

**Story-Gathering Report 2020 - Executive Summary**

*Measuring the Mountain* is a community-based action research project funded by Welsh Government as part of their commitment to evaluate the early impact of the *Social Services and Well-being (Wales) Act 2014*. Focusing on the experiences of people who use care and support services and people who are unpaid carers, the project has two main components: story-gathering of lived experiences from around Wales and a Citizens’ Jury on what really matters in social care.

This executive summary relates to the story-gathering work; the full report, as well as the report of the Online Citizens’ Jury, can be found on [www.mtm.wales](http://www.mtm.wales).

**Background**

*Measuring the Mountain* received initial funding for 2018 and 2019, and following the successful completion of that activity, was funded for further work between May 1st 2019 and December 31st 2020. The aim of this research was:

To understand the early impact of the *Social Services and Well-being (Wales) Act 2014* and people’s experiences of social care, particularly the factors that contribute to whether experiences are positive or negative.

**Methodology**

*Measuring the Mountain* gathered stories between August 1st 2019 and May 31st 2020, utilising *SenseMaker*. *SenseMaker* is a tool designed to support ethnographic research, allowing for data collection to be scaled up and undertaken in a consistent manner across large demographic or geographic areas.

The framework used by *Measuring the Mountain* began by asking for a story the individual wanted to share, and subsequent questions added detail and context. The focus was on lived experiences of social care in Wales and people were free to share whatever stood out to them.

A combination of purposive and snowball sampling was employed to collect stories from around Wales. The primary approach for gathering stories was for someone from the project to be invited to a group or get-together at which people could hear about *Measuring the Mountain* and voluntarily opt to engage with the project. They then either verbally relayed their story to someone from the project for inputting to *SenseMaker* or directly inputted it themselves. People also shared stories themselves by going online and completing the questions, or by sharing their story via one of the project’s partner organisations.

This approach, of creating opportunities for people to share what mattered to them, in whatever way they chose, was an important element of *Measuring the Mountain*. Although there is an element of bias in this method, the snapshots of people’s lives, and the themes that have emerged, are of considerable value to understanding the day-to-day experiences of people across Wales.

**Findings**

*Measuring the Mountain* gathered 520 stories from 421 individuals across Wales. Of those individuals, 68% were women, 40% were disabled and 46% had caring responsibilities; they were aged from 12 to 99 with 28% aged 65 and above.

Analysis of the 85,000 words of narrative revealed 14 primary themes that were grouped under the principles of the Act. Collectively, the stories highlight the complexity of many people’s lives, the significance of the role played by unpaid carers and the value of thoughtful, human interaction in how care and support services are delivered.

**Prevention**

The experiences of unpaid carers revealed the enormous efforts people are prepared to expend in support of a family member, friend or loved one. They illustrate the significant contributions made behind closed doors and the responsibilities that people are prepared to take on to ensure a good quality of life for those they care about.

The difficulty of accessing services or finding appropriate information was a consistent theme and a source of frustration and distress for a number of people. Among the positive stories were examples of services that actively offered support, made themselves available in ways that suited people and prevented things from deteriorating.

**Voice and control**

In relation to voice and control, a number of stories described the struggle many people had to get the right support for them or their loved one. People shared experiences of feeling out of control, without choices, caught up in circumstances out of their hands. Often processes were seen to adversely contribute to these experiences, creating additional obstacles to people getting the right support.

Positive experiences often referenced specific individuals who undertook their professional roles with thoughtfulness, and who paid attention to the things that mattered to the individual. Often, these were straightforward things, for example, knowing the name of the person who would be coming into their home, being kept informed about appointments, having phone calls returned, and being supported to access the activities they enjoyed.

**Multi-agency working**

The narratives that sat under the principle of multi-agency working highlighted issues in how social care interacts with other sectors, and how services within the sector interact with one another. There was a notable correlation between people believing that services had worked together well and them having had a positive experience.

Periods of transition, such as the move from children’s to adult services or from health to social care, were flashpoints in people’s experiences, highlighting the importance of considered interventions. Positive experiences of transition illustrated the significant difference that can be made to people’s lives and reiterated the value of good relationships between those accessing services and those providing them.

**Co-production**

Under the principle of co-production were a significant number of positive experiences relating to community groups and activities. Of particular note are examples of creating networks, meeting others, and developing peer support connections. They suggest valuable methods of supporting people, sharing information and reducing isolation in the community. Many stories further emphasised people’s willingness to work with both statutory and voluntary providers and to take responsibility for their or their loved ones’ support.

**Well-being**

Well-being was a thread running throughout most of the narratives, particularly those that related to family. Stories described people caring for family members while managing their own physical and mental health needs and in some cases, family members caring for one another. Mental health issues were mentioned in a large number of stories and were often described as being exacerbated by interactions with service providers. These stories illustrate the need for easily accessible, high quality support and for approaches within social care that reduce the burden on the individual.

**Conclusions**

The narratives demonstrate the unequivocal value of positive human interactions based on trust, respect, mutual understanding and a meaningful balance of power. Within many of the positive stories were behaviours critical to good service delivery and good experiences: listening to people, working *with* them and recognising individuals as knowledgeable contributors to their and their loved ones’ support.

Accessing support and knowing what is available should not be a struggle or a battle. Creating easy avenues to services, making offers of support and working closely with those that require support, are valuable factors in people’s positive experiences.

Fundamentally however, simply listening to and responding to the specific, individual needs of each person in order to understand what really matters to them is at the heart of every story shared with *Measuring the Mountain.*