

## ***Ethical Issues in a National Mental Health Arts and Film Festival***

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### **ABSTRACT**

The Scottish Mental Health Arts and Film Festival has seen hundreds of arts, public and community groups co-produce over 300 events to over 25,000 audience members. Integral to this arts-based approach, in contrast to social marketing or public education models, is the notion that mental health is an essentially contested concept whereby meanings are negotiated and debate encouraged. With emerging evidence that the festival is an effective way of engaging people intellectually and emotionally, we explore ethical issues, challenges and paradoxes that have emerged as the festival has developed. Consideration is given to issues of power, purpose, opportunity costs, reach, impact, programming risks, and participation from those with experience of mental ill-health. Throughout, we explore practical implications for funding, managing, programming, marketing and evaluation of this and similar endeavours.

**Key words:** arts; film; festival, stigma; discrimination.

**T**his paper seeks to begin a conversation about the ethical issues associated with organizing, delivering and evaluating an arts festival about mental health. In doing so we would acknowledge the thoughtful paper by Krahn (2009) that considers some of the ethical and practical issues in organizing a mental health film series. The potential scope of this territory is extensive,

and this paper does not aim to provide a comprehensive overview of the ethical issues involved. Nor will we be reporting back on the extensive festival evaluations that are being undertaken. Instead we aim to describe and explore some of the challenges, tensions and paradoxes that emerge 'in practice', practice that has been inspired by the ideas and work of Byrne (2009). We hope to generate questions that will provoke and encourage others to respond. In doing so, the authors draw upon our differing experiences of directing and evaluating the Scottish mental health arts and film festival (smhaff). We will briefly outline the development and purposes of the festival and then consider some of the ethical issues in relation to the scope of the festival, its identity, issues of leadership and power, the cost of the festival, its reach and impact on audiences and the involvement of people who use mental health services.

### **The Festival**

The Scottish Mental Health Arts and Film Festival has become a major national cultural event and one of the largest festivals of its kind. Over 300 events have attracted audiences of 25,000 people. Media coverage has been extensive and positive in the press, radio and television, with an emphasis upon high profile artists that appear at the festival. The events are increasingly the culmination of year round collaborations between artists, artistic organisations, community development groups, mental health groups and practitioners and include theatre, film, concerts, exhibitions, dance, comedy, literature and fusion events. Partners

now range from the BBC and national arts bodies through to small community groups. The festival has evolved over 3 years towards a collective model which sees hundreds of partners working locally or nationally and includes a collaborative funding and management model, co-curation between arts, public and community groups, and regional planning networks spanning numerous sectors of civil society. The festival's stated vision is to achieve social change towards mental health through the arts by: 1) Challenging perceptions of meaning, stigma and inequalities in mental health 2) Making connections between community, public, arts, academic and voluntary organisations. 3) Developing audiences and reaching those who are often missed 4) Encouraging participation in the creative process by those who have experienced mental health issues, but also the wider community as a well-being initiative 5) Creating great arts events. It is formally supported by the Scottish Government who lead the national mental health improvement plan 'Towards a Mentally Flourishing Scotland' (Scottish Government, 2009).

## Scope

The initial idea for the festival was a weekend of film designed to challenge stigma associated with mental health problems. Stigma and discrimination towards people experiencing mental health issues remains stubbornly entrenched despite a wide range of national and international campaigns that use public education, mental health literacy and social marketing approaches (Corrigan & Penn, 1999; Thornicroft, 2006). The limitations of these positivistic approaches have led to a reconsideration of the potential of the arts. The multi-faceted role of the arts has been explored in relation to recovery from mental health problems (Crawford & Patterson, 2007; Spandler et al, 2007). Added to the benefits of participation in the creative arts on individuals' mental health, there is potential for using the arts for communicating ideas and effecting social and personal change in mental health (McCarthy et al, 2004). The main premise for the festival is that the arts have the ability to change public attitudes to reduce the stigma against people with mental illness (Chung et al, 2006; Twardzicki 2008).

## Identity, power and partnerships

The approach taken within the festival is to have a broad planning and funding group comprising a diverse range of partners and funders that share the costs and are part of a decision making process. This avoids being too dependent upon one funder and the problems this would create in terms of being restricted to being 'on message' for this particular funder. The range of partners funding and organising the festival hold different philosophical and political positions in relation to mental health and the arts. These include professional groups including psychiatrists, a range of organisations within the service user movement, government agencies and policy makers, social marketers, voluntary and community groups and arts organisations. These positions are informed by both organisational and personal identities. This results in debates and tensions about concepts of mental health and the purposes of the arts in society. Consequently the festival as a whole may be viewed very differently by partners in terms

of its identity and nature and its purposes. The festival can and has been seen as:

- a human rights initiative
- an anti-stigma initiative
- a social marketing tool
- an artistic platform
- an opportunity for members of the public to meet people with mental health problems

This raises ethical issues in relation to the leadership and management of the festival. Is one perspective dominating? Are compromises diluting the focus and value of the festival? Are partners clear about what they are signing up to and what others might try to promote? It may be possible to fulfill a diverse range of organisational aims but this has to be carefully considered. One implication is that potential partners may not join as their positions may not be reconcilable with the concerns of a broader community of practice. For example, the remit of the festival is not to say *how* mental health problems should be treated and therefore accepting funding from pharmaceutical companies might be unacceptable to some partners. For a different reason, certain arts bodies might argue that all work should be artist-led rather than co-created with mental health partners and may exclude themselves from the process for this reason. A community of practice (Wenger, 1998) that is more democratic or equitable creates a process whereby contradictory ideas and intentions can be identified and managed. It has the potential to lead to meaningful festival events shaped by a broad range of partners, in contrast to a model in which a festival is commissioned to a single organisation and thereby dominated by one perspective, which is unlikely to engage the wide range of perspectives, which such a complex and contested issue as mental health needs (Faulkner & Thomas, 2002).

## Cost

One ethical question to emerge from the development of a mental health festival is, '*Can we justify limited resources in the public and voluntary sector being spent upon such a festival?*' Mental health problems are seen globally as one of the major health issues and are an increasing public health burden (WHO, 2001). Given that mental health is consistently an under-funded area of health and the pressures on health budgets in the context of recession, it can be argued that an arts festival cannot be justified. The ethical question is '*Could this resource be better used to provide frontline services?*' In addition, it could also be argued, '*Can the resource be more effectively used in other public health approaches?*' We would argue that mental health services are not an appropriate comparator, partly as the festival aims to create extensive opportunities for people who use services and promote recovery and positive personal identity. In addition, the direct funding and in-kind pro bono money received would not be combined into a central fund and donated to mental health services. Opportunity costs essentially relate to the moderate cost of administering the festival. In relation to public education, the festival offers excellent

economic value being low cost and having extensive reach both directly to audiences/public and through media reporting. Even excluding the economic value from the PR and media coverage and excluding the range of visitors to exhibitions, outreach and education events, the cost per attendee at an event with debate is approximately £5. These figures are a fraction of the costs of national training courses on mental health and national mental health campaigns. The reason that this is possible is that the festival engages hundreds of organisations, who often don't see mental health as their core business, in events. This process is successful in leveraging in huge additional direct and in-kind finance to the area of mental health that other approaches do not. Moreover, it has the potential to make mental health a mainstream issue, which has resulted in the development of formalized multi-agency networks in almost 20 regions of Scotland linking arts, media, public and community organisations.

## Reach

A challenge for the festival is to reach the widest possible range of the community. One potential criticism is that a festival is only likely to reach those who are already well informed about and well intentioned towards mental health issues, such as people who use mental health services and their families and friends, and those who work in mental health.

However, even where a significant portion of the audience and participants have an interest in mental health issues there is still a lot of value in the scope to consolidate and build a community of interest that can challenge stigma and discrimination. The process of practitioners, those that use services, academics and others debating issues through the arts and panel discussions, offers the scope to construct new understanding and insights and challenge the dominant discourses and promote equity (Pilgrim, 2005). In addition, if one of the primary aims of the festival is to challenge stigma, then it seems entirely appropriate that those affected by stigma have the opportunity to come together. There is a tendency among mental health service users to internalise the negative views that they perceive as coming from others, to such a degree that it devalues their sense of self-worth and creates a feeling of 'otherness' relative to the general public (Green et al, 2003). Bagely and King (2005) suggest that a major focus of stigma work should be exploring, and coming to understand service-users' experiences of stigma and use this to inform interventions and campaigns. Moreover, if a central theme of the festival is to challenge stigma then you can argue there is a need to challenge stigma amongst this community of interest, given that service users have reported friends, family and mental health professionals as being sources of stigma (Wahl, 1999).

Another potential criticism is that an arts festival will only be relevant to middle and higher income earners within society. Internationally, there appears to be a relationship between socio-economic standing, and the tendency to pursue artistic and cultural activities. McCarthy et al (2004), argue that the individuals with an interest in the arts will typically be well-educated and hold sizable stocks of cultural and social capital. Thus, there may be a danger that any potential benefits afforded by attending an arts festival may be absorbed primarily by a middle-class subsection of society at the expense of reaching wider communities. Individuals

who earn higher salaries and higher educational qualifications, attend, and participate in, more artistic events than those who earn lower salaries (Hill Strategies Research Inc, 2003; TNS, 2008; NEA, 2009; Timmins, 2009), although this does vary according to art form. This has particular implications for the future of an arts festival as an anti-stigma intervention; if an arts festival cannot reach wider society then its potential for effecting social change must be considered severely compromised.

Equally, there is evidence that mental health awareness campaigns rarely reach communities that are at risk of marginalisation, such as minority ethnic communities (Tilbury et al, 2004). A central question is whether the festival corresponds to this pattern. A strength of arts events in this context is that they have the capacity to be flexible, and to work with and within the explanatory frameworks of diverse cultures and communities – indeed one driver for establishing the festival emerged from community conversation and dialogue with ethnic minority communities about overcoming the deficiencies of existing approaches (Knifton et al, 2009). And in practice, the evidence from the festival is that the events seem to be particularly effective in engaging ethnic minority communities, and low income communities (Quinn et al). One explanation for this is that we have evolved a co-programming model where community development organisations are central to the development of events and the marketing process. This is resource intensive but seen as an ethical imperative (the festival has almost 20 regional and equality/diversity planning groups). Events are often in different languages and ethical programming necessarily involves a broad range of partners from different ethnic minority groups and low-income communities.

In building the ethical case for a mental health festival we have outlined a festival that is collectively managed, cost effective, and reaches a wide range of society. At this point, it is important to consider the impact of the festival upon audiences.

## Impact

Of course impact needs to be considered from a variety of perspectives, but in terms of audience impact (the core stated concern of many stakeholders) this is very complex. It depends upon the broad concepts that are being used in events; there is scope for considerable variation in what different people will take away from events. Traditional social marketing and public education would argue that the safest, most ethical approach would be to focus upon the content of the art/film and present only those that have clear and positive messages and that post event discussions and information should contextualise these with key messages. However, approaches that focus only upon education/information not only exclude a contribution of a range of perspectives, but they are not particularly effective (Corrigan et al, 2007).

However, there is a strong ethical case for avoiding screening suicide and self harm, specifically the problem of graphic depictions of the methods of self harm and suicide, which have the potential to influence vulnerable people within the audience (Byrne, 2003).

There are also other artistic representations which evidence

suggests have the potential to ‘worsen’ attitudes. Gaebel and Baumann (2003) report an attempt to challenge stigmatised attitudes towards people with schizophrenia amongst a sample of 200 participants. Here, participants were shown a film (*White Noise*) that acutely portrays a character’s subjective experiences of paranoid hallucinatory schizophrenia, and attempts to maximise the viewers’ involvement with such experiences. Although the majority of viewers reported an enhanced understanding of schizophrenia following the screening - as well as a greater capacity to empathise with individuals who might be suffering from schizophrenia – the film also appeared to reinforce negative stereotypes concerning people with schizophrenia, and increased social distancing. Gaebel and Bauman (2003) suggest that the nature of the film may have made participants feel too ‘close’ to the protagonist and his plight, which sparked the negative reaction. This impact has been seen with one film in the festival, *The Devil and Daniel Johnson*, which led to dangerousness perceptions worsening amongst the audience (Quinn et al). This documentary is a provocative piece that portrays its subject as unpredictable and remaining unwell with schizophrenia, despite continuing as a highly accomplished musician. Importantly, this film also induced strongly positive responses indicating that evaluating arts events is very complex and demonstrating the need for thoughtful programming, and careful evaluation.

Films that explore more positive themes, such as recovery and rehabilitation, may be more effective in engendering more positive reactions and breaking down stigma. Emerging evidence from the festival also suggests that meaningful involvement in events from people who have experience of mental health problems, or who are from communities that experience marginalization, are crucial to impact (Quinn et al).

The key ethical dilemma here is about the balance between certainty and risk – a continual safe programme may lose the attention of the public and media, and lose the chance to create new insights and create real debate. But on the other hand, this has to be set against the risk that challenging programming might increase stigma and possibly alienate partners who want to stay ‘on message’. The festival has an international film competition, judged by a range of stakeholders, which has consistently identified and rewarded films that are challenging but do not show self harm, suicide or overtly negative portrayals of people with mental illness.

This brings us back to the actors...

## Support

If, as the emerging evidence indicates, the involvement of people who have experienced mental health problems is central to the success of events whose intention is to address stigma, then is this at a cost? It is imperative that a festival has a strong enough contribution from mental health service user groups to ensure that events reflect peoples’ lived experiences, and that people are not being used as puppets of policy makers, social marketers and others. One way of assessing this is to consider to what extent events challenge dominant models and perspectives of mental health. One approach that has evolved in the festival to address this is a devolving of ownership of programming. Our challenge is not

only to create an artistic programme but an artistic platform for a multitude of voices, perspectives and conversations – the balance is achieving and presenting coherence in this collective model. More generally, one can argue that the entertainment aspects of the arts cannot be minimized. Even if well-intentioned, are we entertaining people at the expense of the range of people that experience mental health problems? Green et al (2003) argue that whilst campaigns that stress the prevalence of stigmatisation toward the people with mental illness may be effective in changing the attitudes of the general public, they may have a negative impact on service users.

At an individual level, involvement by people who identify as having mental health issues remains sensitive. Ethical dilemmas in sharing personal narratives are considerable. An ethical imperative is to ensure that involvement is not coercive - there may be formal or subtle pressure to share your narrative. Also, we know very little about the long-term impact on the narrator. Support must be available when people share their experiences with hundreds or thousands of people in arts events or post performance panels, that they are aware of potential consequences - that they can deal with potential hostility. There should be adequate support and safeguards before, during and after events to allow people to withdraw without feeling that they are letting others down.

There is a particular challenge around the issue of informed consent, for example what if people change their minds after it has entered the public domain? Film has particular issues. When experiences and narratives are captured on film this can remain in the public domain forever (or at least it can be difficult to take back). There can be a tension between the documentary filmmaker who wants raw, dramatic footage and the service user who does not want to be depicted as unwell, unstable or dangerous. With film, documentary subject frequently becomes object, and the service user’s story if mistold is forever available for public viewing (Byrne, 2009). The process of sharing your personal narrative on an ongoing basis creates a potential paradox. Personal narratives have the potential to be empowering and transformative (Gergen & Gergen, 2003) but equally to reinforce negative identities. Whilst reducing stigma amongst the audience, you may be reinforcing your negative self-identity based upon your label as part of a stigmatised minority group.

However, the contribution of people who use services drives the festival. As long as consent is informed and people feel supported and can opt out at any time, these risks have to be considered against the immense potential for positive impact, for both the person and the audience, captured well in quotes from an ongoing study on the festival:

- *As a person suffering from mental health problems, being a part of this has given me confidence*
- *Members of our group have gained pride, confidence and had a wonderful experience*
- *It has given me a wide insight into the effects and causes of mental illness*
- *It made me appreciate myself and others for who they are*

Yet, it is also useful to consider the multiple, temporal and fluid nature of identities that all narrators have (e.g. loving parent, creative writer etc). This raises questions of whether it is most useful for narrators to be identified and introduced as 'service users' as their primary identity. It raises the issue of whether we can work towards a different approach to narratives and arts, where the narrative focus is upon mental health as part of the human condition, and where perhaps the audience also engages in dialogue about their own mental health identities.

We are aware that this paper is just the beginning of a dialogue in which only some of the ethical dimensions of the festival have been tentatively explored. We are aware that we have not touched upon a number of areas such as the ethical dimensions of charitable fundraising or profit making from a festival, or the representations of mental health problems as positive states. However, what we highlight is the importance of incorporating different voices into shaping the festival and the need to develop the dialogue to inform the ethical dimensions of planning, implementing and evaluating the festival.

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