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The roving diagnostic unit– art, madness, fun and the potential for change

Tischler, Victoria ORCID: <https://orcid.org/0000-0002-0086-1906> (2019) The roving diagnostic unit– art, madness, fun and the potential for change. Arts and Health, 11 (2). pp. 174-182. ISSN 1753-3015

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Introduction

Mental health issues are common and remain highly stigmatised despite high profile campaigns. In the European Union, the direct and indirect costs of mental health problems including treatments and lost productivity are estimated at €450 billion per year (“European Framework”, 2016). Treatment is typically delivered via mental health services led by psychiatrists, and usually dominated by diagnostic labelling and the use of psychoactive medications. Within the field, diagnosis is contested, with a schism between neurological and socially informed approaches. The push towards advances in neuroscience and the increased ‘biologising’ of mental health means that relationships, meanings and values are demoted, that is, the wider context of a person’s life assumes less importance (Bracken et al, 2012; Rapley et al, 2011).

This paper considers the concepts of labelling and diagnosis and how they may be explored using arts-based practice, specifically *The Roving Diagnostic Project*. The potential of this type of project to influence artistic practice is also explored.

Psychiatric Labelling and Stigma Approaches to mental health diagnostics are formulated via education and training but are informed by multiple factors including social, cultural and economic issues that underpin the history of mental healthcare, and the role and function of diagnosis and labelling in wider society. Diagnoses are socially constructed, that is, they are abstract notions of normality and abnormality, negotiated, understood and enacted through the values, culture and politics of the society that they exist within (Kawa & Giordano, 2012; Maddux et al, 2005). The use of arts based activity is one innovative way to explore and understand such multi-faceted and complex phenomena. This is because they can provide aesthetically interesting and non-threatening modes of engaging with challenging or sensitive material.

Diagnostic labelling can be valuable in terms of explaining and understanding symptoms and to access services. However, psychiatric terminology used within biomedical diagnostic systems, leading to labels such as ‘schizophrenic’ and ‘bipolar’ can be highly stigmatising, leading to discrimination and social exclusion of affected individuals. Psychiatric labels are often equated with negative attributes, such as emotional instability and violence, thus ascribing value judgements to people. According to Becker’s (1997) labelling theory, deviant behaviour may be adopted by people who are labelled. Individuals with psychiatric labels can be viewed as less worthy than others; this influences institutional cultures, policy development, and provision of services, and reinforces social exclusion. Media depictions of mental health conditions reinforce the biomedical position, and are often negative and derogatory, compounding stigma and discrimination.

Labelling is underpinned by widespread use of the internationally influential Diagnostic and Statistical Manual (DSM). Now in its 5th edition, it reflects changes in societal norms. The most recent version introduces diagnoses such as caffeine withdrawal and binge eating disorder that have proved controversial due to the blurred boundaries between ‘normal’ and ‘abnormal’ behaviour in the general population (Wykes & Callard, 2010).

Programme Rationale and Goals

This project sought to investigate public understandings of labelling and diagnosis within cultural settings, and to test out arts-based approaches that impact on individuals, services, and wider public understanding of mental health.

Art, Mental Health and Activism An emerging body of research and activism, for example the Hearing Voices and Mad Studies networks, challenges the predominance of psychiatry and labelling in mental health. Integral to this is the foregrounding of patient or service user perspectives and peer support networks led by Experts by Experience (EbE). These organisations aim to effect political and societal change alongside nurturing individual health and wellbeing. This is in line with recommendations for socially inclusive, community based treatment and meaningful involvement of people who experience mental health problems (Callard & Rose, 2012). The recovery model is now widely promoted within the mental healthcare system. It emphasises personal agency, building opportunities beyond illness, and nurturing hopes and dreams for the future (“What is Recovery?”, 2014).

This paper explores the impact of *The Roving Diagnostic Project*, devised by Daily Life Ltd, an arts charity, based in London. It is led by artistic director Bobby Baker, an acclaimed visual and performance artist. The organisation combines artistic activity with activism, working in partnership with Expert Artists who have lived experience of mental health problems. Daily Life Ltd provides a platform for Expert Artists to showcase their work and to challenge and to use art to change wider perceptions of mental health e.g. Tischler (2017).

The Roving Diagnostic Unit The Roving Diagnostic Unit (RDU) was a year-long project led by Daily Life Ltd and co-created with artists who have lived experience of mental health problems. It aimed to work with the public, artists and professionals to explore meanings of diagnosis and labelling. The approach aimed to widen access to, and deepen, participation in the arts for people who are excluded due to experiences of mental distress and to critically and imaginatively challenge biomedical understandings of mental health and mental illness.

Daily Life Ltd partnered with two cultural organisations for the RDU. These were William Morris gallery and Vestry House Museum, in Waltham Forest, London. A number of activities took place as part of RDU, firstly Expert-Artist led creative workshops at Vestry House museum. Secondly RDU tours took place as part of Walthamstow Garden Party (Summer 2016), and thirdly a Late event was held in Autumn 2016 at William Morris gallery. The latter two activities are the focus of this report.

Project Evaluation

The evaluation aimed to explore the impact of The Roving Diagnostic Unit (RDU) to: assess the quality of engagement with Expert Artists, to gauge public understandings of psychiatric terminology, and to explore the use of interactive, creative activities that engage the public with mental health issues.

The project adopted a co-creative model to ensure full and meaningful engagement with those familiar with diagnosis and labelling; patients and mental health professionals. All materials were designed with a group of people who had lived experience of mental health issues and with mental health professionals.

Data was collected over a six-month period and included online surveys seeking feedback about the Late event, written feedback from the Walthamstow Summer Garden party, led by volunteers who were briefed beforehand, observation at the William Morris Gallery Late event, Expert Artist interviews, and online surveys for attendees at the Late event. One reminder was sent about the Late survey to attendees. Three out of four Expert Artists provided feedback on their experience of taking part in RDU. The 4th artist was unwell so could not participate. The audio-recorded interviews took place at Daily Life Ltd’s studio. They were conducted by Daily Life Ltd staff and took the format of a debrief. The interviews

were later transcribed and pseudonyms assigned. Where possible, participants are identified with a unique number/letter combination and verbatim quotes are reported in italics.

The Walthamstow Garden Party (1) is a free annual event hosted by Waltham Forest Council in East London, held over a weekend during summer, in the grounds of the William Morris gallery, in Lloyd Park. The event attracts over 30 000 visitors and includes 600+ music, arts and community activities, plus food and drink stalls.

Daily Life Ltd set up a stall at the Garden Party in an area designated 'The Island' which featured many community groups and charities. Passers-by were given verbal information about the tours and could take part in 'Fruit Cake' selfies, that is, making your own face from fruit. Four RDU tours were held during the garden party, after the team of Expert Artists identified several park features that could be 'diagnosed'. These included a lake, a tree, a flowerbed, and a public realm sculpture.

[insert image 1 about here].

Attendees signed up for the tours beforehand. Staff and volunteers advised them that the tours were a playful and interactive activity that aimed to explore mental health 'diagnosis'. Forms collected data from attendees before and during the tours. The 'before' questions focused on definitions of labelling and diagnosis, and expectations about the tour. The self-report data recorded during the tours took the form of a 'mock' mental health questionnaire; this data was not part of the analysis. The participants supplied demographic data, and were asked whether their understanding of labelling and diagnosis had changed, and if so, how, and for any other comments on the activity. This data was included if both before and during the event forms were completed or part completed.

The Late event (2) was a free, curated evening of RDU activities. It was billed as a night of music, performance, poetry and participatory art that aimed to widen cultural participation whilst inspiring conversations about mental health. As the flyer stated: 'Join Bobby Baker and fellow artists in their epic quest to diagnose William Morris gallery'. The performances varied according to the artform and practice of the artists e.g. Bobby Baker presented a performance using props and costumes, set to music whilst sean burn used spoken word and audience participation in a workshop format.

One hundred and seventy-six people attended the event and eight Expert Artists led sessions during the evening. Examples of artists and activities were: sean burn – poetry workshop and performance; Sara Haq, Marie-Louise Plum and Kate Rolison - diagnostic expeditions of the William Morris gallery, using standardized psychiatric questions; Priya Mistry- a participatory art workshop making 'power pants' to help deal with everyday life; Dylan Tighe- solo musical performance.

Analysis Braun and Clarke's approach influenced the analysis of observational and textual data (Braun and Clarke, 2006). The approach was broadly inductive, that is, looking for ideas and themes that emerged during analysis, rather than imposing pre-conceived categories onto the data. Descriptive statistics were used for demographics and online survey data. Pseudonyms are used to preserve participant anonymity.

Results

(1) Walthamstow Garden Party - RDU Tours Thirty-four participants completed forms before and during the tours. Of those who completed the demographic data, the

average age was 36 (range: 19-64). Ten were male, 23 female, and 1 was defined as gender fluid. Fifteen lived in East London, 9 were from other parts of London, 4 from elsewhere in the UK, and one was from another part of Europe.

Participants completed a form asking about their understandings of labelling and diagnosis, 'diagnosing' objects in the park (using items adapted from standardized mental health questionnaires), and reflecting on doing this exercise. They gave standard definitions of labelling and diagnosis prior to tours e.g. of labelling: *'naming something in order to make it less abstract and therefore more manageable'*, and of diagnosis: *'establishing the reason behind a set of symptoms'*. Others indicated a value judgment, e.g. in relation to labelling *'restrictive categories'*, and of diagnosis *'diagnosis can be scary but can also enable people to understand why they're feeling what they're feeling'*.

Expectations regarding the event were varied. Most responses referred to learning something about mental health e.g. *'perhaps a conversation about mental health? 7G'*. Others had less obvious or subtle expectations e.g. *'Looking at things with more colour, not black and white'*. Some participants indicated that they may not have known or understood the nature of the activity e.g. one stated *'to look at some trees' 4R'*.

In relation to perceptions of labelling and diagnosis, most participants who responded indicated a shift in their understanding. For example, some noted that they were more aware of stigma e.g. *'It brought others experience [of stigma] to the surface'*. Many referred to the fluid, subjective and sometimes contested nature of diagnosis, e.g. *'Diagnosis can be a waste of time if understanding, vocabulary and end goals are poorly formed' 2G'*.

Similarly participants indicated that labels were subject to interpretation and multiple influences, for instance: *'Labels are loaded, individuals are infinitely complex' 2R'*. It was evident that tour discussions had acted as a stimulus for engagement with mental health issues. For example: *'everyone swims serenely on top of the pond, much like a swan. Who can see what goes on underneath?? 12R'*. Some had negative comments, for instance: *'Took me a while to take this seriously as we were assessing a pond 9R'*.

(2i) Late event-survey Seventeen attendees replied to an online survey, 11 females and 6 males. This asked about motivation for attending, their preferred activities and reflections on mental health content. Fifteen identified as British or White British, 1 as Irish and 1 as White (other). Eight were from London, 8 other UK, 1 did not answer. Participants were motivated to attend for a variety of reasons, the most common were knowing and supporting the work of Daily Life Ltd (3), fans of Bobby Baker's work (2), and professional or personal interest in mental health (2). In response to the question: How would you describe the RDU Late to someone who didn't attend? One said: *'An evening of art, madness and fun'*.

The RDU tours were noted to stimulate conversation about mental health, for example: *'the tours were really interesting and nuanced in a way I hadn't thought about mental health before'*.

(2ii) Late event- observation The event offered choices to visitors with regard to what to participate in and many parts of the venue were utilised. Some offered more interaction than others, in particular Priya Mistry's 'power pants' and sean burn's poetry workshop. Mistry's workshop was noted to mix outlandishness with craftsmanship and care 'that seemed to channel the spirit of William Morris'. Participants in this workshop appeared 'really engaged', transformed and empowered, their 'confidence visibly growing' e.g. they

were observed 'posing and dancing' and wearing their crafted 'power pants' around the gallery.

[Insert image 2 about here].

sean burn's workshop focused upon language and story-telling. The event was sociable yet felt confidential, almost like 'therapy' with participants sharing information about their own mental health and being invited to wear words e.g. fragile or agile to represent how they felt. This was noted to induce a sense of anxiety. The activities were interspersed with introduction of factual material e.g. being transgender is considered a mental illness.

The RDU tours utilised gallery objects e.g. reels of thread (Silks from Merton Abbey) in a cabinet to challenge ideas about diagnosis. The objectification of ideas about mental health gave permission for participants to express ideas and opinions without revealing personal information. The tour guides shared information about mental illness and its treatment. It was noted that this might have broken the narrative.

Dylan Tighe's performance in the Story Lounge was notable e.g. 'no one left or checked their phones'. The audience were hushed and respectful gathered before him. The acoustics of the space enabled the sound to travel across the room and down the spiral staircase, demonstrating a harmony of space and sound: 'it saturated the rooms with a melancholy atmosphere'.

Expert Artist Feedback A number of themes were identified across the interviews. These were: i: Collaboration and its Challenges, ii: Personal Impact and Professional Progression and iii: Feeling Valued.

Artists noted that the opportunity to collaborate brought benefits e.g. *I've grown so much this year. Just working with others and being a bit calmer and more measured* (Sally).

The project was described as 'fun' and an antidote to negative emotions, e.g. *I was definitely feeling a bit angsty at the time and it just got out some catharsis* (Paula). She expressed feeling braver following the project: *Not being so scared and just going to things more*. It was evident that the artists felt supported by Daily Life Ltd. throughout. As one stated: *It's so clear you value the artists you work with as artists and for the work that they are making and trusting the perspective they bring into a piece of work will make it relevant*. (Laura)

Discussion & Future Plans

The evaluation found that the RDU was able to challenge perceptions about mental health problems e.g. that diagnosis can be thought of as dynamic and subjective, and to engage the public using a variety of playful and challenging creative activities. The findings reflect an appreciation for this type of event noted by the strong engagement of participants and their expression of views of the stigmatised topic of mental illness. This suggests that creative activities are a useful way to counteract negative perceptions that the public may hold about mental ill health. The artists involved indicated important benefits to their own mental health and welcomed opportunities to extend their working practice. Visitors to the Late, and the Garden Party indicated a shift in their views about labelling and diagnosis. Further research may usefully explore the use of participatory creative activities as a way of challenging diagnostic categories, and hence the dominance of the biomedical model. Care must also be taken to generate rich data to capture a more nuanced understanding of the

impact of the project on participants and on concepts related to mental health. The use of paper-based and online surveys in the current study limited this.

The project was led by Expert Artists, that is, those labelled 'disordered'. Such an approach challenges the status quo and their feedback indicated that they felt valued, encouraged and motivated through participating in the project. Similar recovery-facilitating reports are made by mental health peer support workers (Repper & Carter, 2011). The model of co-created, Expert-led services signposts an effective way to redress imbalance, counter exclusion, and to provide opportunities and effective support for those marginalised by mental health issues.

The RDU represented a fun, interactive project that had a positive impact on visitors, participants and Expert-Artists. This occurred by combining inspiring conversations about mental health, challenging perceptions about diagnosis and labelling, and involving people in participative, creative activities. The Late event was successful in engaging visitors, artists and staff. The words fun, fascinating and insightful suggested that the project was enjoyable as well as educational. The use of free public museums and galleries highlights the role that community cultural venues can play in facilitating and showcasing socially engaged and high quality artistic performance, and in opening up to scrutiny e.g. in relation to how accessible they are, to those who may feel excluded due to mental ill health.

Art and mental health activities require careful planning, explanation and management as the subject matter remains sensitive and those with lived experience and others involved may require additional support to take part. In terms of future work, effective staffing, funded access (for disability), and mentoring are required to maximise the contributions of those experiencing mental health challenges. Equally building relationships with Expert Artists and cultural organisations is needed to ensure that project impacts are fully realised.

Future projects may usefully explore activities in other venues, with different artists and art forms, and with a broader cross section of the public.

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