



Championing Positive Risk

Esther Veale

There is freedom waiting for you,
On the breezes of the sky,
And you ask "What if I fall?"
Oh but my darling,
What if you fly?"
- Erin Hanson -

Positive Risk is often discussed as a vital element of person centered planning for people with learning disabilities and for those with dementia, and quite rightly so. It is widely accepted that we have a duty to enable people to make and enact choices about their own lives even if those choices don't work out and that equally, we have a parallel duty to ensure that those risks are measured, managed and that people are kept as safe as possible whilst taking them.

For a long time it has been acknowledged that positive risk taking is an essential aspect of achieving full and meaningful life experiences that create opportunities for development and growth. What is less often considered is what positive risk taking looks like for people with PMLD, where there is greater onus on family, support staff, teachers and carers to drive this agenda. Here, positive risk taking has no less importance and it still plays a role in individuals having agency, power and

control over their lives. For these reasons, the notion of positive risk taking is embedded within the Core and Essential Standards; as part of strong leadership, as part of having meaningful life experiences and as part of playing a visible and active part in the local community. This article briefly unpicks what this could look like for people with PMLD and what it looked like for one person in particular; my sister Mary.

Mary was certainly a champion for positive risk taking; a true adventurer and 'adrenaline junkie'. She discovered on her many adventures that 'there is usually a way'. The combination of a Rough Rider wheelchair to tackle tough terrain, a vacuum posture cushion and a bevy of strong friends equipped with will and a keen sense of adventure to lift her over styles meant she could join in on cross country walks. She adored cycling in a Duet; a wheelchair tandem bicycle and feeling the full force of the breeze in her face. She enjoyed the contrast in speed from the

acceleration of Devon's many steep downhill to the slow and steady huffing and puffing of her fellow cyclist as they then pedalled up the other side. She would consistently giggle at the bumps of the potholes and cobbles under wheel. She canoed, she camped, she would gleefully be bounced and buffeted by the surf in a dinghy on the North Devon coast. She stayed up late into the night at music festivals relishing the hubbub and revelry and making connections with her fellow festival goers.

Mary did all of these things and more until her death in March 2017 at the age of 33. She far outlived any life expectations placed upon her and astounded medical professionals with her resilience time and time again. Mary's longevity and her richness of life experiences were down to her own desire to push boundaries, to strive for more, to take positive risks and also to the willingness of those close to her and caring for her to interpret this desire for adventure and create opportunities for these adventures to happen. Mary lived fully and triumphantly within a framework of positive risk taking.

What is positive risk?

The word 'risk' invites a sharp intake of breath. The tension around the concept is palpable, even its utterance sounds like a highly venomous, hissing snake! Risk itself is merely about managing uncertainty, it is only about what might happen. Often the perception is that risk means a harmful outcome will certainly occur. In some social care settings there is the tendency to avoid all 'risks.' But much of the time the negative impact of avoiding all risks is far greater than the potential negative



impact of taking some. Life is inherently full of risk, there is no escaping the fact that living is a risky business, especially so if you are a person with complex needs and medical conditions. Positive risk taking therefore is an acknowledgment of this. It is about striking a balance between safeguarding individuals and providing opportunities for individuals to expand their experiences; to grow and develop. There is a big difference between taking dangerous and hasty action in the hope that it will pay off and taking a considered approach where benefits and dangers are weighed up and steps are taken to reduce the likelihood and severity of these dangers. In essence, positive risk taking is about considering all of the 'what ifs' including those on the flip side. And in considering all the 'what ifs', as well as 'what if this could cause harm' we also include 'what if the outcome of this activity is triumph and joy' - and perhaps most importantly we consider the reality that will certainly be faced if we do not even try.

Why is positive risk taking so important for people with PMLD?

For parents and others charged with maintaining the wellbeing and safety of people with PMLD the desire to maintain a low risk existence is understandable when comfort, health and even life itself are already on a tipping point. In many respects, underneath an outward fragility of people with PMLD is a high degree of robustness. In most cases this is founded in a survival against the odds and as warriors of painful experiences and discomfort. In many ways we must ask ourselves how much more can be achieved by our hardy warriors! There is undeniably vulnerability to be considered and respected but alongside this is tremendous physical resilience and we have a duty to acknowledge this too and to set high expectations of the kinds of lives people with PMLD could and should live.

In setting these high expectations we must also accept the duty of advocacy in all aspects of life. As communities of care around people with PMLD, we are their extended means of accessing all the excitement the world has to





offer. Most people have the opportunity to take their own positive risks, to make considered judgement and to open up their own worlds. From the relative simplicity of choosing something new on a menu to decisions over whether to take up a potentially dangerous new hobby, it is all too easy to be overly cautious with the risks we take when these implications are for someone else. There is a danger of playing it too safe in case they don't like it or it doesn't work out for them. Instead it is our duty to accurately interpret long standing preferences that have been communicated and enable increasing exposure to opportunities that are based on these preferences. Perhaps if someone fleetingly smiles at moving fast in their wheelchair they should have more opportunities to do this in other ways, for example, on an adapted bike or swing. Positive risk taking is about acknowledging these communicated choices and having the bravery to act upon them.

Positive risk taking in the form of embarking on outdoor adventures, is important for many reasons but for my sister it was most powerful in its ability to connect her deeply to her immediate surroundings and, most importantly, to people sharing the experience with her. Through intrinsic enjoyment of having the wind in her hair, the sound of sea birds screeching and feel of sea spray on her face the most profound channels of communication were opened through a shared mindful acknowledgment of immediacy and of a moment lived together: "Did you feel that lurch in your stomach as we went over that humpback bridge on our bike? Me too!" This visceral enjoyment and connection with immediate sensations are often the most powerful arena for

authentic connection with others when your capacity to imagine future and recall details of past events are limited.

What might positive risk taking look like for people with PMLD?

Risk is inherent in the sphere of outdoor adventures. This is what my sister lived for, what enlivened her and what, it can be argued, contributed to her longevity and quality of life.

One story of legendary significance in our family is that Mary once had a cup of tea mid abseil. Admittedly, a cup of tea mid-abseil is not everyone's 'cup of tea' and indeed positive risk taking need not be a literal interpretation of Erin Hanson's 'breezes of the sky'. For some people, those with PMLD and those without, the breezes of the sky offer no joy, indeed, the very idea of climbing or zip lining would be torture! Instead, positive risk taking means that there is will and action to take up safe and carefully planned opportunities to try new things and to gain new experiences or to gently and considerably increase tolerance and push boundaries through careful planning, judgement, reconnaissance and evaluation. It is a step by step process of expanding comfort zones in an effort to create a positive outcome. Expanding comfort zones can also be about the wider community in which people with PMLD live too; by showing greater presence and participation in local community events it is possible to expand comfort zones of people with limited experience of meeting and communicating with people with PMLD. Positive risk is also about embracing and exploring the seemingly mundane, the everyday; perhaps going out in the snow or wind or rain for brief periods and allowing people to feel the wind and rain on their faces. Keeping warm by employing the insulating properties of a space blanket and creating an instant tent to listen to the rain falling from inside a warm cocoon. All before returning inside and enjoying the contrast of a warm footspa.

Ways of including positive risks in people's lives will be different for different people at different times. These outdoor adventures weren't always a preference for Mary. On her first holiday as a tiny baby the wind, rain and change of environment was too much to bear. They were built up bit by bit until being out in the elements was a joyful experience. Later in Mary's life, when it was less appropriate to drink tea mid abseil, positive risk was about delaying the fitting of a gastrostomy feeding device so that she could continue to enjoy those cups of tea for as long as possible until the real risks of aspiration were greater than the sensory benefits of enjoyment from food. Later still, towards the end of Mary's life, positive risk taking was no longer about cycling and staying up all night, meeting new people and dancing the night away. It was about having high expectations for her care and

sadly about making brave decisions about where she should be in the last few days of her life.

Fundamentally positive risk taking for people with PMLD is important because there are very real risks of not taking positive risks. By not taking risks we deny opportunities for development, for growth and for happiness. Without positive risk taking we restrict people with less learning and less adventure. Embedding positive risk taking can be the difference between existing and living, between surviving and thriving. In making space for positive risk taking we must see the essence of the people we wish to plan for; Who are they? What would they do without limits? What makes them tick? What floats their boat? What brings them joy? What makes them sparkle? Can we enable them to sparkle brighter? Can we find more joy?



Mary's Beat

In memory of Mary a small fund has been set for others with learning disabilities living in Devon and Somerset who would like to apply for a small grant to fund some musical or outdoor adventures of their own. For more information and an application form, please visit <http://www.somersetcf.org.uk/marysbeat>

Contact Details

Esther Veale

Email: esther_veale@hotmail.co.uk