

Cultural accessibility of people with Intellectual disabilities: A pilot study in Italy

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Abstract

Self-advocacy process can only be initiated starting from the access to useful information. The process of cultural and social accessibility requires promoting and strengthening the relationship between theories and practices. Macerata University decided to be one of the actors involved in this field, by putting the approaches described in the literature at the service of the people with intellectual disabilities. This study aimed to carry out a pilot study by a multidisciplinary research group of the University of Macerata to increase the level of cultural accessibility of people with intellectual disabilities in the city. The study consisted of 10 master's degrees students, and 10 adolescents, involving them with ID experts in special pedagogy and Easy-to-Read language. This paper sheds light on the Easy to Read Guidelines, published by Inclusion Europe because it explains precisely how cultural heritage can be made accessible and more understandable by everyone.

Keywords: Accessibility; Easy-to-Read; Intellectual disabilities; Social Inclusion.

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1. Introduction and conceptual framework

The UN Convention on the Rights of People with Disabilities (PWD) requires State Parties and institutions to meet the needs of people with disabilities by promoting inclusiveness (United Nations 2006, Art. 4g, Art. 4h). Precisely, Article 9 of this Convention specifies- in paragraph III art.39- that everyone has the right to enjoy access to cultural materials, activities, places, performances, and services. Through this article, the UN stresses the importance of ensuring the cultural and linguistic identity of PWD and of encouraging their participation with others on an equal basis.

Furthermore, in Article 9 the UN reminds us of the necessity to eliminate all barriers to access any physical or communication environment and to consider it as a precondition for persons with disabilities to live independently, as was claimed by the Convention (art.19). This means, in particular, that making cultural knowledge as well as relevant information accessible and available will help people make choices independently and enjoy greater participation within society. In addition, it will enable them to build self-confidence, expand their worldview and take control of their lives (Del Bianco, 2018).

Last but not least, the UN convention highlights another dimension of accessibility, which is related to the cultural environment. Article 30 emphasizes the rights of PWD to enjoy a fulfilled cultural life, not only for their ends but also for the benefit of society. Due to that fact, physical and cultural accessibility of PWD in formal and informal settings becomes crucial to social inclusion (Giaconi et al., 2021a).

While on the subject, the full and equal participation of persons with disabilities in society can be achieved if new technologies are designed and produced in a way to ensure better accessibility (e UN article 9-paragraph II, art. 19). To be able to do so, the concept of *Universal Design* (Persson et al., 2014; Mikus et al., 2020) developed a user-centered approach, through which people can participate in creating a social environment (including services, information, and culture) simply based on their needs and expectations, so they can use it efficiently.

Besides, and to be in line with UN convention, the Universal Design puts high attention on relating accessibility of PWD to sustainability; in a sense that ensuring the sustainability of accessibility can benefit not only the people in the subject but also the society as a whole (Persson et al., 2014; Bricki & Green, 2017). This means that thinking of sustainability is a must to ensure responsible responses that can ensure a better process of inclusiveness and evolve human diversity.

To verify the level of inclusiveness, the Quality of Life provides different types of indexes to measure the well-being of any targeted groups/population. It consists of assessing their physical ability, mental capacity, social ability as well as their level of satisfaction with the social role and with the participation in the society. It can be considered as a tool that can enhance strategies and reforms; It can encompass personal development and social involvement, as well as provide support and relevant opportunities (Schalock et al., 2016, pp. 4-5). For this purpose, social policies are a key element in this direction. If social policies could rely on the Quality of Life indexes and results, they can ensure sustainable accessibility and better inclusiveness. In this regard, social policies can be evaluated not only to increase the level of well-being but also the level of inclusiveness in society.

On the other hand, the level of inclusiveness that people with disabilities can experience is in all ways related to the achievement of a good level of involvement in/ and accessibility to social and cultural environments. The researchers agreed that the access to information and social life determines an increase in the level of self-determination (including the self-advocacy capacity) and the proactivity of PWD to participate in live events. These allow PWD to express needs, necessities, and desires and enjoy a quality of life and wellbeing (Giaconi et al., 2021b; Schalock, Verdugo Alonso, 2006; Giaconi, 2015; Umb-Carlsson, Lindstedt, 2011).

With particular reference to self-advocacy, the literature shows that strengthening this skill can be an area of interest in the development of educational practices for people with disabilities (Test

et al., 2005; Williams & Shoultz, 1982). Also, it is one of the essential prerequisites for experiencing opportunities and personal growth (Wehmeyer, 1992; Field 1996; Johnson, 1999; Algozzine et al., 2001; Agran et al., 2016). Besides, studies show that, once individuals know their needs and know how to express them, they may be able to interact with others who have similar needs and preferences, managing to assert desires and collective needs in political organizations (Test et al., 2005).

However, the self-advocacy process can only be initiated starting from the access to useful information. It is a way to rely on, to value the participation of diverse civil groups, including PWD, in making information accessible and in protecting their rights to physical and cultural accessibility. Thereby, this paper presents the methods used in the pilot study, conducted by the research group of the University of Macerata, to build the process of social inclusion through cultural accessibility. The process implemented by the university consists of fostering the relationship between theory and practices, making information available, increasing self-determination and self-advocacy, and bringing a practical dimension to cultural accessibility. The conceptual framework of this paper relies on two concepts: Universal Design (Persson et al., 2014; Mikus et al., 2020) and the Quality of Life (Schalock et al., 2002; Giaconi, 2015; Cummins, 2020) to present opportunities for Social Inclusion through cultural accessibility of persons with intellectual disabilities in Italy, in formal and informal settings.

1.1. Purpose of study

Since the process of cultural and social accessibility requires promoting and strengthening the relationship between theories and practices (ANVUR, 2015), Macerata University decided to be one of the actors involved in this field, by putting the approaches described in the literature at the service of the people with intellectual disabilities. For this purpose, the University of Macerata's Chair of Special Pedagogy and Didactics and the research group decided to put in place a pilot study to let people with intellectual disability experience self-advocacy and participate in improving cultural accessibility in the city of Macerata. The University believes that involving and working with people with Intellectual Disabilities (ID) can make a difference in the accessibility and understandability of the provided cultural information in the city. This implies carrying out social activities with the involvement of people with ID, to enable them with greater access to cultural heritage and settings (such as libraries, theatres, museums, art galleries, squares, historic buildings, etc.) as well as to increase their participation in the society. The University pursues the following objectives while implementing its pilot project:

- Enrich the Macerata cultural heritage with alternative channels to promote information that ensures total accessibility;
- Create tools that allow people with intellectual and/or relational disabilities to access cultural heritage while using written guides in Easy-to-Read language;
- Promote the accessibility to share the artistic and cultural heritage of the city of Macerata to an ever-wider audience;
- Contribute to building and promoting civic responsibility and participation.
- Strengthen, through a participatory approach, the capacities of social activists as well as social initiatives that are occurring in the city of Macerata to better achieve social inclusion.

2. Materials and Methods

2.1. Participants

To be able to transmit the knowledge from the literature to the field, the group of researchers has equipped themselves with the learning materials they need to use to support and build the capacities of the involved participants- while using the Easy-to-Read booklets "*Teaching Can Be Easy*" and "*Training the Trainers*". The participants consisted of 10 master's degrees students, and

10 adolescents with ID experts in special pedagogy and Easy-to-Read language from the core group of this study, called the co-design team. It is named so to emphasize the importance of designing together all the outputs and activities of the study. This team put an effort to provide, in collaborative methods, the city with culturally accessible texts, to increase the self-determination and self-advocacy of the students and adolescents, and enrich the inclusive practices back.

2.2. Data collection

The methodology used in this paper is the qualitative one in the pre-and post-assessments tools; the pre-assessment is designed to detect and understand the perceptions and expectations of the participants in the co-design team (students and adolescents with ID) regarding cultural accessibility and the quality of their lives. The collected data was analyzed to check the ability of self-advocacy of the team and to offer accordingly the needed support to increase their relevant capacities and skills. Therefore, semi-structured interviews and standardized questionnaires were used (Mortari, 2010; van Loon et al., 2012; Bertram & Christiansen, 2016) to closely explore the perceptions of the involved adolescents as well as the university students. Post assessment tools will be designed before the end of the pilot study to verify the level of satisfaction (from their participation in the study and in implementing the initiatives of self-advocacy) as well as the impact of improving accessibility on the quality of their lives.

2.3. Procedure

The pilot study is tailored attentively to reflect the cultural circumstances and objectives of people with ID. They have already formed bonds with the co-design team and ameliorated their socio-cultural conditions. Due to this, it would be of benefit to explain the procedural and practical phases of the pilot study; they are as follow:

Table 1

Phases in the pilot study

Phase 1. a:	forming the co-design team of participants; it is made up of experts in special pedagogy and Easy-to-Read language, psychologists, adolescents with intellectual disabilities, and university students. And identifying and co-designing phases of the project. The planned duration of 4 months, (from month 1 to month 4).
Phase 1. b:	assessing and analysing perceptions, expectations, and knowledge of the team, and assessing their levels of QoL/including self-determination. Timeline of 6 months, (from month 5 to month 10).
Phase 2:	planning of activities and providing direct support to increase the level of QoL and self-determination, by using the Easy to Read guidelines. Entering into agreements with the existing cultural facilities in Macerata to allow the implementation of the next phase. The planned duration of 2 months (from month 11 to month 12).
Phase 3:	implementing the activities and continuing to offer direct support. Timeline of 12 months, (from month 13 to month 24)
	Detailed activities are:
	<ul style="list-style-type: none"> a. Conducting observations and mapping of cultural facilities to assess the level of accessibility; b. Selecting the facilities as well as the provided written information to be adapted to the Easy to Read language; c. Elaborating Easy-to-Read texts with alternative communication tools; d. Test the text among the members of the co-design team to approve their accessibility and modify them accordingly; e. Providing the modified texts to the cultural facilities to adopt them; f. Monitoring the interaction and the approval of these texts by the visitors of the cultural facilities.
Phase 4. a:	evaluating the implemented activities. The planned duration of 2 months, (from month 25 to month 26).
Phase 4. b:	redesigning the initial plan and activities due to the Covid-19 outbreak and measures. Activities got postponed during this phase. Redesigning duration of 6 months, (from month 27 to month 32).
Phase 4. c:	implementing the activities as per the measures of Covid-19. Duration as re-planned of 6 months (from month

33 to month 38).

Phase 5: assessing and analysing the level of satisfaction of the team and measuring its impact, by assessing and analysing the level of satisfaction of participants' families and adolescents. Self-protection path. Timeframe of 5 months, (from month 39 to month 44).

The pilot study is built around four areas of introducing substantial social change, relevant to the theory of change: firstly, if the research group could objectively assess the needs, expectations, and perceptions of the participants of the co-design team (students and adolescents with ID), they can provide them with appropriate technical support to build together a safe environment allowing a better and inclusive interaction- based on the Easy-to-Read language and guidelines; Secondly, if they increase the level of self-determination as well as self-advocacy of the team all along the pilot study period, they enable them to evaluate their cultural needs and decide on the possible methods to reach them in the contexts in which they live. This can be reached while providing them with direct support from the experts. Thirdly, if the participants increase their self-determination, they become proactive citizens and an advocate for the change they are seeking. For instance, this occurred when they provide the cultural facilities with the modified informative texts as per the easy-to-read guidelines. While doing so, they can feel satisfaction by making their city more culturally accessible for everyone. Fourthly, if the process of self-determination and leadership are applied proficiently and adopted over a certain period, the sense of belonging to the society can be shaped and forged, as well as the level of social inclusion in the city can be improved.

3. Results

3.1. Making knowledge accessible

The researchers (Rondal, 2001; Poncelas, Murphy, 2007) explained that the way to overcome the problems encountered by people with ID in accessing knowledge and information is to transform the presented and published informative texts into a clearer message and by using a simpler format. Due to this, the Easy to Read Guidelines are developed and disseminated through the network of Inclusion Europe that promote proper opportunities for everyone to be active and have full knowledge of their rights. Specifically, the guidelines aim at realizing the rights to self-advocacy and accessibility. They are written in easy language, providing rules and steps that allow practitioners and social actors to know how to simplify the contents of any provided information, and how to increase their understandability and readability. These guidelines have a double purpose: to make information accessible and help PWD adopt and use a simple language while interacting with others. Acquiring an ability to communicate can urge PWD to ask for further exchange of knowledge and thus they can contribute and participate proactively in society.

Due to the importance of the Easy-to-Read guidelines, the research group of Macerata University has adopted its rules in order to implement the pilot study; this latter aims at increasing the opportunities for social inclusion while improving access of people with ID in the cultural environment, and making a larger space for their participation in the whole phases of the project implementation (Giaconi et al., 2021b).

Therefore, after forming the co-design team, participants had training sessions on the rules of the guidelines and on how to assess the accessibility and readability of any informative text (Del Bianco, 2018). Referring to the entitled booklet "*Information for All*", the participants had the chance to learn about the general European indications on making the information easier to read. And they earned knowledge on the special precautions that must be taken to modify any other non-written format such as digital, audio, and others. These learning sessions are followed by practical exercises to enable the participants to possess a sensitivity to cultural accessibility.

Participants have initiated field activities in order to assess the level of cultural accessibility in the existing cultural facilities in Macerata, with the support of pedagogical and Easy-to-Read experts. They have prepared a map of the existing cultural facilities, assessed the presented information in

each room of these facilities, and they got approval from the senior management to modify the non-accessible information. They have proceeded as per the Easy-to-Read booklet “*Do Not Write About Us Without Us*”, exploring the added value of the participatory approach and of involving people with intellectual disabilities in producing the simple texts.

They have worked in two separate groups to transform several messages into an Easy-to-Read language. These texts have been shared among the two groups and reviewed for final modification; because any content should be formatted concerning different needs. and here comes the importance of sharing perceptions and expectations among the members of the co-design team. This step has taken a certain time to be achieved since the need to read and understand a simple text is different from one person to another, even among adolescents with intellectual disabilities. Today 4 cultural facilities in Macerata become culturally accessible to everyone because the co-design team put in place a signage system (as captions, department signs, canteens, libraries, etc.) as well as modified informative texts (40). As per the Easy-to-Read language, accessible information can be developed either in written texts or in visual images (Giaconi et al., 2021a).

However, the process to monitor the interaction of the visitors of these facilities with the new signage system and the developed texts is still in process. Unfortunately, it got postponed for almost 6 months due to the Covid-19 measures. This is to say that the construction of Easy-to-Read texts can be drafted in a participatory method. This latter allows to provide better results and reach a larger scope of users. It involves the PWD becoming part and lead of this process. It values participation and sharing of knowledge, perceptions, and expectations. It encourages the involved actors to face and investigate different realities. Therefore, this dynamic interaction can result in increasing the self-determination of the involved participants, mainly the adolescents with ID.

3.2. Increasing self-determination and self-advocacy

Self-determination is a range of attitudes and skills that can be developed according to the context in which PWD exists and through a long process (Dispenza,2021). It is an index related to Quality of Life that shows the ability of individuals to understand and identify at first their needs and desires, to assess secondly the choices and options for fulfilling them, and then to assert themselves and take actions to reach the chosen choices, needs, rights, and options. Therefore, the promotion of self-determination is of fundamental importance, as it is « at the heart of the process that will be necessary to enable youth and young adults to learn to self-regulate learning, planning, goal setting, and attainment and to achieve the life and career outcomes that reflect their preferences, interests, abilities, and values» as explained by (Wehmeyer et al., 2019).

To increase the level of self-determination of the participants in the pilot study, the research group put an effort into strengthening their relevant skills such as communication, problem-solving, and decision making, as per (Field, 1996; Wehmeyer, 1992; Johnson, 1999). Just to make certain that they can self-advocate for their rights regarding cultural accessibility. In other words, for people with intellectual disabilities, embracing the different skills and abilities of self-determination means being able to communicate, assert and advocate their interests, needs and rights. The ability of assertiveness and advocacy represents the ultimate result of self-determination, which is the self-advocacy level.

Leadership implies working on awareness and collaboration, as well as on opportunities to experiment with group dynamics inappropriate and guided contexts. In this regard, Ryan and Griffiths (2015) state: «For adults with developmental disabilities, increased leadership capabilities and the evolution of new self-concepts are powerful examples of the impacts of self-advocacy» (p. 49).

Alternatively, to gain leadership in improving cultural accessibility, adolescents with ID and students benefited not only from the access to the cultural heritage but also from being included in a social group and becoming part of the society; so, they can enjoy a sense of belonging and of civil responsibility. For these reasons, strengthening and developing self-advocacy skills becomes crucial for the success in the transition phases (i.e. from school to work, from family to independent life) of people with intellectual disabilities, to reach a qualitative adult life (Ibem et al., 2017; Wehmeyer, 1992; Giaconi, 2015).

4. Discussion

In continuity with other research (Giaconi et al., 2021a,b) this pilot project has shown the importance of the participation of the people with disabilities from the moments of planning until the evaluation of the project. It also highlights the importance of developing participatory methods to involve the PWD in the decision-making process. Results can be achieved effectively in establishing an inclusive environment when considering PWD as proactive actors- rather than end-users of any provided services. In this way, the slogan of “Nothing About Us Without Us” is confirmed (Charlton, 1998; Franits, 2005; Crowther, 2007).

The participation and presence of PWD in the pilot project have been accepted and legitimized. Greater attention should be given to increasing participation, especially in environments that are considered crucial for the growth and development of young people with and without disabilities such as universities and cultural centers. Similar attention should be considered to make sure that participatory channels are in place and are giving a voice to people with disabilities.

In other surveys, some members of the research group have underlined- (D’Angelo & Del Bianco, 2019; D’Angelo et al., 2020; Giaconi et al., 2021a)- how fundamental it is to listen attentively to the voices of students and adolescents with ID from the starting point of any project, and to rethink the accessibility and active participation in university premises and social life. Achieving self-advocacy for people with ID has drawn the attention of the University of Macerata/research group to increase similar opportunities. On the other hand, the achievement itself of self-advocacy happened because proper means and support have been offered; Putting the voice of people with intellectual disabilities at the center of the work, results in having better accessibility and in increasing the enjoyment of rights.

As emerged from previous studies (Del Bianco, 2018; D’Angelo, 2020), communication skills, which are part of self-advocacy include the expression of one's strengths and needs, oriented towards reaching growth. As Test et al., (2005) specify: «Learning to communicate information effectively with others through negotiation, assertiveness, and problem-solving personally and in a group is critically important to improving self-advocacy» (p. 45).

It follows from these considerations that the implementation of similar studies can be better oriented towards including more activities to strengthen the self-advocacy level of people with intellectual disabilities; which can lead to an increase in self-determination. Deepening the understanding of the opinions and experiences of people with ID on reaching self-determination while exercising self-advocacy, can be considered the golden rule of building and implementing opportunities and supporting the growth of social groups. Through active participation, people with and without disabilities can be part of developing accessible information. This participation allows them to enhance their Self-advocacy skills (Del Bianco, 2019; D’Angelo, 2020).

Finally, the personal and social groups growth can lead people with disabilities not only toward personal empowerment (Atkinson 2002; Chappell et al., 2002; Goodley 2005; Barnes, Mercer 2006; Nind, Seale, 2009) but also increase their sense of belonging and social inclusion (Beart et al., 2004; Frawley & Bigby, 2015). This result was also seen in enabling cultural accessibility in Macerata.

5. Conclusion

The process of self-advocacy cannot reach its fullest if the leadership skills are not developed and if a shared responsibility to address common concerns of a social group couldn't manifest. Due to this, the pilot study requires the participation of students and adolescents with ID in the co-design team to share knowledge and to apply the newly learned skills within the group; this happened through the implementation of the pilot study activities as the mapping, the assessment of the level of accessibility of the existing cultural facilities, the modification and re-writing the informative texts in an Easy-to-Read language, as well as while sharing perceptions and understanding of what accessibility can be.

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