Performance Poetry as a Method to Understand Disability

Lee-Ann Fenge, Caroline Hodges & Wendy Cutts

Abstract: The Seen but Seldom Heard project was a performative social science (PSS) project which used performance poetry to illuminate the experiences of young people with physical impairments. Two performance poets, a group of young people with physical impairments, and academics from social science and media/communication backgrounds worked together to explore various aspects of the lived experience of disability exploring issues associated with identity, stereotypes, stigma and representation. In this article, we will present an overview of the project and consider how PSS offers a method to engage seldom heard voices, and illustrate this through two poems which shed light on the lived experience of disability. The article will consider the impact of these poems as PSS, and how this method allows the audience to develop a deeper understanding of the "lived" experience of disability and to reflect upon their own understandings of disability and discrimination.

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1. Introduction

This article explores how performative social science (PSS) methods (GERGEN & JONES, 2008; JONES, 2006) can be used to co-produce knowledge with young people with physical impairments using an approach which recognizes their skills as poets and co-producers of knowledge. Discussion of this topic will be illuminated by reference to the Seen but Seldom Heard project which used performance poetry as both a research and practice method to engage voices of young people with physical impairments in a small scale project in South West England. This project was funded by Bournemouth University Fusion Investment Fund and Bournemouth University Aimhigher funding and represents a collaborative project between the university and a local education center offering education to young people from 3-19 years old with physical impairments or complex medical conditions. Staff from the Faculty of Health and Social Science,

and the Faculty of Media and Communication at Bournemouth University, were involved in developing the project, and this supported an approach which fused social science and arts-based approaches. The project received ethical approval from the University Research Ethics Committee and was carried out within the British Educational Research Association Guidelines. [1]

The arts-based approach directly involved participants in both the development of research data/knowledge, and the dissemination of findings through performance to a wider audience including health and social care practitioners and members of the public. We were guided in our approach by Recommendation 7 of the World Health Organisation Report on Disability (WHO, 2011, p.19) which is concerned with promoting an inclusive society by increasing public awareness of disability. We were mindful of how attitudes towards impairment result in discrimination and prejudice and that "the dominant model of what it is to be human disables impaired people" (LEIPOLDT, 2006, p.16). Of all groups with a disability, the groups we know the least about are disabled adolescents and young adults (GROCE, 2004). We believed that performance poetry provides a platform for young people with physical impairments to explore and share "their unique insights about their disability and their situation" (WHO, 2011, p.18) through live poetry performances and film of these events. [2]

Poetry as a medium has the potential to connect with audiences on an emotional level, and through this connection it touches hearts and minds in a way that traditional academic dissemination of research fails to reach (HODGES, FENGE & CUTTS, 2014). Performance poetry, and more generally PSS, therefore offers a way of engaging with audiences to challenge assumptions and initiate social change. PSS offers an approach which is a fusion of the arts and social science which is grounded within relational aesthetics (BOURRIAUD, 2002), and emphasizes the collective experience of coming together and creating meaning. Due to the potential to illuminate experience and challenge stigma, PSS has been used with other seldom heard groups such as those living with dementia and refugee youth (GREGORY, 2014; GURUGE et al., 2015). As GERGEN and GERGEN (2011, §3) assert "[t]he use of theater in communicating about the nature of prejudice ... has a far different impact on one's audience than a graphic or statistical form of representation." [3]

For health and social care agencies working disabled service users it is important that their practice is imbued with knowledge and research that helps practitioners understand "the emotional and contextual realities of people whose life experiences are often very different from theirs" (FURMAN, LIETZ & LANGER, 2006, p.25). This can be achieved through arts-based methods, which have the ability to connect on an emotional level with the audience, engaging them in an interpretive process which promotes dialogue (HODGES et al., 2014; JONES, 2006). Arts-based methods have been described as "enacted living inquiry" (SPRINGGAY, IRWIN & WILSON KIND, 2005), offering interconnected ways to create meaning through knowing and being. Poetry as an arts-based method can be used to encourage young people to challenge stereotypes through roles as "poet-citizens," enabling them to "engage in conversations and communities that

might otherwise be inaccessible to them" (INGALLS, 2012, p.101). Performative social science places communication and dialogue center stage, and these are important processes in negotiating inclusive structures and relations (FOOK, 2002). [4]

Section 2 will explore the background to youth, identity and disability, and how performative social science can be used as an empowering method to engage marginalized voices. Section 3 will discuss performance poetry as a method underpinned by social justice. Section 4 will consider how performance poetry was used within the project, and Section 5 offers some analysis of two examples of poems produced by the group. Section 6 provides some concluding remarks about arts-based approaches. [5]

2. Disability, Youth, Identity

Recent UK policy has highlighted the importance of co-production and self-directed support as a key tenet of working with people with disabilities (DEPARTMENT OF HEALTH, 2010). Such an approach can enrich understanding of issues related to the wider psycho-social context of their work and support them to develop less oppressive ways of conceptualizing disability issues. Approaches which explore the social dimensions of experience sit comfortably with developing understanding of the importance of "person-in-environment" (SZTO, FURMAN & LANER, 2005, p.154); and the use of arts in social science research can be linked to a number of metaphors including one which is concerned with "walking in another's shoes" (SINDING, WARREN & PATON, 2014, p.193) and, therefore, developing insight into the lived experience of diverse groups and individuals. As part of this developing insight it is important to understand the roots of prejudice and discrimination linked to constructs around ableism and disablism, ability and disability within society. As WOLBRING describes (2012, p.79), "ableism in its general form leads to an ability based and ability justified understanding of oneself, one's body, one's relationship with others." [6]

Cultural norms associated with ableism, stigmatizing language and negative images about disability reinforce the marginalization and oppression of disabled people (DUPRÉ, 2012). Marginalized groups are often invisible and silenced and "one of the characteristics of being oppressed is having one's stories buried under the forces of ignorance and stereotype" (SALEEBEY, 1996, p.301). Disability research has often neglected individual and collective lived experience and how this is influenced by questions of culture, representation and meaning (SHAKESPEARE, 1997). However, the disability arts movement in the UK has for a number of decades used music and lyrics to resist mainstream disability discourses to develop an understanding of a positive disability identity (CAMERON, 2009). Disability arts, music and poetry can therefore challenge understanding about disability by "extending or changing the terms of the conversations that people are having about disability, the body, aesthetic theory, accessibility and communication" (SCHEUER, 2011, p.159). We hoped that an

approach which embraced PPS at its core would similarly challenge audience understanding about disability and facilitate social change. [7]

Some studies have used poetic transcription to illuminate the voice of young people with disabilities, but this involves researchers interviewing and transcribing interview data into a poetic form rather than the young people producing poetic form themselves (GASSON, SANDERSON, BURNETT & VAN DER MEER, 2015). However, arts-based performative research offers a participatory approach to co-produce artistic outputs with young people promoting the development of empathy and understanding of the lived experience of disability (SWENSON, 2004). It offers disabled people a voice through which their individual and collective experiences of disability and stigma can be heard. Performance poetry has also been used as a method to enable academics, researchers and practitioners to explore their own experiences of stigma linked to mental health and disability (SETHI, 2012). [8]

A number of themes were explored by the project including identity, acceptance, belonging, and exclusion. Although research has been undertaken exploring the lived experiences of young people living with impairments with regards to participation in Higher Education (REDPATH et al., 2013), and social inclusion (YATES & ROULSTONE, 2013), there is limited research exploring identity and discrimination for young people with physical impairments. Poetry has "a potential for making the unseen seen and for making the familiar strange, new and afresh" (AADLANDSVIK, 2007, p.668). Using performance poetry as a research method therefore enables us to reflect upon the world with a different lens, unsettling preconceived notions and prejudice by exploring different perspectives which provide an emotional link to the participant/poet's world. Like artists and poets, researchers can seek to create a powerful emotional impact upon their audience, (EISNER, 1981) which can challenge taken-for-granted understandings about the lived experience of physical impairment and being disabled given the social and cultural contexts in which people live. The two poems within this article encourage the audience to reflect upon assumptions about disability, and such reflection aids reflective practice and transformative action as it can contribute to unearthing the impact of power upon social relations (GILES, IRWIN, LYNCH & WAUGH, 2010). [9]

3. Performance Poetry and Social Justice

One of the central aims of the project was to support participants to engage with creative activities to explore issues related to identity, inclusion and participation. This approach was informed by the emancipatory disability research paradigm identified by BERESFORD and CROFT (2012, p.9) which is guided by three principles:

- research is concerned with changing and equalizing relationships between the researcher and the researched;
- research seeks to advance the personal empowerment of participants and service users;
- research prioritizes and makes broader political and social change in line with the rights and interests of service users. [10]

The project team members were mindful of the potential paradox that exists within emancipatory and participatory approaches (FENGE, 2010), in which some individuals can become silenced by the oppressive exercise of power (DANIELI & WOODHAMS, 2005). We were therefore concerned with the social relations within the project and how this influenced knowledge production. For example, we made an effort to ensure that all participants had the time and space to have their work heard. This was particularly important for those individuals with communication difficulties or those who used specific communication devices. It was therefore important that the research develop understanding of the ways in which disability is socially produced (BARTON, 2005), and this was achieved through participatory co-production with the young participants (STOVALL, 2006). It was important that this approach recognized the contested realities which exist within disability culture and the disabled people's movement. For example, where diversity of experience is recognized and where some disabled people assert disability allows for different ways of knowing the world and being. This includes owning language to describe experience such as "cripple" (MAIRS, 1986) and disability as art through "crip culture" (KUPPERS, 2006). [11]

The crux of arts-based inquiry "is a radical, politically grounded statement about social justice and control over the production and dissemination of knowledge" (FINLAY, 2008, p.72). A key aspect of this approach was to view the participants as experts within this process and the researchers as co-learners (MINKLER et al., 2002). Arts-based approaches to research, such as performance poetry, can legitimize the perspectives of marginalized groups and individuals (MOXLEY, FEEN-CALLIGAN & WASHINGTON, 2012). This was evident within the "Seen but Seldom Heard" project as the work placed an emphasis on the positive portrayals of people with physical impairments, and involved the manifestations of disability culture identified by DUPRÉ (2012, p.168) including "humour, language, beliefs, values and aspirations for the future." Later in this article we explore examples of the poetry and see how humor is used as a device by the poets, and the ways in which their fears and aspirations are reflected in their work. [12]

Performance poetry is a powerful tool of communication which can touch the hearts and minds of the audience and encourage empathy (FOSTER, 2012). Confronting issues of prejudice, oppression, ableism and disablism occurs as the audience is invited into a relationship with the "live" performed work and the performers, and the audience is invited into the world of the performers. The effectiveness of the performance poetry is that the audience "feels with" the performers rather than just about the poem (FAULKNER, 2007, p.230) and an emotional connection is made through the performance. The audience is not passive but invited into a dialogue (HORDYK, SOLTANE & HANLEY, 2014) which has discursive and emotional elements. As academics who had previously been in social work practice, the poems touched us on several levels. On a personal level we started to confront our own personal beliefs and values about disability. We also found ourselves reflecting back on our previous professional roles and the ways in which we may have been perceived by our clients; were we "dream social workers" or had we been perceived as being out of touch with our clients' aspirations, or as someone who rationed the resources available to them? Arts- based approaches therefore assume that the audience "will construct their own interpretations of presented data based upon their own history, present social context and needs" (SZTO et al., 2005, p.138). [13]

4. Performance Poetry and the Performance Poetry Workshops

The aim of performance poetry has been defined as striving to "compose superior poems and perform them with exquisite precision" (SMITH & KRAYNAK, 2009, p.7). Performance poetry is increasingly being seen as a powerful method of self-representation for young people (CAMANGIAN, 2008), and has been used to explore issues associated with exclusion and community with a variety of groups including homeless immigrant women (HORDYK et al., 2014) and Puerto Rican youth (NOEL, 2011). However, it is more than just the performance of poetry; this method offers an approach which engages the audience as "co-performers." The audience is often invited to join in with the performance through techniques such as "call and response" (HOLBROOK, 2002, p.12), where they are invited to memorize and repeat certain lines of the poetry. For example in the "dream social worker" poem explored later in this article, which was written as a group poem by the young poets, the audience is invited to join in with the chorus. In this way the audience became co-disseminator of the work alongside the young poets, an innovative approach which sits comfortably under an overarching PSS umbrella. This can also be seen to sit within BOURRIAUD's (2002) principles of relational aesthetics as the performers and audience encounter each other in a collaborative social space. This not only leads to increased understanding and empathy of the "lived experience" of being a young disabled person, but offers a more "nuanced and memorable way of understanding relations of power" (PHILLIPS, 2007, p.200). It supports us to reflect upon the power relationships which exist between practitioner and service user, disabled and non-disabled, performer and audience and develop a deeper understanding of the dominant cultural discourses surrounding disability which continue to silence and oppress individuals. An in depth discussion of the "Seen but Seldom Heard" project is available elsewhere (see HODGES et al., 2014). [14]

A series of participatory performative poetry workshops ran over period of 24 months, facilitated by two performance poets. The aim of the project was to enable participants aged 14-20 years to explore the nature of disability within society and their own experiences of living with a physical impairment. As the project developed, the group used performance poetry to explore issues affecting them, including the types of services and support they received from health and social work practitioners. Performance was a key element of the project and a number of live performances took place including an event which coincided with the Paralympic Cultural Olympiad in 2012, performances at literary and arts events in South West England, and a performance at the House of Commons in Westminster in 2014. [15]

During the workshops participants were shown how to develop the craft of performance poetry, including expressing themselves through creative means, and this involved individual and small group poems as well as collective large group collaborations. As the workshops developed, the participants started to use props and musical accompaniment to embellish their live performances and to tell their stories in a fun, entertaining and engaging way. [16]

5. Examples of Group Performance Poetry

This section explores two examples of poems that were written collectively by the group with the support of the two performance poets. The first was written early in the project during a session where the two performance poets encouraged individuals to contribute a line to a group poem exploring issues around disability, identity and expression. Once written the collaborative poem was performed in front of an audience of other young people with disabilities, parents and school staff. [17]

5.1 Salad cream on toast

> By the Poetry Sensations
> I normally think about my disability in a bad way
> But it's just a fence that you need to climb over
> Into Richard Branson's hotel on the moon.
>
> To become a famous basketball player,
> Or a gymnast, or an actor
> Or simply drive a car…
>
> To do a wheelchair long jump
> And perform in Ibiza and all over the world
> On an eternal adventure
> With Evil Knievel, Bart Simpson and Mr. Bean.
>
> To always look up and never look down
> On a never-ending water shoot on an uphill slide.

> To be a writer or a director and create strange things
> Like a musical forest in a haunted castle
> Or a magical electrical wheelchair.
>
> To make people realize
> That disability is just a silhouette
> That disappears.
> As the headlights of WHO WE ARE
> Shine through the mirage.
>
> Now I see disability in a good way … [18]

This collaborative effort demonstrates some of the aspirations and experiences of the young people involved in the project. The audience interpreting this piece may see different possibilities within it; this may include seeing disability through a different lens in order "to make people realize that disability is just a silhouette that disappears," or equally seeing a statement about the positive aspects of disability "as the headlights of WHO WE ARE shine through the mirage." Both perspectives have implications for the overall well-being and experience of young people with impairments, particularly in light of research which highlights that disabled youth experience poorer subjective well-being as a result of differential exposure to disadvantage and discrimination. In other words "lower subjective well-being of disabled youth may be socially patterned, preventable and therefore inequitable" (SAVAGE, McCONNELL, EMERSON & LLEWELLYN, 2014, p.877). [19]

It is important for us to confront the social factors which lead to disadvantage and discrimination which disable young people with physical impairments, and for those who work as professionals in the health and social care sectors to champion the needs and aspirations of these young people. It is equally important to recognize the complexities and intersections involved in disabled identity. For example intersections with age and gender and the way in which some individuals may wish to be seen as young people first who share similar aspirations to other young people, and not to be seen differently because of the disability they experience. This is supported by research which identifies the desire to be just like everyone else (GILSON & DePOY, 2015). However, other individuals may wish to celebrate their disabled identity as offering a unique perspective of being within the world. Crip theory (McRUER, 2006) suggests that there are other ways to live than those offered by able bodiedness, and supports an approach which explores different options and a critical understanding of the socially constructed origins of disability. [20]

As the project developed we also supported the participants to explore their perceptions of receiving support from health and social care professionals and their experience of this. To begin with, these sessions generated many negative perceptions of young people's experience of social workers and other caring professionals, particularly in terms of being ignored and having needs unmet. This may reflect the impact of austerity on health and social care practice and assessment, and highlights the difficulties faced by practitioners whose practice is restricted by agency function and budgetary restraint (MILNER, MYERS &

O'BYRNE, 2015). As a result of financial restraints within the public sector, access to services is becoming limited as eligibility thresholds are "creeping higher and higher thus restricting community care services to fewer people" (MANDELSTAM, 2009, p.151). As a result, individual choice and needs become compromised within a system which increasingly targets only those most at risk, and where practitioners are part of a process for managing scarce resources (LEECE & LEECE, 2011). [21]

As the session went on the participants produced a collaborative group poem which described an "ideal social worker." This poem draws out the young poets' negative emotions regarding how they perceive support from a range of professionals, but this is presented with a positive spin by focusing on the qualities of an "ideal" social worker. The performance of the poem was enhanced by musical accompaniment which included audience participation through a "call and response" method (HOLBROOK, 2002, p.12). It was an amusing poem but one in which the undertone illustrates the lack of understanding that young people perceive from some practitioners. [22]

5.2 My dream social worker

> By the Poetry Sensations
> Here comes the dream social worker
> Disco afro and Bart Simpson Tie
> A funny nutter, a happy dude
> Goldfish in his platform shoes
> Open the door and he says "hi"
>
> Chorus
>
> My dream social worker, doesn't know of any barriers
> My dream social worker, doesn't ever stop at "no"
> My dream social worker, he gets the job done
> My dream social worker, is jolly and fun
>
> Here comes the dream social worker
> With his instant funding and good advice
> He listens, he battles, he fights for you
> Tries his hardest to make your dreams come true
> He brings you bling and jewellery—NICE
>
> Chorus
>
> My dream social worker, doesn't know of any barriers
> My dream social worker, doesn't ever stop at "no"
> My dream social worker, he gets the job done
> My dream social worker, is jolly and fun
>
> Here comes my dream social worker
> Giving voice to the seldom heard
> Helps you live where you want to live
> Pushes the system to make it give
> I wish he had the final word

> Chorus
>
> My dream social worker, doesn't know of any barriers
> My dream social worker, doesn't ever stop at "no"
> My dream social worker, he gets the job done
> My dream social worker, is jolly and fun. [23]

Through the poem the group conveyed a commentary on their everyday experience of social service contact (MOXLEY et al., 2012). Negative views of social work are perhaps understandable in light of negative experiences as a result of assessment processes and rationing of services (EVANS, 2012). Pressures on practice as a result of budgetary constraint and a focus on risk management also impact upon the way in which practice is perceived and results in "defensive rather than empowering practices" (ELLIS, 2013, p.2284). Through their poetry and performance participants were able to highlight the impact of power on social relations (GILES et al., 2010), including the divisions between service user and practitioner, recipient and provider, disabled and non-disabled. Moves towards more integrated working across health, social and the voluntary sectors, alongside a focus on well-being through person-centered approaches (The Care Act, see DEPARTMENT OF HEALTH, 2014) will impact future practice in this area. However, it is important that all agencies involved in support planning offer a commitment to uphold the autonomy and choice of service users (WILLIAMS, PORTER & MARRIOTT, 2014), and this can be fostered through increased understanding of the lived experience of disability. The power of the poetry and performance is that it enables both practitioners and the wider audience to develop insight into the lived experience of the poets by seeing the world through their lens (SINDING et al., 2014), and "can enhance dialogues on important societal issues" (GERGEN & GERGEN 2011, §9) such as public policy and funding priorities. The project team has started to use learning from the project to inform teaching with social workers and other allied health professionals through guest lectures and conference presentations. For example, we were invited to present at a [Communications Matters Conference](#) in 2015, alongside one of the young poets, in front of an audience of over 100 social workers, occupational therapists and other care professionals. Feedback was positive and comments included:

> "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."
>
> "The credibility of these young people is astonishing and provides a truly valuable insight into the lives of those living with disability." [24]

As the quotes illustrate, being part of the audience allows us to develop an emotional connection with the performer and their poem and encourages a process of critical reflection on our own attitudes and values in a way which challenges stereotypical views of disability (LEAVY, 2009). By challenging taken-for-granted understandings of what disability means, and our own professional

roles and tasks, we can gain insight into ways in which we can promote social justice rather than perpetuate oppression (FOOK, 2002). [25]

6. Conclusion

Arts-based approaches, and more specifically performance poetry act as an aid to encourage audiences to question the basis of knowledge and the power relations which underpin everyday accepted practices. It can challenge understanding of what counts as research data and the complexity and multidimensionality involved in creating new types of knowledge (BOYDELL, GLADSTONE, VOLPE, ALLEMANG & STASIULIS, 2012). The audience can also become "co-producers" and "co-disseminators" within a collaborative social space through "call and response" (HOLBROOK, 2002, p.12). This is a potentially innovative approach which sits comfortably under an overarching PSS umbrella. The audience makes sense of what they hear and observe within their own interpretative frames of reference (HODGES et al., 2014). They are drawn into a process in which they are encouraged to reflect upon how their own interpretations of disability are mediated by their own beliefs, experiences, and social and cultural contexts (SZTO et al., 2005). Arts-based approaches therefore support the audience to reflect upon the data/poems presented to understand the social constructions that service users have about their lives, and the professionals and services they come into contact with. By challenging taken-for-granted understandings of what disability means, public audiences and professionals and gain insight into ways in which we can promote social justice rather than perpetuate oppression. [26]

As well as providing the opportunity of expressing their needs and experiences, the project also provided a space for participants to tell their own story in response to negative media representations of disability. The opportunity to perform their work in front of a live audience, as well as being captured on film, also gave the participants the opportunity to gain new skills and confidence which we hoped would open up new opportunities for further education and/or employment. [27]

Acknowledgments

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Authors

Lee-Ann FENGE, DProf (Doctor of Professional Practice), is Deputy Director for the National Centre for Post-qualifying Social Work at Bournemouth University. Her research interests include participatory methodologies, ageing and sexuality, and using arts-based methods with seldom-heard groups.

Contact:

Lee-Ann Fenge

National Centre for Post-Qualifying Social Work
Faculty of Health and Social Science, Bournemouth University
Royal London House, Christchurch Road
Bournemouth BH1 3LT
United Kingdom

Tel: +44 (0)1202 961693

E-mail: lfenge@bournemouth.ac.uk

Caroline HODGES, PhD, is principal academic in public relations in the Faculty of Media and Communication, Bournemouth University. She is concerned with the relationship between communication and culture. Her interests include using arts-based methods to offer "voice" to seldom-heard groups.

Contact:

Carrie Hodges

Faculty of Media and Communication, Bournemouth University
Weymouth House W408, Talbot Campus
Fern Barrow, Poole, BH12 5BB
United Kingdom

Tel: +44 (0)1202 966748

E-mail: chodges@bournemouth.ac.uk

Wendy CUTTS is a senior lecturer in community development in the Faculty of Health and Social Science, Bournemouth University. She is particularly interested in working with marginalized communities and groups and in using arts-based methodologies.

Contact:

Wendy Cutts

Faculty of Health and Social Science, Bournemouth University
Royal London House R205, Christchurch Road
Bournemouth, BH1 3LT
United Kingdom

Tel: +44 (0)1202 961788

E-mail: wcutts@bournemouth.ac.uk

Citation