

“I Discovered I’m An Artist!” An Evaluation of the Impact of a Collaborative Arts Project on the Wellbeing of Young Adults with Learning Disabilities

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Abstract

In a climate where arts-based interventions are under increasing pressure to justify activities in terms of instrumental benefit, this small case study sought to evaluate a collaborative arts project, seeking an understanding of the ways in which it impacted on the well-being of adults with learning disabilities. Recognising arts-based practice as a location for further investigation into civil rights and drawing on an interpretivist paradigm, the study facilitated the investigation of potential contributory factors to wellbeing. The capabilities approach has been applied throughout as the inclusion of the participant’s voices was central to the research. Their narratives illustrated that increasing feelings of well-being related to connections with others, positive relationships and sense of self-worth.

Keywords: arts practice; rights; disability; well-being, mixed methods approach

Introduction

The educational value and therapeutic properties associated with arts practice has long been recognised and the growing body of recent evidence correlates active participation in art with positive life outcomes and wellbeing (for an overview of evidence see Parr et al, 2016 and for further information of the impacts of art, please see *The Value of Arts and Culture to People and Society*, 2014, and *Understanding the Value and Impacts of Cultural Experiences*, 2014 both published by the British Arts Council and more recently, the All-Party Parliamentary Inquiry Report into Creative Health: The Arts for Health and Wellbeing, 2017). There has also been a burgeoning interest in the ways arts practice impacts on disabled people (Darcy and Singleton, 2015) with research focussing specifically on the ways in which it reduces social isolation, promotes health and well-being (Stensaeth, 2013), builds confidence and self-esteem, and develops both a sense of belonging (Hall, 2013; Parr, 2006) and a positive identity (Watts and Ridley, 2012). Koppers (2014) also argues that arts practice has the potential to move boundaries of limited realisations, creating new and inclusive spaces for disabled people, shifting the emphasis from the deficit model which focusses on the individual’s disability to a more positive approach that identifies ways to fulfil potential, creating opportunities to lead ‘ordinary lives’ with the same opportunities for realising their aspirations and having the same life chances as other citizens (for further information about the concept of ‘Ordinary People Leading Ordinary Lives, please see the Learning Disability Strategy for Hampshire, 2009-2011).

That said, the Equality and Human Rights Commission (2014) reported that disabled people were significantly less likely to be included in cultural activities than their non-disabled peers, with issues of inaccessibility being the main reason for unequal participation in cultural life (lack of accessible facilities, services and transport, for example). Indeed, it appears that exclusion from participating in ordinary, everyday activities is something of the ‘norm’ for disabled people (WHO 2011) and according to Goodley (2017), those who find themselves on the periphery of a community feel of less human worth than those who occupy more of a central location.

This paper will demonstrate that arts practice has the potential to disrupt socially constructed boundaries of exclusion by upholding the participatory and civil rights of disabled people (Blandy 1991, 1994) through the creation of inclusive spaces where people have the freedom to be creative and achieve, and not be defined by what they cannot do. Arguably, this juxta positioning has the potential to unsettle and disrupt the marginal social positioning of disabled people.

Engaging further with the social (re)positioning of people with learning disabilities, and wishing to disrupt the 'norm' of the traditional ways in which disabled people are viewed, this paper draws on Goodley's (2017:20) seminal work relating to Critical Disability Studies whereby space for deep consideration is sought, questioning 'what it means to be human in a contemporary world that is shaped by inequalities'. Encouraged by Goodley and Runswick-Cole's (2014) ideas about troubling the normative, rational, independent, autonomous subject that is so often imagined when the human is evoked, the discussions here will also apply the prefix *dis* which indicates that the norm is recognised but that it is disrespected, troubled or troubling. For example, rather than setting disability and human as polar opposites whereby people are judged by what they can and cannot do, the term *dis/human* will be used provocatively to open up critical debates as to what the norm actually is (to follow further discussions about the term *dis/human*, see Goodley and Runswick-Cole, 2016). This study carries the conceptual re/positioning of *dis/human* onward, disregarding the deficit theory and linking to Levy et al's work (2017) whereby personalisation is applied through the capabilities approach. The discussions then converge around the focus of the research project, namely the evaluation of *make+create*, a community-based arts project based in Suffolk, UK. The background to this study provides a rationale for the methodological approach adopted and the findings discussed before the links to well-being are considered. Although the paper is based on a small-scale study, the emphasis on a rights-based approach whereby all disabled people are recognised as active agents is applicable globally.

Changes in the Landscape of Disability Studies

Disability is a complex concept that pays no heed to societal boundaries of religion, culture, gender and age. It is also a personal and socio-cultural phenomenon that cuts across academic disciplines. Despite the politicisation of disability in the 1960's which was led by academic activists who campaigned for the civil rights of disabled people to be upheld by breaking down physical and attitudinal barriers, traditional discourses of disability that emphasise vulnerability, incompetence and incapability continue to persist. This is not helpful. It results in the exclusion of social groups on the basis of inability. Goodley (2017: 126) therefore proposes that we use the term *disability* more critically. He suggests using the term *dis/ability* where the slashed '/' acknowledges the ways in which the terms *ability* and *disability* are produced and reproduced in relation to one another. In this way, he argues, they become synonymous and one cannot be referred to without considering the other. This thrusts *disability* to the foreground, making it visible. He also suggests that the inter-play between *dis* and *ability* will generate further exploration of the ways in which co-construction and reliance on one another can take place. This disruption is intoxicating because it not only has the potential for the excluded to become included but it also forces acceptance of individual's diversity and difference.

Personalisation and the Capabilities Approach

Fundamentally, personalisation is centred on making services more responsive to the individual needs of disabled people, transferring greater choice and decision-making to service users themselves. This is not a new concept. It forms the basis of the social model of disability where for decades Oliver has argued fiercely in favour of disrupting physical and attitudinal barriers that disable people (1983, 1990, 2013) by disregarding difference and diversity, trying to make one size services fit all. However, the very notion of disabled people negotiating and leading discussions about their own lives challenges traditional hierarchies of knowledge and oppression (Levy et al, 2017) and it necessitates professionals working collaboratively with service users in order to facilitate choice and agency. Here we draw on the work of Sen (2009) and Nausbaum (2011) who use the terms *functioning* and *capabilities* whereby *functioning* is taken to meaning outcome, and *capabilities* as being the 'freedom that a person actually has to do to be this or that, things that her or she may value doing or being' (Sen 2009 page 232). For example, if a person wishes to take part in an art collaborative, they are likely to need access to inclusive art practice along with (potentially) specialist support and equipment. The art here being the outcome (*functioning*) and the *capabilities* being the support that needs to be put in place to facilitate inclusion. As discussed previously, disabled people have been subjected to inequalities that restrict their freedom to make life choices and fulfil their capabilities, so it is suggested that the facilitation and creation of appropriate opportunities for disabled people and adopting the capabilities approach will address inequality and social injustice empowering disabled people to lead full and rewarding lives.

Well-Being

Defining well-being in order to capture it is a complex task. Whilst a vast amount of literature discusses the meaning of well-being, it appears that no universal definition has been agreed. Indeed, there are debates as to whether well-being should reflect a personal life overall, or if a more fleeting 'here and now' perspective is more important (Ryan and Deci, 2001). Huppert et al (2009) argue that personal fulfilment and self-actualisation is also relevant. To complicate things further, the term well-being it is also often used interchangeably with happiness, quality of life and satisfaction. However, three domains of well-being feature most prominently: the first emphasises social indicators which identify a collection of measures relating to objective circumstances; the second defines well-being in economic terms measuring consumer choices and behaviours; the third frames well-being in a more subjective manner, focussing on how people experience their lives. Drawing on the third domain and adopting a more subjective standpoint where well-being is emphasised through lived experiences, this study recognises it to be an holistic and multi-dimensional term that encompasses subjective evaluation of physical, mental, social and spiritual life experiences (Friedli, 2009). A defining feature of this concept of wellbeing is the ability to fulfil one's own individual and social potential. It is this that is central to this report.

The Study

This collaborative arts project, sourced by the Baily Thomas fund (<http://www.bailythomas.org.uk/>) and co-produced by Ace Anglia (<http://www.aceanglia.com/>), make+create (collaborative arts project), Autism and ADHD (<http://www.autismandadhd.org/>) and the University of Suffolk (<https://www.uos.ac.uk/>), aimed to evaluate the impact that a ten week participatory arts project had on the arts practices and wellbeing of a group of adults who have learning disabilities.

Adopting a capabilities approach, this research set out to investigate the possible links between arts practice and the wellbeing of young disabled adults.

Methods

The collection of evidence relating to wellbeing includes both research and evaluation whereby research answers a general question or tests a hypotheses, and evaluation uses a specific framework or a set range of criteria as tools to gain an in-depth understanding. It is the concept of evaluation that is important here as participatory arts tend to foreground the importance of experience and process. That said, in order that a 'breadth and depth of understanding' (Johnson et al, 2007: 123) of the ways in which participatory arts potentially impact on the wellbeing of adults with learning disabilities could be sought, the study adopted a mixed methods approach. Using both quantitative and qualitative methods of data collection to support the research process actively enabled participation in dialogue of what Greene (2007: 20) terms as 'multiple ways of seeing and hearing, multiple ways of making sense of the social world, and multiple standpoints on what is important and to be valued and cherished'. Inferences were therefore drawn from these.

The artists attended weekly sessions that spanned several months. Two different venues were used and the artists learned a range of techniques using a variety of mediums, creating individual portfolio's of work. Data was collected by researchers from the University of Suffolk throughout the duration of the study and the artists and researchers becoming well known to each other.

Measuring wellbeing is as complex as the definition itself. However, based on the premise that subjective wellbeing can be used to measure a particular programme's effectiveness, we used the Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS). The scale was developed in 2006 by a group of researchers from University of Warwick and University of Edinburgh, in order to assess positive mental wellbeing in the general population (Tennant *et al.*, 2007). The instrument is based on a model of wellbeing that is defined as more than just the absence of mental illness. The items of the instrument are all positively worded and cover the participants' experiences over the previous 2 weeks in terms of subjective wellbeing and psychological functioning. The original instrument consists of 14 items with specific wording, asking, for example, "I've been feeling optimistic about the future". The participant can select an answer on a 5-points scale ranging from "None of the time" (scored 1) to "All of the time" (scored 5). The final score is calculated by taking the sum of all the items on the questionnaire.

Because the WEMWBS was validated in the general population only, we decided that the measure should be adapted by a panel of experts (known to the study as the ‘Involvement Panel’ and made up of four people with learning disabilities who had participated in previous arts collaboratives), making the information sheet and questionnaire bespoke and more ‘user friendly’. The panel decided on the final version of the instrument, both in terms of number of items – they decided to keep 11 out of the original 14 items – and the wording. The score on the questionnaire can therefore range from 11 to 55. The questionnaire was completed by the participants before and after the project, enabling a direct comparison to be made.

In addition to the wellbeing questionnaire the participants were invited at various points over the ten week period to take part in research conversations, giving testimonials about the project and their participation in it. This produced qualitative data that enabled an in-depth exploration of individual and shared experiences. Mindful that previous evaluations of art projects have relied heavily on anecdote, a more rigorous method of sampling of participant testimonials was adopted for this study and given that the subject under scrutiny was the impact of participatory art, it seemed fitting that a creative form of data collection and analysis was developed. With this in mind, research conversations took the form of semi-structured interviews, participant observation and expressive art journals (these being both a tool of documentation and on-going mode of self-reflection). Utilising qualitative and quantitative methods in this way allowed a nuanced illustration of commonality and difference to emerge.

Sampling

Eight artists signed up for the ten week participatory art collaborative make+create project. The sampling strategy was one of convenience whereby during the familiarisation visit, all artists were invited to participate in the research firstly by explaining orally what the study was about and also by giving out bespoke and ‘user friendly’ information to take away, discuss and consider. A style of written communication that the participants were familiar with was adopted and formatted using short sentences and photographs that facilitated understanding and conveyed meaning. All eight artists consented, returning the consent forms the following week when the art sessions started in earnest.

Ethical Processes

Ethical approval for this study was provided by the University of Suffolk Ethics Committee. Individual informed consent was then sought from all participants who signed a participation agreement which set out the aims and objectives of the research. The information given to the participants explained clearly the duration of the project and the expectations of the research. Aspects of withdrawal and anonymity confidentiality were emphasised within the information sheet and oral confirmation of participation and withdrawal was reinforced each time the artists shared their experiences with the researcher.

The Involvement Panel members were instrumental in producing information that was appropriate for the participants and several meetings were held to discuss the use of appropriate wording, images and amend the information. They were ferocious in giving feedback, paying attention to detail and ensuring that the information was clear and unambiguous without being tokenistic.

Results and Discussions

With such a small sample the results of the quantitative analysis are only tentative and should be interpreted with caution – they are not expected to reach statistical significance. The average wellbeing score as measured before the participation in the series of art sessions was 43.4. On a scale ranging from 11 to 55, this score reflects a rather high level of wellbeing before the art sessions started. At the conclusion of the series of art session the average wellbeing score was 44.6, higher than the initial score (Figure 1). This can be cautiously interpreted as an increase in wellbeing. At individual level we can see that 3 out of the 5 artists who completed the second questionnaire have reported an increase in their score, on participant had the same score at the end of the art session series, while another one recorded a decrease by 3 points.

Figure 1. Average wellbeing score, at the beginning and at the end of the series of art sessions

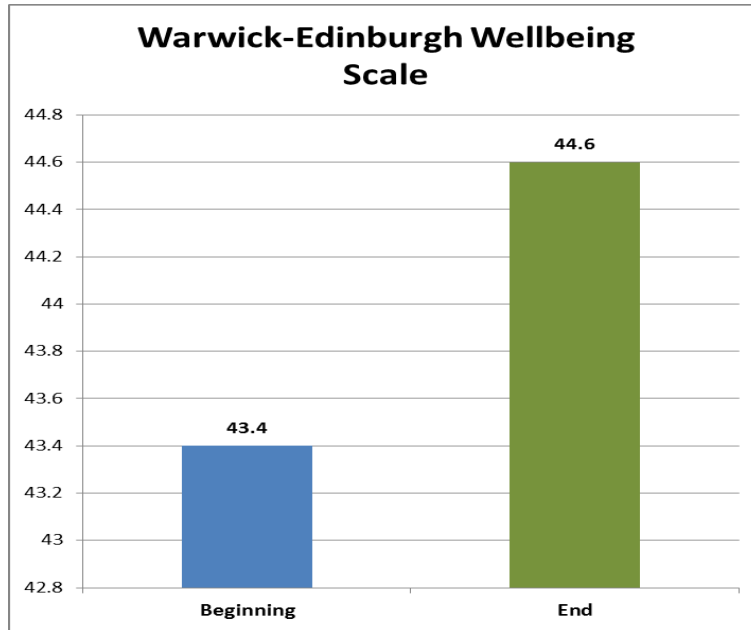
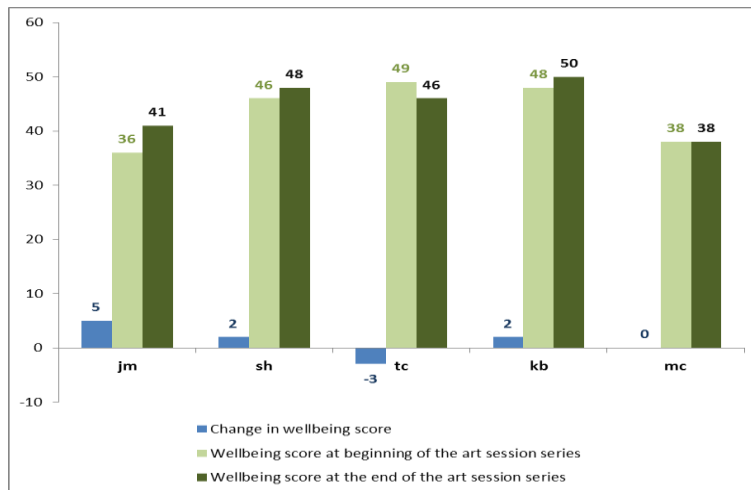


Figure 2. Change in wellbeing score at individual level



Themes

Three main themes emerged from the qualitative data: friendships; confidence and learning new skills. These are examined in detail below and direct extracts from research conversations have been used to support the discussions.

Friendships:

The research conversations in the form of semi-structured interviews that took place during the familiarisation phase revealed that some of the artists had joined the project because it was an opportunity to “do the art work and to meet new people and make new friends.” The familiarisation session enabled the group to get to know each other before the first art session as they explored the environment and were told more about the project and the research. Most of the research participants told us that they were “excited but a bit nervous about coming to a new place with people I don’t know”. Researchers observed that two participants were accompanied by personal assistants who stayed throughout the familiarisation session.

For one artist, friendships became more important than the art work itself. He felt that the art work was hard and felt that he wasn’t particularly creative but making new friends and meeting new people was of importance to him; “talking to them about art and this and that every time we met...saved me a lot.

I feel very worthy to do this.” During the exhibition, this participant also told us that after the weekly art sessions some of the artists organised to continue their conversations over lunch and when the project had ended, they made arrangements to “meet for a coffee and a chat”. Indeed, we observed three participants deep in conversation and taking lunch together in the University café on several occasions during the project and also after it had ended.

One participant told us that living in sheltered housing was quite isolating but that this project had given them “somewhere to go, something to do. It has been quite relaxing and I feel I have made lots of friends. It’s been amazing spending weeks doing art and stuff. It really means a lot to me”. By the end of the project, all artists mentioned that the project had provided opportunities for them to “meet new people” and “make new friends”.

Confidence:

The majority of the conversations during the familiarisation visit suggested that the participants were nervous and anxious about joining the project. For example, most were hoping to make new friends, but worried they might not; most did not rate their creativity and hoped they wouldn’t “get it wrong”. One participant told us that they were worried that they might not be able to “tap into their imagination and be creative enough” and another thought that using their “imagination and creativity was going to be difficult”. Some participants told us that although they “liked art” they were “not very good at it”.

However, once the project got started, the conversations between the artists and the researchers began to take on a more positive tone. All artists told us that they looked forward to their art sessions and were disappointed if they couldn’t attend. It was clear that all had started to gain respect for their own work and that of their peers as we observed them working alongside each other. Some clearly relished the opportunity for expression and creativity in ways they had not thought was possible. As one participant articulated, “I have really started to enjoy it and am feeling good about being part of it. I didn’t realise how I done because of my disability. I thought, could I really do art? Then I realised, yes I could. I discovered I’m an artist!”

During the pre-exhibition catch-up session, the conversations demonstrated that all artists were eager to see their work displayed. Whilst we were collectively viewing the art as projected images and the artists were curating the work, one participant told us “I have done some great art work. I’m excited and can’t wait to show people”, another suggested that there were “no words to describe it [the artwork], it’s all beautiful and heartfelt”. The artists collectively told us they felt “good” and were “excited” about the forthcoming exhibition: “it means a lot to me. It shows I could do everything. I am lucky to get this opportunity”. One participant was quite emotional, telling us that she was “really sad that it [the project] was coming to an end. I would now like to do another art class in the future. I never thought I would enjoy it so much.”

During the pre-view exhibition evening, the artists told us that they were delighted that family and friends were there supporting them. One artists said that he felt “very great” about seeing his art work displayed and was more “confident to talk about it” when people asked him questions about it. Another artist told us that it had “given me a lot of confidence. I have actually discovered that I have some artistic features in me that I never knew I had. I just explored it and developed it”. When asked how he felt to see his work displayed, he said “its, um very surreal. I never thought that any of my work would be used for people to look at. Here I show people my art and explain the reasons behind it and they like it. I am proud of myself”.

Learning new skills:

Whilst some artists were rather daunted by the artistic and creative aspects of the collaborative art project, one participant articulated very clearly how he had developed his skills during the programme: “The first time I started the classes, I found it hard to tap into my imagination and be creative. After a while, I got used to it and didn’t mind trying new things”. Some of the participants showed us their expressive art journals, talking us through the different techniques they practiced outside of the art sessions and others showed us their work on tablets and on a projector. In general, the participants did not use the journal telling us “I forgot about it”, or that “I kept my art work separate when Max was around”.

All artists articulated very clearly that they had developed their creative skills whilst attending the collaborative art project, some explaining to us in detail how they had experimented with different mediums to produce their work, “using different pencils and pens”; “flicking paint”; “dragging paint”; “joining numbers as a group to produce a massive picture”; “using technology”; “cutting out words and sticking them together to make something different the using our own words”.

Some told us that trying new things, working together, discussing ideas and listening to others perspectives had not always been easy when so many opinions were involved, but one participant told us how her peers had inadvertently supported her develop her skills: "I didn't get it, I just didn't understand. Then we started talking and I watched the others for a while then I thought now I get it. I really do get it! That made me happy".

Whilst the project was driven by art work, it became apparent that the development of new skills was not confined to creativity and art. By the second week of the project, all artists were observed accessing the building independently; collecting ID badges and signing in as necessary. They competently and successfully navigated the organisation's wifi system to access the internet, and all took turns to select background music of their choice as per the collectively agreed schedule. From the beginning of the second week to the end of the project, all stayed for the duration of the sessions without their support workers. At the end of the project some of the artists made spontaneous speeches to an audience of over fifty guests, articulating the personal gains they had made throughout the project.

Conclusion

The project provided a platform for creativity and voice. Not only did the participants engage in art activities that provided opportunities for creativity, their rights of participation were upheld as they proactively engaged in the research study. Voices were sought and listened to, and disabled people were key players in terms of shaping the research, the project and the making/creating, curating and exhibiting of their art work.

The collaborative arts project was heralded by the artists and their families as a great success. The active engagement in the project, the expressive creativity and ability to communicate was clearly demonstrated through the work the artists produced and the appreciation of the work during the exhibition. As the results and discussions within this paper have captured, a great deal of positive impact has resulted from the participation in the project in terms of gaining confidence, learning new skills and forming new friendships. Reimagining participation and disregarding deficit based exclusion clearly paid dividends.

The research process itself was both enjoyable and successful, and as researchers we take forward valuable research experience for future projects. Indeed, whilst deep consideration was given to the ethical processes involved and of the bespoke information and gaining of consent, it was the Involvement Panel and the artists themselves who taught us a great deal about researching with adults who have learning disabilities and for this we are very grateful.

However, there were some unintended outcomes that emerged from the research process that we viewed as being just as valuable as the project itself. The first being when artists gave presentations about the project at two conferences held at the University of Suffolk. The artists were invited to attend a BERA funded event for over 100 postgraduate students which took place a short time after the project had started. A few months later, the artists were invited to a Research Forum attended by 50 or so academics. At both conferences, they confidently gave presentations that they had prepared and co-produced. They also took part in the traditional question/answer session after the presentation, enlightening delegates about their roles and participation within the project. The delegates were very complimentary about the presentations and were interested in the project, asking when the art would be on sale. As a result, there have been follow-up invitations for further discussions with the artists and invitations for future presentations at the University.

Artists were invited to an impromptu social gathering of international academics where they mingled together, engaging in conversations about the project and displaying their art work. The evening raised much needed funds for the final exhibition and the art work was positively previewed.

Finally, a small group of academics at the University collectively published a text book to accompany a taught undergraduate degree course. During the publishing process, the authors unanimously chose a piece of artwork designed and produced by one of the artists on the project which was later used as the front cover of the book. The artist and the project have been acknowledged and the publication has been viewed by an international audience.

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