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WILL STRINGER

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Negotiating care: an exploration of non-place within a deafblind performance project

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This article brings together diverse theories on disability, place, non-place and care to explore a process involving deafblind performers. The article is based upon work within a five-month residency with a performance group in a social care organisation. The article seeks to unpick and uncover the role of care in the creation of performance with disabled performers.

Keywords: disability, care, contemporary practice, participatory performance, deafblind.

Over the last few years the prominence of disabled artists within theatre has grown. In Scotland there are a number of artists, companies and festivals integral to this current movement including *Unlimited Festival*, Robert Softley-Gale, *21 Century Challenges*, Caroline Bowditch and Claire Cunningham. The growing strength in this area of performance has increased its reach, with Scottish works staged as far afield as Australia and South America (*21 Century Challenges*, 2017; Cunningham, 2016). This article is a result of workshops undertaken with a performance group whose participants are congenitally deafblind. The term congenital deafblindness is used to describe a person 'who is born with a sight and hearing impairment or develops sight and hearing loss before they have developed language in their early years' (Sense, 2015).

Although the participants within the workshops were congenitally deafblind, this article has wider implications for the field of disability and participatory arts as I unravel the complexities of care within these projects. The five-month residency involved a two-hour workshop with participants and support workers every Tuesday. These would usually be led by Jon Reid (director) and supported by myself, and we would plan the workshop together, including which activities we would like to use and which areas of the performance to develop. The workshops followed a similar structure throughout the five months. We would begin in a circle, enquiring as to how people were and catching up on any events that had happened since we had met last. In this introduction, we would also inform participants what we would be doing over the course of the workshop. We would then begin a variable warm-up exercise where people would explore the space, usually in pairs, consisting of a person who is deafblind and a support worker. The workshops were centred on the creation and realisation of the performance *It's All Allowed*. 'It's all allowed' was a phrase synonymous with the late performance-maker Adrian Howells who worked on the project in its infancy. The performance was for one audience-participant at a time. The participant is blindfolded, and then explores a room within the building of the organisation, guided by one of the actors. Whilst in the room the audience-participant engaged in a series of sensory experiences, from playing a harp with an actor, through to being made a heady chai infusion.

The performance was for invited audience-participants consisting of artists and support workers. It was exclusively performed in the building belonging to the organisation due to the procedural and financial complexities of realising the performance in another space. The six congenitally deafblind performers were part of a group with over ten years of activity. When I began the residency the structure of the performance had already been loosely decided. Within

the performance there would be stations for each performer, the audience member would be blindfolded and support workers would be on the periphery of the performance space. Outwith the workshops, I would be involved in scouting for potential opportunities for presenting the work, contacting audience members, and exploring funding opportunities. During this time I worked closely with the director, whose wealth of expertise and experience in working with congenitally deafblind performers was invaluable to this project.

This article will seek to establish connections between theories on disability, non-place, deafblind communication systems and care, in the context of a performance project. In doing so, the article will demonstrate the disabled performer's position within non-place, and how care as a transformative act can change non-place into place. I will argue that care within a social care organisation can reinforce feelings of non-place, but that the theatrical medium of performance holds the potential to reverse symbols and sign systems. Through the creation and realisation of performance, care can be established.

Within this article, I am working with an enhanced version of the social model of disability, as set out by Philip Cole in *The Body Politics: Theorising Disability and Impairment* (2017). Cole describes a bolstered politicised social model of disability through:

a relational model...the relevant relationships are between (1) a bodily impairment, (2) a particular action or ability, and (3) the social structure that frames that impairment and the action or ability in such a way that the person with the bodily impairment cannot perform it (Cole, 2017, p.171).

Cole claims that we should reject ideas suggested by Terzi (2004) of disabled people having more needs in order to achieve normal function. Instead, Cole argues that we should view this in terms of a political model of citizenship whereby, in this case, society is disabling the performer who is deafblind by not allowing them to engage in active citizenship (2007, p.174). This article represents a view of disability that sees social structure and impairment causing the disability as opposed to social structure alone (Cole, 2007).

In the seminal book *Space and Place*, Yi-Fu Tuan (2001) posits space and place as co-dependents. He writes:

What begins as undifferentiated space becomes place as we get to know it better and endow it with value...the ideas 'space' and 'place' require each other for definition. From the security and stability of place we are aware of the openness, freedom, and threat of space, and vice versa. Furthermore, if we think of space as that which allows movement, then place is pause; each pause in movement makes it possible for location to be transformed into place (Tuan, 2001, p.6).

If space is movement then it relies on our pauses of reflection and stability to give it meaning. There were challenges to this during our project due to the process being held within a social care organisation. I often found myself wondering what space / place and movement / pause were allowed, and how this was negotiated between support worker, performance makers and disabled person.

The congenitally deafblind person's experience of the world is constantly negotiated via a support worker who operates in a variety of capacities. Within the social care system of the

UK, and in Scotland where this residency was undertaken, the social care worker's role is largely reduced to the logistical and operational. For example, when the person needs to use the bathroom and may need physical support doing so, the support worker would provide the solution—the 'access'. It is often the support worker getting to know the person on a regular basis that forms the relationship needed for the individual to communicate to others. Due to the myriad of other support needs that may go along with and be linked to their congenital deafblindness, there is not a standard communication system that can be relied upon unlike, for example, the use of British Sign Language within the Deaf community. Therefore, the support worker constantly defines the deafblind experience and the person's relationship to the world due to the need to know and develop individual communication methods with that individual. Tuan states 'experience is directed to the external world. Seeing and thinking clearly reach out beyond the self. Feeling is more ambiguous' (Tuan, 2001, p.9). Tuan also draws on the work of Paul Ricoeur who writes:

Feeling, for instance love or hate, is without any doubt intentional: it is a feel of "something"—the lovable, the hateful. But it is a very strange intentionality which on the one hand designates qualities felt *on* things, *on* persons, *on* the world, and on the other hand manifests and reveals the way in which the self is inwardly affected. (Ricoeur, 1986, p.84).

This is an eloquent description of experience and the external, providing a source of considerable concern. If feelings are not translated and placed within the external world, the person who is deafblind can become agitated. They may do seemingly irrational things in order to express what is happening for them, and to receive communication.

Once communication is understood, their inward experience is being confirmed or 'listened to', thus reinforcing that what they feel / think has consequences to other people and the wider external world. One of the actors repeatedly touches hair and is regularly informed by his support workers to 'not do this', therefore he repeats the action. In this example, his inward experiences are being confirmed by other people, 'the external'—there are consequences to what he does within the world. There are a number of quite clear opportunities for performance acting as a method of translating and curating collective and individual experiences, offering a medium in which there is representation of expression(s) of the individuals.

This article has so far touched upon two main protagonists in this project, namely the actor / performer and the social care worker. It would, however, be remiss to negate the role of performance maker / director and audience-participant when attempting to problematise the relationships within the space.

Within this project there were two performance maker / directors within the room, myself and Jon Reid. Jon had significant experience with the performance group, working with it since its inception. There were clear, comfortable relationships between him and the ensemble built up over the years. I was a new and fleeting addition to the ensemble, spending only five months with the group, though I had previously known and worked with one of the performers intermittently for almost three years.

There was a significant challenge to making a performance within a space of a social care organisation, not least due to the frequent conferences that forced us to vacate the room. As directors, we believed in the ability of the project to negotiate and transform symbolic orders, norms and values through a well-discussed heterotopic lens (Wihstutz, 2013).

Critically analysing the extent to which we as performance-makers were effective in making this possible lies outwith the remit of this article. It is, however, important to discuss the potential of the performance to negotiate and transform symbolic orders by summarising the variety of relationships within the room, and their relationship to the disabled performers.

The support workers engaged in the process by being invited to participate in the making and rehearsal exercises to varying degrees. This altered the existing relationship between the person who was deafblind and the support worker. Within the process, the three roles within the room, that of director, performer and support worker, were worn lightly. This allowed a co-creation of experiences that supported communication between the deafblind person and the non-deafblind person as shown by Souriau in *Blended Spaces and Deixis in Communicative Activities Involving Persons with Congenital Deafblindness* (2015). In one of Souriau's examples, a child (Emil) who is congenitally deafblind and his mother are having a conversation about meeting a girl with a cochlear implant (2015, p.19). Souriau describes how Emil's translation of what had happened with his body does not directly match what had happened. The mother and child understand each other because of their shared experience. One such example occurred within the workshops: I had forgotten to put out the paint for one of the performers, and we were about to do a rehearsed performance, when she indicated to me with a gesture of her thumb. This could have been read as a 'thumbs up' to begin the performance. However, having worked with the performer before, I understood that the thumb and paint were linked, thus jolting my memory to retrieve the paint.

The body is involved both in producing standard signs whose form-content relationship is

iconically based (the form of the sign looks like the content from a given perspective) and when partners perform body movements grounded in the shared space in order to collaboratively implement their communicative project (Souriau, 2015, p.6).

It should be noted that this did not mean that the support workers, directors or performers divulged experiences in some cathartic explosion, but that we experienced making the work together; for example, reflecting on rehearsals where a support worker would be guided through the work and then feed back their experiences within it. Often, we would then ask questions to provoke solutions from the participants. This had deep ramifications for the real space-blend. As we were making together, co-creating as a community, we had a wider shared vocabulary on which to draw upon for the creation of the real space-blend, whereby narrative space (what has happened) was translated onto physical objects and / or people, for example, through gestural language. The narrative space is informed by these dramatic-framed collaborative experiences, allowing for a broadening of communicative approaches and methods that can then be used as tools for the creation of a performance. Due to the nature of communication systems and impairments of many of the actors, touch and holding provided ample opportunity for intimacy. In Edward Hall's proxemics model, the radius of skin through to eighteen inches is regarded as intimate space, 'the distance of love-making and wrestling, comforting and protecting' (Hill and Paris, 2014, p.12). The described conflict within intimacy of vulnerability and protection mirrors the complexity of care (Trigona, 2012, p.199). I propose that this intimacy provided opportunities for exchanges of care between the participants (directors, support workers, performers) throughout the performance-making period. This intimacy could be regarded as being at odds with the social-care environment within which we operated, and certainly gave

rise to fascinating conflicts of interest. However, underscoring ‘intimacy’ and a ‘social care environment’ as being mutually exclusive would be a reductive interpretation of the social care environment.

One important aspect to highlight is the time frame allowed within this context. We met once a week, and, as mentioned above, the Performance Group had been creating *It's All Allowed* for over three years with no financial pressure on the product, allowing for relationships and experiences to inform communicative systems between the director, performers and support workers. Seen by some areas of the organisation as simply another timetabled event to fill up the day of the participants, the performance could be nurtured, performed and re-worked over a relatively long period of time. This time-intensive method which would be considered rare in the arts funding climate was standard practice due to the activity being held within a social care organisation.

Whilst many of the support-workers were supportive of directorial risks, others erred towards the protective, seeking to prevent risk. This latter group struggled to accept the complex relationship of co-dependence (being cared for / caring for) with people they were used to viewing as to-be-cared-for, and as such the social structure often disabled the performers from engaging with the co-creation of performance. This disabling via the social structure is demonstrated through the disabled performers often looking to the support worker(s) and / or director(s) for instruction. To refer back to my earlier comments on space and place, the performer's emotions and movement were placed within this disabled realm, therefore the role of movement with abandon, figuring out and making / creating together was frequently lost. I propose that the performer's actions are disabled to such an extent that they are cradled within the field of non-place.

Augé describes non-place as a term that 'designates two complimentary but distinct realities: spaces found in relation to certain ends (transport, transit, commerce, leisure) and the relations individuals have with these spaces' (2008, p.76). This is a marked difference from an anthropological place; as places 'create the organically social, so non-places create solitary contractuality' (*ibid.*). Augé uses this to describe how individuals interact with motorways:

if a place can be defined as relational, historical and concerned with identity, then a space which cannot be defined as relational, or historical, or concerned with identity will be a non-place. The hypothesis advanced here is that supermodernity produces non-places, meaning spaces which are not themselves anthropological places (Augé, 2008, p.63).

Within this article, I am primarily concerned with how non-place denotes actions based on instruction and a feeling within the solitary experience. I propose an extension of this: that the deafblind body within the social care system can be at threat of being positioned within non-place. As care is an inherently relational action, participants are disabled from engaging with care when through the process they are constantly awaiting instruction from director(s) and support worker(s) to determine their actions.

However, there is an interesting duality occurring within the performance project, that of the performance process and the performance product. Within the field of participatory performance / social theatre we often celebrate the process, and rightly so—it can provide citizens with the skills and the ability to amplify voices on issues relevant to individuals and communities, with the subsequent product / performance reflecting the process.

Interestingly, within the performance of *It's All Allowed* the influence of the support worker was reduced, allowing for more dynamic exchanges between audience-participant and performer. As space and place also negotiate between risk and support, I suggest that a significant method of that negotiation is through care. If you are able to negotiate that care for yourself, with or without support, then you are provided with the tool to create from experience. The placement of experience in the external world is a vital and challenging part of creating with congenitally deafblind performers.

The performer is liberated from the social care worker within the performance, and the relationships of care are negotiated between the performer and the audience-participant. Through this intimacy and care, the individuals can find new conversations, even if just for the brief duration of the encounter. There remain questions over the long-term effect of such a performance. It is easy to confuse visibility and encountering of the other with sustainable and fundamental political and social change (Wihstutz, 2013, p.191). However, the potential for care to transform non-place into place is a powerful one.

Within this article, I have sought to demonstrate that the disabled performers operated within non-place particularly when undertaking the process of making the material for the performance. Through the staging of the performance, care can allow for a co-placement of experience between audience-participant and performer. This transforms non-place into place. This posited the disabled person as the person with knowledge to negotiate through the space, and the audience-participant as reliant upon this. Care that navigates muddy waters of trust and risk became the communicative form that transformed non-place to place. Care is a transformative act within participatory performance and its value within work with disabled artists

should not be underplayed. Whilst doing so we must wrestle care from a sanitised notion that disables participants and performers and does not recognise its complicit relationship to non-active citizenship. As festivals, theatrical spaces and performance projects open up to different bodies and experiences, care can be a vital tool for all involved. We do not need to relegate this care to the exclusive realm of performance-process, but we must allow the potential power of the performance product to radically change theatrical spaces from within.

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About the author

WILL STRINGER is a performance-maker and graduate of the Royal Conservatoire of Scotland. His research interests include the role of care in contemporary performance, performance research and participatory art.