



Premature Deaths of People with Learning Disabilities - film

The Misfits Theatre Company

ARTS & HEALTH SOUTH WEST PRIZE 2015 SHORTLISTED CASE STUDY



Name of organisation:

The Misfits Theatre Company

Title of project/programme:

Film "Premature Deaths of People with Learning Disabilities"

Dates of project/programme:

March 2013 - December 2013

Summary:

The Misfits Theatre Company, a unique Bristol based theatre and social group led by People with Learning Disabilities (PWLD), evolved from a drama group at a local day centre (2000) to an established Community Interest Company (2010). Our mission is to improve life opportunities and aspirations of PWLD and to challenge their discrimination in society. We aim to enable PWLD to be creative and reach their full potential through participation, performance, volunteering and employment.

Recognised since 2005 for providing unique tailor-made training for professionals in the public, private and voluntary sector, we use theatre to tackle difficult issues, describe experiences and challenges faced by PWLD and how they want to be treated by the services and professionals they meet.

Commissioned by the University of Bristol in 2013, we devised and performed a film with the key findings and recommendations from their research 'Confidential Inquiry into Premature Deaths of People with Learning Disabilities'. The aim was to illustrate the complex messages of the research by portraying individual experiences of primary and secondary healthcare.

The film was formally presented at a fully booked Bristol cinema in January 2014, followed by a Q&A session with researchers and actors. The project exceeded our expectations, with The Royal College of Nursing and The Royal College of Paediatrics using the film as a learning resource; NHS England using it as part of their 'Patient Stories Week of Action' and by the end of 2014, the film was screened at two international conferences in France and Austria.

Overview:

The Misfits Theatre Company has been working with People with Learning Disabilities (PWLD) for over 10 years, providing artistic and life skills development whilst emphasising independence, healthy living, self-advocacy and creative practice.

Through our experience and consultations we have identified the most recurrent issues of PWLD as well as the needs of the professionals and services they regularly use.

We found that PWLD are more isolated and overlooked, lack confidence and skills; have fewer opportunities, less services and activities; have changing needs; have problems dealing with statutory agencies and employment; often suffer physical and verbal abuse, leading to a negative effect on their wellbeing and health.

People without disabilities generally have a limited awareness of the problems and needs of PWLD. They rarely meet or have little experience liaising with them, therefore feeling uncomfortable, cautious or apprehensive around PWLD. Professionals, service providers and businesses frequently struggle to understand and communicate with PWLD or to recognise their needs, appearing uncaring as they lack the necessary confidence, skills and experience to address them.

Misfits' aims to enable people to be creative, have fun and reach their potential through participation, performance, volunteering and employment. Our programme of activities has tried to redress most of the issues and needs described by both groups and from 2005, we offer tailor-made training for professionals in the public, private and voluntary sectors. Using theatre we draw out the subtleties of discriminatory practices and the impact they have on people who experience discrimination and inequality, challenging perceptions and practices.

Each of the 46 PWLD that currently make up the Misfits Theatre Company, as Directors and Members, benefit from being part of a unique user-led organisation. Working with health professionals (doctors, social workers, councils, public services) we use theatre to show them how to work with PWLD and tackle difficult issues, like bullying, domestic abuse, relationships and sexual health. We have been building our good reputation for our 'training with a difference' over the last 10 years and our regular clients include Bristol NHS Services and Bristol City Council.

In May 2013 Misfits was commissioned by a team of researchers from the School of Policy Studies of the University of Bristol (Norah Fry Research Centre), to

devise and produce a film to present the key findings and recommendations from their "Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD)". A population-based study, funded by the Department of Health for England that looked at the deaths of 247 PWLD and 58 people without learning disabilities. They found that the health and social care given to PWLD could be better and made some suggestions about how services could be changed to help them live longer, healthier lives.

The project was commissioned to Misfits, as our reputation for devising and performing original drama with PWLD and training professionals preceded us, so we were allowed quite a lot of creative freedom. The University research leaders and a film company worked with 2 freelance artists and 15 Misfits actors to develop the script and re-word the key messages into a language that the actors could understand and were comfortable using, making all of the film captions in 'easy read'.

We invited PWLD from day services across the city to take part in the film.

The CIPOLD report key message was that PWLD continue to have poorer health care experiences and outcomes, compared to people without disabilities. The most common reasons identified were delays or problems with diagnosis and treatment or not providing appropriate care in response to changing needs. The recommendations included clear identification of PWLD in information systems, recording and sharing their need for reasonable adjustments and best practice.

The film was to help professionals and PWLD to reduce premature and avoidable deaths, with the aim to increase awareness of the issue and introduce local good practice and start national initiatives. The NHS, Public Health and Health Education departments have critical roles to play and we will only achieve the equal rights, access and outcomes for PWLD by working together, making a concerted national effort.

There are a wide range of beneficiaries from this project. Misfits actors overcome many communication and cultural barriers when devising and acting, gaining confidence, skills and experience. Being part of the project has led to opportunities to appear in local, national and international conferences and media.

The film has been used by a network of health and social care professionals to raise awareness about premature deaths in PWLD. For example The Royal College of Nursing, Royal College of Paediatrics, NHS England, Patient Safety Leads and Learning Disability Nurses are all using film clips as a teaching resource.

PWLD have benefited from the film by being included in local and national discussions about managing their health, asking for 'reasonable adjustments' from service providers and thinking about how to live long and healthy lives.

Our tailored-made training is often based on Misfits' own experiences of living with a disability, and although initial sessions with researchers, artists and actors

were quite challenging, the researchers commented that Misfits members dealt very well with handling a difficult, sensitive subject.

We had 10 sessions (April-August) at Hamilton House (Bristol), devising and rehearsing with 15 actors, researchers and film crew. We spent 7 days filming at various locations across Bristol (August-September), with main actors and extras. We spent 3 more sessions (December) editing and commenting on the film.

The film was first screened in January 2014 at a sold out Watershed cinema (Bristol), followed by Questions & Answers with researchers and actors.

The devising, filming and editing work took place between March and December 2013. The film was 'launched' in January 2014.

Throughout 2014 the film was shown at a number of regional, national and international academic conferences by both researchers and Misfits actors. This included the 4th International Association for the Scientific Study of Intellectual and Development Disabilities (IASSIDD) Europe Congress "Pathways to Inclusion" in Vienna, Austria (July 2014), a major event presenting and debating the advances in research from around the globe.

Innovation:

We believe Misfits' work enables service users to become service providers.

This is the first film, that we are aware of, that has been developed and performed by PWLD about death and the circumstances leading to death.

It was a challenging topic for all the involved, particularly for PWLD who are usually shielded from issues of this nature. We wanted to use the film to tell powerful stories about what we could all do to reduce premature and avoidable deaths and for it to be relevant, not just to PWLD but also service providers, health and social care professionals, families, commissioners and advocates.

Making the DVD has been a great cooperative venture for Misfits and the university researchers. Having both academic and actor input strengthened the film content and presentation. There is also a booklet included in the DVD that suggests ways of using the film as a teaching resource, enabling professionals to use short film clips to highlight a particular issue. After its successful screening and international conferences there has been a request to have the sub-titles translated into French in 2015.

The film has had approximately 4,000 'hits' on YouTube and the researchers have distributed almost 1000 copies of the DVD.

Participation:

The Misfits is a user led company, 8 out of 10 Directors are PWLD. The directors look at the future of Misfits and think about the direction they are taking, helping to make the bigger decisions about the company, including the development and review of the business plan for the organisation, meeting once a month.

There are other monthly meetings, attended by Directors and Members, providing an opportunity for all to work together and shape the drama group activities, games and new ideas for sessions and projects, as well as raising any issues about their role in the company. These meetings are also the forum for working on **commissioned projects**. In this case, the Members met with the University of Bristol researchers, who commissioned the film, and worked together to decide how they wanted to be involved and what they wanted to do. They develop the sessions as required and planned the logistics for this work, such as checking out the locations for filming and recruiting extras from local day services.

Outcomes:

The CIPOLD report found that care too often took a 'systems' approach rather than looking at the holistic needs of the individual and suggested measures to counteract this disadvantage for PWLD. These included recommendations for a named healthcare co-ordinator; patient-held records, and standardised health checks leading to health action plans.

Misfits main outcomes through this project were:

- To increase the self-esteem and skills of the Misfits members, to help them feel empowered to make decisions and feel more able to work with others through participating in drama
- To increase care and health professionals' understanding of the lives of PWLD
- To increase the social inclusion of PWLD and improve their wellbeing

We constantly review, evaluate, monitor, maintain and improve what we do by meeting regularly with Misfits Members, Artists, staff and volunteers; we use Evaluation sheets for each activity, training and performance and conduct interviews with people who commission training and performances; we have a Comments Walls at our social events and use Social media (website, Facebook & Twitter) to gather feedback.

Misfits also commissioned the researchers at the Norah Fry Research Centre, (University of Bristol) to undertake an evaluation of the impact of our work. This included analysis of data they collected at Misfits performances as well the development of some new surveys.

Qualitative and quantitative analysis of the data from feedback forms has shown that not only do audience members enjoy the performances by the Misfits but they virtually all report finding their shows educational. The vast majority of respondents reported they would be able to apply what they had learnt from the session and there is evidence that the work by the Misfits seems to be improving peoples' awareness of the issues faced by people with learning difficulties. The follow up survey found that such benefits were maintained over time and most professionals were able to identify changes in their practice as a consequence. There is evidence that they have an important role in educating medical students and students report learning more from such interactive sessions than from traditional lectures.

Misfits work on CIPOLD has been much lauded and is having an ongoing impact in teaching professionals about the health inequalities faced by PWLD. Our work is clearly valued in the local community and they have an important and unique role in the ongoing education of students and professionals.

In September 2014 the Department of Health published a report updating progress against the 18 recommendations made by the CIPOLD research. This progress update summarises action taken or under way against each of the themes identified by the Confidential Inquiry, both locally and nationally. Examples of local good practice are included as well as national initiatives and arrangements that PWLD have found helpful in improving the uptake and quality of health checks.

The link to access the reports

is: <https://www.gov.uk/government/publications/progress-on-premature-deaths-of-people-with-learning-disabilities>

Learning:

Misfits actors learned that by working together with other teams and respecting each other's strengths, could create a better outcome for the project. Although it was hard work we had lots of fun – particularly going out 'on location' to different places.

The researchers said that what had been helpful for them was meeting with Misfits several times before we even started looking at the script to get to know each other and discuss how it might work. Then when we suggested some changes to the script they felt confident in us and we trusted each other. They said that they learned that it takes time for some PWLD to learn their lines, and they were interested in the techniques we use to do so. They also said that if they were to change anything, they would like to have worked with us on developing the script from the outset.

The main challenge was organising where people had to be, as the project was so involved with using as many PWLD as possible and using real locations when possible (Hospitals, Doctors surgeries) all at different locations and at different times. Booking taxis and making sure people were where they were supposed to be was extremely time consuming and worrying.

In the future we would employ a person specifically to take on this role as project coordinator.

Critical success factors:

Making the film has been a great achievement for Misfits and the university researchers. We put its success down to a number of factors:

- It was a cooperative venture and the film content and presentation was strengthened by having both academic and actor input
- The stories of four people, although closely linked into a cohesive overall story, can be separated, so professionals are able to use short film clips to highlight a particular issue

- The DVD includes a booklet that suggests ways of using the film as a teaching resource
- Accessible to professionals as well as to PWLD
- It's high quality film – professionally filmed and professionally acted

Although communicating the key messages from the CIPOLD report was the most important aspect, the devising and performing work we delivered gave Misfits members the opportunity to work on a sensitive subject professionally and to travel abroad to showcase the film.

The best part of the project was the involvement of PWLD from the beginning and being involved in every aspect of the project, leading to a real ownership and sense of pride in what was achieved.

Since the screening of the film, we have had more interest in our commissioned training, especially from health professionals. We are now getting ready to deliver sessions for students at:

- University of West England (UWE) for Learning Disabilities Nurses
- University of Bristol for Social and Community Medicine student Doctors
- Bristol City council, Domestic & Sexual Violence practitioner training
- Nursing & Midwifery Conference for Plymouth Hospitals NHS Trust

Funding and Resources:

The School of Policy Studies of the University of Bristol (Norah Fry Research Centre), paid Misfits Theatre Company £5000 to devise and perform the film. The budget covered all the costs.

Image titles and credits (L-R)

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