

Artlink



**Making The Most of
What We've Got**

Liz Davidson

From the beginning of March 2020 through to the present we have asked different artists and thinkers to respond to issues that were being unearthed as Covid-19 took its toll on our communities. Each writer was asked to respond to a simple brief that in some way related to their lived experience, providing the opportunity to open up these issues, to better understand what we could and should have in common.

Like most working women and mothers, I have many roles in my life. I am a multi-faceted multi-tasker. Generally I don't itemise these tasks because if I do I will implode from the pressure of my to-do lists for each of these roles. I'm a mother, a wife, a daughter, a sister, a friend, a boss, a colleague and a carer to a terminally ill parent. I have two adult sons, one of whom has Learning Disabilities and Autism.

It's assumed that I must be a strong woman. To those looking in on my life, I appear resilient, stoic even, but inside I'm wavering. My survival kit is my sense of humour, always cracking a joke and laughing in the face of adversity, whilst in the privacy of my own home I quietly weep over the ironing board.

I want to live in a world that truly values people. I hate injustice, the inequalities and the inequity of a society which flies a banner falsely stating that it supports our freedoms and wellbeing.

I believe that the systems and people that govern and control us truly struggle to acknowledge the differences between what's socially and morally right and wrong.

I also work as a professional in Health and Social Care with adults with complex and profound learning disabilities. I was born with a revolutionist's heart, to fight for what is right, although my energy for this ebbs and flows in these times of contradictions and confusion.

I value my Dad and his influence on me. He was intelligent, determined and

curious. He was always fighting for what was fair and just. He taught me to respect people, to value their contributions, to work to the best of my abilities and never turn my head away from injustice and the suffering of others.

The Zombie Apocalypse

What impact has COVID-19 had on my life and the life of my sons?

My son who has learning disabilities and autism had his services stopped in the initial lockdown in March 2020. The loss of these ordinary opportunities from his life was a real shock to him. He was confused and disorientated by the overnight disappearance of the life he had. To help weather this storm required creative planning, regular supportive calls to home throughout the day, packed lunches and essential equipment and supplies, his Oculus and Xbox to maintain his virtual existence, as well as regular supportive calls to home throughout the day. These games informed his understanding of the pandemic, referring to it as the “Zombie Apocalypse.”

My main concerns for my son as this “apocalypse” wreaks its chaos on his world is that he may become too comfortable without the stressors of real life and lose many of the skills we have spent the last couple of decades teaching him. The fragile structures that maintain his confidence and the reassurance needed to maintain his social and personal life skills will start to erode if he is not using these skills and completing these daily activities.

My other son was working in social care, supporting people dying of Covid-19. I was terrified for him. He is young and was surrounded by death in the first half of 2020. How can you protect your family from this pandemic?

My Dad's years in the mines meant he had a serious respiratory condition and my Mum was given a diagnosis of untreatable cancer in 2020. Access to treatment and support for my parents became more difficult: appointments cancelled, treatment delayed, information not shared and anxieties building. Sadly, I lost my Dad to Covid-19, his death made worse by the loss of all the social and emotional connections that would normally have helped us through this time.

Fortunately, my sons and I are able to hug each other and be a tight supportive group but I have painfully missed the hugs of significant people in my life and never realised just how much strength I gained from these human connections. I have missed quality times with friends and family, bookshops and swimming which is meditation and exercise rolled into one, the only place I can really escape from the demands of the world and everyone in it.

For me a true reflection of the emotional pain of COVID-19 is in my Mum's experience. She and my Dad survived months of shielding together. Then Mum and Dad were hospitalized with Covid 19. She lost her soulmate of 62 years. We wanted Mum to be well enough to attend my Dad's funeral, so we had to delay it until she had recovered. The pandemic restricted the numbers of people who could attend, so we didn't get the chance to celebrate his life in the way he deserved. My Mum remained isolated, her health deteriorating as a result of the cancer. She could not be with family and friends who could support her through her devastating grief and loss.

We had a coffee just a few weeks after the restrictions were lifted and she reminded me that she had not seen my whole face since March 2020. That is such a difficult thing to get your head around. The fact that all the things that

we have taken for granted, the network of supports that would have naturally come into place, the faces we would have seen, the supportive hugs we would have got ... just weren't there.

Working Together

Accessing Health and Social Care is something that nearly every person does at some point in their lives. It therefore needs to be fit for purpose and accessible to all, but the system has been severely challenged by Covid. When I talk about the system, I don't just mean the NHS, but the many different services within health and social care that rely on each other to operate effectively.

I am aware that within the system and its institutions there are many hierarchical power imbalances, that the freedom and control we think we have over our own lives is partly an illusion but if this pandemic has taught us anything, it's that it's ok to admit that we don't have all the answers. There is great strength to be found in our shared vulnerabilities and I'm convinced that the continued health of our communities rests on acknowledging what hasn't worked as much as what has and building on our new connections to each other.

Within my work, what shifted in the dynamics of care was the ability to take time and really value the people that are cared for.

During the pandemic many people who had to shelter at home lost most if not all of their day services. It's hard for people to understand that they can't see their friends or do the things they've been doing for years. So, the impact

of these losses has been dramatic, causing physical and emotional pain.

It is clear that a sense of being, of having purpose and feeling valued is essential to our health and wellbeing. In this context what do I mean by wellbeing? It's in a sense of identity, the quality of relationships, about feeling valued and secure, having experiences that enrich our lives and leave you feeling happy, all this on top of the essential care that supports physical and emotional wellbeing.

We need to think beyond the reality of crisis-driven institutional care, past compartmentalised management systems and their blinkered need to measure success through unrealistic outcomes. During the pandemic, when the system could not be so rigid, we had the freedom to take our own journeys; journeys that would introduce us to new ways of being.

Within my work those people who had more critical needs had to have their day services continued. These services were delivered within the context of altered environments, rooms changed with social distancing allowing more time to spend with just one person. Out of necessity we were thrown at warp speed into truly interpersonal ways of working, where being creative ensured that what we did could evolve each day, reacting to the person and what was essential to them. This has been both inspirational and revolutionary. Whilst the wider systems became chaotic and confused, the people on the front line became resourceful, working together to just get through it.

Before the pandemic people struggled to achieve true collaboration within learning disability services. This has something to do with competing for care contracts within what was a marketplace for care. In this new reality, people

and organisations really wanted to work together; they were open to being more creative, spontaneous, instigating new experiences and really focusing on more personalized ways of working. As a result, staff felt more valued, motivated. They naturally started to open up and with that came personal skills and greater confidence. This has been transformative across local social care staff teams who remained supporting people with complex learning disabilities. It's about people collaborating, whether carer or the recipient of care services, and fundamentally about shifting the culture of social care. With fewer bureaucratic distractions, it became focused on the individual. By working together we made the best of what we have had.

Staff became invested in the relationships they were building. They expressed that they often felt blessed, that they could get away from their homes and be with people outside of their own household. Some staff had no other contact outside of their workplace and as a result of this experience they started to really value the human contact they had through work. Staff found great camaraderie and emotional support from colleagues. This helped them get through difficult times.

Creative Thinking

Throughout this process we have found that using a model of support that fully utilizes art, in its truly multifaceted context, facilitates creative and resourceful opportunities for people to explore ways of working and being together. It removes the rigid and often obstructive processes and structures found in social care models of working.

It places people on equal ground, where they explore together an experience

that they have perhaps never had before. They learn about each other through the actions of doing something together. I suppose it helps people to realise that creativity is not about being able to draw or paint; it's about something that is much more experiential. It's about safe spaces that support equal vulnerability and equal learning.

Recently, I've had a few staff say that they have realised that by doing little things differently that they have been able to discover things about themselves as well as the people they support.

Recognising the skills we all have has energised us all and given us confidence to do amazing things. For some, this is something they most likely have never experienced in their working lives.

I have come to the conclusion that Health and Social Care with its plethora of value-based theories - which on paper make a great deal of sense - needs to be a lot more creative. The policies and ideologies they wrap us in become irrelevant in the harsh reality of budget restrictions and desperate inequalities. This ideological "instruction manual" approach with its inaccessible and generic demands on people is no longer the way forward.

A good life for all of us is achieved by finding purpose within experiences and opportunities that have true meaning. It's about being valued, having purpose, receiving quality medical care, being warm, having food, feeling safe, being loved, being appreciated and forming relationships. It's also about a sense of wellbeing that we experience when positive things happen. For people with complex learning disabilities the list goes on, but what is essential is that we need to be more flexible, changing in relation to the individual, encouraging

people to work together to ensure that what we do is of real meaning.

Within this, art helps us to explore and translate what's important; it changes how we see each other and as a result it transforms lives. Rather than seeing someone as dependent and vulnerable, it provides a series of very different positive perspectives and views. Talents and strengths are recognised and built upon; it becomes about mutual learning, respecting the fact that we have much to learn about how people with complex learning disabilities influence the world around them and share meaningful experiences with others. When we understand and respect just how rich and diverse that is, then that's where the transformation is.

As an example, when Laura (artist) worked with Tina, the sense of mutual discovery and exploration - where there were no rules to follow or break - ensured that Tina had the confidence to do things with the artist that no one else could encourage her to try. This happened once a week for an hour. The staff supporting Tina did not have the freedom the artist had, and so they never quite shared the magic of the relationship she had with the artist. During the pandemic, with smaller numbers of people attending day services, we had the opportunity to offer more individualised support and as a result we worked with people in a very different way. We worked more slowly, adapting spaces to suit people; we became more flexible and responsive. When Tina returned for a few days a week after the initial lockdown, she was being supported by unfamiliar people who decided to adopt the artists way of working to replicate what they had seen had meaning for her. Learning from each other has been evident in the experiences shared. She's gone from a narrow, rigid way of being with her support team where she repetitively did the same 4 tasks throughout the day to exploring new things, wanting to

do anything that's offered to her. She's become much more communicative with staff, letting them know what they are doing works, by hugging them and asking for more. These outcomes are achieved by asking the right questions, making considered observations, stopping, listening without making assumptions. It's become important to ensure that people with complex disabilities are fully involved, that it's on their terms and that we have the space and time to do that; as a result, we can significantly change the person's life and the relationships they have with others.

We (the people I work with) truly value diversity, understanding the value in bringing people who have many different backgrounds and experiences together. What is meaningful differs for each person and it's the journey we take and our willingness to collaborate that will create engagement that will truly enrich all of our lives. Through art we strive to collaborate, to create opportunities together, to learn from each other and through that we facilitate different and more relevant forms of Agency. We believe the notion that an elite group of experts with social care is out of date. When we all work together and share our many different perspectives then all of our worlds become more representative and 3 dimensional.

Post-pandemic, the answers for an individual with complex learning disabilities seem to be achievable: make it relevant; be flexible; work together; respect difference and be creative. I often feel when I observe these changes in people's life experiences and relationships that they should be saying to us, "Bloody hell, why has it taken you this long to work this out?"

In the end it's not about what you are or even who you are. It's about what we are together, what we can learn from each other. That's what's important. The

fact that we all need each other. That we need positive relationships. That's what makes us human.

This gives me hope for the future.

Artlink

Established in 1984, Artlink is an arts and disability organisation. We believe participation in the arts has an important role to play in realising personal and social change.

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