
Chapter 48

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WHO'S GOT THE POWER?

Performance and self advocacy
for people with learning disabilities,
London

THIS CHAPTER BRINGS TOGETHER THE reflective voices of three people who worked together for a period of eight months within the context of a newly formed drama group in South East London. The group was self-initiated, by the members of a (leisure) service-provider for young people and adults with learning disabilities, primarily run by a committee consisting of parents of the young people and adults with learning disabilities. The drama group consisted of twelve people between fifteen and thirty years of age (approximately). Following an interview with the groups' key worker, notably, without the actual members being present, I was invited to work with the group.

From October 2005 until May 2006 we staged two very different performances in two very different spaces, however, there were important similarities in terms of intention, ethos and process.

The first production, entitled *Who Stole the Beautiful Octopus?* was performed at a popular arts venue in South East London in December 2005, as part of Heart 'n' Soul's live performance/night club called The Beautiful Octopus Club. Heart 'n' Soul is one of the UK's leading musical theatre companies run by and for people with learning disabilities. In May 2006, a second production was created called *Who's Got The Power?* and was performed as part of the organisation's annual general meeting. Guests to this performance included the Mayor of the borough, representatives from social services and care services, parents and other members of this service-provider organisation.

Two key voices in this chapter are Ian David Roberts and Emma Selwyn, who were two of the twelve collaborators and performers involved in the project. My voice represents the perspective of the drama facilitator. I conducted and documented several discussions with Ian and Emma with the intention for each of us to reflect deeply on our experiences. Through consultation with Ian and Emma I have structured

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and edited their responses (and mine) into the material that follows which forms the basis of the six key questions that were asked.

How did we work as a group?

Liselle: My approach was informed by a self-advocacy model, based on People First, a national organisation founded in 1984 as People First London Borough (Buchanan and Walmsley 2006). It is a self-advocacy organisation led by people with learning disabilities with the overall aim to enable people with learning disabilities to have choice and control over their own lives. I wanted to work collaboratively with the participants to ensure that they had a genuine ownership of the intention, process and outcome of the project. In order for this to happen it was important to establish methods of communication that embraced the different ways that the participants interacted and communicated (which proved to be crucial in providing a clear and sturdy foundation for the devising process). We had to make sure that our working methodology would enable everyone to find a 'hook-in' for themselves.

Emma: We had creative freedom and choice. The facilitator used simple language but never patronising and was part of the group as much as we were. There was independence because we weren't ordered about, because that's what people get all the time.

Ian: I felt on an equal level, something I don't often feel outside of the group.

The first production – *Who Stole the Beautiful Octopus?*

Performed December 2005 as part of The Beautiful Octopus Club (Heart 'n' Soul).

What was the play about?

Ian: It was a dark musical comedy play that was set in a nightclub where we all played famous comedy TV characters. I played Johnny Vegas who owns the nightclub and he has a pet octopus that lives in a very small cage in his office. One day, the janitor Seymour, secretly lets the octopus free.

Emma: Johnny Vegas then hires Pet-Detective Ace Ventura and he takes everyone on a musical dancing journey to find the octopus. Each of the characters represented different people, but could also represent the different sides to one person as well. For example, Stan Laurel represented how people can be very nervous and confused and have their own innate sense of humour; Johnny Vegas had power, Seymour was bullied, Ace Ventura was resourceful, Bart Simpson (the club bouncer) was calm and chilled, Janet Jackson helped to hide the octopus, and the pink octopus represented freedom.

Ian: I chose Johnny Vegas because I think people who act like him in front of the public eye have lots of guts.

Liselle: There were many layers to the play and each was told through a different medium; dance, song, music, slapstick comedy, large photographic images projected behind the performers of the famous characters they were

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portraying, and a brief step-by-step outline of the story as it developed through words and symbols.

What did we want to say?

Emma: For me the play was saying don't trap us, give us the opportunity to speak and to have freedom but at the same time protect us when necessary.

Ian: It's about when people become awake and aware they become quite frightened, but it can make them stronger. If you try to hide and move away from frightening situations then it's more dangerous for you because you will be less cautious and let people be not good to you.

Liselle: For me it was a story about being trapped by someone with power, and this is then juxtaposed with the idea of being able to not just survive in that situation but change it. It was also about the responsibility of others. In addition to this, the actual staging of this performance was also about celebrating equal opportunity by the mere fact that this production was watched by over 500 people with learning disabilities.

Who was it for?

Emma: The audience were lots of people with learning disabilities at the nightclub, and judging by the audience's reactions, there were lots of people laughing, clapping and cheering throughout the play.

Ian: It was something very different for the audience at The Beautiful Octopus Club to see. A lot of plays I have watched are about standing up for yourself, and I think that we wanted to put something comical but with a serious message underneath into it. If we just had the fear and dark without the comedy then the audience might be scared, but if it is a dark comedy play, then they will be less scared and they will want to see it.

How we made the performance

Liselle: During the first several weeks it was essential to establish a strong foundation for the devising process. We achieved this through participant-led drama games and exercises as well as exploring what type of performance the participants wanted to create, and indeed what they wanted to say through their performance. I brought in questions that we used as a basis to stimulate material for devising. The group were adamant that they did not want to create a serious piece about their lives as people with learning disabilities. They were interested in comedy and wanted to use humour, dance and song to perform a story.

Ian: We were asked to bring in something that we found funny and something that made us angry. I said that when people stand too close to me and shout at me that makes me angry; another person in the group said that he knows someone is being bullied at his school and that makes him angry. But we wanted to concentrate on what made us laugh. Most of the group brought in our favourite funny TV characters and decided to be those characters. It worked because no-one was telling us who to be. I liked it because the

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characters we played were funny; they were a little bit eccentric. We made the story to fit the characters' personalities.

Liselle: We took the concept of the actual nightclub where the play would be performed (The Beautiful Octopus Club) and created a storyline about the fictitious characters who worked for and ran the nightclub using the comedy characters and celebrities brought in by the participants.

Ian: The character I played was Johnny Vegas. He could be a little rude and cheeky sometimes, and sometimes when I feel like being cheeky to people I feel like I'm having a Johnny Vegas. I'm probably the opposite of Johnny Vegas but I try to imagine if I was him how I would pull him off. If Les Dawson was a little younger and still alive, I would choose to be him but it was important that Johnny Vegas is alive as he comes on TV a little more so I can observe him.

We rehearsed, analysed and discussed things, balanced them out and negotiated them. We didn't not do peoples ideas [sic]; we just made more different ideas rather than getting rid of some. If someone forgot their lines, then someone else could ad-lib and step in and improvise to help the person out. I took my ideas forward that were the basis for the play. I felt respected.

What did we get out of making the play?

Ian: The production let me show a little bit of myself that other people wouldn't normally see. I wouldn't normally be allowed to make those jokes in front of people if I wasn't on stage because I don't think people would understand them. Someone would say not to do it but if you are on stage then you are appreciated.

Emma: There was an escapism from real life because although real life is good most of the time, there are problems sometimes as well, people need to retreat to their own world – it depends on the person though.

The second production – Who's Got the Power?

Performed in May 2006 at the organisation's annual general meeting.

What was this play about?

Liselle: The play took the form of a montage of short stories told through ensemble sound- and word-scapes; music, live song, dance, dialogue, narration, and visual images and words projected behind the actors onto a large screen. The overall performance raised the question, *Who's Got The Power* within these young people's lives? Within the performance there were two scenes where the protagonist in each experienced a loss of power. We used an adaptation of Augusto Boal's Forum Theatre to explore various options that the protagonist could use in order to overcome the misuse of power that they were experiencing.

Ian: We took off the comedy mask to show what was underneath in a serious piece which was about letting people speak out.

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Emma: It was about asserting yourself, and having a voice. It showed different stories about solving problems, but also about things that are important to us, and ultimately about having power.

What did we want to say?

Emma: We wanted to say to these important people who have more privileges in life usually, that sometimes they need reminding that not everyone is as fortunate as them, although everybody can be fortunate if given the chance to speak out about what they want and need. I think the play showed sides of us that people don't want to normally see. A lot of people in the group find it hard to talk about their feelings, for example when you get stressed, you get a feeling inside of you and I think that everyone can only hold so much feeling and after a while they need to let it out. I wanted to say, accept us all for who we are, and myself as an individual with special needs and for people to be more tolerant please.

Ian: The short plays were about speaking up for yourself. We also decided to perform our inner characters. Mine was fire and explosive. Our inner characters are parts of us that other people never see. We also performed what we would do if we ruled the world.

Who was *Who's Got The Power?* for?

Liselle: The audience consisted of the Mayor of this London borough, residential care managers and other people who work in the care services, and other people with learning disabilities and their parents. When I suggested to the groups' key-worker that perhaps the group might want to use this as an opportunity to use performance to raise some key issues and concerns, I was gently informed 'Don't be too political'. When I put this suggestion to the group, their answer was that they wanted to make a play that showed the audience things about themselves that they might not know about; which then led to the creation of *Who's Got The Power?*.

Emma: We made it especially for the AGM because we wanted to show them that given the chance special needs people have more of a voice than they originally think – as they are quite prone to being excluded.

Ian: It was important for the audience who watched it because they could see what those people go through everyday. People don't see what goes on in care homes and they only see the nice bits when they get welcomed into the house. It was important for me to perform in it because I wanted to have the power. I could see the audience engaged in the performance, and some of the clients could probably picture themselves in that situation and that could help them. It could show the parents and committee that we can express ourselves and our experiences.

How we made this performance

Emma: We discussed things we did and didn't like and how we would like things to be. We did this through games and role plays. We brought in ideas that we

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thought made our lives better. We didn't have to speak out necessarily as the person we are in real life. It's easier saying what you want or need to say, as someone else because people who know the real you, have decided already what they think the real you is, and not all of them will take your real view seriously as their real view [sic]. I think we did it by giving the ones that did hold back a push, and they weren't ever actually told what to say.

Liselle: I tried to ensure that the outside-directing-eye was shared and negotiated with the group. I achieved this by structuring in time for us to critically reflect upon our choices, ask questions and ultimately make group decisions about the devising process and the blocking of the play. We had some new members in the group with more severe learning disabilities who communicated mainly through gesture and sound rather than through the spoken word. I remember some of the participants actually saying that they had spent most of their lives learning to 'know-their-place' and to only talk when told. Other participants said that they had learned to be silent and that it was less confrontational to just say yes. Therefore ethically speaking, a self-advocacy model had to be our guiding principle.

What did we get out of making the play?

Ian: I played the nasty carer. It let me release a lot of bad feelings I have that I didn't like towards the carers in my house. I felt I wanted to strangle them but you can't do that, and the play looked at different ways of standing up for yourself. One particular carer kept coming into my room without knocking and I tried to tell him to go away. He had army instincts in him. I think he probably reckoned I needed the discipline which I got quite annoyed about. The danger is I become weaker as a person if I don't react to it in any way. We wanted to say that those carers like that should not work in care homes and that also that people should have the right to speak up for themselves. Putting this on stage meant I could express how I was feeling. I wanted to get my own back on people, how they had upset me personally.

Liselle: In *Foucault and the Government of Disability* (2005) Scott Yates examines the forms of power that operate in community care accommodation. The author researched how people experience this power and how they understand themselves as subjects in relation to it and how these power relationships are institutionalised and normalised. He also interviewed several people with learning disabilities who lived in care accommodation who had similar experiences like Ian's:

Anne: '... if you want anything, you have to ask for it ...'

Paul: '... The managers don't like you to speak your mind ... you have to fight for what you believe ... you're just a bad boy ... because you're not being quiet ... You're supposed to take what they give you, and not say no. We've got a voice, we should be able to use it.'

SY: 'Do people listen to you?'

Paul: 'No, they don't listen'.

(Yates 2005: 72-3)

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Yates analyses the interviewee's responses to his questions and points out that both Anne and Paul use the pronoun *you* when they talk about their experiences of living in the residential care and the rules that are imposed on them. They both seem to be very aware of the injustice that they experience daily, however they also seem to say that there seems nothing much they can do about it.

What we got out of being part of the drama group

Emma: I gained more confidence in myself and with others, and an ability to empathise with the others in the group. Everyone was treated like equals and it gave everyone a way of voicing their feelings without having to worry about rejection and having their opinion valued because everyone was important in the group regardless of what they did, like there was not really just one star role. In traditional plays they have a leading character and a definite hierarchy and in this one, to be honest, there were a few people that don't consider themselves that highly anyway, and the fact that there was no star meant it wasn't that one person was getting special treatment and the others were lower down, they weren't like the spare strings for a guitar.

Ian: It was really important for me to be involved in the project because it got me involved in things I wouldn't normally do. It makes me assert myself better and to speak up. We had to use our imaginations all the time which is a good thing.

Emma: I also learnt that people are more likely to listen to what you are saying and understand what you are saying if you perform it through drama, art, song or dance, than if you just say it. I think that humanity needs to grab onto as much as they can to enable their understanding.

Liselle: I became more aware of the multifaceted role of the facilitator and specifically the level of power instilled in this role. I still believe ethically the facilitator/director must de-mystify this role and indeed find accessible, creative and collaborative ways to hand-over this power to the participants; ways that are guided by a self-advocacy model. In order for this to happen, the facilitator needs to ensure that there are structures which are integral to the process that enable participants to have choice, and to gain the skills and insight needed to create performance. One of the key ways of achieving this is to rely on the participants' own judgements and choices.

The future

Emma: [If the project were to continue] I would like the project to use the same formulae; everyone having the opportunity to speak up and perform at the same time. I would like there to be places all around South East London where people came to do workshops as well. The aim of it would be an opportunity for people with learning disabilities to voice their opinions and thoughts on life through a creative medium. I also think dance and song are all expressive too, some messages might come across through dance, and

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through dance you wouldn't have to worry about dialogue, and those with communication difficulties would have a real voice through their bodies to give people a better understanding of themselves and what they go through.

Liselle: Following the success of these two performances, we had to move venue and change the day of the weekly sessions which meant that some of the original members could no longer attend. We were then told by the committee that we should make a musical play that would be performed at the next annual event for committee members and their families. I was aware that I felt uncomfortable with being told to do this, feeling as if we were perhaps owned by the committee. I started to become aware of a divide between the ethos of the drama group that we had developed over the past eight months, to that of the ethos of the committee, which seemed to see the group as more of a show-case opportunity for the organisation. I wanted to create more of a bridge between the participants in the group and the committee so that the actual members could vocalise how they wanted the group to develop. I tried to instigate a meeting to discuss the long-term aims however; unfortunately, a three-way conversation was never able to happen. I started to feel that my belief in a self-advocacy approach was being really challenged and unacknowledged. It was at this point that I made the decision to resign as I felt I could not and did not want to be accountable to the committee. I wanted, rather, to be accountable to the members of the drama group.

Aftermath

Following the interviews with both Ian and Emma they each commented that they had gained a great deal from revisiting, discussing and reflecting upon their own experiences as participants in the project. They felt that having this reflective time following the project was just as important as it was being part of the actual project itself. Ian and Emma were constantly making connections to their own lives and they said that they had gained a deeper understanding and awareness of the process that they had been part of. Both participants commented that reflecting on the process had enabled them to gain more of an insight into themselves and that they would use this as a way of challenging the constant prejudices and ignorance's experienced by people with learning disabilities that has been normalised within our society, that they both still experience in their everyday lives.

By revisiting the project as well, I have also been able to find clarity within my own practice (led by a self-advocacy approach) and place it within the wider political context of the discrimination still experienced by people with learning disabilities. On reflection, I believe that at the outset of the project I should have perhaps communicated more succinctly my intentions and indeed ideology to the committee/key worker. Prior to this project I had made the naive assumption that this organisation would have had self-advocacy embedded, so that the participants would be able to use the project as a way of gaining as much ownership as possible. Perhaps my own key learning curve is not to make these assumptions in the future, but to make the politics of this work explicit for all involved.

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Bibliography

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- Yates, S. (2005) Truth, Power, and Ethics in Care Services for People with Learning Difficulties in Tremain, S. (ed.) *Foucault and the Government of Disability*, The University of Michigan: 65–77

Notes

- 1 Heart 'n' Soul is an arts organisation led by artists with learning disabilities <http://www.heartnsoul.co.uk> (accessed 8 January 2007).
- 2 <http://www.peoplefirst.org.uk/aims.html> (accessed 12 May 2007).