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“Something’s got to change”: A free video and report for professionals and policy makers



Abstract

We have created a short video with family members and specialist day centre staff who care for people with PMLD. The video consists of key messages that families and staff would like professionals and policymakers to know about people with PMLD. The video is free for everyone to view.

Introduction

In a previous article for *PMLD Link* (Simmons, Churchill and Crouch, 2024) we described the beginning of a project to create a resource about the PMLD community. We have reached the end of our project and would like to share our approach, some of the findings, as well as links to free resources – a video and a report.

Approach

We partnered with a specialist day service provision and their strong community of family members to develop a project together. Staff and family members indicated that they would like a friendly and safe space to meet each other and share stories about caring for people with PMLD. They also wanted to create a resource that could be used

to educate policymakers and professionals (e.g., in healthcare and social care) about the PMLD community.

We worked together to create drop-in 'coffee mornings' over a four-week period that provided space for families and staff to share their experiences. About 16 people joined the coffee mornings and offered insightful comments and stories. We took notes, recorded the conversations, used mind maps, drawings, and looked at parents' personal collections (e.g. photos and medals). Parents submitted poems and other materials that expressed their views. The research team analysed the recordings and summarised what was said in an illustrated report. We checked with family members and staff that they were happy with how we have represented their views. Below is a summary of our findings.

Findings

Four big themes, or topics, were discussed.

1. Loved, lovable and loving.

Family members and staff talked fondly about people with PMLD. They wanted to emphasise that people with PMLD are very much loved, are easy to love, and love others in return. Family members and staff were keen to share stories that highlighted the unique personalities of loved ones with PMLD. A rich tapestry of hobbies and joyful activities was described – watching canal boats, listening to the football results, having nails painted, going on holiday, visiting the theatre – and these stories were saturated in affective language that highlights the inner life of people with PMLD (what they enjoy, love, laugh at, etc):

“I still don't understand the magic spell they have over us but they're more precious than anything. The love that they give is immeasurable.” (Mother, participant)

2. The system and professionals

Whilst stories about who people with PMLD are were positive, we discovered that stories about health and social care were largely negative. Families and paid carers recognised that some professionals were knowledgeable about and compassionate towards people with PMLD. However, the layers of bureaucracy associated with caring for somebody with PMLD (e.g., the sheer volume of paperwork, the jargon, the number of meetings, the lack of accessible spaces) were described as difficult to navigate and sometimes overwhelming:

“We often get asked by professionals how we are doing, feeling etc., so that they can put a tick in the box. Most of us feel trapped inside a box as the rest of the world rushes past us getting on with life. We are still stuck in the box struggling” (Mother, participant).

Families described medical decisions being made without being consulted (e.g., Do Not Resuscitate orders being placed in medical notes) and inconsiderate comments being made about their loved ones with PMLD.

3. Time and the future

The family members who joined coffee mornings were typically older people in their 60s and 70s. Their children with PMLD were now adults and major source of anxiety was about who would care for their loved ones in the future. Older participants described the difficulties of caring duties, and they wanted to know that whoever cares for their son or daughter in the future would have their best interests at heart. Participants also felt an urgency to make a difference – they wanted the system to change before they passed.

4. Empathy

The final theme was about empathy. This theme cut across the rest insofar as empathy was seen as being at the centre of joyful lives, and a lack of empathy from professionals and services was said to be the root cause of problems. Family members and staff want people with PMLD to be seen as individuals with rich inner lives, who are loving, loveable and loved, and they wanted health and social care professionals more broadly to become more empathetic towards those who have the most profound needs.

Creating a video

The report became the basis of a short video. We commissioned Fable Studios to work with us (the research team), family members and day centre staff to turn the report into an animated video, with narration provided by family members and researchers. Due to ethical constraints, we were unable to include photographs of people with PMLD in our report. However, family members submitted photographs of loved ones with PMLD to an artist, and our video/report is illustrated with beautiful illustrations of the PMLD community (individuals cannot be identified by their drawings).

Sharing the video and report

The video and report are free and available to everybody. To access the video you can scan the QR code (below) using your phone, or visit the following address:

<https://bit.ly/SomethingsGotToChange>



To access the report please see the following page:

<https://www.bathspa.ac.uk/media/bathspaacuk/projects/Somethings-got-to-change-Research-Report.pdf>

Feedback and help with distributing the video and report

If you have any feedback about the video and report, or suggestions about where to send them, please let us know. We are keen to hear your thoughts and to share our work widely. You can get in touch with us by contacting Ben Simmons:

b.simmons@bathspa.ac.uk.

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