Sabina Pawlik
Poland

The New Educational Review

Artistic Work of People with Intellectual Disabilities as a Laboratory of Social Practices. Research. Action. Solving Problems

DOI: 10.15804/tner.2018.51.1.20

Abstract

People with intellectual disabilities (IDs) are often recognised as suffering from "social exclusion". Attempts aimed at combating this exclusion include support in finding employment and preparing them for living independently. Unfortunately, for a large group of people with intellectual disabilities the aforementioned strategies of promoting social inclusion are unattainable, and thus alternative areas of social inclusion are sought after. The arts/artistic work may be one of them. Due to the fact that the study was conducted as participatory action research, the main areas of social exclusion of people with intellectual disabilities were exposed. This allowed for attempting to prevent this phenomenon. In this study, artistic work has become a laboratory of social practices toward people with intellectual disabilities and the solutions created in the realm of the arts may serve as an example for designing a normalising model of support for people with intellectual disabilities in other areas as well.

Keywords: *intellectual disability, Participatory Action Research, inclusion and belonging, the arts*

Introduction

The places where people with intellectual disabilities can engage in artistic work are usually facilities providing day- or full-time care and support – nursing homes, art therapy facilities, centres for people with special needs, and social clubs. According to Bakiera and Stelter, art workshops are found in as many as 91% of art therapy facilities in Poland (Bakiera, Stelter, 2010, p. 150). Artistic activity usually performs a therapeutic function, and therapy through art plays a crucial role in the process of treatment and rehabilitation of people with intellectual disabilities and as such is treated as complimentary to social rehabilitation of people with disabilities. At day care facilities for people with intellectual disabilities art classes are also seen as a way of organising their leisure time. Regardless of whether the artistic practice performs its therapeutic function or is treated only as a leisure activity, it often happens that the resulting work itself is of secondary importance or may even be perceived as waste of undetermined purpose.

For the researcher, exploring the subject of arts/artistic activity stems from the conviction that the artistic work of people with intellectual disabilities may become a strategy for promoting their social inclusion understood as a process of returning to society of individuals as well as entire social groups, in this instance people with intellectual disabilities. The intellectually disabled are often defined as "socially excluded" and the policy of "social inclusion" aims to counter this by the provision of employment opportunities and preparing them for independence. Unfortunately, the above-mentioned methods of social inclusion seem unattainable for a large group of people with intellectual disabilities, and therefore alternative areas of social belonging are sought after (Hall, 2010, p. 48). One of these areas may be the arts/artistic work. Owing to its universal language, it is an opportunity for the voice of the people with intellectual disabilities, initially "weak, shy and helpless," to be heard (Krzemińska, 2009, p. 574). This may constitute a seed of tolerance and ultimately of social belonging. The prerequisite, however, is that the artistic work becomes legitimate and that it can leave the niche of art with the stigma of being created by the intellectually disabled and as such considered worse.

The issue explored in this study was social and cultural exclusion of people with intellectual disabilities in the area of the arts. The aim of the descriptive and diagnostic research was to identify the main areas of exclusion of the intellectually disabled in the realm of the arts. And the practical and social aim of the research

was to promote artistic work of the intellectually disabled as occupying a certain space in the social and cultural life, by means of which their discrimination in this area can be actively challenged and their social belonging fostered.

Research Methodology

General background of the problem

The primary aim of the participatory action research was defined as a method of empowering the subjects by utilising their own knowledge in the research process (Whyte, 1991). The main focus of the research are collective and self-reflective research practices which help both parties[1] to properly understand their situation and identify ways to mitigate it. Nowadays the need to conduct participatory action research among people with disabilities, including those with intellectual disabilities, has been increasingly stressed. It results from the need to protect the rights of persons with disabilities as well as from demands for their full inclusion, which would radically change their place in society (cf., Hall, 2010). Participatory action research requires that the role of the person with intellectual disability should be changed from the subject to an active participant in the entire research project, in which they influence the research concerning their life and aimed at improving its quality, according to the principle of participatory action research: "nothing about us without us" (Stack, McDonald, 2014, p. 83). The outcome of the participatory action research, as emphasised by Kemmis and McTaggart (2000, p. 596), should be real and material changes in the studied community as to: what people do, their interactions with the world and others, what they find meaningful and valuable as well as the discourse through which they understand and interpret the world (Kemiss, McTaggart, 2000, p. 596).

Following the guidelines proposed by Kemmis and McTaggart, the presented participatory action research aims to promote changes in the areas outlined in the table below.

[1] The researchers and the subjects, however this traditional division seems to be no longer valid within PAR.

Table 1. The intended changes

Intended Change in the Studied Community Acc. to Kemmis and Mctaggart	Intended Change within the Research Project
CHANGE IN WHAT PEOPLE DO	Change in the ways and places in which the artistic work is exhibited and promoted (location, descriptions)
CHANGE IN HOW THEY INTERACT WITH THE WORLD	Changes in the reception of art created by people with IDs, perception of a person with ID as an autonomous artist
CHANGE IN WHAT THEY FIND MEANINGFUL AND VALUABLE	Change in the evaluation of art created by people with IDs (with reference to its artistic value and not the artist's disability)
CHANGE IN THE DISCOURSE THROUGH WHICH THEY UNDERSTAND AND INTERPRET THE WORLD	Change of the language used to describe art created by people with IDs and showing links between the discourse relating to art created by people with IDs and their perception in the community

Source: Kemmis S., McTaggart R. (2000) Participatory action research. (In:) K.N Denzin, Y.S. Lincoln, Handbook of Qualitative Research. Thousand Oaks, CA : Sage Publications, p. 596.

The Committee

Artists with intellectual disabilities, instructors, representatives of cultural institutions and parents were asked to participate in the research project.

The artists with intellectual disabilities:

- *Person 1* – an author of several hundred works – drawings and prints; one of the most widely recognised and original representatives of naïve art in the region,
- *Person 2* – a class participant at the community centre for people with special needs, her works are remarkably dynamic,
- *Person 3* – a participant in art therapy classes; creates drawings and linocut prints (mainly with animal motifs),
- *Person 4* – a class participant at the community centre for people with special needs; a self-taught artist with a great creative potential,
- *Person 5* a participant in art therapy classes, the eldest research participant, incapable of verbal communication; the human motif dominates in her works – it is present in most of them,
- *Person 6* – a class participant at the community centre for people with special needs; human beings are the exclusive motif in her works,
- *Person 7* – a class participant at the community centre for people with special needs; a characteristic feature of her artistic work is unusual precision and fondness for neatness and order.

- *Person 8* – a class participant at the community centre for people with special needs; his artistic work mostly revolves around daily life.

Instructors:

- *Person 8* – secondary school of fine arts graduate, art tutor.
- *Person 9* – an instructor in charge of the arts workshop, artist, painting faculty graduate.
- *Person 10* – an artist, print-maker, art therapist, special education teacher, art therapy class teacher.
- *Person 11* – facility manager, a specialist in management and therapy of emotional disorders.

Family:

- *Person 12* – a single mother raising an intellectually disabled son.

A cultural institution representative (as an expert):

- *Person 13* – museum employee dealing with non-professional art, including art created by people with intellectual disability, responsible for promoting it at the museum and local communities.

Instruments and procedures

The methods of collecting data in the research were "dictated by action itself". The data collection methods were as follows:

- participatory observation conducted from the insider's perspective (Angrosimo, Mays de Perez, 2000, p. 678), in which owing to the undertaken steps it was possible to approach the studied environment involved in the artistic work of people with intellectual disabilities as well as practices employed in promoting this form of art,
- note-taking was a method employed throughout the process, whose role was not only to record the events, but also to interpret them (Have, 2004, p. 119),
- unstructured interviews (Fontana, Frey, 2000, p. 645) with research participants – artists, their families, instructors and members of audience regarding the artistic work of people with intellectual disabilities.

The process of participatory research

Planning change (Kemmis, McTaggart, 2000). In this part of the study, thanks to the interviews conducted with its participants, several major problems emerged and finding means to solve them should provide guidance for further action.

1. Art created by people with intellectual disability remains in a niche designated for it. The artistic work of artists with IDs is only perceived in the context

of their disability, and different criteria are employed for the evaluation of their work than for other artists.

> *It is often the case that the artistic work of people with IDs is appreciated only because it was created by people with disabilities and it is not appropriate to say that you don't like it, as this is "politically incorrect". Very often "we like it" because at the back of our minds there is this thought that it was painted by someone worse, who does it worse, so we must like it* [act. int. 6].[2]

The notion of an "artistic niche" also relates to exhibition venues which offer no opportunities to leave the isolated environment of the disabled. Thus, there is a closed circle where the art created by intellectually disabled people can only be seen by other disabled people and their families.

> **Researcher:** *Have you had any exhibitions yet*?
> **Person 1**: *Yes.*
> **Researcher**: *Do you remember where they were organised?*
> **Person 1**: *Well… at the library* (the local library branch) [act. int. 1].

> *In order to allow the people in care of other facilities to attend them [day care facilities and centres are meant here – ed.], the exhibitions are held at noon, when it is impossible for other audiences to attend them, two or three representatives of the local authorities come at the most. I haven't heard of any other way. But if there was a will to educate people, the works of these disabled artists would be shown at a museum and subject to the same rules as other artists'. Nobody is going to worry then if it's possible for other disabled artists attending art classes to come* [act. int. 6].

Artists with intellectual disabilities remain in the "artistic niche" also due to some mental barriers existing in society which result from fears and prejudice against people with intellectual disabilities.

> *No other form of disability is as stigmatising for a human being as an intellectual disability. The intellectually disabled are treated as if their condition was an infectious disease. All physical barriers are easy to remove, whereas the mental barriers in society are hard to eliminate* [act. int. 6].

[2] Interview code

2. Limited respect for the artist's individuality can also be observed. At the facilities providing care for people with intellectual disabilities, artistic activity is often guided by a predetermined schedule, and individual preferences or talents are not taken into account. This is due to the excessive standardisation of services provided for people with disabilities.

I wanted to work with D., he drew one incredibly good thing then. I went to talk to our psychologist about that and she said that 'unfortunately there were groups', and the will to create is so transient […]. Artistic work should give pleasure and joy… you can't just tell someone: 'create something here and now'… for me talent is the most important thing [act. int. 4].

[…] I can be more independent now. When I'm alone, I can do what I want, and when I'm in class, activities change, for example, there is ceramics or glass art or crafts… and they are not my favourite… taking part in other workshops was tiring for me and I wasn't very good at these things [act. int. 2].

3. Another issue is compensation of people with intellectual disabilities. Artists with IDs and their families point out that they cannot decide how to spend the money earned from selling the works or cash prizes won in art competitions. Yet another problem is the negligible worth of non-cash prizes in competitions for people with disabilities.

It's better for me to work on my own, because if my drawings are sold, I can earn some money, and when I was in workshops, when some works were sold, we didn't get any money [act. int. 2].

They don't give us any money… it doesn't work like that at all. But he sometimes tells me: 'Mummy, look, this was sold for this much and that was sold for this much, and I got nothing'. And I tell him then that all the money was for the centre […]. This is how I explain it to him. For the first grand prix… it was agreed that he wouldn't get the money, but they would buy something for him… he got something instead of money [act. int.5].

Researcher: *Have you won any competitions?*
Person 1: *Yes.*
Researcher*: And what was the prize?*
Person 1: … *A T-shirt and crayons and a paint set.*

In conclusion, three main areas of exclusion of people with intellectual disabilities in the field of art have been identified:

- exclusion due to little social awareness of the value of art created by people with intellectual disabilities resulting from social prejudice against them and unprofessional strategies of presentation and promotion of the artistic work of people with IDs,
- exclusion due to little respect for their artistic uniqueness and individuality,
- financial exclusion of people with intellectual disabilities in the field of art, resulting from a lack of clear and transparent criteria for sharing profits from the sales of art created by people with intellectual disabilities at the care and support facilities, a lack of clear criteria for the assignment of non-cash prizes and the low worth of prizes in competitions exclusively addressed to people with disabilities.

Action and observation (Kemmis, McTaggart, 2000). The main part of the research project involved action whose aim was to address the issue of exclusion of people with intellectual disabilities in the field of art. The action was focused on the organisation of an exhibition titled *Trzecia Przestrzeń* [The Third Space]. The space mentioned in the title refers to an area where relations between the non-disabled and the intellectually disabled can be transformed thanks to art, by creating a "borderland culture" (Krzemińska 2006, p. 574), wherein the universal language of art blurs the differences between the two, bordering worlds, thus creating a new form of social solidarity.

Preparations for the exhibition involved collecting and selecting the works created by artists with intellectual disability. The opening of the exhibition was preceded by promoting the event on social networking sites and on posters. Invitations to individual representatives of local authorities, cultural institutions and scholars were also sent out. The venue of the exhibition was the local cultural centre. The curator of the exhibition was the manager of the department of non-professional art at the regional museum. Seventeen works by eight artists were finally displayed.

An exhibition catalogue was published to accompany the exhibition featuring the introduction by the exhibition curator. The catalogue comprised the artists' profiles, which in itself emphasised the artistic individuality and autonomy of the people with intellectual disabilities.

Discussion

Action evaluation and reflection on the research process (Kemmis, McTaggart, 2000). An inherent part of the participatory action research is its evaluation as an element helpful in finding ways to further improve this practice. The is presented in three key areas as presented in the following table.

Table 2. Reflection and evaluation of the conducted research

	area I creating an environment	**area II action**	**area III participation**
Successes	Forming a group of individuals (instructors, therapists, museum workers) willing to engage in the process of preventing discrimination of people with intellectual disabilities in the arts.	Publishing a professional exhibition catalogue with the artists' profiles, which emphasised respect for the artistic individuality and autonomy of the people with intellectual disabilities participating in the study.	Engaging people with intellectual disabilities at the stage of planning change. They expressed their own views on discrimination in the arts, primarily regarding their own artistic preferences and compensation for their work.
Challenges	Failing to arouse interest in the issue of discrimination of people with intellectual disabilities in the arts in a larger group of people working in this field. The problem still remains unnoticed, and actions focused on changing the situation are seen as unnecessary.	Leaving the "artistic niche". Due to the time of the opening of the exhibition and its venue, the event was mainly attended by people with disabilities.	Full commitment of the people with intellectual disabilities at the action stage and changing the pattern in "the non-disabled" working for people with disabilities according to the principle "nothing about us without us". Lack of long-term action.

Source: own study

Repeated planning cycle. Reasons for continuing the action research. The issue of discrimination of people with intellectual disabilities has proven extremely complex and further research in this area conducted as participatory action research is considered necessary by the author. Designing further change will be focused on the same areas as those reflected upon and evaluated with regard to the research project.

1. Participation. Further research process will be focused on forming a research team including self-advocates as its legitimate participants and engaging them in the research at every stage thereof.
2. Creating an environment. Further action will be aimed at establishing a local sub-institutional, independent environment concentrated on the artistic activity of people with intellectual disabilities, composed of people actively involved in changing attitudes and practices regarding the art created by people with intellectual disabilities. The goal will also be to include in the research process experts professionally promoting art of people with intellectual disabilities as well as some scholars.
3. Long-term action. The action in the next cycle of the research will concentrate on four main pillars for fighting discrimination of people with intellectual disabilities in the arts.
   - PERSONAL AND ARTISTIC DEVELOPMENT of the participants, wherein the undertaken action will stem from their interests and preferences, and forms of artistic expression will not be forced upon them.
   - VOLUNTARY PARTICIPATION contrary to the observed excessive standardisation of support of adults with intellectual disabilities; only self-advocates willing and interested in the action will participate in the study.
   - DEMOCRATIC STRUCTURE based on cooperation of all research participants at each stage of the study.
   - INCLUSIVE NATURE of the action thanks to cooperation with professional artists, cultural institutions and museums and due to creating opportunities for artists with intellectual disabilities to meet the audiences while maintaining professional strategies of presentation and promotion of their works.

Conclusions

The research on the strategies for fighting social and cultural exclusion of people with intellectual disabilities in the area of the arts was an attempt to follow the principles of participatory action research with regard to studying groups of people with intellectual disabilities. In the author's view it is an important step toward protecting the rights of people with disabilities as well as meeting the demand for their social belonging.

The study showed that despite a number of obstacles hindering full social inclusion of people with intellectual disabilities, owing to the presence of art created by them in the public, mainstream space, it is possible to create a "social laboratory" of practices and attitudes toward these people (cf., Hall, 2010). If people with intellectual disabilities are recognised as individuals capable of conceiving their own artistic message, the field of the arts will become a space where they can be seen and heard. As a result, people with disabilities gain "the right for their expression to be recognised as socially meaningful" and thus their message goes beyond pure aesthetics and becomes a political manifesto (Godlewska-Byliniak, Lipko-Konieczna, 2016, p. 15).

In conclusion, in this research studying the subject of artistic work (the arts) has become a laboratory of social practices toward people with intellectual disabilities. The solutions created in the realm of the arts may serve as an example for establishing a normalising model of support for adults with intellectual disabilities in other areas as well.

References

Angrosino M.V., Mays de Perez K.A. (2000). Rethinking Observation. From Method to Context. (In:) K.N Denzin, Y.S. Lincoln, *Handbook of Qualitative Research*. Thousand Oaks, CA: Sage Publications.

Bakiera L., Stelter Ż. (2010). Wspomaganie rozwoju osób niepełnosprawnych intelektualnie. [Supporting Development Of People With Disabilities] (In:) A.I. Brzezińska, R. Kaczan, K. Smoczyńska, *Diagnoza potrzeb i modele pomocy dla osób z ograniczoną sprawnością*, [Diagnosing Needs and Models of Support for People with Disabilities] Warszawa: Wydawnictwo Naukowe Scholar.

Balcazar F.E., Keys B.Ch., Kaplan L.D., Suarez-Balcazar Y. (1998). Participatory Action Research and People with Disabilities: Principles and Challenges. *Canadian Journal of rehabilitation*, 12, pp.105–112.

Fontana A., Frey H.J. (2000). The Interview. From Structured Questions to Negotiated Text. (In:) K.N Denzin, Y.S. Lincoln, *Handbook of Qualitative Research*. Thousand Oaks, CA : Sage Publications.

Godlewska-Byliniak E., Lipko-Konieczna J. (2016). Public to Private: A Theatrical Game with Disability. *Polish Theatre Journal*, 2.

Hall E. (2010). Spaces of social inclusion and belonging for people with intellectual disabilities. *Journal of Intellectual Disability Research*, 54, pp. 48–57. DOI: 10.1111/j.1365–2788.2009.01237.x

Have t. P. (2004). *Understanding Qualitative Research and Ethnomethodology*. Thousand Oaks, CA : Sage Publications.

Krzemińska D. (2006). Kod językowy i dyskurs osób z niepełnosprawnością intelektualną.

O bytowaniu na pograniczu. [The Linguistic Code And Discourse Of People With Intellectual Disability] (In:) J. Baran, S. Olszewski (ed.), Świat *pełen znaczeń.* [The world full of meanings]. Kraków: Wydawnictwo Impuls.

Lincoln Y.S., Denzin K.N. (2000). *Handbook of Qualitative Research*. Thousand Oaks, CA: Sage Publications.

Stack E., McDonald K.E. (2014). About Us Without Us: Does Action Research in Developmental Disabilities Research Measure Up?, *Journal of Policy and Practice in Intellectual Disabilities*, 11 (2), p. 83–91. DOI: 10.1111/jppi.12074

Whyte W.F. (Ed.). (1991). *Participatory action research*. Newbury Park, CA: Sage Publishers. DOI: 10.1097/00006199–199207000–00009.