

Co designing inclusive museum itineraries with people with disabilities: A case study from self-determination

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Abstract

In the present paper, after a description of the theoretical framework used to define self-determination, we will describe the importance of structuring a research context that fosters the self-advocacy of people with disabilities. In this direction, a protocol of participatory research with people with intellectual disabilities will be presented in the third paragraph. Specifically, we will expand the procedure to support the creation of accessible museum captions, thanks to the application of Easy-to-Read guidelines.

Keywords: Self-determination; People with intellectual disabilities; Easy-to-Read

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1. Introduction

The level of inclusiveness that people with disabilities can experience is always related to the achievement of a good level of involvement in cultural and social environments. The researchers (Shogren & Raley, 2022; Giaconi *et al.*, 2021a; Shogren *et al.*, 2015) agreed that access to information and to social life can lead to an increase in self-determination and of the opportunities for people with disabilities to participate in life's events.

This means, in particular, that making cultural knowledge as well as relevant information accessible and available will support people to make choices autonomously and enjoy greater participation within society. In addition, it will enable them to build self-determination, expanding their

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worldview and taking control of their lives (Shogren & Raley, 2022; Giaconi *et al.*, 2021a; Shogren *et al.*, 2015).

The present paper, describes the theoretical framework used to define self-determination, and describes the importance of structuring a research context capable of fostering the self-advocacy of people with disabilities. In this direction, a protocol of participatory research with people with intellectual disabilities will be presented in the third paragraph. Specifically, we will expand the procedure to support the creation of accessible museum captions, through the application of Easy-to-Read guidelines.

2. Theoretical framework

Among the main theoretical references related to self-determination we will delve into the Causal Agency Theory (Shogren & Raley, 2022; Shogren *et al.*, 2015) because it brings together related theories to define self-determination and describe its development. It highlights the role of building (a) personal capacities for self-determination, (b) environmental supports for self-determination and (c) supports that are personalized to each person's support needs enabling them to express self-determination across environments. Causal Agency Theory suggests that humans act on their environments and shape and self-direct their own outcomes. However, such actions and the outcomes of such actions are shaped by environmental factors, namely the degree to which environments promote or introduce barriers to self-determined actions. For example, environments that pathologize disability and perpetuate ableist policies and practices will limit self-determination. The context, then, shapes self-determination and its development. This means it is essential to engage in work focused on supporting self-determination and self-representation in people with intellectual disability through multiple modalities, including co-design of accessible materials.

Causal Agency Theory provides a framework for thinking about systems of supports for self-determination that are strengths-based, recognize the role of person-environment fit, and highlight how supports can be leveraged to create supportive environments and enhance personal abilities to promote personal self-determination while also changing the context and recognizing the role of the person with intellectual disability in making such change. Specific to disability, Causal Agency Theory pushes forward a social-ecological approach that emphasizes the only contexts that should be the reference point for planning for supports for self-determination should be inclusive, community-based settings. Segregation and separation are rooted in a deficit-based model and limit the actualization of the human right to self-determination and

supportive contexts meet basic psychological needs and that promote personal self-determination outcomes. Third, Causal Agency Theory advances the integration of strengths-based models rooted in positive psychology into the disability field (Shogren *et al.*, 2015).

Causal Agency Theory defines self-determination as a «dispositional characteristic manifested as acting as the causal agent in one's life» (Shogren *et al.*, 2015, p. 258). Self-determined actions function to enable a person to be the causal agent in his or her life. Self-determined actions are influenced by the contexts and environments that people experience and have access to across the life course. While self-determination is influenced by a variety of social-ecological factors, the focus of Causal Agency Theory is understanding how to support the development of the disposition of self-determination, or the enduring tendency that is expressed differently across people and time. We assert that self-determination can be expressed in different ways and at various times across the life course and that we can devise strategies to measure it and observe variability across individuals and within individuals over time as supports change. The purpose of such assessment is to inform supports in the environment and in building personal capacities to further enhance self-determination. Additionally, we assume that cultural values and beliefs also influence the expression of self-determination, particularly how goals are defined and actions taken toward them. Causal Agency Theory rejects the notion that there is a “right” way to engage in self-determined action, and instead presumes that with supportive environments that all people can determine the most effective, interdependent ways to engage in self-determined actions that embrace their values, beliefs, visions, and self and communal goals.

Self-determination, therefore is not an end, but a continuously evolving process. Self-determined actions are self-caused; volitional and agentic, driven by action-control beliefs about the relationships between actions (or means) and ends. Volitional actions describe how self-determined people act intentionally, deliberately, and purposefully as they work toward goals in their lives. In other words, they act make conscious choices based on their interests, preferences, values, desires, and beliefs. Volitional action includes three abilities and attitudes: autonomy (acting based on one's preferences, interests, beliefs, and values without undue outside influence), self-initiation (initiating actions to identify a goal using past experiences as a guide), and inhibitory control (suppressing attention or prepotent behaviors in order to adapt to environmental demands). Agentic actions are self-directed steps a person takes in service of a goal and serves as the means through which one makes progress on goals that they have decided to act on, volitionally. Agentic action involves four abilities and attitudes: self-regulation (internal process of using coping responses to direct goal-guided activities over time and across contexts), self-

direction (directing actions toward goals and responding to challenges along the way), pathways thinking (identifying different ways to solve problems while working towards goals), and cognitive flexibility (learning from and integrating feedback from one's environment and then adapting responses to changing contextual demands and relevant feedback). Action-control beliefs involve recognizing that one's own abilities support goal achievement and feeling empowered to act based on the beliefs that one's volitional and agentic actions will lead to or cause desired outcomes. Action-control beliefs which include self-awareness (learning about oneself as well as needs, dreams, and goals) and self-knowledge (developing more and more understanding of what one's dreams are, how others can support in achieving them, and how to build a long-term vision for the future).

3. Implementing accessibility through Easy-to-Read guidelines

The theoretical framework, outlined in the previous section, provides a guide for the implementation of opportunities and practices aimed at implementing self-determination and self-representation, especially in people with intellectual disability.

Among the various protocols that can be implemented, the value of collaboration between theories and practices unfolds, in our opinion, in the realization of opportunities for all to be active and conscious users of information and content starting from the guarantee of full accessibility. Indeed, accessibility to information allows people to know and reaffirm their rights, making their own choices independently in order to have more control over their lives and future (Gilmartin, Slevin, 2010).

With reference to intellectual disability, studies show that issues of full accessibility to knowledge and information can be supported by transforming data into a clearer and easier to understand format (Wolman, 1991; Rondal, 2001; Poncelas, Murphy, 2007; Mayer, 2021). In this direction, the use of Easy-to-Read guidelines, or simplified texts, allows for greater accessibility of concepts and more comprehensive usability of information, facilitating reading performance and comprehension. Such standard advice is, in fact, a set of basic rules for creating accessible information for all. It is a list of suggestions produced to approach any content, no matter how complex, in ways that it is accessible to all, including people with intellectual disability. Despite the fact that the need for further empirical evidence to guarantee Easy-to-Read recommendations for such disabilities is stressed (Nomura *et al.*, 2010; Fajardo *et al.*, 2014), the easier to understand documents are intended to represent the concretization of a need's expression, with the intention of bringing everyone

closer to the acquisition of new skills. Consequently, this can support the exchange of knowledge and the active participation in society and, therefore, self-representation.

The design itself or the selection of Easy-to-Read texts is not a simple issue, so educators usually use recommendations made by international organizations such as the Guidelines for Easy-to-Read Materials by the International Federation of Library Associations and Institutions (Nomura *et al.*, 2010) (Tronbacke, 1997), the Make It Simple Guidelines by the International League of Societies for Persons with Mental Handicap (ILSMH) (Freyhoff *et al.*, 1998) or the Easy-to-Read guidelines made by Inclusion Europe¹

The development of the reference material, which these organizations have made, makes it possible to bring anyone closer to the rules for Easy-to-Read writing. For example, the Easy-to-Read guidelines, made by Inclusion Europe, present a booklet called “Information for All”, which offers general guidance regarding the European guidelines to be used to make information easy for everyone to read and understand. Specific cautions, consistent with each type of format (written, digital, audio, etc.), are offered. The booklet “Don’t Write About Us Without Us”, delves into the possibilities of involving people with intellectual disabilities in writing Easy-to-Read text. Two different modalities are presented in this booklet: writing a document directly in Easy-to-Read language (a strategy that is recommended) or translating a difficult text into accessible language. The “Teaching Can Be Easy” booklet encapsulates recommendations for education staff, in fact, it was outlined precisely to help teachers make their courses more accessible. This booklet is intended to help teachers in writing materials to meet the special needs of students. Lastly, “Training Trainers” offers tips and recommendations on training trainers and teachers to bring them closer to the modalities of accessible reading and comprehension. In addition there is “Text of the checklist to be translated”, which is a series of final checklist questions that help capture the level of accessibility of the text. Inclusion Europe has also prepared a logo to identify texts written in compliance with the criteria that can be used, just like the guidelines, free of charge and by everyone to help expand the possibilities of accessibility more and more.

The general aim of the Easy-to-Read to contribute to the facilitation of notions that are too ‘hostile’ is combined with the possibility of calibrating any type of content in relation to the peculiar needs of each person. The adaptability perspective of Easy-to-Read is understood as a personalized pathway aimed at adapting content and strategies to facilitate its communication in modalities that are preferred by the person with intellectual disability (Bortolotti, Paoletti,

¹ <https://www.inclusion-europe.eu/>.

2021). We agree with Lascioli and Pasqualotto (2021) that making learning environments as accessible and adapted as possible contributes to guarantee the right to achieve educational success and participate in all aspects of society.

From these considerations, emerges the need to create Easy-to-Read text or information from joint work with people with disabilities. Joint work to construct such easy-to-read information can become, therefore, an opportunity to share knowledge and competences with a group composed of people with and without disabilities. This creates spaces where the person takes an active role in the construction of his or her own knowledge, and the inclusive declination of the process of creating accessible information.

In this direction, educators can follow the steps that are given in the Easy-to-Read booklets:

1. know the target audience (disabilities, needs, etc.) to whom the information will be addressed;
2. choose the best format for the information (digital, paper, etc.) in relation to the accessibility needs of the people to whom the content will be addressed;
3. choose the most appropriate language with reference to the age of the people to whom the information will be addressed;
4. adhere to the principles of clarity of exposition while maintaining adherence to the semantic areas and meanings of the topic being made accessible;
5. explain and make understandable any “difficult” words that may be related to the topic you are making accessible;
6. always involve people with disabilities when information is being shared, enabling them to take part in decisions.

Taking into consideration the assumptions that have emerged, we are going to present an application protocol for the co-design of research with people with intellectual disabilities aimed at creating accessible museum captions through the application of Easy-to-Read guidelines.

4. How to make museum captions accessible: an application protocol

Accessibility through Easy-to-Read guidelines can be implemented with reference to different types of cultural products (Giaconi *et al.*, 2021a, b). In this section we will explore a co-design process with people with intellectual disabilities aimed at the transformation of museum captions into easy-to-read text.

The research is part of a larger project that is directed to achieve the transposition of a museum environment into a Virtual Reality Museum², with the aim of implementing the ways in which cultural heritage can be enjoyed by

² <http://www.labh.it/disuff/download/>.

all (Todino *et al.*, 2022a, b). We agree with Lisney *et al.* (2013, p. 7) that «accessibility is often seen to be a technical issue...Technology is a fact of life in the modern world and museums are no exception...Indeed, there are opportunities for museums to become even more accessible through technological means if used appropriately». New technologies offer enormous opportunities for the effective realization of inclusivity and social contexts that promote the full participation of all users while respecting diversity and different needs (Giaconi *et al.*, 2021b).

The pilot project that we are going to present, is undertaken by the University of Macerata's Chair of Special Pedagogy and Didactics and has been designed through co-planning methods, tools, and strategies with museum art historians, pedagogists, people with disabilities, and university students, to allow greater usability of museum cultural products.

4.1. Procedural steps

The work group involved have agreed on a protocol that follows these procedural phases:

1. Knowledge of the Easy-to-Read guidelines for the entire group. An expert presented the Easy-to-Read guidelines in theoretical form (importance, implementation procedures, etc.);
2. Observation, knowledge and mapping of Museum's environments that will be transformed in a Virtual Reality;
3. Choice of objects of the museum whose caption will be transformed into Easy-to-Read language;
4. In reference to captions, art historians point out the terms that cannot be changed due to the specificity of the objects under consideration;
5. Creation of Easy-to-Read captions by the group composed of pedagogists, adolescents with intellectual disability, and university students:
 - 5.1. *reading the entire text;*
 - 5.2. *identification of difficult periods and terms;*
 - 5.3. *rephrase of difficult periods and terms into Easy-to-Read language;*
 - 5.4. *reorganization of information;*
 - 5.5. *rereading of the revised text;*
 - 5.6. *any changes or additions.*
6. Re-test phase (the captions were read crosswise by other people with intellectual disability that collaborate with the TincTec Research Center³);
7. Any corrections to the captions.

³ <https://sfbct.unimc.it/it/ricerca/laboratori-e-centri-di-ricerca-1/centroTincTec>.

4.2 Realization of captions (data collection)

For the brevity of this discussion and the specificity of the topic we are addressing, we will present in this section only the steps that characterized phase number 5 of the implementation protocol and the re-test phase (phase 6) with subsequent corrections (phase 7).

As previously anticipated, these phases were conducted by the team composed of pedagogists, adolescents with intellectual disability, and university students. With reference to the captions, the group considered a number of factors: simplification of vocabulary, reduction of text and sentence length, replacement of Roman numerals and terms that were too difficult, replacement with simple forms of verb tenses, in full compliance with Easy-to-Read guidelines.

Below we are going to present an example of the work conducted with a museum caption through the sub-steps characterizing phase 5.

Starting from viewing the image and reading the entire text (Fig. 1), the group identified the critical and difficult aspects for each period of the caption.

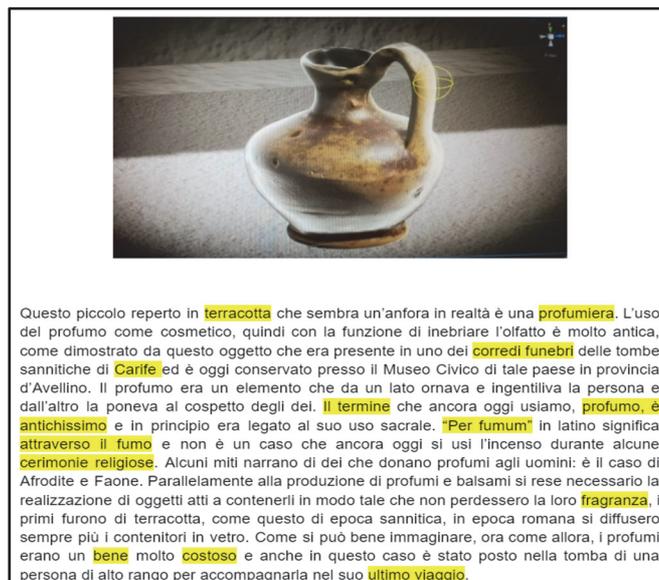


Fig. 1 - Initial caption of the "Perfumer"⁴

⁴ The literal translation of the caption: This small earthenware artifact that looks like an amphora is actually a perfume maker. The use of perfume as a cosmetic, thus with the function of intoxicating the sense of smell is very ancient, as evidenced by this object that was present in one of the grave goods of the Samnite tombs of Carife and is today preserved taken the Museo Civico of that town in the province of Avellino. Perfume was an element that on the one hand adorned and gentrified the person and on the other placed it in the presence of the gods. The term

Thanks to the work conducted together with the person with intellectual disability, reformulation of difficult terms and periods was carried out. With reference to the “non-editable” terms, accessible descriptions were made that could specify their meaning.

In addition, the revision of the text made it possible to reorganize the information into a new logical order.

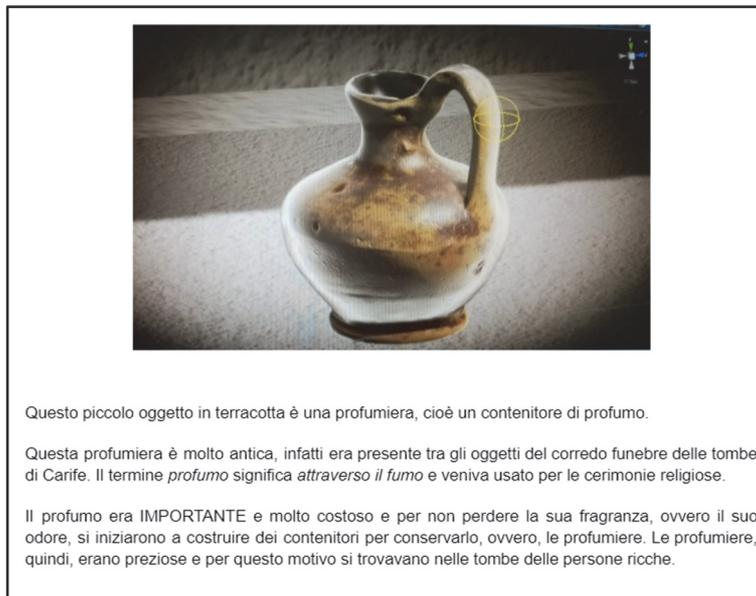


Fig. 2 - First caption in Easy-to-Read of the “Perfumer”⁵

that we still use, perfume, is very ancient and in the beginning was related to its sacral use. “Perfumum” in Latin means through smoke, and it is no accident that incense is still used today during some religious ceremonies. Some myths tell of gods giving perfumes to men: this is the case of Aphrodite and Phaon. Parallel to the production of perfumes and balms it became necessary to make objects to contain them in such a way that they did not lose their fragrance, the first were made of terracotta, such as this one from the Samnite period, in the Roman times glass containers became increasingly popular. As you can well imagine, now as then, the perfumes were a very expensive commodity, and again it was placed in the tomb of a person of high rank to accompany her on her last journey.

⁵ The literal translation of the caption: This small terracotta object is a perfumer, which is a perfume container. This perfumer is very ancient, in fact it was present among the objects of the funeral equipment of the tombs of Carife. The term perfume means through smoking, and was used for religious ceremonies. The perfume was **IMPORTANT** and very expensive and in order not to lose its fragrance, or its smell, containers were built to store it, that is, the perfumers. The perfumers, therefore, were precious and for this reason they were found in the graves of rich people.

Once the text underwent the re-test phase (phase 6), meaning it was proofread by a control group of people with and without disabilities, further modifications and additions were made (phase 7). The final result can be seen in Figure 3. Finally, the product was submitted to the museum experts for final approval.



Fig. 3 - Caption in Easy-to-Read of the "Perfumer" after the re-test phase⁶

4.3. Discussion

Among the strengths of the protocol we highlight is the joint work conducted by a multidisciplinary team. Preliminary training on the criteria of the Easy-to-Read guidelines to the entire team allowed all participants involved to identify the same project framework. However, the implementation of the Easy-to-Read criteria in context has not always been easy. The adjustment of verb tenses and the syntactic transformation of sentences generated significant discussions

⁶ The literal translation of the caption: This terracotta object is a perfume container. It is called a perfume box. Perfume was important and very expensive. In order not to lose its smell, i.e., its fragrance, containers were built to preserve it, i.e., perfumerae. The term "per fumum" means through smoke and was used for religious ceremonies. Perfume boxes were valuable and for this reason they were found in the funeral trousseaus of wealthy people. The funeral trousseau is a collection of items of the deceased that were in the tomb. This perfume box is very ancient and was found in Carife in a funeral trousseau.

within the team. In particular, the choice of terminology that was both adherent to the content and accessible to the target audience proved complex.

The group of people who carried out the design experiment is not a representative sample of the entire museum audience, so the effectiveness of the captions produced in accessible language will have to be further validated by collecting feedback from a wider audience, i.e. museum users.

But, in line with other research (Giaconi *et al.*, 2021a, b) the project has shown the importance of the participation of people with disabilities starting from the moments of planning of the procedural steps. The initial identification of roles, starting with the enhancement of the abilities of each member of the workgroup, made it possible to specify objectives and commitments. Joint work with people with intellectual disability guarantees a better quality of the results obtained as it directly involves the main stakeholders, already in the early stages of the procedure.

The protocol highlights the importance of developing participatory methods to involve people with intellectual disability in the decision-making process. Results can be achieved effectively in establishing an inclusive environment when considering people with intellectual disability as proactive actors- rather than end-users of any provided services. In this way, the rallying cry of the disability advocacy community, “Nothing About Us Without Us” is confirmed (Giaconi *et al.*, 2021a; Franits, 2005; Crowther, 2007). Deepening the understanding of the opinions and experiences of people with intellectual disability on reaching self-determination while exercising self-advocacy, can be considered the golden rule of building and implementing opportunities of active participation in social life.

5. Conclusions

Since effective communication in museums allows every visitor to understand the environment, it is important to enable them to find their way into and around the museum (Ibem *et al.*, 2017). In this process, we decided to adopt the participatory research method, in which people with intellectual disability have had a significant role within the development of the whole pathway. We also used Causal Agency Theory to shape our focus on creating opportunities and supports for self-determination. Through collaboration with the main stakeholders, we have promoted actions attributable to *Collaborative design for all* (Giaconi *et al.*, 2021a). In greater detail, thanks to this research, it was possible to observe how adolescents achieved improvements in the following areas of competence: the ability to choose and control decision-making processes; the skills necessary to manifest one’s needs, and protect one’s rights. We have already underlined in our

previous research (D'Angelo, Del Bianco, 2019; D'Angelo *et al.*, 2020; Giaconi *et al.*, 2021a) how fundamental it is to listen attentively the voices of students and adolescents with intellectual disabilities from the starting point of any project and to rethink the accessibility and their active participation in cultural context. In general, 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 cultural environments. As we have outlined in this paper, through a social-ecological approach, such as Causal Agency Theory, it is possible to emphasize that the only contexts that should be the benchmark for planning supports for self-determination should be inclusive and community-based contexts.

The present research is intended to represent only an implementation model, a starting point for the implementation of co-design work with people with intellectual disability that builds self-determination skills and opportunities. The results obtained allow us to develop further possibilities of the protocol, which goes beyond museum contexts toward cultural places in general (Sandell, 2003; Deng, 2017). The realisation of other cultural contexts (e.g. libraries, public parks, etc.), co-designed with persons with disabilities, would thus contribute to a diffusion of sensitivity and thus accessibility of the contexts themselves, as well as to the implementation of inclusive processes.

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