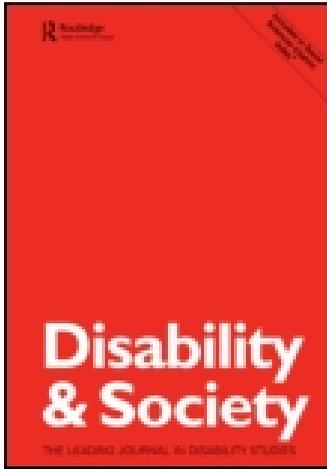


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Challenging perceptions of disability through performance poetry methods: the ‘Seen but Seldom Heard’ project

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This paper considers performance poetry as a method to explore lived experiences of disability. We discuss how poetic inquiry used within a participatory arts-based research framework can enable young people to collectively question society’s attitudes and actions towards disability. Poetry will be considered as a means to develop a more accessible and effective arena in which young people with direct experience of disability can be empowered to develop new skills that enable them to tell their own stories. Discussion of how this can challenge audiences to critically reflect upon their own perceptions of disability will also be developed.

Keywords: arts-based methods; disability; participatory research; poetic inquiry; performance poetry; voice

Points of interest

- This paper considers performance poetry as a method for researching and communicating young people’s everyday experiences of disability.
- Poetry is used to explore issues associated with identity, stereotypes and representation.
- We discuss how, through poetry, young disabled people are able to collectively question dominant, largely negative, attitudes towards disability and to challenge them.
- We argue that poetry workshops can empower young people to develop new skills that enable them to tell their own stories.
- We suggest that by engaging audiences on an emotional and intellectual level, performance poetry can encourage members of the public to think differently about disability.

Introduction

This paper discusses how performance poetry can be used as a research and practice method to engage with the voices and experiences of young disabled people. The backdrop to the initial phase of this project was the 2012 London Paralympic

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Games, which raised the profile internationally of disabled athletes as well as disability issues. The unprecedented media attention and coverage surrounding the Paralympics provided a valuable platform upon which to develop the ‘Seen but Seldom Heard’ project, with the aim of exploring young people’s lived experiences of disability through a creative methodology. The London 2012 Cultural Olympiad was the largest cultural celebration in the history of the modern Olympic and Paralympic Movements and encompassed a wide range of arts and cultural events, providing the project with an opportunity and a platform to raise the profile of a group of young poets who sought to challenge existing dominant perceptions and representations of disability by sharing their own personal stories through the medium of performance poetry.

Context

The 2012 Paralympics raised the profile of disability more than any previous event, yet following previous Paralympic events, concerns have been expressed about how representative the images of elite Paralympic athletes are for most disabled people. Following the Olympics and Paralympics hosted in Sydney in 2000, it was suggested that the portrayal of elite Paralympic athletes did little to challenge the negative media portrayal of disability generally (Goggin and Newell 2000). Others have questioned how representative the increasing ‘techno-centric’ ideology of the Paralympics is for most disabled people, who are largely excluded from accessing such high-tech equipment (Howe 2011). The stories of elite sport and super humans associated with the Paralympics can divert attention away from the real issue, whereby individuals are labelled by society as being ‘disabled’, and not defined by their impairments *per se* (Ellis 2009). This leads to further marginalisation of disabled people within society, culture, economics and politics (Goodley 2011; Dupré 2012). The lived experiences of many disabled young people are linked to negative attitudes, beliefs and prejudices that constitute barriers to education, employment, and social participation (World Health Organisation 2011). Those who face specific communication challenges may be further marginalised (Mackenzie, Bennett, and Cairney 2011).

Despite the positive representations of disability through the Paralympics, depictions of disability within the media and popular culture remain largely negative due to the limited number of stereotypes used; in particular, those of helpless, passive victims who are dependent upon others (Barnes and Mercer 2010). Despouy (1991) argues that the greatest barriers in the lives of disabled young people are prejudice, social isolation and discrimination. It is therefore important that these young people are supported to voice their experiences and opinions. Professor Stephen Hawking (2011, 3) in the foreword to the first World Health Organisation report of disability advocates: ‘we have a moral duty to remove the barriers to participation, and to invest sufficient funding and expertise to unlock the vast potential of people with disabilities’.

Methodological background

Disability theorists argue that culture has largely served to create and maintain the marginalisation of disabled people through negative imagery, stigmatising language, and adherence to normative standards of appearance and behaviours dictated by the dominant culture(s) (Dupré 2012). As Saleeby suggests

groups who suffer the domination of broader social institutions or their own cultural devices under the dominant culture frequently do not have their stories told or heard ... one of the characteristics of being oppressed is having one's stories buried under the forces of ignorance and stereotype. (1996, 301)

Such marginalisation becomes compounded when, at the structural level, economic, legal, political, social and cultural institutions, policies and practices, all work together to benefit the interests of the dominant group(s). Oliver (1998) argues that a new epistemology for disability studies research is required, one which rejects a discourse that prioritises investigatory research and replaces it, instead, with one of emancipation. Disability activist and theorist Tom Shakespeare (1997) has argued that studies of disability often neglect questions of culture, representation and meaning, and ignore the individual and collective lived experience. In contrast, studies that seek to integrate a 'disability culture' approach place emphasis on the positive portrayals of disabled people, communicating not only shared experiences of oppression, but also dimensions and manifestations of culture in terms of art, humour, language, beliefs, values and aspirations for the future (Dupré 2012).

The use of arts-based research can shift our understanding of what counts as evidence and highlights the complexity involved in creating new knowledge (Boydell et al. 2012). Personal interpretations of lived experience can contribute to a sense of 'shared identity' amongst disabled people (Peters 2000), as disabled people become active agents in the creation of both knowledge and culture (Dupré 2012). Identifying and communicating the relationships between cultural representations of disability and the authentic experiences of individuals is fundamental to understanding the conditions that shape the everyday lives of disabled people. Disability arts offer an important way for disabled people to communicate their experiences, whilst offering a critical response to issues of social marginalisation (Dupré 2012). This involves 'the development of shared cultural meanings and collective expression of the experience of disability and struggle; this entails using art to explore the discrimination and prejudice disabled people face and to generate group consciousness and solidarity' (2012, 207). Disability arts, therefore, seek to educate, communicate and encourage action for change.

Arts-based research is a means to legitimise, empower and promote the voices of those who are historically silenced or marginalised (Bagley and Castro-Salazar 2012), enabling them to frame the issues that are important in their lives. By communicating these issues through creative means, it is possible to evoke an emotional response amongst an audience, which helps to construct alternative forms of representation that promote dialogue (Jones 2006). The approach we adopted within the project we discuss was informed by our desire for the research to be emancipatory and empowering for all participants. This included a commitment to use a participatory methodology working in collaboration with young disabled people as opposed to conducting research about them (Thomson 2008). We believed that arts-based methods would engage with them, enabling the young people to construct the images used to tell their own stories whilst, at the same time, developing confidence in their own creative potential through the process of writing, producing and performing poetry.

Performance poetry as a research method

The aim of the 'Seen but Seldom Heard' project was to provide an opportunity for a group of young disabled people to engage with creative activities designed to encourage them to reflect on their lived experiences and to empower them to challenge dominant societal perceptions of disability through poetry and performance. Previously it has been suggested within disability research that emancipatory approaches have in themselves been an exercise of power that can become an instrument of oppression by silencing some voices (Danieli and Woodhams 2005). In other words, it is important to examine both the material and the social relations of knowledge production. In our research, we were mindful of the three domains for disability research identified by Barton (2005): firstly, research should concern itself with issues of social justice, equity and citizenship; secondly, research should be conscious of barriers to participation; and thirdly, the research should be transformative, and develop understanding of the ways in which disability is socially produced (Barton 2005, 318).

Methods of poetic inquiry (Prendergast 2009) potentially address all three of these areas as disability poetry has the potential to challenge existing individual and social preconceptions about disability (Scheuer 2011). Poetic inquiry is a relatively new approach within qualitative research, primarily dating from the 1980s onwards, and examples can be found within a variety of social science disciplines including sociology, anthropology, education, management and social work. The characteristics of poetic inquiry proposed by Prendergast (2009, xxxv–xxxvii) are deliberately broad, and range from researcher/poets analysing data from field notes and/or interviews and then presenting such insight in the form of a poem, to auto-ethnographic poetry produced to communicate the researcher's experiences when undertaking a particular project of field research. These approaches are different, however, from working directly with participants to develop poetry. This latter approach characterises poetic inquiry as 'VOX PARTICIPARE' (Prendergast 2009, xxii), whereby participant-voiced poems are solicited directly from participants in an action research model where the poems are co-created with researchers. This is the approach we take in our work. We draw on and apply the following from Prendergast's extensive list of definitions of poetic inquiry as a foundation for our study, which engages with the following (see Prendergast 2009, xxxv–xxxvii):

- Poetic inquiry as a form of qualitative research in the social sciences that incorporates poetry in some way as a component of an investigation.
- Poetic inquiry as interested in drawing on the literary arts in the attempt to more authentically express human experiences.
- Poetic inquiry as being aware of ethical practices in the use of human participants when engaged in poetic transcription and representation of the voices and stories of others.
- Poetic inquiry as a response to the crisis of representation experiences in post-modern critical perspectives on traditional approaches to ethnography and other social science research paradigms.
- Poetic inquiry as sometimes a socio-political and critical act of resistance to dominant forms and an effective way to talk back to power.
- Poetic inquiry as philosophically aligned with the work of poets through literary history who were committed to using poetry as a means to communicate experiences of memory, identity, place, relationality, hope, fear and/or desire.

- Poetic inquiry as, along with all arts-based inquiry approaches, deeply concerned with aesthetic issues around quality, qualifications, preparedness, elitism and expertise.

The approach we adopt is deliberately participatory and engages young people in a creative and fun way; therefore responding to Barton's (2005) domains for disability research in three ways. Firstly, it is grounded in social justice, equity and citizenship through its participatory approach, which engages directly with the experiences and feelings of the young poets to explore issues related to disability, identity and marginalisation. This links to Boal's (1979) notion of the 'Theatre of the Oppressed', and sits comfortably with disability research that seeks to work with oppressed groups to effect change (Oliver 1992; Zarb 1992). Research poetry has been described as a 'practical and powerful method for analyzing social worlds' (Richardson 2000, 931), and for communicating 'the slipperiness of identity, the difficulty of capturing the shifting nature of who we are and want to be [...resonating] more fully with the way identity is created, maintained, and altered through our narratives and interactions' (Faulkner 2006, 99). Poetry therefore offers a way for young disabled people to explore identity and their lived experiences in a sensitive and meaningful way through words and performance (Edghill 2009).

Secondly, we were mindful of Recommendation 7 of the World Health Organisation (2011, 19) *Report on Disability*, which concerns increasing public awareness and understanding of disability as part of promoting an inclusive society, and were keen to ensure that all participants were supported to have their poems heard. Performance poetry has been used as a method to explore issues related to belonging or not belonging; for example, in Noel's research carried out in a Puerto Rican context, performance poetry is described as developing 'self-reflexive practice that rethinks ... the terms of community, belonging, and exclusion' (2011, 92). In a similar vein, the use of performance poetry within the 'Seen but Seldom Heard' project can be seen as a device by which participants explore issues of belonging and exclusion related to their experience of disability. In this way, poetry might be regarded as a form of 'qualitative phenomenological inquiry – a way of making sense of lived experience, a conversation with one's environment and a way to give voice to that which is not easy to articulate' (Gold 2012, 757). As a creative research medium, performance poetry engages participants and supports them to develop their own stories in their own language and words using poetry and drama to nurture the written and communication skills of those involved.

Finally, performance poetry becomes a form of intervention or social action that reaches out to touch the hearts and minds of the audience in a direct and transformative way as the poet/performer becomes the educator; the performance setting itself may also provoke social interaction and dialogue, which encourages the audience to recognise themselves as having a part to play in finding a greater solution (Moxley, Feen-Calligan, and Washington 2012; Potash and Ho 2011). Similar to other arts-based research approaches, it was hoped that the process of writing and performing poetry would also provide those participating in the project with a critically 'reflective lens' to explore their experiences and longer term aspirations (Palidofsky 2010) and also to empower them as active knowledge creators and artists who exercise creative control over their work, telling their own stories in ways they find most meaningful (Moxley, Feen-Calligan, and Washington 2012). As Foster (2012, 748) and Pelias (2005, 419)

suggest, poetry (particularly performative writing) calls for empathy, allowing the audience into another world in order to feel what the poet might feel. This is perhaps ‘the most significant benefit of the use of poetry as social scientific data [...] to encourage empathy in its audience’ (Foster 2012, 748). Performance was not without risk to the participants, however, especially in making commitments to significant public events and performances in front of their peers, teachers, family and members of the public. We consider this in more detail within the following section of the paper.

Case study: ‘Seen but Seldom Heard’

The ‘Seen but Seldom Heard’ project is a collaboration between university academics from a School of Health and Social Care and a Media School and a local residential and day school offering specialist care and education to young disabled people from three to 19 years old with physical disabilities or complex medical conditions (and in some cases also additional needs including communication challenges, learning difficulties and sensory impairments). The first two phases of the project involved a series of participatory performative poetry workshops over a period of 14 months, working with a group of between 10 and 15 young people, aged 14 to 20 years, to explore the nature of disability within society and their own experiences of being disabled. The workshops began by using both the achievements and media portrayals of Paralympic athletes as a focus for individually written and collectively authored poetry, which sought to enhance public understanding and confront negative perceptions of disability. As the project progressed, the group began to use poetry as a way to engage in conversation about issues, policies and practices that affected them and others with similar experiences. The work has culminated, so far, in five live performances, including an event that coincided with the Paralympic Cultural Olympiad celebrations in Weymouth in August 2012 and a performance at the Bridport Literary Festival in October 2012.

Workshops of either one full day or one half-day were delivered at the same time and place each time in order for the group to establish a familiar routine and a feeling of safety and consistency, which was important for all involved to work together effectively. The group also collectively established boundaries in terms of behavioural expectations, and the importance of respecting these boundaries were communicated amongst all members. Each workshop was facilitated by two professional performance poets supported by two academic researchers, the school’s drama teacher and a group of support staff (approximately 1:2/3 students). The poets leading the workshops acted as ‘group conductors’ (Harris 2011, 80); that is, enabling ‘each group member to join in and contribute to the group in their own way in much the same way that an orchestral conductor enables a group of musicians to play together’ (2011, 80). The young people were shown how to craft and perform their own poetry. They learned how to express themselves through poetry and how to communicate their experiences and feelings effectively through creative means. For example, one workshop focused on the communication of emotions such as frustration, anger, and so on, whilst in another session the group learned about the importance of avoiding the cliché in artistic work.

Examples of poetry

Poems were written individually, in small groups and collectively as a large group, and were developed around a series of key themes relating to the images and values associated with the Paralympics and everyday life as a young disabled person. Creating a series or ‘cluster’ (Butler-Kisber and Steward 2009, 4) of poems around a theme is a powerful way of expressing a range of subtle nuances about a topic whilst also producing a more general yet in-depth overview of an issue. As Butler-Kisber and Steward argue: ‘[t]he clustering of poems that are unique and at times even contradictory allows for an up-close and granular reading of a theme and a more general reading simultaneously’ (2009, 4). Each poem on its own provides a specific viewpoint on the experience, but when performed together as part of a public showcase, this cluster of poems provides various nuances that illustrate powerfully how members of the poetry group thought others saw them and how that made them feel. For example, a number of the poems produced encapsulated a feeling of powerlessness and frustration. Sullivan (2007 cited in Butler-Kisber and Steward 2009, 5) has indicated that there is a delicate architecture in poetry that includes: concreteness; voice; emotion; ambiguity; tension; and associative logic. Clusters of poems, these authors argue, make these characteristics more robust due to the complex web of connections that can be made within and among texts and the richer meanings that develop as a result. The same could be seen when the group worked collectively on a poem, each member contributing a line, phrase or idea. The poem below, ‘For the People Who Stare’, is an example of early work produced by the group that, when combined as part of a live performance with close-up footage of the pairs of eyes of each member, created a powerful audio and visual message:

For the people who stare (‘The Poetry Sensations’)

Get to know the person you’re staring at.
 What’s your problem?
 What’s your problem?
 Try to step into my shoes.
 Don’t. It makes me scared.
 It makes me feel sad.
 Everyone is different but judgments take over.
 I can’t do anything about it.
 People are always scared of what’s different.
 You are disabled to me. I am disabled to you. We are both aliens on this world.
 I am crazy but I’m just me, don’t look at my wheelchair.
 I am open like a magic door.
 I am pretty white teeth but yellow on the inside.
 I am an actor, gifted with every emotion.
 I am a titanium spine worth thousands on Ebay.
 I am my own person.
 I am a unique cloud, always different every-day.
 I am Sean the funny sheep.
 I am a football Nickipedia.
 I am full of a thirst for knowledge. I want to see a change for the better.
 I am everything that I am, I can’t change. I wouldn’t change it for the world.

Disseminating the poetry

It was not only the writing of poetry that was important for this project, but also the performance of it and how the poetry is received and interpreted by the audience. The performance and dissemination of the work required complex methods because of the need to consider every person's needs and abilities. The finished poems were disseminated through live performance and on film. Performance poetry is considered by many to be the most intense form of poetry, given the rhythmic form of writing that, when performed, requires dramatic breath-pauses supported by the use of corporeal and voice expression. Within the particular context of this project, the varied devices and forms of communication used by members of the group made the experience even more intense. Film as a means of documenting the project and as a dissemination tool has been key in our working practice. Initially, the filming of the workshops had been intended to assist the research team in their observational research and to record interviews with those involved in the project. However, it soon became an integral tool for capturing and disseminating the views and experiences of the young poets. Some of the young people's difficulties in communicating did not easily facilitate live participation at performance events, integrating footage of them writing or performing their work into the live presentation enabled their voices to be heard. The use of film also meant that those for whom various geographical and logistical reasons meant they were unable to take part in the performance could also share their message. An anthology of the students' poetry was also produced with the aim of giving audience members something tangible to take away with them. The book was produced by the project team and printed at a minimal cost so as to provide an accessible and sustainable further funding stream for the project. The book has so far helped to fund two additional poetry workshops and has been reprinted twice.

Poetry workshops and live performances were also captured on film in order to further disseminate the creative work, to share elements of the project journey, as well as to share the young people's everyday experiences developing and performing the poetry, including the challenges encountered during the process and the solutions found. A preliminary 'taster' documentary was edited and uploaded onto YouTube. At the time of writing, this has received more than 2000 views. The initial purpose of the 'taster' was for it to be used as a vehicle for obtaining feedback from various disability rights activists and professionals to inform the production of the finished documentary. The short film then became part of a small online viral campaign to whet the public's appetite for the full-length film. The intention is to showcase the final documentary, 30 minutes in length, at film festivals and other public events, as well as academic conferences, and to develop it as part of a multi-media educational tool for use with students within schools, youth groups and universities.

The performance element of the research has at its heart the empowerment of young people as a central part of the dissemination process. Such approaches offer the opportunity to see 'through the eyes of research participants, and a belief that social behaviour cannot be grasped until the researcher has understood the symbolic world of the research participants' (French and Swain 2004, 17). The young poets became engaged and productive commentators on social conditions relevant to their everyday experience (Moxley, Feen-Calligan, and Washington 2012), seeking to move their audiences closer to an understanding of what disability means for them, a tradition consistent with activist poetry (Kaminsky 1984; Schiff 1995; Gold 2012).

Ethics

The research was carried out within the British Educational Research Association ethical guidelines. The negotiation of ethical procedures was a continuous process between the research participants, the relevant teachers, carers and managers at the school and the families of those taking part (Walker, Schratz, and Egg 2008, 173). Permission for involvement in the project was sought from both the young people and their parents/guardians. Arts-based methods raise obvious issues concerning control, authorship and representation. It was important to negotiate who 'owns' the creative output, whether poems, performance or images. It was made clear to the young co-participants from the outset that creative approaches would be integral to the research process but that, overall, the creative rights to their work would be their own.

The young poets took responsibility for their work and made individual and collective decisions about how they wished to represent their experience(s), and were able to stipulate how they wanted the poems to be used, performed and presented. It was acknowledged that within this process it would have been impossible to guarantee anonymity due to the small sample size and the performative element of the research. As regards ethical and authentic representation, it was acknowledged that an element of this project was to use live performance as an important way to engage with the general public and to positively influence perceptions of disability by raising awareness of the ways in which students with severe and complex difficulties can participate in public life and how such participation can be facilitated to be effective. One of the greatest causes of stigma surrounding disability is the lack of direct experience members of the public have of disability. There is a fine line between confronting disability and encouraging voyeurism, however, and we were careful to avoid patronising the young poets. Instead, performance was used sensitively as a way to challenge discriminatory barriers and attitudes. We were able to achieve this by ensuring that the young people worked closely with the professional poets, teachers and academics actively engaging in planning and producing the live public performances and contributing thoughts and suggestions to the editing of the film and other audio-visual materials. Such a collaborative process enabled each member of the project group to learn from each other. Our initial anxieties as researchers about exposing the young people to public critique were allayed by the strategies they had developed over time and use in their everyday lives to deal with discrimination faced in different social contexts. In this way, the young people became the experts in showing us what to anticipate and how to deal with it non-confrontationally.

Evaluating the poetry

The results of poetic inquiry can be very challenging to evaluate, assess and/or review because few established criteria exist (Prendergast 2009). The aim of any arts-based research project is to produce work of artistic/aesthetic merit, yet we must be careful to avoid imposing criteria used to assess the work of professional poets to evaluate the quality of the poetry work produced by previously 'untrained' research participants, and instead must recognise the process within which participants are engaged and the context in which the work is presented (Piick 1992). As Sherry and Shouten (2002, 231) suggest: '[t]he validity of the poem lies in its ability to resonate in the reader, to communicate emotional truths in language that is fresh and

engaging'. The feedback we have received from audiences at the live performances supports this. Denzin (1997, 200) concurs, suggesting that poetic texts 'should be a stimulus for social criticism and social action – a joining of the personal, the biographical, with the political, the social'. Within a participatory approach to poetic inquiry, participants emerge as artists who engage in the production or co-production of art for the sake of enhancing understanding, finding meaning, and stimulating a response, determining the value and quality of their work themselves rather than placing this judgement in the hands of experts or critics (Glesne 1997, 209). Each reader of the poetry anthology, audience member at a live performance or viewer of the project documentary will take what they will from the poetry. Often the message, deliberately or otherwise, is not explicit and its interpretation cannot or should not be controlled. Instead, the audience(s) employs their own interpretative frames of reference to make sense of what they read, hear and observe.

From an academic perspective, when assessing the value of the data generated through participatory poetic inquiry it might be helpful to draw on the five criteria/guidelines for creative analytic practices proposed by sociologist Richardson (2000) for reviewing social science papers submitted for peer review and publication. These have been adapted for the purposes of this research study as follows:

- (1) Substantive contribution: does the piece contribute to our understanding of social life?
- (2) Aesthetic merit: does the poem succeed aesthetically? Does it invite interpretative responses?
- (3) Reflexivity: how did the author come to write the poem? Are there ethical issues? How has the author's subjectivity been both a producer and a product of the text?
- (4) Impact: does it affect me – emotionally, intellectually? Does it generate new questions? Does it inspire people to take action? Has it conveyed something that motivates?
- (5) Expression of reality: does this poem as written and performed communicate authentic lived experience? Does it provide a 'credible' account of individual or collective real-life experience?

Conclusion and final reflections

This paper has considered performance poetry as a method used within a participatory arts-based research framework to engage young disabled people in a project to explore issues associated with identity, representation and living with disability. Poetry can provide a powerful therapeutic and creative outlet to communicate lived experiences of disability, and performance offers a way of addressing the causes and consequences of the social issues the young people face in their daily lives (Moxley, Feen-Calligan, and Washington 2012). As reflected in the feedback from three of the young poets who participated in the first two phases of the project:

I learned how to send a message through poetry. I'm misunderstood, and poetry was a good way to put that message across and a way to express myself. I was hoping to move people. (Male, 18 years old)

In a later interview, this same student also commented:

I wanted to express my story and show people that disability isn't all about the wheelchair. Some people found the poetry humorous, some people found it emotional [the most important thing about the project was] that we all got our individual voices heard ... everyone deserves a say.

A colleague, also aged 18, suggested in his feedback:

Writing helps me to explain to people that even though I find physical tasks difficult, my inner strength and courage strengthens my resolve and I will find a way to accomplish all that I want to do. So you see, even though I'm disabled I do have a great life. I do everything I can and anything that's possible (and some things that are not). I don't care that I am just I'm 17 and I like to do whatever I want whether it be playing on my play station or doing something crazy like a live poetry slam [...] I don't class myself as being disabled so in my poems I ask the question 'why I am disabled if I am capable of doing all the things I want to do and I lead as much a normal life as anyone else? It is my belief that everyone is disabled in one way or another and I try to portray this vision in my poem in an unusual way.

Another member of the group added:

Poetry has taught me how to be open and talk about it [disability] and write deep-down poetry. At the beginning [I found poetry difficult] but then I got used to it and it was fine [...] I am very open now. Before I was very shy and nervous and I didn't really want to talk about it, but I did get on with it and talk about it [...] I am very open about it [...] I know it sounds silly but I really don't like talking to my parents about it, I really don't like talking to other people about it [...] it really helped me deal with what I've got. (Male, 18 years old)

As Moxley, Feen-Calligan, and Washington (2012, 705) have argued elsewhere, 'the power of the arts resides in its capacity to foster human expression, document human experience, and legitimize the perspectives of those who are otherwise marginalized'. When performed live or on film, poetry can engage the public on an emotional level, fostering a human connection between the poet/performer and the audience, encouraging them to critically reflect on their own attitudes and transgressing stereotypical ways of thinking about disability (Leavy 2009, 70), as some of the following reactions from audience members suggest:

Very powerful – challenged my pre-conceptions. Broken down barriers – mainly based on fear. Very effective – the poems I heard today were very evocative and moving. (Anonymous)

Poetry can be an excellent way for individuals to express their feelings including frustrations/annoyances along with what makes you happy and excited. Again, this enables you to get to know people as individuals and see beyond disabilities. (Anonymous)

Extremely powerful as by making a serious topic more fun and informative, people feel relaxed and are more likely to listen. (Anonymous)

Some audience members were even inspired to write themselves. For example, we received a piece from a member of the public written from the perspective of a composite character based on the stories and performances from two of the young people involved in the project.

Finally, the experience for academic researchers can be equally as transformative as roles extend beyond that of researcher to collaborative agents actively involved in the process of creating awareness and change. We have continuously found ourselves enacting the ‘expected’ role(s) of ‘researcher’ alongside those of ‘event organiser’, ‘community development worker’, ‘performance curator’, ‘PR/promotion’, ‘arts advocates’, and so forth, which was, at times, exhausting and frustrating but always, ultimately, rewarding. Our primary motivator has always been a strong desire to ensure that the young poets had the opportunity to have their voices heard and we did not want to let them down. Our engagement with the project was such that some of us even began to write poetry ourselves. Overall, the success of the project was due to the fact that, collectively, each participant had different skills and experiences to contribute and, importantly, an incredible amount of enthusiasm and commitment.

As we have seen, in research terms, the use of performance poetry as an arts-based method can help shift our understanding of what counts as research data and highlight the complexity and multidimensionality involved in creating new knowledge (Boydell et al. 2012). Importantly, however, it can also serve as a means to empower and promote the voices of those who may otherwise be seldom heard, constructing alternative forms of representation that challenge dominant narratives and perceptions and help serve as a catalyst for change.

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