

EMPOWERING PEOPLE THROUGH USER-LED ORGANISATIONS



By Khatija Patel

We have talked in our Putting Relationships First cell about the importance of recognising and showcasing the strengths in the people we serve and giving them leadership roles. Khatija Patel writes here about the role of user-led organisations in this respect.

I am always in awe of how the disabled people's user-led organisation that I am now CEO of came into being, and what can be achieved when people with lived experiences are empowered!

In 1997, it was the ambition of a group of disabled people to access services under one roof and receive up-to-date, accurate information, advice and guidance. Their ambitions were to develop person-centred approaches to care including developing, co-designing and delivering additional accessible services.

It helped that at that time there was a national movement to support the establishment of centres of independent living. However local challenges were many, yet the group persevered, challenged and negotiated with statutory bodies. In partnership, securing millions of pounds of funding to build a state-of-the-art Independent Living Centre.

When council officers showed them dozens of sites for the build, hidden away in industrial estates, that were not suitable in terms of access and transport links, the group refused these even with the threat of withdrawal of funding. Until a suitable site that ticked all accessible boxes was found.

During the build, disabled people worked with contractors, architects and stakeholders ensuring the design and infrastructure were inclusive and accessible. This included where light switches and door handles were placed, to the colour of paint on the walls.

The centre opened in 2000 and during the build the group developed a user-led membership governance structure, registered as a charity, changed its name from Sandwell DLC to 'Ideal for All' and secured further funding to deliver independent living services under the management of people who use the services.

The centre became a hub for local disabled people and is recognised nationally by government as an example of what can be achieved when working in partnership with communities. With councils and health professionals visiting from around the country.

By 2012, Ideal for All was delivering support to thousands of people, working within its user-led ethos, and developed further services and activities: an information, advice and guidance hub point, a drop-in duty service for low level mobility aids, an occupational therapy and a sensory equipment service. We also deliver strategic engagement and enablement, co-production, consultation on national strategies like benefit transformation and personalisation and supported the first person in Sandwell to receive their personal budget as a 'direct payment'.

Ideal for All brought in millions of pounds of investment into the borough, developing – to name but a few – three derelict pieces of land into accessible market gardens and therapeutic gardening spaces and trialling social prescribing as part of 'allotments on prescription'.

However, despite all the successes, lessons were learnt when austerity measures hit and 'market shaping' meant tendering for service delivery.

In 2013, the core work of the charity and the management of the Independent Living Centre were reviewed by local politicians and council officers, culminating in a substantial loss of funding and service delivery. Ideal for All were held to ransom over contracts and had to relinquish the leasehold of the Centre. This was a difficult time for the charity where we asked ourselves, 'Should we wind down or review options and carry-on invaluable work?'

The Board and staff (all on redundancy notices) rallied and worked hard to restructure and focus on core strengths, continuing to negotiate with the 'powers that be' and source additional opportunities. We also responded to the environment with a new way of working, ensuring the user-led ethos was embedded throughout.

As an employee, I saw the determination of disabled people coming together to challenge the authority's intended way forward, meet with politicians and officers,

develop petitions and even get their voices heard on local news channels. They supported me to take a leadership role in the charity, focusing on the core of our work to help people to live independent lives and be heard.

For me and the fantastic staff team it was a very difficult time, a roller coaster of emotions, managing conflicting priorities of job security and wanting to ensure the continuation of the invaluable work of the charity.

Six years on, resilience has shone through, and we have a thriving disabled people's user-led organisation, with doors remaining open during the pandemic, which has widened its geographical reach supporting around 2,000 people per year with Direct Payment Support Services and around 5,000 people with integrated health and wellbeing support, comprising peer support and condition management, community engagement and support, employment and skills development and mental health and well-being services, incorporating the fantastic horticultural sites into service delivery.

The charity has built long-lasting partnerships and is a part of established (co-founded) consortia, which means, together, we can reach further into communities delivering social and health care outcomes.

We are ambitious for our innovative social enterprise activities and the most recent business plan aims to achieve sustainability and ensure we are here as long as disabled people and people who need the support to be empowered exist.

What has struck me most – and it is still prevalent in our society today – is that too many disabled people and people who require support must challenge and fight for their statutory rights. It takes determined people who run user-led organisations which empower individuals and communities with information and support to show there is a better way and make life better for all of us.

Khatija Patel is the CEO of Ideal for All, a user-led registered charity and social enterprise based in Sandwell and working to make life better for disabled, elderly and vulnerable people and their carers in the West Midlands and neighbouring regions.