

Programmes by the Ethnographic Museum for Persons Suffering from Autism Spectrum Disorder

- The article provides an overview of educational programmes held during one year (from October 2016 to October 2017) for a specific group of users of the Ethnographic Museum – persons suffering from autism spectrum disorder. The presented educational activities were performed against the backdrop of the previously developed programmes for this specific user group and they primarily comprised of workshops. An important segment of the text is the evaluation of the previously mentioned programmes by the expert staff at the Centre for Autism, which can be used in the development and improvement of further programmes for persons from autism spectrum disorder.

Key words: The Ethnographic Museum (Zagreb)
educational programmes, autism spectrum disorder

INTRODUCTION

Educational activity of most museums, and hence also of the Ethnographic Museum in Zagreb, is primarily focused on work with pre-school and school-aged children who visit the museum in organised groups. A significant share of the programmes is intended for families, tourist groups and the wider public. Nevertheless, educational programmes of contemporary museums are striving to be and need to be more than that.

Considering the history of the museum, although it had played an educative role since its inception, its focus was on museum collections and objects. The museum evolved in line with social development. Should one consider

the definition of a museum, and should one take the definition by ICOM as relevant, it becomes clear that this definition has changed over time. Since its foundation in 1946, ICOM has been updating this definition in accordance with the actual situation within the global museum community (cf. ICOM 2017). According to the latest definition by ICOM dating back to 2007, museum is a non-profit, public institution in the service of society and its development, open to the public, which, for the purpose of study, education and satisfaction, collects, preserves, researches, communicates and exhibits tangible and intangible heritage of mankind and its environment. (cf. ICOM 2017) This definition has been integrated into the applicable national Act on Museums.¹

The role of museums in society has changed and it has been increasingly focusing on visitors (Jelavić 2014: 7). However, who are museum visitors? They need to include all those who wish to be included. Hence, the museum needs to be accessible to all user groups, which includes people with disabilities. According to the National Strategy of Equalisation of Opportunities for People with Disabilities from 2017 to 2020, persons with disabilities need to be ensured a greater accessibility of all the contents linked with cultural life in the community intended for all other members of the general public. Moreover, projects that affirm creative and artistic potential of persons with disabilities need to be encouraged and provided support.²

Moreover, since the museum is an institution “in the service of society and its development”, its role in the society has been highlighted, as the venue intended to point out open-ended questions and exert a positive impact on society. Through its educational activities the museum is intended to raise the public awareness about the rights of persons with disabilities and in this way increase the overall tolerance of differences within the society and combat stereotypes and discrimination of persons with disabilities (cf. Miklošević 2013: 12).

The Ethnographic Museum has been implementing programmes intended to encourage creativity and education of persons with disabilities and children with developmental delays, led by Željka Jelavić, Head of Education, for years. During one year of education organised by the Ethnographic Museum (from July 2016 to November 2017), we had the opportunity to participate in most of these programmes. Within the project *Two Museums in the Neighbourhood*, implemented in co-operation with the Museum of Arts and Crafts,

1 *Museums Act (Official Gazette 110/2015).*

2 Cf. National Strategy of Equalization of Opportunities for People with Disabilities from 2017 to 2020 (*Official Gazette 42/2017*).

intended for patients of children's oncologic wards at the Children's Hospital Zagreb and the University Hospital for Tumours, three creative workshops were held at the University Hospital for Tumours. A similar programme – a workshop for children patients was also held at the Division of Oncology and Haematology at the University Hospital Centre Zagreb. Patients at the Special Hospital for Protection of Children with Neurodevelopmental and Movement Disorders Goljak were provided expert guidance and a workshop held at the Museum, as well as expert guidance for adult patients at the University Hospital Centre Sisters of Charity. During the previously stated period, six visits by the users of the Centre for Autism were organised at the Museum, on which occasion thematic and creative workshops were held. Amongst the programmes intended for persons with disabilities, programmes for persons suffering from autism spectrum disorder accounted for the highest share. Concerning the specific features of the requirements of that specific group of visitors, the work in question presented the greatest challenge. The previously stated reasons provided encouragement for a comprehensive overview of the work with that specific visitor group, which I am going to present hereafter.³

ABOUT AUTISM SPECTRUM DISORDER

Autism spectrum disorder is a neurodevelopmental disorder that manifests itself from the earliest childhood age. The fundamental features⁴ are deficits in social communication and social interaction, as well as restricted, repetitive patterns of behaviour, interests and activities, which limit or impair the functioning on a daily basis. The manifestations of the disorder differ, depending on the gravity of symptoms, developmental stage and the chronological age, hence the expression spectrum. (APA 2014: 50-59).

Deficits in social communication and interaction show as the following deficits: social and emotional mutuality (the ability to participate with others and share thoughts and feelings), in non-verbal communication behaviour (e.g. no eye contact, unusual body language), as well as in establishing, maintaining and understanding relationships.

Restricted, repetitive patterns of behaviour, interests and activities show as stereotyped and repetitive motor movements, the use of objects or speech, in-

3 This text is a partially adapted paper that had been written for the purpose of passing the professional exam for the profession of Museum Educator.

4 Autism spectrum disorder is diagnosed in accordance with the *Diagnostic and Statistical Manual of Mental Disorders DSM-5* of the American Psychiatric Association, published in Croatia in 2014, which resulted in considerable changes in the previous diagnostic criteria and categories. (APA 2014).

sistence on the identical, inclination towards routines or ritualised behavioural patterns, very limited interests abnormal in intensity or focus and hyper-reactivity or hypo-reactivity of sensory stimuli or unusual interest in sensory aspects of the environment.

The severity of the disorder is determined by the levels or the level of the required support and is defined as autism spectrum disorder Level 1 'Requiring support', Level 2 'Requiring substantial support' to Level 3 'Requiring very substantial support'.

Many people suffering from autism spectrum disorder also have intellectual disability and / or language impairment; whilst motor deficits are also frequently present (cf. APA 2014: 50-59, Ceganec et al. 2015).

Irrespective of a wide range of research, the causes of autism spectrum disorders have not been completely explained. Scientific research points out that we are dealing with hereditary neurodevelopmental disorder, about the impact of environmental factors and it is up to five times more frequent amongst boys than amongst girls (cf. Bujas-Petković, Frey Škrinjar et al. 2010).

According to the information provided by the Centers for Disease Control and Prevention in the United States, the incidence of the disorder amongst the members of the general population shows that one in 68 children suffers from autism spectrum disorder (CDC s.a.).

In accordance with the professional literature and the analysed data, children suffering from autism spectrum disorder need to be ensured the required support from the earliest possible age. Work with persons suffering from autism spectrum disorder requires an extremely individual approach, since each of them is unique – they have different symptoms and, according to the symptoms, they have different levels.

Multidisciplinary team approach is normally adopted to determine and provide support, through which good results can be achieved and the quality of life of persons suffering from autism spectrum disorders can be significantly improved (cf. Vragović et al. 2014: 220).

MUSEUMS AND PERSONS WITH DISABILITIES

Visits to cultural institutions are organised, amongst other things, in order to improve the quality of life of persons with disabilities. Experiences of a large number of world museums that implement programmes for persons with disabilities show that there are multiple benefits for such people from visits to

museums. This has also been verified by professionals (cf. Leiner 2001: 204-207).

“Museum visits cause a feeling of satisfaction and happiness; the feeling of wellbeing is linked with psychological satisfaction which is connected with physical health.” (Sušić 2016: 24).

In order to make possible museum visits for persons with disabilities, museums are frequently faced with a large number of challenges such as: limited access for persons with diminished mobility due to the inadequacy of the building in which they are located or for example an inadequate method of presentation of museum collections and exhibitions for persons with sensory impairment such as blindness, low vision and deafness or hearing impairment.

As opposed to the previously mentioned, primarily physical obstacles, the main challenges upon visits paid by the persons suffering from autism spectrum disorder, are communication problems and their inability to focus their attention and hypersensitivity to sensory stimuli. Communication with persons suffering from autism spectrum disorder is impaired on several levels. Irrespective of the fact that the level of problems differs (a high percentage of people suffering from autism spectrum disorder have very limited speaking skills), most of them are faced with difficulties in verbal expression (inability of expressive speech, echolalia, limited vocabulary, neologisms, metaphorical language) and non-verbal communication (inappropriate non-verbal behaviour and gestures, as well as difficulties in interpreting other people's non-verbal behaviour) and difficulties in language comprehension. Social interaction is very poor, as a consequence of the inability to understand the social rules. Persons suffering from autism spectrum disorder are frequently hypersensitive to sensory stimuli, which means that they can find the environmental stimuli disturbing and even painful (cf. AGOO 2008: 17-26).

EXPERIENCES IN WORKING WITH PERSONS SUFFERING FROM AUTISM SPECTRUM DISORDER

Co-operation between the Head of Education at the Ethnographic Museum and the Centre for Autism Zagreb has been ongoing for many years, during which period a large number of educational programmes have been held at the Museum for the users of the Centre. These programmes are organised upon invitation by a social worker or any other member of the professional staff with whom the date and the programme content appropriate for its users is agreed. This paper provides a description of the programmes held from October 2016 to the end of October 2017 for adult persons suffering from autism spectrum disorder.

The first meeting with the users of the Centre was preceded by a feeling of uncertainty, as well as of slight concern, due to a lack of experience in working with persons suffering from autism spectrum disorder, which disappeared already during the participation in the first workshop. That meeting provided the motivation to organise quality time spent at the Museum for these people in our further programmes, striving to bring them a feeling of satisfaction and fulfilment.

The first programme of this type was a music workshop entitled *The Rhythms of Africa* – playing of *djembe* drums – held in October 2016. This is a workshop that is regularly organised by the Museum and it is linked with the Permanent Collection of Non-European Cultures. It is popular amongst visitors of all age groups. It is led by the Workshop Manager Sam Bushara, an External Associate of the Museum. He always adapts the approach and the methods used in managing the workshop to a specific group of participants. The workshop was attended by two groups from the Programme for Adult Persons Suffering from Autism Spectrum Disorder, which comprised of a total of fifteen users, accompanied by one assistant per two to three users.

Most of them found it difficult to follow the instructions of the workshop manager within the group. They first needed to master the technique of holding the drum between their legs, so their hands would be free for the rhythmic drumming. Concerning the alternate banging the drum with two hands, most of them needed individual instructions and even physical guidance. There was only one user who was able to successfully follow the workshop manager, showing a good sense of rhythm and the ability to accurately repeat the melodic sequences. This workshop clearly showed the differences in the needs and inclinations amongst persons suffering from autism spectrum disorder. Some participants showed that they enjoyed playing the instrument, whilst two of them had to leave the room in which the workshop was held, due to the overburdening of their senses caused by the noise and they retreated into quieter Museum premises, accompanied by their assistant.

The second visit paid by the users of the Centre was organised in November 2016. On that occasion the Museum was visited by ten users. Their stay at the Museum was organised in such a way that during the first part of the visit there was an organised tour of a pertinent museum collection of traditional Christmas ornaments with relevant professional guidance. A workshop was held following the tour in which traditional Christmas ornaments were made of crepe paper. This type of Christmas ornaments are referred to as *kinč* and they come in different forms and versions, from simple to more complex. Consequently, the workshop is suitable for persons with different motor skills, as it can be adapted to individuals. Some of them needed more assistance, yet all of them managed to successfully make their *kinč*. This workshop is an

example of a quiet activity, which requires a minimal level of motor skills, yet with the possibility to adapt and it obviously suited all the users of the Centre who participated in it.

The third visit was paid in December 2016 and the content was identical as during the previous visit. It was organised upon a request by an occupational therapist from the Centre for Living with Autism Jelkovec that operates within the Centre for Autism, since at that time students of the University of Applied Health, enrolled at the Occupational Therapy Department, were attending their internship. Within that programme, they were presented the work at the Museum with the users of the Centre at the Museum. This time the users were provided more available assistance and they were all successful and satisfied with their works.

The following visit paid by the users of the Centre was held on the occasion of Easter festivities, in March 2017. The programme was adapted to the occasion. An Easter egg decorating workshop was held after a short tour of the exhibited traditional dyed Easter eggs. Six users participated in the programme. They decorated wooden eggs using tempera paint.

In June 2017 seven users from the Centre, accompanied by seven students from the University of Applied Health visited the exhibition *Of Animals and Humans* at the Ethnographic Museum with relevant professional guidance. A creative workshop was organised, after the tour, in which animal forms were sewn following cardboard patterns. Hand sewing is a suitable activity for perfecting motor skills, which amongst persons suffering from autism spectrum disorder are frequently poorly developed. As any other time, some participants in the workshop showed higher-level skills than others. One user had considerable difficulties in the accomplishment of the task, yet with continuous guidance provided by her assistant, she eventually succeeded and was satisfied with the result and proud of her achievement.

After the summer break, the users visited the Museum yet again in October 2017. Upon the agreement on the programme with the social worker from the Centre, a wish was expressed to organise a workshop linked with the actual season of the year – autumn. Hence, a workshop was organised about painting the motifs of autumn leaves through dot painting within a limited colour range comprising of four colours, using tempera painting technique. As in every previously held workshop, the participants, the users of the Centre, showed different levels of visual expression skills. Consequently, some of them required help in the way that someone had to show them several times how to dot paint, whereas several of them needed help in terms of working together, providing guidance to their hand. Ten users of the Centre participated in the workshop,

two of whom required continuous help in work, which was provided by their assistants from the Centre. Notwithstanding the fact that this workshop was a quiet time activity, an unpleasant incident happened whilst they were dot painting. One of the users of the Centre who was continuously helped during work, overreacted and he hit the assistant several times. Other assistants move away the young man who obeyed them and sat at a separate desk, which soon calmed him down. This incident upset another young man, which was expressed through his wish to leave, walking up and down the room in fast movements, whilst waving his arms uncontrollably and an unintelligible flow of speech sounds. After the situation had calmed down and the previous activities continued, he showed similar behavioural changes several more times. Until the end of the workshop the young man who had assaulted the woman assistant sat quietly and before the end of the workshop he was allowed to finish his work.

The previously described anger outburst caused amazement amongst the Centre staff, since, according to them, that person had never previously exhibited this sort of unwanted behaviour, nor had they, according to their knowledge, ever previously shown aggression. He is even-tempered, which is why he frequently participated in different activities outside the Centre premises. Anger outbursts (temper tantrums) are always caused by a 'trigger' (Stošić 2009).

Since this outburst was preceded by a quiet time and silent activity, it is difficult to conclude what may have caused it. The members of the Centre staff who were present during the incident mentioned the possibility that it may have been caused by the fact that the woman assistant was helping the young man who assaulted her by guiding his hand. Perhaps he did not want that or perhaps, after she had given him all her attention, the fact that she attempted to help the other young man, may have caused jealousy. All these assumptions were stated cautiously by the staff, emphasising that perhaps none of the mentioned possibilities may have caused this incident and that it was impossible to establish its cause with certainty. This is a clear indicator of unpredictability of behaviour of persons suffering from autism spectrum disorder (cf. Bujas-Petković and Frey Škrinjar et al. 2010).

EVALUATION – OPINION OF THE EXPERT STAFF FROM THE CENTRE FOR AUTISM

During the implementation of the programme for the users of the Centre for Autism, through a conversation with the expert staff from the Centre, we were striving to learn more about in what way the implemented programme affected the users. During the collection of information concerning this issue, considerable assistance was provided by Marlena Kovačević, Senior Occupational Therapist, Head of the Centre for Living with Autism Jelkovec II, who cleared our doubts. After the implementation of the six previously described programmes, interviews were conducted with the abovementioned occupational therapist, the social worker Sonja Škrbić-Deskar and the defectologist Tanja Biloglav from the Centre for Autism.

About the reasons and the objectives of the visit paid by the persons suffering from autism spectrum disorder, all the three members of the professional staff pointed out the overall experience of the Museum visit.

Persons suffering from autism spectrum disorder are excluded from many social activity segments and hence a visit to a cultural institution helps them in social skill development, encourages their understanding of social communication and acts as social support. They are positively affected by a change in their daily routine, the journey to the Museum and back (physical activity, dealing with the public transport experience) and frequently such a short trip also includes a walk around the city and stay at a coffee shop, which particularly delights them. Marlena Kovačević, an operational therapist, added that even persons suffering from autism spectrum disorder are able to acquire new knowledge and skills, irrespective of the fact that it is all much slower amongst adults, it is still visible that, in addition to maintain the functions, the users of the Centre remember new content and activities. Moreover, she pointed out that there are multiple effects of participation in a creative workshop – from building their motor skills to the satisfaction due to a successfully accomplished task. Through their work in the creative workshop, they make a concrete product, which results in pride. An additional advantage is the fact that they are allowed to take away with them the objects they have made as souvenirs. They are also equally delighted with the fact that they are allowed to leave the objects created, as a contribution to the Museum collection.

The previously described programmes saw the participation normally of the same users from the Centre. They are well acquainted with the Museum building and its staff involved in museum education. For persons suffering from autism spectrum disorder, who do not enjoy changes and unknown situations, this means they feel comfortable and relaxed at the Ethnographic Museum.

The defectologist Tanja Biloglav stressed that the workshop activities are the most suitable educational programme provided by the museum for persons suffering from autism spectrum disorder. On the other hand, the social worker in her review assessed that the users of the Centre who pay visits to the Museum can benefit also from the tour of the Museum. Nevertheless, she did not deny the benefits of the special programmes. Concerning the issue of programme planning, she believes the programmes need to be implemented and the assessment as to whether they are suitable for persons suffering from autism spectrum disorder needs to be made during their implementation and hence they can eventually be repeated. The latter primarily refers to whether the djembe drumming workshop should have been held after all, since it did not suit most participants. She pointed out that she did not expect most users of the Centre would not like that programme, but it was a praiseworthy attempt. In her opinion, the educational programmes provided by the Museum are quality and they achieve their purpose.

According to the opinions provided by all the above-mentioned interlocutors, the positive effects need to be considered through the overall museum experience, ranging from the feeling of social inclusion, the encouraging effects of the museum environment – the architecture, museum objects and the specific atmosphere, to the benefits of the educational programmes.

Tanja Biloglav drew attention to a significant impact exerted by coming out of the users of the Centre beyond their everyday living premises in terms of the creation of a positive perception of persons suffering from autism spectrum disorder amongst the public.

The defectologist Tanja Biloglav and the occupational therapist Marlena Kovačević assessed the need for education of the members of the museum staff who are involved in work with persons suffering from autism spectrum disorder both as imperative and useful. This type of education would provide insights about methods of communication with these specific people and adequate reactions in specific situations, as well as about a higher quality planning of the programmes intended for these specific people.

They were also asked to provide an opinion concerning the global experiences about the usefulness of inclusive programmes that encompass the inclusion of persons suffering from autism spectrum disorder into joint programmes with other Museum users (Stošić et al. 2015). All the interviewed members of the professional staff at the Centre assessed such global practices as positive and pointed out the requirement of its corresponding introduction into the museum programmes. Marlena Kovačević comprehensively elaborated on this issue as follows:

“An inclusive programme would imply that every person would acquire new content in accordance with their potential and progress in line with what had

previously been mentioned. This would mean that the content and the speed of its acquisition would be adapted to every individual, irrespective of the environment in which the individual was placed. Every individual would acquire and/or maintain their skills at their own pace, as much as possible, without being demoralised and/or feelings of inferiority concerning their potential/value. I believe that perhaps the insufficient education amongst the general public and the insufficient awareness about the differences are amongst the factors that are crucial for the implementation of this type of work, yet the attempt to develop personal experiences would also be valuable. [...] Co-operation between the Museum staff and the staff working with persons suffering from autism spectrum disorder is important, as well as a comprehensive assessment of every user and providing the Museum staff with an insight on potential undesirable behaviour during social interaction with other people.”

CONCLUSION

This overview of work on educational programmes for persons suffering from autism spectrum disorder simultaneously also strives towards a further improvement of these programmes. In addition, it all occurred against the backdrop of these programmes are normally held upon the initiative of the individuals, whereas the co-operation between museums and institutions or associations involved in the issue of autism spectrum disorder is sporadic. Concerning the proven benefits of the museum visits for persons suffering from autism spectrum disorder, the organisation of such visits or programmes needs to be systematically addressed, through improved connections between relevant institutions and museums. Special programmes adapted to meet the specific requirements of the people suffering from autism spectrum disorder could be developed against the backdrop of the previously mentioned.

During the work on these programmes we were faced with a wide range of uncertainties and doubts concerning how to behave and in what way establish communication with persons suffering from autism spectrum disorder. Education is required in that sense, which would provide fundamental insights not only about the specific features of working with persons suffering from autism spectrum disorder, but also with persons with other types of disabilities and disorders. Such education would provide invaluable assistance in working with museum educators and other members of the museum staff involved in work with the visitors. Moreover, educational programmes need to also include the fundamental insights about art therapy – visual arts creation with therapeutic effects. Visual expression may positively affect persons suffering from autism spectrum disorder, as well as all other groups of people with difficulties in

communication competencies, since it gives them the opportunity to express anything they are not able to express verbally or in any other way. This can reduce the feeling of failure due to the inability of expression in other ways and encourage their emotional development (Ivanović 2014: 191). In the absence of such education, professional development of persons working on programmes intended for persons suffering from autism spectrum disorder is fundamental through acquisition of knowledge from the available professional literature and the communication with professionals in this field.

Finally, a proposal is being put forward to systematically approach the preparation of a national programme intended for persons suffering from autism spectrum disorder that would include museums as partners, similarly as has been regulated in the US⁵ and in many European countries. Until then, in the absence of such a programme, the Ethnographic Museum will continue the implementation and improvement of its educational programme intended for persons suffering from autism spectrum disorder. It is important to point out the usefulness of the expansion of these programmes on an inclusive basis.

Work on the implementation of the programmes intended for persons suffering from autism spectrum disorder provided invaluable professional experience and personal satisfaction through its modest contribution to the improvement of the quality of life of these people, which will also provide the motivation for further work and improvement of the programmes.

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5 For an overview of the museum programmes for persons suffering from autism spectrum disorder in the US see Varner 2015.

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