**'I Feel Like a Giant, Like a Star, a Proper Actor' –
Reflections on a Service User Led Evaluation of a Drama Project
Using Participatory Visual Research Methods**

**Helen Charnley [1], Se Kwang Hwang [1]
(with members and supporters of Full Circle from ARC, Stockton)**

[1] Durham University

'I Feel Like a Giant, Like a Star, a Proper actor'. Reflections on a Service User-Led Evaluation of a Drama Project Using Participatory Visual Research Methods

Helen Charnley, Se-Kwang Hwang with members and supporters of Full Circle from ARC, Stockton.

Abstract

This article describes the processes of supporting 'Full Circle from ARC, Stockton', a group of nine men and women with learning disabilities[2], to develop skills in using visual research methods to evaluate their own drama project that grew from their ambition to escape the boundaries of conventional day care services and have a go at being 'real actors'. With the help of support workers, members of Full Circle worked with a drama practitioner to script, design, direct, produce and perform *Is Toto Dead?* their alternative version of The Wizard of Oz. Invited to evaluate the project, the first two authors acted as research supporters and discussed different approaches and methods of evaluation with members of Full Circle who embraced the opportunity to extend their repertoire of skills to undertake their own evaluation using visual research methods. Here we offer a reflective account of the process that attempts to remain as close as possible to the experiences of members of Full Circle[3]. Following an introduction that locates the work of Full Circle in a contemporary policy context, we provide brief overviews of the literature on the involvement of people with learning disabilities in the performing arts, and in participatory research. We then focus on the achievements as well as the methodological and ethical challenges in using participatory visual research methods. We end by reflecting on the potential of these methods, as well as the potential of performing arts, for promoting the development of self esteem, confidence and competence in adults with learning disabilities.

Key words: Performing Arts, Learning Disabilities, Participation, Evaluation, Visual Methods.

The Policy Context: Valuing People Then and Now

Following the community care reforms of the 1980s, the majority of adults with learning disabilities live in community based settings. Despite over twenty years of developing community care services, and despite the vision of Valuing People (Department of Health 2001) based on principles of inclusion, independence, choice and rights, concerns are still expressed about the continuing social exclusion of adults with learning disabilities. Specific concerns relate to limited development of social networks and failure by 'non-disabled' citizens to develop social connections with learning disabled adults supporting the development of social capital and social citizenship (Duffy 2006, Gilbert et al 2005). Drawing attention to the negative experiences of many adults with learning disabilities who continue to experience constrained, unimaginative services and unfulfilled lives, the Joint Committee on Human Rights (2008) recommended the adoption of a human rights framework for the revised version of Valuing People Now (Department of Health 2009). This outlines key policy objectives for people with learning disabilities including: having a fulfilling life of their own including opportunities for study, leisure and social activities; and having the opportunity to

---

[2] The term 'learning disabilities' is used throughout this article in order to achieve consistency. However, we acknowledge preference for the term 'learning difficulties' by self advocacy organisations such as People First (http://www.peoplefirstltd.com/) subscribing to the social model of disability that sees disability as the result of social processes rather than being located in the individual.

[3] Who have discussed the article, made amendments, and offered their full approval.

speak up and be heard about what they want from their lives – the big decisions and the everyday choices. If they need support to do this, they should be able to get it (Department of Health, 2009:14).

The Involvement of People with Learning Disabilities in the Performing Arts

Mainstream arts, produced largely by non-disabled people for non-disabled people, remain inherently exclusionary for disabled people. However, creative work and performance by disabled people have increasingly been regarded as important vehicles for promoting inclusion (Goodlad et al 2002), opening up new areas for self-determination and empowerment. Taking a broader view of the arts, White (2009) presents evidence of the positive connections between the arts and health, what he refers to as 'a social tonic', and argues the need for creative partnership working to develop imaginative opportunities for public involvement in the arts.

Since the 1980s many disabled people have sought to organise, control and produce their own arts through the disability arts movement (see Conroy 2009) seeking to 'strategically deploy difference in order to make a political difference' (Singh 1995:197). There are a number of performing arts organisations involving people with learning disabilities. But while these groups raise awareness of disability issues and showcase the creativity of disabled performers, Goodley and Moore (2002) argue that the disability arts movement has not heralded equal progress for all disabled people. They outline a number of challenges to be addressed to increase the effectiveness of involvement in performing arts. First is the importance of active personal choice to be involved so that it is not experienced simply as another occupational activity. Second is the need for meeting places that constitute social spaces and do not unwittingly encourage segregation. Third is the importance of opportunities for learning and personal development. And fourth there is a need for a model of support focusing on capabilities and the exercise of self determination that may be different from the model of support offered by social care practitioners among whom, they argue, there is more likely to be a culture of low expectations. The danger is that 'support' has the potential to be 'disempowering' by compromising principles of self advocacy in the different context of artistic performance.

Warren et al (2005) identify a further challenge beyond the performance space. They acknowledge the power of drama to support people with learning disabilities to express feelings, develop personal abilities, social and communication skills, greater independence, self advocacy, decision making and problem solving skills. But while many people with learning disabilities enjoy active participation in art, drama, dance and construction of stories, their role in the arts attracts limited attention, is little understood and suffers from a lack of recognisable discourse that addresses meeting points for drama and political disability movements.

Adults with Learning Disabilities as Researchers

Since Oliver's assertion that academic research had done 'nothing to serve the interests of disabled people' (Oliver 1996:139), there have been significant developments in the use of participatory research with people with learning disabilities (Chappell 2000, Gilbert 2004). Traditional qualitative research methods involving documents, interviews or observation by non-participant observers (Silverman 2004) often present barriers to the inclusion and representation of people with learning disabilities (Aldridge 2007). The generation of visual data by participants, using techniques such as photography and film, can be powerful in reaching the hidden worlds of participants and, applied with skill, can reduce power differentials and biases of interpretation (Prosser and Loxley 2008).

Participatory visual methods do not produce objectivity or visual truths (Hwang and Charnley, 2009), but they can help to move towards understanding of the ways in which learning disabled people's social worlds are shaped and controlled. It is against the background of these arguments that we critically analyse a service-user led evaluation of the work of Full Circle from ARC, Stockton.

Whose Evaluation is This Anyway? Methodological Considerations

An initial invitation to undertake an evaluation of the work of Full Circle led the two lead authors to meet with members of Full Circle, their support workers and drama practitioner. Conscious of the limitations of conventional research methods such as interviews and questionnaires in working with learning disabled people (Minogue 2005), and building on earlier experience of the rich possibilities of using visual research methods (Hwang and Charnley 2009), we discussed the possibility of the group becoming actively involved in making an evaluative record of the development of their own project using visual and audio techniques that would avoid reliance on reading or writing. This involved discussing 'why?', 'how?', 'when?', and 'where?' For some this evoked excitement: 'like interviewing like on Big Brother?' For others 'being given a free hand' involved a level of responsibility that was unfamiliar. But with reassurance that their familiar support workers and drama practitioner would be there to help if requested, all members of Full Circle expressed interest in taking part. They were given an information sheet that was explained by support workers they knew well and trusted, and were invited to give their own consent to participate. The consent form explained that they could participate in as much or as little as they felt comfortable with and that they could withdraw at any time.

The Evaluation Process

Evaluation research took place weekly over four weeks during rehearsal sessions that lasted approximately four hours including refreshment breaks. At the start of each session participants considered and discussed what they would like to do and the process of undertaking this evaluation emerged as a process of reflective learning, leaving control of the process with members of Full Circle. Supporters responded to questions, offered assistance in the development of technical skills and gave reassurance in the face of anxieties and frustrations to support the growth of self confidence.

In the first two sessions, following basic instruction in the use of the equipment, all participants experimented with digital cameras and a camcorder to take photographs and film footage of people, places and things that they 'particularly liked' in the rehearsal room, surrounding spaces and the café bar. No specific guidance was given, leaving participants free to follow their own wishes. In total they filmed approximately 90 minutes of drama rehearsals and break time activities, and took 180 still photographs of each other in rehearsal. All participants were eager to watch and discuss their videos and photographs with each other and their supporters, and analysed their data by selecting five images each, presenting them to the group and explaining the personal significance of each image. This process has much in common with 'photo/image elicitation' techniques (Harper 2002), with all members of Full Circle engaging in the process rather than a single researcher engaging with each participant to elicit meaning from the visual images. During the second meeting, participants also considered the idea of recording interviews with each other about their experience of involvement in the production of *Is Toto Dead?*, and in the third and fourth meetings interview questions focusing on individual experiences were developed and used by participants. They were given some tips to develop skills as interviewers using face to face and video diary techniques. Subsequently, all participants were involved in interviews that lasted approximately ten minutes and were recorded by camcorder or a digital voice recorder.

Ethical Considerations

Although visual methods provide a more accessible medium for the involvement of people with learning disabilities in research (Booth and Booth 2003, Aldridge 2007), the use of visual images in research with human participants raises ethical issues that are further compounded when that research is undertaken with people with learning disabilities, particularly with respect to consent and confidentiality procedures.

In line with Durham University ethical approval procedures, verbal and written consent was given by each participant for the use of still and moving images. We considered the cognitive capacities of participants to grasp conceptual notions of confidentiality, and the consequences of granting permission. The consent form was directly explained by support workers who not only knew the participants well, but were also passionate about supporting members of Full Circle to achieve their aspirations. They demonstrated a skilful balance encouraging self determination and the acquisition of new skills, and acted as a quiet presence to provide reassurance and support the development of self confidence. Assurances about the right to privacy and confidentiality were repeated throughout the course of the research, but in practice all participants welcomed the opportunity to show their work to others. As 'owners of their own data', each participant was given a CD copy of the photographs and film they took themselves and gave written permission for these to be used in other settings.

Findings and Discussion - Achievements and Challenges

Methodology

Participatory research is evolving as a methodological approach that ensures the involvement of participants in designing and 'doing' research as well as interpreting findings to 'make their own meaning', addressing the well argued critiques of conventional research methods as being suffused with problems of power imbalances (Kindon, Pain and Kesby 2007). Previous participatory research with learning disabled adults has evolved mainly through collaboration between 'non-disabled' researcher and 'disabled' respondents. But it is often unclear exactly how people with learning disabilities have been involved in collecting, analysing and reporting data. In particular, there is very little empirical research in which all stages of the research are fully controlled by people with learning disabilities (Williams and England 2005). Research with Full Circle embraced a commitment to participant-led approaches and the employment of visual methods. The purpose was to reflect accurately the views of participants using their own lenses to present their own experiences and interpretations in ways that they chose. Giving digital cameras and a camcorder to participants and inviting them to lead the research process during their rehearsal time demonstrated new found capacities among participants in techniques of data collection, data analysis and reflection as well as heightened self awareness, self confidence, and expressions of pride and pleasure in their achievements.

Data Collection

Despite critiques of more conventional methods that rely on verbal communication or observations by third party researchers, there is still much debate about whether participatory research with learning disabled people is possible because of the prevailing tendency in research studies to focus on the nature and outcomes of 'deficiency' rather than 'capacity' (Gilbert 2004). The use of visual methods enabled participants to capture and convey their own points of view, literally, through the lens of a camera or camcorder. Anxieties about the technical challenges involved were quickly overcome and despite physical challenges experienced by one participant, all succeeded in taking still and moving

images with cameras, and in using the camcorder or voice recorder in interviews with each other. With the research process under the control of participants, inherent difficulties of accurately representing participants' experiences were overcome as members of Full Circle were involved as active, responsible researchers rather than passive respondents.

Data Analysis

Instead of undertaking traditional 'research as usual' data analysis (Cahill 2009:182) this evaluation encouraged the development of analytical skills among members of Full Circle. Each member chose what they considered to be their best five images following criteria relating to content and quality established by the group. Images were to go beyond a single individual, to portray 'best acting' in rehearsal, and 'best group activities' during breaks from, or after, rehearsal. They also specified that images should be in colour and clear. All participants were also able to indicate their 'favourite image' representing Full Circle as a group, and to explain the reasons for their choices. In doing this they critically considered the quality and representation of images and reflected on the significance or importance of each image. The main challenge in this process was limiting the choice of images to five, reflecting the level of enthusiasm and sense of pride at having produced their own images.

Reflection

As well as giving participants the opportunity to exercise choice in selecting precise methods of data collection, providing effective ways to learn new, or develop little used, skills, the methodology adopted in this evaluation fostered participant reflection on both processes and achievements. Reviewing video footage allowed participants to see themselves in action, gaining heightened awareness of their physical and vocal selves and a better understanding of the exercises introduced by the drama practitioner to develop their acting skills, poise and confidence. The use of cameras enabled participants to express themselves beyond the medium of verbal responses and all those involved acknowledged the added value of participant-led visual methods. These prioritised participant choice, facilitated the learning of new skills, and celebrated achievements in producing still and moving images that conveyed meaning beyond the spoken and written word. Participants' feedback on the detail of the evaluation was uncompromisingly positive. "I'd like to do it again" was a common expression at the end of each meeting.

Reflecting more widely on the experience of this evaluation, we believe it is important to avoid 'romanticising' the achievements of Full Circle members by unwittingly adopting the low expectations reported among professionals who work with adults with learning disabilities (Goodley and Moore 2002). The involvement of people with learning disabilities in research is still in its relative infancy and practical and methodological questions continue to be raised. In practice, participants' lack of experience led initially to hesitation and reluctance to take control of the research process. None of the participants had experience of using a digital camera or camcorder. And learning new technical skills can, initially, be disempowering. After the first meeting, feedback from two participants indicated that they had been 'nervous in front of the camera', lacking confidence and feeling anxious about the research process. All participants were initially anxious about making a mistake with the camera, and physical challenges and different levels of dexterity made the use of cameras more or less of a challenge for different members of the group. But all managed to use the technical equipment to produce images with different levels and types of help to learn the necessary techniques, a useful reminder that research methods should always be adapted to match the abilities and needs of individual participants.

In selecting and presenting visual images, participants described the significance of pictures in term of friendships and engaging in drama work. For example, 'I like this photo because of

K. He is my friend and he is acting as barman'. This additional information enriches our understanding of the meaning attributed to the images by those who created them, adding invaluable insights that may be missed through what might seem more straightforward question and answer approaches.

Conducting the recorded interviews posed various challenges. Training in interviewing techniques was provided and a set of questions devised together for testing in a pilot interview but this process took longer than anticipated. All participants had a go at interviewing and being interviewed, and it was clear that developing the necessary communication skills was the greatest challenge as participants found it difficult to maintain continuity in the interview process. Limited literacy skills and memory problems presented other challenges in achieving successful interviews in contrast to the comparative ease with which camera techniques were learned.

Conclusions and Recommendations

In this section we summarise the challenges, achievements, and added value of this participatory evaluation with Full Circle from ARC, Stockton. Our intention is to contribute to the small but growing evidence base of the possibilities and potential of participatory visual methods not only to aid researchers but also enhance the capabilities and confidence of people with learning disabilities.

On one hand this was not an easy process. With little or no previous experience of using cameras participants explained: 'it was hard', and training and ongoing support were vital ingredients. On the other hand members of Full Circle enjoyed the opportunities that were offered. They expressed a desire to do more camera work and they plan to continue. What we see here is that with sensitive and constructive support, greater learning occurred by 'pushing the boundaries', successfully addressing challenges and overcoming anxieties. The presence and constructive support of staff known to participants, as well as the drama practitioner, were crucial. In articulating their personal and professional commitment to the principles espoused in Valuing People they supported members of Full Circle to face challenges and confront problems. An example of this was in responding to continuing failure by an organisation to live up to its promise to provide the group with its own video camera. Rather than accepting the initial 'there's nothing we can do' response of the members, support workers suggested that they might invite a representative of the organisation to a meeting at the theatre. One member made a phone call immediately using a mobile phone, witnessed by all the other members, and issued the invitation. The following week they were able to express their disappointment face to face and called the organisation to account. Although this did not resolve the problem immediately, it gave the group confidence in its ability to challenge those in positions of authority and opened up discussion of how to overcome problems by seeking alternative solutions.

Notwithstanding wider critiques of the potential disadvantages of working with existing support staff (Goodley and Moore 2002), none of those supporting Full Circle members had low expectations. And we argue that even if they had, academic researchers with a commitment to participatory action research are in a pivotal position to observe, reflect back and ultimately to challenge, directly or indirectly, such low expectations. Chappell (2000) also argues the critical importance of the roles of academic researchers as supporters or advisers as a way of countering any disempowering tendencies of family members or support workers (Freedman 2001). The main roles of the academic researchers in this project were to provide technical support and gentle encouragement in response to the two most commonly expressed concerns: 'What do I do with camera?' and 'Is it OK to use the camera?' But just as family members and support workers can consciously or unconsciously bring limited expectations and powerful influences to a research setting, academic

researchers also run the risk of imposing their views and influencing key decisions about the focus and direction of the research, to the detriment of input from participants (Walmsley, 2004). We do not claim that we have 'got this evaluation right'. But we do have confidence that Full Circle members have engaged in new experiences, confronted and overcome some new challenges, enjoyed themselves in producing still and moving photographs, and learned that Big Brother style interviews are not as easy as they might seem. They have also opened doors to new opportunities that have the potential to enhance their social networks, and further extend their range of skills.

Measured against Goodley and Moore's (2002) four key challenges to increase the effectiveness of learning disabled people's involvement in the performing arts outlined at the beginning of this article, we also have confidence in arguing that:

1. The question of personal choice lay at the heart of Full Circle which, in its early days, had been created as a result of pressure from members to do something more interesting than what was on offer at the day centres they attended, and to have a go at being real actors.

2. The use of ARC, Stockton, enabled by the positive and inclusionary vision of the director and community arts development officer, has ensured that the space used by Full Circle is indeed a social space, accessible to the public. In addition to the use of rehearsal space, members of Full Circle have also engaged in developing social skills, and engaging with a new set of routines involving choices and challenges in the café-bar and beyond.

3. Opportunities for learning and personal development have been rich, both in the production of *Is Toto Dead*? and in the process of evaluating their own work. The title of the article 'I feel like a giant, a star, a proper actor' are the words of one member following the first public screening of *Is Toto Dead*? The group chose to produce a film of their production to address the additional pressures of performing live. But having gained confidence through their achievements, Full Circle has developed its repertoire to include live public performance of a new piece, live presentation of the experience of collaborating with academic researchers and involvement in the education of social work students.

4. Full Circle was conceived as an enterprise focusing on the capabilities of its members, encouraging self determination and self advocacy. This did not preclude the support of existing staff who had high expectations of Full Circle members and a realistic understanding of their need for support and encouragement. Family members also played their part, not by attending rehearsals but by attending and celebrating the first public performance and, in the case of one family, by publicly raising a significant sum of money to support the ongoing activities of Full Circle.

We end by arguing that Goodley and Moore's injunction to beware the limiting tendencies of professional staff and families should be joined by an injunction for action researchers and practitioners to identify opportunities for empowering practice through involvement in performing arts. This should reflect the choices and aspirations of learning disabled adults and offers opportunities for the development of skills in social spaces that facilitate wider public participation.

References

Aldridge, J. 2007. Picture This: The Use of Participatory Photographic Research Methods with People with Learning Disabilities. Disability and Society, 22(1): 1-17

Booth T; Booth W. 2003 In the Frame: Photovoice and Mothers with learning difficulties. Disability and Society, 18 (4): 431-442

Cahill C. 2009. Participatory Data Analysis. In: S. Kindon, R. Pain & M. Kesby. (eds.) Participatory Action Research Approaches and Methods: Connecting People, Participation and Place. London: Routledge. 181-187

Chappell, A. L. 2000. Emergence of Participatory Methodology in Learning Disability Research: Understanding the Context. British Journal of Learning Disabilities, 28 (1): 38-43

Conroy, C. 2009. Disability: Creative Tensions Between Drama, Theatre and Disability Arts, Research in Drama Education: The Journal of Applied Theatre and Performance, 14(1): 1–14.

Department of Health. 2001. Valuing People: A New Strategy for Learning Disability for the 21st Century, London: The Stationery Office.

Department of Health. 2009. Valuing People Now: A New Three Year Strategy for People with Learning Disabilities, London: Department of Health.

Duffy, S. 2006. Keys to Citizenship: A Guide to Getting Good Support for People with Learning Disabilities, Vancouver: Paradigm.

Freedman, R. 2001. Ethical Challenges in the Conduct of Research Involving Persons with Mental Retardation. Mental Retardation, 39(2): 130-141.

Gilbert T. 2004. Involving People with Learning Disabilities in Research: Issues and Possibilities. Health and Social Care in the Community, 12(4) 298–308.

Gilbert, T; Cochrane, A; Greenwell, S. 2005. Citizenship: Locating People with Learning Disabilities. International Journal of Social Welfare, 14(4), pp. 287–296.

Goodlad, R; Hamilton, C; Taylor, P. 2002. Not Just a Great: Arts and Social Inclusion. Report to the Scottish Arts Council. Glasgow: University of Glasgow.

Goodley, D; Moore, M. 2002. Disability Arts Against Exclusion: People with Learning Difficulties and their Performing Arts. Plymouth: British Institute of Learning Disabilities.

Harper, D. 2002. Talking About Pictures: A Case for Photo Elicitation, Visual Studies, 17 (1): 13-26.

Hwang, S.K; Charnley, H. 2009. Honourable Sacrifice: A Visual Ethnography of the Family Lives of Korean Children with Autistic Siblings. Children and Society, online Early View: 1 May.

Joint Committee on Human Rights. 2008. A Life Like Any Other? Human Rights of Adults with Learning Disabilities, London: The Stationery Office.

Kindon, S; Pain, R; Kesby, M. (eds) 2007. Participatory Action Research Approaches and Methods: Connecting People, Participation and Place. London: Routledge.

Minogue, V. 2005. The Value of the Creative Arts for People with Mental Illness or Learning Disabilities, Mental Health and Learning Disabilities Research and Practice, 2: 110-122.

Oliver, M. 1996. Understanding Disability: From Theory to Practice, London: Macmillan.

Prosser, J; Loxley, A. 2008 Introducing Visual Methods, ESRC National Centre for Review Methods Paper. <http://eprints.ncrm.ac.uk/420/1/MethodsReviewPaperNCRM-010.pdf> (accessed 4.8.2010)

Silverman, D. 2004. Qualitative Research: Theory, Method and Practice, London: Sage.

Singh, P. 1995. 'Voicing the "Other", Speaking for the "Self", Disrupting the Metanarratives of Educational Theorizing with Postructural Feminism.' In: K. Smith, and P. Wexler. After Postmodernism. London: Falmer Press.

Walmsley, J. 2004. Inclusive Learning Disability Research: The (non-disabled) Researcher's Role. British Journal of Learning Disabilities, 32(2): 65-71

Warren, B; Richard, R.J; Brimbal, J. 2005. Drama and the Arts for Adults with Down Syndrome: Benefits, Options and Resources. Portsmouth: The Down Syndrome Educational Trust.

White, M. 2009. Arts Development in Community Health: A Social Tonic, Abingdon: Radcliffe Publishing.

Williams, V; England, M. 2005. Supporting People with Learning Disabilities to do their Own Research. In: L. Lowes and I. Hulatt. (eds.) Involving Service Users in Health and Social Care Research. London: Routledge: 30-40.