitations presented can be described by the small number of students interviewed in the university context.

For suggestions for future studies, there is the possibility of implementing and identifying how students feel about consistently producing content (monthly) and widely disseminating the content they create for the academic community, peers, teachers, and family. The impact of this contribution can be extremely relevant in the university context, as many people are still unfamiliar with or have not been part of programs such as PIEM.

9. Conclusion

The students' voices were of utmost relevance to the course. Understanding the perspective of the students provided by themselves enabled the emergence of a series of recommendations to be implemented in the second edition of the course. Photovoice, in addition to being a methodological intervention strategy for research, also contributes as a formative strategy for both students and mentors throughout the process. It is evident that mentoring, as reflected in the peer relationship, contributed to enabling students with IDD to integrate into the social and academic environment with increased capacity for participation and a sense of belonging.

This role in mentoring is also self-reflected in the mentor's own development as learners. The contributions of the students were crucial for the organization and recommendations of the course, as the personal perspectives provided the basis for the development of a new digital literacy initiative incorporating the suggestions and needs of students with IDD.

Moreover, both students and mentors experienced personal and professional learning in the realms of photography and engagement with diversity. This partnership facilitated the organization of community awareness moments within the course, involving actions planned by the film and photography nucleus, and the coordinator/tutor of PIEM for the academic community, to be executed in the second edition of the course.

Acknowledgement

This work is financially supported by National Funds through FCT – Fundação para a Ciência e a Tecnologia, I.P., under the project UIDB/00194/2020.

References

- [1] Bardin, L. (1979). *Análise de Conteúdo*. Edições 70.
- [2] Biesta, G. (2020). Risking Ourselves in Education: Qualification, Socialization, and Subjectification Revisited. *Educational Theory*, 70(1), 89–104. <https://doi.org/10.1111/EDTH.12411>
- [3] Coutinho, C.P. (2011). *Metodologia de investigação em Ciências Sociais e Humanas: teoria e prática*. Almedina.
- [4] Diário da República (Portugal), 2a Série, Parte E, no 140, de 21 de julho de 2021.
- [5] FPDD. (s.d.). Polybat. Recuperado de <https://fpdd.org/polybat/>
- [6] Griffin, M., Wendel, K., Day, T., & McMillan, E. (2016). Developing Peer Supports for College Students with Intellectual and Developmental Disabilities. *The Journal of Postsecondary Education and Disability*, 29(3), 263–269.
- [7] HiLives. (2022). *Foundations for the Development of an Inclusive HE Curriculum*. Recuperado de [http://hilives.web.ua.pt/docs/IO1/HiLives_IO1_Foundations_for_the_development_of_an_inclusive_HE_curriculum_2022_EN.pdf]
- [8] O'Brien, P., Gadow, F., Bonati, M., & Slee, R. (2019, July). People with intellectual disability experiencing University Life: Emerging themes from around the Globe. *Journal of Intellectual Disability Research*, 63(7). NJ USA: Willey.
- [9] Kubiak, J. (2017). Using 'voice' to understand what college students with intellectual disabilities say about the teaching and learning process. *Journal of Research in Special Educational Needs*, 17(1), 41-48. DOI: 10.1111/1471-3802.12098.
- [10] Machado, M. M., Santos, P. C., & Espe-Sherwindt, M. (2019). Inclusão de jovens adultos com dificuldades intelectuais e desenvolvimentais no ensino superior: contributos da literatura no contexto europeu. *Revista Portuguesa De Investigação Educacional*, 19, pp.141-166.

- [11] Pereira, M. (2017). *Pertencer & Participar para Aprender*. Oliveira de Frades: ASSOL.
- [12] Santos, S., & Morato, P. (2012). Acertando o passo! Falar de deficiência mental é um erro: deve falar-se de dificuldade intelectual e desenvolvimental (DID). Por quê? *Rev. Bras. Ed. Esp.*, 18 (1), 3-16.
- [13] Shalock, R.L., Borthwick-Duffy, S.A., Bradley, V.J., Buntinx, W.H.E., Coulter, D. L., Craig, E. M., Gomez, S. C., Lachapelle, Y., Luckasson, R., & Reeve, A. (2010). *Intellectual Disability- Definition, Classification, and Systems of Supports*. 11.Ed. Washington DC: AAIDD
- [14] Wang, C. & Burris, M. (1997). *Photovoice: Concept, methodology, and use for participatory needs assessment*. Health Education & Behavior.