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Published by: TURISTIKA Skopje, North Macedonia

ISBN 978-608-4872-11-5

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ACCESSIBLE MUSEUMS

Abstract

Republic of Macedonia has been working on an inclusive policy and accessible society for decades, but most often, we associate this term with educational processes and institutions. The social part of integrated rehabilitation, which includes culture, remains in the shadows and is usually in the background when creating an inclusive society.

The purpose of our research was to determine how accessible museums in the Republic of Macedonia are for people with disabilities, specifically for people with autism spectrum disorders (ASD). In this regard, we surveyed 39 families of children with ASD, and 112 families of children with typical development as a control group. Possibility of cultural development during the COVID 19 pandemic additionally was analyzed.

According to the results, both groups of respondents rarely visit museums (usually once a year), and as a reason for the rare visits they cite that contents are not adapted for the needs of their children.

The results of the research indicate the need to expand the concept of an inclusive society and adaptation of the content to the needs of people with ASD.

Keywords: Accessible museums, ASD, families

INTRODUCTION

The number of institutions that try to be accessible to as many people as possible, including children / persons with disabilities and their families, is constantly increasing. In this way, institutions demonstrate their important role in promoting inclusiveness, social cohesion and respect for diversity.

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Museums should be an inclusive environment that supports lifelong learning, promotes meaningful experiences between art and visitors, and supports diverse perspectives.

Misunderstanding and lack of information about people with ASD has a negative impact on their quality of life and the lives of their families. In order to create an accessible museum according to the needs of people with autism, it is necessary to understand ASD from clinically and social aspect. In the last few years, we have witnessed the expansion of science and a deeper understanding of this situation that has resulted in a series of changes in the treatment of ASD from an educational and social point of view.

Our research covers the experiences of families of children with ASD in experiencing museums as an opportunity for informal education and social stimulation. This research is an indicator of one of the segments of the inclusive climate in the Republic of Macedonia, which covers the institutions related to cultural heritage and defocuses the concept of inclusion from educational to social institutions.

AUTISM SPECTRUM DISORDERS

According to the American Psychiatric Association (DSM-5), the autism spectrum disorder (ASD) is classified as a neurodevelopmental disorder and is characterized by persistent deficits in social communication and social interaction, including deficits in social reciprocity, nonverbal communication behaviors, and in skills for developing, maintaining, and understanding relationships. In addition to the deficit in social communication, children/people with ASD have limited, repetitive patterns of behavior, interests or activities⁵.

From a social perspective "triad of impairments in social interaction" is defined. The three aspects of the triad are: [1] impairment of social relations; [2] impairment in social communication and [3] impairment in imagination⁶.

ASD is characterized with inflexible, restrictive, and repetitive behavior. This behavior can include unusual preoccupations, limited interests, and attachment to unusual objects. Other associated features include obsessions and rituals, unusual movements of the hand, fingers, or whole body, repetitive use of objects; unusual visual interests, sound, smell or touch of objects or people. Children with ASD can also be preoccupied with the monotony of everyday life and extreme anxiety in dealing with change⁷. People with ASD have language development problems. Some of them have not developed speech, while if they develop, it can be echolalia, without intonation, with problems in the language structure, without body language and eye contact.

INCLUSIVE STRATEGIES FOR ACCESSIBLE MUSEUMS FOR PEOPLE WITH ASD

Visiting museums can be very challenging and stressful for people with sensory hypersensitivity, such as people with ASD. To overcome these problems, many museums

⁵ American Psychiatric Association. Diagnostic and statistical manual of mental disorders. 5th ed. Arlington, VA: American Psychiatric Association; 2013.

⁶ Aarons M, Gittens T. The handbook of autism: a guide for parents and professionals. 2nd ed. London and New York (NY): Routledge; 1999.

⁷ Le Couteur A, Haq I. Autism spectrum disorder. *Medicine* 2004; 32(8): 61-63.

around the world are trying to increase their accessibility and respond to the needs of people with ASD.

Access museums are cultural sites that promote inclusion and respect for diversity. They have a positive effect on the stress and anxiety that children with ASD experience. They are an informal learning environment that accelerates the development of social and communication skills, as well as the improvement of challenging behavior.

The museums that have adapted to people with disabilities, ie people with ASD in their contents have provided sensory activities, art therapy for a small group of visitors, as well as dark and quiet rooms for rest and relaxation. Allow the visit to be organized in quiet periods (before the official start of the working day, set an "open day" for people with ASD or organize the visit in periods when there is not a large number of visitors), in order to eliminate possible stressors and make the stay as pleasant experience as possible. Physical accessibility of the building is also important, such as reducing the lighting and sound system and simple signposts⁸. Large museums pose an additional challenge, without a clear movement route a child's experience with ASD can be very stressful and distressing. These problems can be overcome by accessing resources for the preparation of the visit, through which research is done on the facility and the visit is structured according to the needs and interests of the visitor with ASD.

Accessible museums provide education of museum workers. It is necessary for them to be acquainted with certain strategies for working with a child / person with ASD. Knowing the characteristics, specifics and needs of people with ASD will be of particular benefit to the staff in performing their work effectively, or providing the most enjoyable experience for visitors.

Langa et al. (2013) detected several motivating factors for families with children with ASD to visit museums. The most important factors are related to mutual enjoyment and learning: "to enjoy each other's presence", "to be intellectually stimulated", "to be better informed", "to spend quality time with family"⁹. Kulk and Fletcher (2016) find that a sense of belonging and the need for new experiences are greater motivating factors for these families, compared to the desire to learn new artistic content¹⁰.

Improving accessibility highlights museums' commitment to supporting people with ASD by offering a friendly environment with content tailored to their needs. Research on the effect of access museums points to positive experiences for people with ASD and their families, educational activities through play provided a sense of involvement with people with ASD, as well as pleasant family moments¹¹.

⁸ Charlotte Coates. Making the Museum Autism Friendly – Best Practice from Around the World., available at: <https://www.museumnext.com/article/making-the-museum-autism-friendly/>

⁹ Langa, L. A., Monaco, P., Subramaniam, M., Jaeger, P. T., Shanahan, K., & Zierbarth, B. (2013). Improving the museum experiences of children with autism spectrum disorders and their families: An exploratory examination of their motivations and needs and using web-based resources to meet them. *Curator: The Museum Journal*, 56(3), 323–335.

¹⁰ Kulik, T., & Fletcher, T. (2016). Considering the museum experience of children with autism. *Curator: The Museum Journal*, 59(1), 27–38

¹¹ Lussenhop et al (2016) Social participation of families with children with autism spectrum disorder in a science museum, *Museums & Social Issues*, 11:2, 122-137, DOI: 10.1080/15596893.2016.1214806.

TECHNOLOGICAL SUPPORT FOR ACCESSIBILITY

The development of assistive technology has played a major role in improving the quality of life of people with ASD. Intense technological development has resulted in a variety of gadgets, virtual reality, mobile applications, touch screens, robots and many other achievements that have significantly increased the selection and effectiveness of assistive devices. These devices play a significant role in overcoming/alleviating problems in cognitive development, communication and social skills. Computer applications enable the control of auditory and visual stimuli, and enable the person with ASD to be in a controlled and predictable environment¹².

Infinitech¹³ is an American start-up company that develops mobile applications (Apple and Android) whose goal is to improve educational opportunities and increase the participation of people with ASD in the community. The application is free and so far allow the adaptation of several museums, including: The Chicago Children's Museum, The Field Museum, The Shedd Aquarium, Houston museum of Natural Science, Children's museum of the Lowcountry, Long Island Children's Museum, Milwaukee Public Museum and others. . Infinitech provides a social guide through museums, games on museum-related topics, tips and maps of quiet places in the museum, places with tactile information, as well as places that can be sensory triggers, ie a potential danger to people with ASD. The application provides a visual layout, which allows visitors to better orient and mark the desired area. The application also provides support to non-verbal people with ASD. It contains communication tools, and by clicking on a certain button a person can ask a question or answer someone, e.g. "Where is the toilet?", "I need a break", etc.

Virtual Reality (VR) is another resource in creating accessible museums. Its use promises benefits for people with ASD as it provides an individuality, controlled, predictable and "safe" learning environment. VR provides exercises to improve interaction and behavior with the real environment through programs with reduced sensory and social inputs at a level tolerable for the person with ASD¹⁴, and further increases the motivation to learn¹⁵.

Newbutt (2018) researched how a virtual reality application helps people with ASD prepare for a real museum visit. According to the results, the respondents showed a high result of enjoying the virtual visit, and at the same time the application enabled the reduction of stress and anxiety from visiting an unknown museum, and facing large and noisy rooms¹⁶.

Some of the accessible museums in their services also offer headphones for reducing the sound from the external environment, as well as sensory toys for reducing stress.

¹² Fletcher-Watson S, McConnell F, Manola E, McConachie H. Interventions based on the Theory of Mind cognitive model for autism spectrum disorder (ASD). *Cochrane Database Syst Rev.* 2014 Mar 21;2014(3):CD008785. doi: 10.1002/14651858.CD008785.pub2. PMID: 24652601; PMCID: PMC6923148.

¹³ <https://www.infinitech.com/apps/>

¹⁴ Parsons, S. and Cobb, S. (2011), "State-of-the-art of virtual reality technologies for children on the autism spectrum", *European Journal of Special Needs Education*, Vol. 26 No. 3, pp. 355-66.

¹⁵ Parsons, S. and Mitchell, P. (2002), "The potential of virtual reality in social skills training for people with autistic spectrum disorders", *Journal of Intellectual Disability Research*, Vol. 46 No. 5, pp. 430-43.

¹⁶ Newbutt, N (2018). Virtual reality tour: Experiences of autistic children, available at: <file:///C:/Users/angel/Downloads/Brief%20report%20on%20using%20a%20virtual%20reality%20museum%20tour%20pre.pdf>

POSITIVE EXAMPLES OF ACCESSIBLE MUSEUMS

Accessibility programs usually are developed in collaboration with people with ASD. Autism Speaks (USA) is one of the organizations dedicated to improving the quality of life of people with ASD, increasing understanding and creating services for people with ASD. The organization was founded in 2006, and for the first time, in 2012 in collaboration with the Grand Baseball League, they created social storytelling guided images of 30 different baseball parks to help guide ASD fans. A "quiet zone" was created, and staff were trained to interact with people with ASD. Further activities were transferred to zoos and museums. To date, the organization has collaborated with a number of museums, including the Intrepid Sea, Air & Space Museum (Manhattan). In this museum, before the visit, the educators inform the families with visual vocabulary, schedule and illustrated social stories. Museum staff also offer sensory toys and headphones to reduce auditory stimuli. Other museums have similar programs, such as The Walters Art Museum in Baltimore, which since 2010 has offered early entry for people with ASD, social stories or narratives, thematic and sensory stations where people can create handicrafts, practice yoga or just relax in a dimly lit area¹⁷.

According to the experiences of parents of children with ASD, Children's Museum in Indianapolis is one of the most accessible in the United States. It presents its contents through a number of sensory displays and interactive experiences for children of all ages. A therapist accompanies families with a child with ASD during their stay. Before arrival, parents can download a sensory map from the museum's official website, as well as social stories important for the child's adaptation to the museum premises. These families are not waiting in line¹⁸.

"Autism in a Museum" organization from England, led by a mother of two children with autism, is actively involved in creating as large a map of accessible museums as possible, as well as other cultural heritage institutions. To date, the organization has collaborated with many museums, including the Victoria and Albert Museum, the British Museum, the Jewish Museum and the Museum of London.

In the Republic of Macedonia, during 2018, a project "Open Museums" was conducted, through which an analysis of the accessibility of museums was made and a "Guide for a museum program for children / people with autism and their families" was prepared. The guide presented a research according to which in 57% of the museums there is no museum program for improving accessibility, and even in 75 % there is no museum program for improving the accessibility of cultural heritage intended for people with ASD and their families. Furthermore, this guide offers useful information on museum accessibility: recommendations for museum staff, the need for visual support for people with ASD, and adaptation of work materials. The guide was prepared in cooperation with the NI Museum of the Macedonian Struggle for Independence, which further introduces this guide in its program and opens the doors for people with ASD and their families¹⁹.

¹⁷ Shrikant, A. (2018), How Museums Are Becoming More Sensory-Friendly For Those With Autism, пристапно на <https://www.smithsonianmag.com/innovation/how-museums-are-becoming-more-sensory-friendly-for-those-with-autism-180967740/>

¹⁸ <https://familytraveller.com/usa/travel-tips/special-needs-travel/top-museums-explore-autism/>

¹⁹ Трошанска Ј., Шикалеска А., Трајкова-Крстиќ Д., (2018), Отворени музеи : водич за музејска програма за децата/лицата со аутизам и нивните семејства, НУ Музеј на македонската борба за државност и самостојност, Скопје

RESEARCH METHODOLOGY

The purpose of the research was to determine how many museums in the Republic of Macedonia are adapted according to the needs of people with ASD. The possibility of cultural development during the COVID 19 pandemic was analyzed as an additional variable.

The research was conducted online through a Google form intended for parents. The sample is convenient and it consists of two groups, the target group of parents with children with ASD, consisting of 39 (25.8%) parents, and the control group consisting of 112 (74.2%) parents of children with typical development.

We analyzed the results using descriptive statistics, using frequency, percentage and X^2 at a significance level of $p < 0.05$.

RESULTS

According to the obtained results (Table 1) 57.1% of the parents of children with typical development, together with their child visited a museum, as opposed to 38.5% of the parents of children with ASD. The additional analysis with X^2 confirmed a statistically significant difference between these two groups of respondents at the level of significance of $p < 0.05$. Families with a child with ASD visit museums less often, then other families.

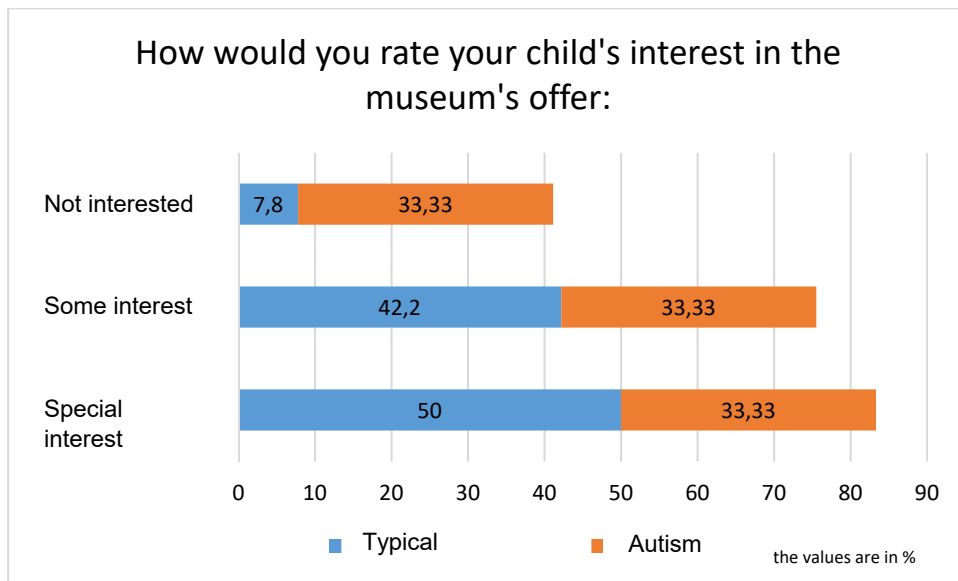
Table 1: Overview of whether the family has ever visited a museum

Parent of a child	Yes		No		Total
	N	%	N	%	
With ASD	15	38.5	24	61.5	39
With typical development	64	57.1	48	42.9	112
Total	79	52.3	72	47.7	151

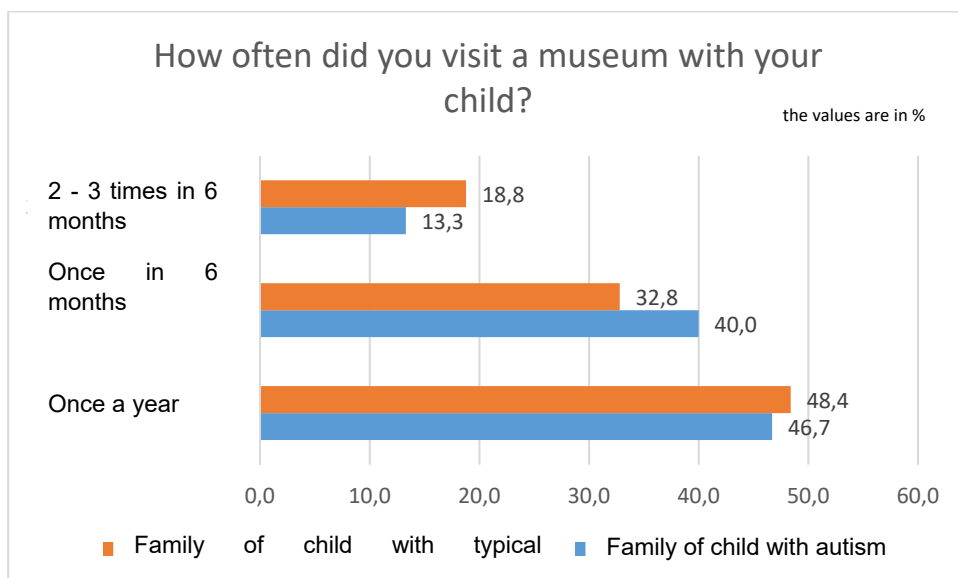
$$X^2(1, N=151) = 4.0468, p = .044254$$

Furthermore, the analysis focused to families who have visited a museum, in order to determine the interest in the contents intended for children. In the group of families with children with ASD we got quite similar results between the variables, probably due to the individuality of each of the children in terms of their interest, needs and abilities.

According to the results, an equal percentage of children (33.3%) showed special, partial or no interest in museum contents. In contrast, in the control group, the results showed greater interest among children, 50% of children showed special interest, and only 7.8% were not interested in the offered content (Figure 1). The analysis with X^2 showed us a statistically significant difference in the level of significance of $p < 0.05$, $X^2(1, N = 79) = 7.2058$, $p = 0.027208$. This shows that condition of ASD affects the level of interest of the offered contents.

Graph 1. Overview of the interest of children in relation to the offer of the museum

In terms of how often museums are visited, both groups of respondents presented similar results. From the group of respondents who visit museums, they usually do it once a year (48.4% in families with ASD, 46.7% in the control group). A small part of the respondents visit a museum much more often with a frequency of 2-3 times in six months (18.8 in families with a child with ASD, 13.3 in the control group) (Chart 2). The most common reason why families rarely visit museums with children with ASD is the non-adaptation of the content for the needs of people with ASD, 82.1% of families agree. While in the control group, the most common reasons are the ignorance of the offered programs, in 39% of the respondents.

Chart 2. Frequency of family visits to the museum

Both groups of respondents did not visit a museum during the pandemic COVID 19. Taking care of their own health and the health of their loved ones was paramount, visits to cultural

institutions and the desire for social interaction was postponed for a future period when they would feel safe.

DISCUSSION AND SUGGESTIONS

Families in the Republic of Macedonia rarely visit museums. According to the results, 38.5% of families with a child with ASD have visited a museum at least once, compared to 57.1% of families in the control group. This indicates that both groups of respondents have a high percentage of families who have never visited a museum. Analysis with χ^2 showed that there is a statistically significant difference between the two groups of respondents and the condition of ASD negatively affects the decision of the family to visit a museum ($\chi^2 (1, N = 151) = 4.0468, p = .044254$).

Further analysis showed that families who visit museums, no matter what group they belong to, do so very rarely. Approximately half of the families visit a museum only once a year, but the two groups of respondents differ in the reason why they do not visit a museum. The control group stated that the reason was the ignorance of the offered programs or the non-adaptation of the contents to the calendar age of the child. While in the families of children with ASD as the main reason is the non-adaptation of the contents for the needs of people with ASD (82.1%). The need to adapt the museum contents is also confirmed by the interest shown by the children when visiting the museums. Percentage analysis and analysis with χ^2 ($\chi^2 (1, N = 79) = 7.2058, p = 0.027208$) showed that people with typical development show more interest compared to people with autism.

These data are of particular importance and point to the need for greater engagement in creating an inclusive climate in cultural institutions, specifically museums. To improve its accessibility, we suggest museums in the Republic of Macedonia to take the following steps: (1) encouraging creativity and proactivity among museum workers in making and adapting materials for children /people with ASD, (2) using assistive technology in adaptation of museum contents, (3) improving the information and communication skills of museum staff with children with autism, (4) using experiences from accessible museums around the world. When developing a museum program, it is necessary to approach it interdisciplinarily, by networking knowledge in the field of special education and rehabilitation, pedagogy, sociology, museum practice and art therapy. In addition to satisfying interdisciplinary, the program needs to be flexible and able to adapt to multiple cultural environments and different museum conditions. According to the experiences from other countries, in the development of these programs it is necessary to involve the persons with ASD themselves.

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