ISSN: 2230-9926

Available online at http://www.journalijdr.com

IJDR

International Journal of Development Research
Vol. 11, Issue, 11, pp. 52160-52164, November, 2021
https://doi.org/10.37118/ijdr.23395.11.2021

RESEARCH ARTICLE OPEN ACCESS

ACCESSIBILITY TO PEOPLE WITH AUTISM SPECTRUM DISORDER IN MUSEUMS

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ARTICLE INFO

Article History:

Received 24th August, 2021
Received in revised form
07th September, 2021
Accepted 15th October, 2021
Published online 30th November, 2021

Key Words:

Cultural access; Autism;
Assistive technologies; Inclusion.

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ABSTRACT

Autism Spectrum disorder (ASD) is a neurological condition that affects the brain development of individuals and consequently has an adverse effect on their social interactions and the manner in which they communicate. Characterized by stimulus hyper selectivity or hypo selectivity, autistic patients often develop stress and pressure resulting from over stimulation as they cannot concentrate on multiple stimuli. This explains why they may not have a pleasant experience when visiting museums. It is therefore very necessary that museums find ways in which they can ensure accessibility and inclusion of every person, without leaving out those with special needs. The first step towards achieving this end is recognizing the unique characteristics of each individual with ASD, then developing the necessary assistive technologies and strategies that incorporate them into the new environment. This research discusses the various tools, guidelines and assistive technologies that may come in handy in ensuring there is inclusion of autistic people in museums and visual art environments.

Citation: ***Louise Bogéa Ribeiro, Jussara da Silveira Derenji and Manoel da Silva Filho.*** "Accessibility to people with autism spectrum disorder in museums*", International Journal of Development Research*, 11, (11), 52160-52164.

INTRODUCTION

Accessibility of museums by persons with disabilities is a topic that is gaining popularity over the years, having been championed by both activists and even scholars. Autism Spectrum Disorder (ASD) is a neurological condition that affects the brain development of an individual, as such causing problems in communication, learning, behavior as well as social interaction (THE WORLD HEALTH ORGANIZATION, 2019). It is characterized by among others, selective response to stimuli. Put differently, ASD people can only pay attention to a part of a stimulus as opposed to the entire set up. The implication of this is that if they visit a new environment, they may develop stress which results from over-stimulation since they cannot concentrate on multiple things. Up until January 2016, Brazil had no definitive legislation catering for persons with disabilities. The law no. 13, 146/2015 defined a person with disability as referring to any individual who has a history of a long-term mental, sensory, physical or mental impairment (MANTOVANI; MANTOVANI, 2018).Following the enactment of the Inclusion of people with Disabilities Act of 2015 in Brazil, it is safe to assume that every public institution is tasked with the responsibility of ensuring there is inclusion of all groups of people in their provision of services. Besides expounding the definition of the term disability, the law specifically addresses public agencies and demands that people with disabilities be given priority. It recommends imprisonment up to three years as punishment for those people found discriminating against people with disabilities (GODOY *et al*., 2019). These rules should form the basis upon which the museum community in Brazil expands its accessibility to people with ASD. While several museums across the globe always try to accommodate people with other disabilities for instance the deaf and the lame, there are little efforts to assist autistic people. For instance, it is common to find that all museums and visual art environments have incorporated ramps to enhance accessibility by people who are using wheelchairs. Likewise, most of the institutions will usually have closed captions to help people with hearing impairments (VALENCIA *et al*., 2019). Over the last two decades, most of the museums have risen to the occasion to make sure they are responding to the needs of people with ASD. In the United States of America (USA), for instance, directives were issued by the Institute of Museum and Library Services to the effect that discrimination based on disability be eliminated. Pursuant to these regulations as well as the Americans with Disabilities act, the museum communities are discovering new ways to play their role. Although most of the museums are responding to the plight of persons with disabilities, there is little effort to address problems faced by people with ASD. This is especially the case with smaller institutions that may not be in a position to implement innovative practices for the development of assistive technologies, which play a role in expanding the inclusion of people with ASD. Whereas much has been written surrounding the topic on inclusion of autistic people in museums and visual art galleries, there is little information of how this is being implemented in Brazil. This is especially the case since there was no definitive legislations in the country addressing people with disabilities till the year 2015 when the Inclusion of People with Disabilities Act was passed. Therefore, this study will contribute information by doing a comparative study of how the research topic has been addressed in other areas like the other parts of America. Our

study seeks to interrogate the various tools, guidelines and assistive technologies adopted to enhance accessibility of museums as public institutions to persons with ASD, and discuss their efficacy. It is worth noting that following the legislation that requires the inclusion of persons with disabilities, most museums have made concerted efforts to ensure they upscale their accessibility. In literature, there are many advantages that are to be gained from accessibility of museums and visual art environments by people with ASD.

Therefore, the following objectives were considered in the course of this study: to assess the various tools, guidelines and approaches that can be utilized by museum staff to enhance the experience of people with ASD while visiting the institutions; to critically interrogate the effectiveness of the various tools, guidelines and approaches that have been suggested by the various literature materials; and to analyze innovations for the development of assistive technologies to promote access to cultural and historical heritage. The following research questions were formulated so as to ensure every all aspects that were of importance to this study were addressed: what tools, guidelines and approaches should be employed by museum staff so as to allow inclusivity and accessibility of the said institutions by people with ASD disabilities? How effective have those tools, guidelines and approaches been in the past in the quest to indulge people with ASD and to provide a sensory friendly environment? And what are some of the innovations that can be used to develop assistive technologies to promote access to cultural and historical heritage?

The next part of this paper will outline the research methodology adopted for this study. The subsequent section will be dedicated to an in-depth literature review on the same topic. Finally, the research will critically analyze how museums can utilize innovation in the pursuit of developing assistive technologies that promote the access to cultural and historical heritage. This includes approaches such as the development of programming options for people with ASD. These options seek to make the museum environment sensory friendly, thus enhancing the experience of the target group as well as their accessibility. Further, some museums have opted to make available gears that are sensory friendly, for instance headphones with the ability to cancel or minimize noise. Others settle for training of their staff and bigger institutions use technology to their advantage. Although the implementation of these measures may vary according to the size of the institutions, it is nonetheless vital to ensure that they are not excluding the minority groups among the populace.

METHODOLOGY

Our study is an integrative review surrounding the importance of inclusion and accessibility of museums by persons with ASD. As such, it was largely library based, making use of both the physical library and electronic library. The review was carried out in five stages, where the first involved the conceptualization and analyzing of the research area. At the second stage, a framework against which work would be included or excluded was defined. This was based on the research subject, and as such any material that was not contributing to the topic on ASD and museums was left out. Further, material that had been published more than three years ago were left out. Next, the sort of information that was to be gathered from the included materials was set out to ensure relevance. This was followed by a critical analysis and evaluation of the same, while the last stage pertained to the synthesis of the collected data. This writing employed a mixed methods approach. For instance, the qualitative research method was used in the collection of data. That was achieved through carrying out desk-review, library research as well as carrying out a case study of how the topic has been handled in other countries like the USA. The quantitative approach was necessary to determine the rate at which museums have embraced the new legal provisions that require inclusivity of autistic persons. In addition, this study used the doctrinal research methodology as well as the empirical research methodology. In doctrinal research, it sought to critically evaluate existing information on the accessibility of museums by people with ASD.

The relevant information was searched on public databases such as Google Scholar, Wiley Online Library and Ebscohost. The following search strings were useful while hunting for material that would adequately answer the research questions; “museums”, “accessibility”, “inclusion”, “Autism Spectrum Disorder”, “sensory friendly” and “assistive technologies”. Consequently, only information addressing the inclusivity of people with ASD in museums was retrieved. The selection was done based on reading of the abstract, introduction, conclusion and findings. For those that were relevant, the process was followed by reading of the full text. Included data was critically analysed and synthesized, taking note of materials that had been criticized by other scholars in the field. This was useful in determining the amount of weight to accord to a given piece of writing.

LITERATURE REVIEW

As noted, the core purpose of this study is to do a systematic review of existing knowledge that relates to accessibility of museums by people with ASD, critically analyze and synthesize it so as to answer the research questions. In an attempt to accomplish the research objectives, an analysis of literature was categorized into different areas: understanding the history and nature of ASD, whether a legal framework can be instrumental in ensuring inclusion of autistic people in museums and visual arts centers; a case study of America, current interventions, tools, guidelines and approaches being used by museums to increase accessibility for people with ASD and their effectiveness, and finally, some of the innovations that can be used to develop assistive technologies to promote access to cultural and historical heritage.

Understanding the nature and history of ASD

The history of ASD is not a clear one, having been disguised under various different illnesses over the centuries. First recorded in the 1799 in the Bethlem Hospital of London, the condition was regarded as a form of schizophrenia associated with childhood and poor parenting. This is following the fact that victims of the condition displayed some detachment from world, often staying alone and not playing with others. The condition was later to be described as a psychiatric disorder, underpinned by theories such as those advanced by Leo Kanner. Writing in 1943, the psychiatrist described the condition as one where the children had “extreme autistic aloneness”. Bruno Bettelheim, in support of this assertions, also linked the condition with poor and cold motherhood, something he called “refrigerator mothers” (ZELDOVICH, 2018). During the 1960s, the “refrigerator mother” notion was disproved and a new theory coined. During this period, ASD was described as a developmental disorder related to brain development of the individual, and that it had nothing to do with schizophrenia. Biological evidence was presented to support the same.

The third edition of the Diagnostic and Statistical Manual of Mental Disorders, published in 1980, listed the following as the characteristics associated with ASD: disinterest in people, communication problems and poor responses to the environment. It was asserted that these characteristics were noticeable within the first 30 months of the child’s development (MINTZ, 2017).With further research by individuals such as Hans Asperger, ASD was later described as a spectrum of disorders that not only present during the first 30 months of a child’s development but rather throughout the life of an individual. The fourth edition of the Diagnostic and Statistical Manual of Mental Disorders that was published in 1994 as revised in 2000 was the first to recognize ASD as a spectrum of conditions and not a single condition. The edition listed five conditions that fell under the spectrum, including: Autism, Pervasive Developmental Disorder (PDD), Asperger’s Disorder, Childhood Disintegrative Disorder (CDD) and Rett Syndrome (MINTZ, 2017). The fifth edition saw some of these conditions dropped from the spectrum, while a few were retained. It is therefore important to note that the nature and characteristics of ASD differ widely from one individual to another.

As such, museums and other visual art environments ought to identify and understand the specific as well as general characteristics associated with ASD so as to design interventions that adequately respond to the situation. Often, people with ASD display signs of poor social interaction with others and prefer being in isolation. Some will tend to adopt a restricted or repetitive pattern of behavior as they experience difficulty in transition from one interest or activity to another. Consequently, they prefer maintaining the status quo, often manifested in wanting to eat particular types of food or wanting to do the same thing each day, something the early scholars dubbed as "sameness"(ST CLAIR; DANON-BOILEAU; TREVARTHEN, 2018).When it comes to communication, people with ASD experience a degree of difficulty in reading and interpreting nonverbal cues. Furthermore, victims of the condition tend to be sensitive to sights, tastes, sound, light and smells. As a result, they tend to avoid places that are prone to loud noise or bright lightings, and may prefer wearing clothes that are soft. This therefore explains why museum environments can be very traumatizing to autistic individuals. Often, there will be noise perhaps from machined dinosaurs or the large crowds of people. Lights will always be flashing from one screen or another. There will be too many visual arts that may end up stimulating ASD individuals. What happens is that a visit that was supposed to be all fun turns out to be overwhelming and leaves the individuals with a lot of anxiety.

Can a legal framework be instrumental in ensuring inclusion of autistic people in museums and visual arts centers? A case study of America

When it comes to use laws and regulations in enforcing accessibility and inclusivity of people with ASD in museums and visual art centers, America becomes a case study that anyone can go by. Their revolutionary efforts were manifested by the enactment of the Americans with Disabilities Act of 1990, as amended in 2010. Section 202 of the said act states that: "[…] no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity" (AMERICANS WITH DISABILITIES ACT, 1990). The further amendment to the Act in 2010 dubbed "ADA: Standards for Accessible Design" brought forth guidelines and standards that ought to be adhered to when designing public facilities. The aim was to ensure that the facilities remained accessible to people with disabilities. These directives had a direct implication on museums and visual art centers, as it means they had to revisit their building plans as well as the designs of their exhibitions to cater for persons with disabilities (SWARTZENBERG, 2019). They were embraced by a number of institutions across America. The Institute of Museum and Library Services (IMLS, USA), for instance, issued regulations to their grantees to ensure that discrimination based on disability was eliminated.

Further, many museums have worked very hard to ensure that their infrastructures and exhibition spaces have a universal design, accessible to all members of the society. This is guided by the principles that were published by the Center for Universal Design (CUD) relating to universal design and learning. According to Swartzenberg in her thesis "Utilizing Mobile Technology to Improve Accessibility for Museum Visitors with ASD", the notion of 'universal design' is premised upon "physical, cognitive, and social inclusion of visitors with disabilities in museum experiences" (SWARTZENBERG, 2019). A point in case would be the Boston University Arts & Sciences (USA), which has always endeavored to ensure that the design of its facilities and exhibit spaces is drawn while taking account to ensure inclusion and accessibility. On the contrary, Swartzenberg also argues that laws in themselves may not be entirely effective in ensuring inclusivity of people with disabilities into museums. She opines that more emphasis should be given on the importance of understanding the individual characteristics of museum users as oppose to compliance with set statutory guidelines. She draws upon the undergraduate thesis of Ruth Starr, dubbed Accessibility Practices and the Inclusive Museum: Legal Compliance, Professional standards, and the Social responsibility of Museums, where it is argued that museums are more responsive to changes brought about by complaints from their visitors than those endorsed by the law. She further argues that museums that are pushed to bring about changes in an attempt to comply with set regulations will in most cases just do the bare minimum to ensure there is reasonable accommodation (SWARTZENBERG, 2019).

What is reasonable accommodation is subjective and varies from one institution to another. In response, the American Alliance of Museums (AAM, USA) developed standard characteristics to supplement the requirements of the Americans with Disabilities Act. These have become to be known as the "characteristics of excellence", and each accredited museum has to comply with them. For starters, museums are required to acquaint themselves with the various groups of people they are serving so as so understand their needs. They should then understand the nature and characteristics of their target audience, as this will come in handy when preparing interpretations and exhibitions. In addition, the facilities ought to demonstrate a commitment to provide access to the general public, as well as employing appropriate methods that suit their audience. In a nutshell, museums should put more emphasis on the special needs of their visitors in order to help them tailor their services in a manner that responds to them adequately.

Current interventions, tools, guidelines and approaches being used by museums to increase their accessibility for people with ASD and their effectiveness

For emphasis, museum are public institutions and are therefore expected to be open and accessible to every member of the community. Above, we have had a snippet of how museums have employed the 'universal design' approach as a way of ensuring inclusivity. This may be very helpful for people who use wheelchairs and other assistive technologies. However, the approach may not be the answer that people with ASD are looking for. Likewise, provision of Braille and captioning may be very helpful for other groups with special needs, but may not be effective when it comes to ASD. As a result, individual museums have taken up the responsibility of designing programs that best suit people with ASD by providing a sensory friendly environment. Perhaps, training of museum staff is one of the important ways that enhance inclusion. This is owing to the fact that people on the ASD all have different needs, and it may therefore not be possible to come up with a one size fits all solution. What may be a problem to one person may not be an issue to another. As such, the staff should be flexible to handle each and every need as it arises (COATES, 2019). Another inclusion approaches that is gaining recognition fast is giving priority to people with ASD, something that has been dubbed the 'early entry' approach. First attributed to the Smithsonian Institution (Washington DC, USA), the museum came up with the "Morning at the Museum" program in 2011 to facilitate inclusion of people with disabilities. The effectiveness of this program was buttressed on the notion that people with ASD would be given early entry into the museums, during which time the museum staff would be able to provide sensory friendly activities to them. For instance, the flashing lights at the institution would be dimmed and the sounds coming from automated exhibits lowered. This is also advantageous following the fact that the number of people at the museum were few, therefore the noise that would likely be experienced from large crowds was mitigated (SHRIKANT, 2018). This system has been adopted by other museums such as the Intrepid Sea, Air and Space Museum (NYC, USA) and the Walters Art museum (Maryland, USA) which now has a "sensory morning" program.

Almost similar to the 'early entry' approach is the 'late entry' approach. Here, people with ASD are allowed to visit the museums in the evenings when the places are less crowded and thus there is less noise. Consequently, it is possible to provide a sensory friendly environment to them by dimming lights and turning down loud sounds. For instance, the Science Museum (UK) has adopted a program designed for people aged between 16 and 25 years, and has

been dubbed 'Night Owls' (COATES, 2019). Likewise, the Children's Museum in Easton-MA (Massachusetts-USA) organized a night program for people with ASD. The program was called the "Family Autism Night", and was designed for children on the ASD aged 10 years or below. The Kids Quest Children's Museum, on the other hand, hosts an event called "Low Sensory Evenings". Here, attendance is limited to a few people, mostly enforced by requiring that those willing to attend must register prior to the day of the event. However, the Low Sensory Evenings are not specifically meant for people on the autism spectrum or with Sensory Processing Disorders. They are open to kids with all forms of special needs as well as their families. In addition, the Hands on Children's Museum (Washington DC, USA) has also developed a program called The Special Night of Play. This one is meant for people with ASD and their families, as well as all other children with special needs. Like the rest, the intention of the museum is to provide a less stimulating environment for these people, and enhance their levels of accessibility and inclusivity (PREECE et al., 2019). Provision of museum tools and resources is also another technique that has been employed by visual art institutions to ensure there is accessibility by people with ASD. For instance, the Walters Art museum now provides social narratives whose role is to explain to prospective visitors the expected form of interactions and behavior at the museum. The Intrepid Sea, air and Space museum, on the other hand, provides prospective visitors with information materials such as social narratives, virtual tours, sensory guides, visual vocabularies and videos. The visitors are expected to go through them and plan for their visit ahead of their visit. This is especially effective in reducing stimulation overload. For instance, a parent will be prepared to avoid a particular path where there is flashing lights or here there are loud sounds, as they are already acquainted with the structure of the museums (INTREPID SEA, AIR & SPACE MUSEUM, 2018). Likewise, the V&A Museum of Childhood has come up with a backpack tools they call "Making SENse Family Pack", which provides items like maps, play toys, visual support in the form of PECS Symbols and noise cancelling headphones. These items are expected to help people with ASD to avoid sensory overload and thus have a friendly visit.

Other museums have also taken to the internet to enhance their accessibility to people with ASD. For instance, websites have been a useful tool used by museums to make available necessary resources that may be required by autistic people. The V&A Museum of Childhood (London, UK) is a point in case. The institution has provided information about itself on its website page, and also engages its prospective visitors on questions that they may be having so as to plan ahead of their visit. For instance, a person may want to know on which days the museum is not flooded by a lot of people, so as to make arrangements to visit on the said days. Further, it has used their webpage to provide a free pre-visit guide to interested people. Usually, this takes the form of a photograph but some museums provide a video to guide autistic people (COATES, 2019). Finally, some museums have adopted after-school programs to help autistic people to work on their social interactive skills and to boost their confidence. This is achieved by bringing together people who are on the spectrum and yet have shared interests. For example, the Transit Museum (NYC, USA) runs a program called 'Subway sleuths" which unites ASD people who have an interest in trains. Often, the programs are facilitated by experts in speech and communication. Since the people on the spectrum work in groups, they are able to make new friends and feel a part of the community. These connections are maintained even after the end of the program (COATES, 2019). Likewise, the Creative Discovery Museum located in Chatanooga (Tennessee, USA) designed an after-school program called Club discovery. The aim of this program is to offer support to children who might not be able to participate in school field trips and normal museum experiences such as those on the ASD. This is achieved by giving them a chance to explore and lean, and is facilitated by museum experts who engage them in wide ranging activities like socialization and team building. Furthermore, they provide a sensory camp for children with ASD, which entails off-site field trips and museum exploration. Generally, these efforts by various museums to integrate people with ASD into their world are a positive step towards the right direction. However, as we have already seen, there is no single one size fits all solution to this problem of inclusivity. In as much these steps have proved to be effective, they also have their down sides. For instance, the early entry or late entry into the museum limits people with ASD to the number of visits they can make. This is owing to the fact that most institutions that have employed this approach have designated days when they offer the programs. Some offer the program 12 times a year, while some offer the program on specific days. For instance, the Cheshire Children's Museum (New Hampshire, USA) designed a program that was named "Sensory Saturdays". As the name suggests, the museum offers the program on each first Saturday of the month. Cumulatively, that translates to about 12 days that the people with autism spectrum and their families have to enjoy museum experiences (PREECE et al., 2019). What this means is that there is some sense of separation between the community and those people with ASD as they cannot enjoy as often as they can. Thus, there is need to find alternative solutions.

Innovations for development of assistive technologies to promote access to cultural and historical heritage

Technology, perhaps, may provide a better solution that does not tend to exclude people with autism disorders from the mainstream society. For a long time now, innovation has been widely embraced in developing assistive technologies that enhance the promotion of cultural and historical heritage. For instance, technology has been embraced to supplement the traditional classroom learning for people with autism. Research has shown that assistive technologies such as computers are more sensory friendly to people with ASD. This is because of their ability to filter information and present only what is relevant on the screens. Furthermore, computers may prove to be friendlier to people with ASD given that the condition is characterized by forming of repetitive habits (VALENCIA et al., 2019). This is made possible by the predictable and structured nature of computers, hence giving allowing people on the spectrum to form a routine and be consistent in how they function. In her Thesis "Utilizing Mobile Technology to Improve Accessibility for Museum Visitors with Autism", Swartzenberg argues that mobile phones provide a more user friendly interface than computers and laptops. This is supported by a study that was conducted in 2016 at the Federal University of Rio Grande (FURG, Rio Grande do Sul-RS Brazil), which opined that use of mobile phones and tablets was more friendly to people with ASD since they are "[…] used more naturally, using fingers to touch the screen", and following the fact that they can be used "[…] anywhere and in any position, which is good for students who are hyperactive" (SWARTZENBERG, 2019). She further triangulates that the fact that using a computer or laptop involves using a mouse and a cursor may work to the disadvantage of a person with ASD, as they will have difficulty integrating the many sensory perceptions involved. Therefore, touching what they want with their fingers is easier.

As such, computers and mobile phones as assistive technologies have been widely utilized to impart skills to people with ASD and to ensure inclusivity. One such technological approach is the use of sensors. To pin point, a mobile phone application has been developed that works with the help of Estimote Beacon Sensors to identify things. For people with ASD, this means that they can pronounce words as well as identify their corresponding meanings (WOJCIECHOWSKI; AL-MUSAWI, 2017). Further, Kinetic tools have been used as assistive technologies to people with ASD to help them explore visual arts in environments that are virtual and touchless. This includes the avatar-based touchless gestural interfaces proposed by Sorce and others in their studies. These assistive technology enhances the interest of people with ASD towards visual arts that are in digital forms like the paintings in museums. Consequently, the visual arts are made more accessible to people on the spectrum, enhancing their inclusivity (SORCE et al., 2018). The other assistive technology that has been developed to help people with ASD in their learning environments include: applications that employ virtual reality and cameras to develop social skills by

detecting their emotions and consequently adjusting system interactions, the development of ECHOES, a game that aims to improve communication skills in autistic children, a mobile application dubbed "Mobile Social Compass" (MOSOCO) which is an assistive technology that supports autistic kids to develop social skills, and Knowledgemon Hunter, a game advanced by Silva and others that seeks to support kids with ASD and learning difficulties through geolocation as well as virtual and augmented reality (VALENCIA et al., 2019). In response, museums such as The Chicago Children's Museum (Chicago, USA) and The field Museum (Chicago, USA) have also adopted mobile phone applications to enhance their accessibility to people with ASD. The popular application is the Infiniteach app, which contains maps, social guides, games and tips. As a result, prospective visitors to the museums are able to understand the surroundings of the museums. The app indicates areas that are quiet, and even points that are sensory stimulating. To people on the spectrum, they are able to circumnavigate their ways through the museums. Questions can as well be asked through the application by the help of some buttons, and answers are provided instantly (COATES, 2019).

CONCLUSION

Museums can employ various tools, approaches, guidelines and interventions to assist them in the quest to effectively reach and accommodate people with ASD. However, they may not be adequate remedies in themselves to ensure there is inclusion and accessibility of those museums by people with ASD. This is following the various shortcomings that are accompanied by the various interventions, and also following the fact that each person on the spectrum has varying needs. As such, this study appreciates the fact that there can never be a standard one size fits solution to accommodate each and every member with ASD. Nonetheless, this study also appreciates the fact that although there is no single solution to ensure inclusion of autistic people in museums, innovative developments can be used to mitigate the situation. This includes the use of computers, laptops, mobile phones and tablets. Mobile phones applications have proved to be more effective over the years. Although pre-written sensory guides and social narratives may serve the purpose, a pocket gadget may prove to be more efficacious when it comes to stimuli that originates from other museum users as opposed to the museum itself. The study therefore recommends that each museum adopts to the use of museum-specific mobile phone applications to further expand their accessibility and inclusion of people with ASD.

ACKNOWLEDGMENT

This study has been funded by the Federal University of Pará. MSF is a research fellow of the National Council for Research and Development (CNPQ). The funding providers had no role in the study design, data collection, and analysis, decision to publish, or preparation of the paper. Funding provider's websites: http://www.ufpa.br/, http://www.cnpq.br/.

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