



"People with PMLD are the bravest people in society... we have to do our best to listen, to hear and to act on their behalf because no one deserves it more"

Pat Graham

My name is Pat Graham and I am the parent of a daughter who has a profound learning disability. I'm also the chair of the board of governors of a charity called PAMIS (Promoting a More Inclusive Society).

When I was invited to write a blog about people with profound and multiple learning disabilities (PMLD) for 'This is Me: Valuing the lives of people with learning disabilities' project I was really delighted, but my dilemma was where to start and indeed, would I be able to stop? I speak and write often about people with PMLD in the hope that someone, somewhere is listening and will help to change their lives for the better. Given the times that we live in, it is inevitable that the content and context can be negative and sometimes shocking, so I wanted to take this opportunity to focus on the positive.

So what is PMLD? PAMIS is a charity that supports people with PMLD and their families and carers and this is PAMIS's definition:

"People with PMLD have learning disabilities in the profound range who have a number of complex healthcare needs. Their disabilities can present challenges for them and those providing care. PAMIS recognises that 'profound' also means deep, intense, wise and requiring great insight or knowledge.

Although many people with PMLD have significant disabilities, they are also teachers and facilitators and can make a great contribution to our lives”.

The latter part of that definition is what I would like to talk about.

My daughter Lauren is 33 and lives in a housing support service with 3 others. She has a profound learning disability, is unable to communicate using speech and has complex epilepsy but there is so much more to Lauren than that. She has a zest for life and the capacity to inspire joy, affection and laughter in everyone she meets. These qualities are not exclusive to Lauren but are demonstrated by every person with PMLD that I have ever had the pleasure to meet.

How is it that someone who may have little speech, who may not be able to walk, who has difficulty expressing themselves, whose brain may work differently from most others can add such value to the lives of everyone around them? I have always known this to be the case but for the purposes of this blog I'm going to try to work out why that might be.

The relationship with someone with PMLD is based on mutual love, trust, generosity, friendship, unselfishness and is informed by all of the senses. It's a paired back sort of relationship that's unencumbered by so many of the trappings of modern life.

You don't have to be beautiful, clever or rich because they accept you just the way you are and as a result you accept them just the way they are. They challenge you and give you opportunities to learn and develop in more ways than you would ever have thought possible. They may keep you on your toes but you can also have so much fun and pleasure together.

Beyond that, it has to be said that people with PMLD are the bravest people in society. They face serious challenges every minute of every day of their lives. They may be in pain, they may not understand, they may not be understood, they may be frightened, they may be lonely, and they are unlikely to be able to express those anxieties other than by their behaviour, which may well be misinterpreted. The courage that requires is beyond our understanding, but we have to do our best to listen, to hear and to act on their behalf because no one deserves it more.

As a parent, I could not be prouder of my daughter. She should never be defined by her learning disability. She is a wonderful, engaging, funny individual who has achieved so much in the face of so many challenges. She has enhanced our family's life in every possible way and we have learned more from Lauren than we could ever have imagined. Lauren and her peers have lives that are of value and add value to the lives of everyone around them.

That is why I have been so pleased to be involved in the 'This is Me: Valuing the lives of people with learning disabilities' project which so wholeheartedly recognises that value.

If you would like to see more of Lauren and her friends enjoying life then use the following link to download PAMIS's presentation, "I Can If You Can":

<https://pamis.org.uk/news/news/i-can-if-you-can/>

