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# Measuring the Mountain: What Really Matters in Social Care to Individuals in Wales?

**FINAL REPORT**



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## Contents

.....	5
PART A – BACKGROUND .....	5
1. Inception.....	5
2. Selecting Methods: SenseMaker and the Citizens’ Jury.....	8
Phase 1 – SenseMaker.....	8
PART B – SENSEMAKER .....	12
3. Developing the SenseMaker Framework.....	12
4. Delivering Phase 1 – Story-gathering.....	17
5. SenseMaker Analysis .....	21
6. Thematic Exploration of the Data .....	27
7. People and Well-being.....	28
8. Co-production / Working Together.....	41
9. Time-wasting .....	44
10. Prevention, Information and Carers .....	46
11. Perceptions of the Act.....	58
PART C – CITIZENS’ JURY .....	61
12. Phase 2 – Citizens’ Jury.....	61
Preparation .....	61
Delivering the Programme .....	63
13. Citizens’ Jury Recommendations .....	64
14. The Citizens’ Jury and SenseMaker .....	69
PART D – REFLECTIONS.....	71
15. Reflections .....	71

16. Story-gathering .....72

17. The Citizens’ Jury .....74

PART E – CONCLUSIONS AND RECOMMENDATIONS .....78

18. Conclusions.....78

19. Recommendations .....80

PART F – NEXT STEPS .....82

20. Next Steps.....82

Individuals and Carers .....82

Perspectives of Social Care Providers and Staff.....83

PART G – THANKS AND ACKNOWLEDGEMENTS .....85

21. Thanks, and Acknowledgements .....85

ANNEX 1 – SenseMaker Framework.....86

ANNEX 2 – Citizens’ Jury Prog.....90



## PART A – BACKGROUND

### 1. Inception

- 1.1. Responding to the 2011 White Paper, Sustainable Social Services for Wales: A Framework for Action<sup>1</sup>, the Social Services and Well-being (Wales) Act 2014 came into force on April 6<sup>th</sup> 2016 providing a new legal framework for improving the well-being of people who need care and support and carers who need support.
- 1.2. The Act enshrined into law principles that improved people's voice and control in their care; provided renewed focus on prevention and early intervention approaches; offered enhanced support for carers, and was underpinned by the values of co-production.
- 1.3. The Act offered an opportunity to transform the delivery of social care, putting people at the centre of delivery, encouraging more collaboration and partnership working, and extending a clearer offer of support to carers. To support its successful implementation, on March 31<sup>st</sup> 2016, in a written statement, the then Minister for Health and Social Services, Mark Drakeford AM<sup>2</sup>, set out the commitment to evaluate the Act.
- 1.4. The evaluation work would have three phases:
  - Phase 1 - monitoring policies under the Act during the initial year of implementation to understand whether policy was being implemented as intended and to support policy improvement
  - Phase 2 - on-going evaluation through the national outcomes framework and the local authority performance measurement framework
  - Phase 3 - an independent long-term, one-off evaluation that would commence in the third year of the implementation of the Act.
- 1.5. The Phase 3 evaluation would give an unbiased assessment of the Act's implementation and impact, and provide valuable information as to how, if needed, further implementation of policy and legislation could be improved. It would not only provide direct benefits in terms of policy performance and its effectiveness, but was also fundamental to the principles of good government, policy making and supporting improvement across the social care sector.
- 1.6. To support the Phase 3 evaluation, Welsh Government established a Stakeholder Evaluation Group, drawing together individuals and organisations from across social care and related sectors. They provided sector-specific insight to shape the specification of the evaluation, ensuring it was comprehensive and would meet the aim of measuring

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<sup>1</sup> Welsh Assembly Government (2011). Sustainable Social Services for Wales: A Framework for Action. Accessed here: <https://gov.wales/topics/health/publications/socialcare/guidance1/services/?lang=en>

<sup>2</sup> Written Statement - Evaluation of the Social Services and Well-being (Wales) Act 2014. Retrieved from: <https://gov.wales/about/cabinet/cabinetstatements/previous-administration/2016/socialserviceswellbeingact/?lang=en>

the impact of the Act on the well-being of people who need care and support and carers who need support.

- 1.7. Understanding the experiences of Welsh citizens in relation to social care was fundamental to the evaluation of the Act. Having identified that capturing people's voices as part of more formal processes can be challenging, and that early insight into these experiences would be beneficial, Welsh Government commissioned the Measuring the Mountain (MtM) project.
- 1.8. The origins of MtM lay with members of the Wales Co-operative Forum who, following the March 2016 Written Statement on evaluating the Act, had begun discussing the feasibility of taking a co-productive approach to the evaluation work, seeking a means to embody the values of the Act in the delivery of its evaluation. These individuals formed, what would become, MtM's Steering Group to collaborate with Welsh Government in developing and delivering the project. *See Part G for Steering Group members.*
- 1.9. The group worked with Welsh Government to address core challenges related to the gathering of citizens' views on their experiences of social care. Primary among these was creating opportunities for people to share their views and experiences independently of their social worker, family, or others who may influence what they contributed.
- 1.10. Engaging with citizens separately to their engagement with social care and facilitating honest sharing of experiences was a necessary element of evaluating the Act. It required peer-to-peer networks and grassroots approaches to promoting and delivering the work, with strong support from the third sector.
- 1.11. The core purpose of MtM was to engage with a wide range of service users from across Wales using co-productive approaches to seek their views on their experiences in relation to the Act. The data gathered from this project would be critical in shaping two main areas:
  - It would inform the independent evaluation by providing rich and detailed data directly from service users, to shape its direction and ensure service users' views were embedded into the formal evaluation process from the start
  - It would shape the Citizens' Jury element of MtM, a public involvement activity which would concentrate on, and explore, themes specifically related to people's experiences of social care.
- 1.12. MtM was a pan-Wales, community-based initiative which harnessed the knowledge, expertise and collective wisdom of citizens in Wales to better understand their experiences of social care and the early impact of the Social Services and Well-being (Wales) Act 2014. It utilised a range of engagement approaches and robust methods of public involvement. Findings from the project will be shared with Welsh Government, the evaluators undertaking the formal evaluation, and people in Wales.

1.13. The aim of MtM, as outlined in the proposal to Welsh Government was:

**To implement a community-based evaluation of the effectiveness of the Social Services and Well-being (Wales) Act 2014, providing a robust data platform of authentic user experience to inform and focus the Welsh Government’s formal evaluation programme.**

1.14. The project ran in two phases:

- **Phase 1** – a distributed ethnographic approach to collecting stories from people in receipt of care and support and carers. The majority of those stories were to be collected by a network of Listeners
- **Phase 2** – a Citizens’ Jury which explored a key question arising from the stories that had been collected.

1.15. The project offered an unparalleled opportunity to understand more about whether social care was working where it mattered most, in the lives of people across Wales. In doing so, MtM aimed to understand what was important to people, what was working well and what was working less well, building a detailed and valuable picture of current experiences of social care.

1.16. Utilising the story-gathering and Citizens’ Jury methodologies as independent, community-based approaches to involving people and capturing citizen voice, the project provides evidence for Welsh Government and partners on people’s experiences of social care and the early impact of the Social Services and Well-being (Wales) Act 2014.



## 2. Selecting Methods: SenseMaker and the Citizens' Jury

- 2.1. Measuring the Mountain's purpose was to engage with people in Wales to produce an authentic, experience-based assessment of social care provision. The activities of both phases required robust approaches to independent, qualitative research. The methods enabled individuals to share stories that were important to them, and them alone, and the Jurors to control much of the Jury proceedings.

### Phase 1 – SenseMaker

- 2.2. Phase 1 of MtM was story-gathering using SenseMaker, a software tool that facilitates the collecting and analysing of experiences, stories and fragments of narrative. The tool provides a framework that guides participants through submitting their story and responding to questions. The questions encourage a focus on personal experience, enrich the descriptive element of each story and facilitate analysis. The process, for the participant is not an evaluative one: they are encouraged to describe rather than judge their experience.
- 2.3. SenseMaker enables people to identify and record what matters to them and how they feel. This information is plotted, recorded and displayed without any interference from others; it is designed to support a co-productive, citizen-centred approach to monitoring, evaluation, improvement and action<sup>3</sup>.
- 2.4. SenseMaker was developed to enable ethnographic approaches to data collection (anthropological story-collecting) to be scaled up, and undertaken in a consistent manner across large areas or population groups<sup>4</sup>. Trends and themes are identifiable from the data provided by participants in the form of their individual stories and responses to the questions that are asked.
- 2.5. SenseMaker can be utilised in many ways, addressing a variety of research needs. It fit well with the purpose of MtM, providing participants with voice and control, capturing felt experiences and reducing the need for third party interpretation. The tool could be engaged with in one of two ways:
- People submit their own stories
  - People are supported by someone who submits the story on their behalf.
- 2.6. Enabling people to submit their own stories eliminates dependence on professionals, a research team, family or friends, and promotes the submission of unbiased stories, free from the influence of others. SenseMaker stories can be submitted online, via an app or

<sup>3</sup> CognitiveEdge, 20.10.2009 *Introducing SenseMaker®* [online video] available at <https://www.youtube.com/watch?v=SkRe7Xg7pk4> [accessed 20.02.2019]

<sup>4</sup> AcademiWales, 07.26.2016, *Dave Snowden - How leaders change culture through small actions* [online video], available at [https://www.youtube.com/watch?v=MsLmjoAp\\_Dg](https://www.youtube.com/watch?v=MsLmjoAp_Dg) [accessed 20.02.2019]

by completing a paper copy of the framework which provides a range of accessible options.

- 2.7. The scope for individuals to submit stories of just a few words which, alongside responses to associated questions, provided useful information and was a significant benefit to MtM. It was important the tool could be used effectively in several circumstances including in workshops, as part of face-to-face conversations and at events. This was further supported by submissions needing to only take two or three minutes to complete if necessary, although people could also share much longer stories.
- 2.8. Similarly, the option for people to keep their narrative private, while still allowing the responses to their questions to be seen, reduced the potential barriers for people to get involved in the project. This enabled them to share a personal experience, contribute to the project but not feel exposed by doing so.
- 2.9. The opportunity for people to be supported to share stories, to have new conversations or to enhance existing conversations was a valuable element of SenseMaker, which supported MtM's commitment to community-based activity. Gathering stories in environments outside of the social care sector allowed these conversations to occur more freely, with minimal influence. *Full discussion of the delivery and engagement approaches is in Part C, Citizens' Jury.*
- 2.10. SenseMaker offered MtM a consistent approach to gathering data that could be utilised with minimal direct support from the project. Its focus on description and narrative made it simpler for people to engage with and the analytic capability within the tool facilitated straightforward understanding of what had been shared. SenseMaker displays elements of the data as graphics which illustrate the findings in an accessible way. *See Part B, SenseMaker.*

## Phase 2 – Citizens' Jury

- 2.11. Welsh Government's commitment to evaluating the Social Services and Well-being (Wales) Act, and their wider commitment to valuing the views of Welsh citizens, necessitated tangible approaches to public involvement that offered individuals a substantial means of having their voice heard.
- 2.12. Citizens' Juries are an established method of involving the public in important debates in a way which is open and transparent and supports all those involved to have their voices heard. The concept originated in the early 1970s with the development of the approach in both the US and Germany, and it has been used around the globe since then in a variety of ways.

- 2.13. In the UK, Citizens' Juries were first used in the mid-1990s in a collaboration between the Institute for Public Policy Research (IPPR), and the market research company Opinion Leader Research (OLR). Since then, they have been used to involve the public in debate on topics including the happiness and well-being of children and young people, designer babies, local authority governance structures and priorities in dementia service provision<sup>5</sup>.
- 2.14. The first Welsh Citizens' Jury took place in 1997 and was organised by the Welsh Institute for Health and Social Care. It explored potential applications of 'new genetics', specifically Genetic Testing for Common Disorders in the National Health Service and was the first public engagement exercise to tackle this controversial topic<sup>6</sup>.
- 2.15. At the core of the Citizens' Jury methodology is the understanding that anyone, given enough time, enough information and with that information presented appropriately, can reach conclusions, and make decisions about, even the most complex of topics. The method promotes inclusivity, deliberation and, through the topics discussed, citizenship. It is deliberative democracy in practice.
- 2.16. During the Jury process citizens become lay-experts in the area under investigation, as well as competent and confident decision makers. They listen to expert witnesses, examine the evidence, deliberate on the issues and arrive at a policy decision or set of recommendations. The approach supports the public and policy-makers to come together in meaningful dialogue and collaborative inquiry.
- 2.17. Significantly, the Citizens' Jury method offers an approach to bridging the gap between top-down consultation and bottom-up community participation; the former offering little public involvement and the latter being based primarily on lay knowledge and interests<sup>7</sup>. When evaluating legislation and its impact on citizens, a means of drawing together the views and experiences of the policy-makers, those that are delivering the policy and those that are in receipt of services, is critical.
- 2.18. In seeking to understand the early impact of the Social Services and Well-being (Wales) Act, the Citizens' Jury method offered MtM a robust, recognised and practical framework for bringing expertise from across the social care sector together and involving citizens of Wales in complex policy debate. The method promotes the independence of the Jurors, enabling them to control aspects of the process, determine their own questions, and identify their own conclusions and recommendations.

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<sup>5</sup> K. Purdham, 2012, *What are Citizens' Juries?* Available at <http://hummedia.manchester.ac.uk/institutes/methods-manchester/docs/citizensjuries.pdf> [accessed 20.02.2019]

<sup>6</sup> Iredale R and Longley MJ (1999) *Public involvement in policy making: the case of a Citizens' Jury on genetic testing for common disorders*. *Journal of Consumer Studies and Home Economics* 23: 3–10.

<sup>7</sup> R. Gooberman-Hill, J. Horwood, M. Calnan, 2008 *Citizens juries in planning research priorities: process, engagement and outcome* Available at <http://hls.uwe.ac.uk/suci/Data/Sites/1/citizensjuryarticle.pdf> [accessed 20.02.2019]

- 2.19. For MtM and Welsh Government, in their capacity as funders and supporters of the project, the method provided a way to meaningfully explore issues that arose from the story-gathering phase. It exemplified an approach underpinned by co-productive values and demonstrated the value of involving the public in complicated, social issues.

## PART B – SENSEMAKER

### 3. Developing the SenseMaker Framework

- 3.1. SenseMaker offers a range of question types for creating a story-gathering framework; determining the construction of the framework is dependent on the aims and approaches of the research being undertaken.
- 3.2. MtM's questions needed to meet several objectives:
- Provide information that was useful towards evaluating the early impact of the Social Services and Well-being (Wales) Act as well as towards informing the focus of the formal evaluation work
  - Require only information the participant was likely to know
  - Be easy for participants to understand and reasonably quick for them to respond to
  - Offer in-depth means of analysing the data
  - Enable discussion about social care and the Act without closing lines of enquiry.
- 3.3. The process for outlining, drafting and finalising these questions took three months and the design underwent several test phases and iterations. This work was undertaken by members of the Steering Group who had expertise in, and experience of, using SenseMaker, story-gathering, and of the social care sector and the Act.
- 3.4. It was agreed to use the principles of the Act as a focus: voice and control, prevention and early intervention, co-production and well-being<sup>8</sup>. These four principles are the core pillars of the Act and galvanise the values and approaches of the social care sector.
- 3.5. While the Act legislates for several aspects of care including finance, safeguarding, relationships between statutory bodies, complaints procedures and a range of technical, legal and administrative concerns, the Principles of the Act are the elements most pertinent to the day-to-day experiences of individuals. They are therefore also the elements which are most straightforward for people to comment on and most likely for them to have feelings or experiences about.
- 3.6. In SenseMaker frameworks the initial question is designed to elicit the story, reaction or experience being shared. Following testing, MtM's framework started with:

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<sup>8</sup> Welsh Government, 2015, *Social Services and Well-being (Wales) Act 2014: The Essentials* available at <https://gov.wales/docs/dhss/publications/160127socialservicesacten.pdf> [accessed 20.02.2019]

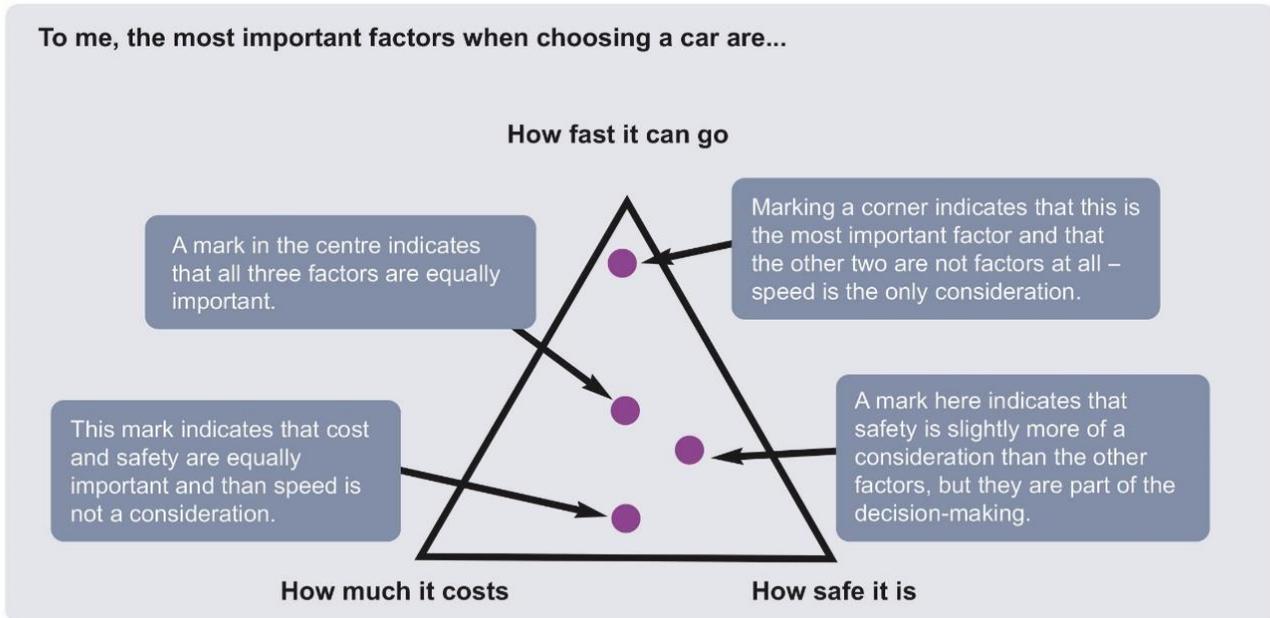
**What experience of social care have you had in the last 12 months? This could have been advice, care, or support for you, or someone you know. Please tell us about an experience that stands out to you.**

- 3.7. The prompt was intentionally broad to allow the respondent the freedom to discuss what mattered to them. This was important to elicit a wide range of stories illustrating the diversity and complexity of social care, and also to promote greater independence and control for those providing responses.
- 3.8. The timeframe was included as a necessary parameter to ensure stories related to social care after the Act had come into effect.
- 3.9. After sharing each story, respondents were asked to self-analyse it by answering a series of questions to provide metric data. These helped quantify perceptions, provided context for people's experiences and supported the identification of trends. The questions were a mix of:
- Multiple choice questions
  - Free text boxes for further or explanatory comment
  - Triads
  - Sliding scales.
- 3.10. The 10 multiple choice questions enabled respondents to provide basic monitoring information about themselves and their experience. They provided insight into the types of service being referenced, their status as either a carer or someone receiving care and support, their views on their story over-all, whether others might have experienced anything similar and who else, if anyone, should hear their story.
- 3.11. The four free text boxes enabled respondents to give their story a title, comment on any changes in their experience of social care since April 2016, provide the prefix of their postcode and any additional comments.
- 3.12. Of the remaining eight questions, five were triads. Triads ask a respondent to consider three factors, in relation to an aspect of their story, and place a mark on a triangle that indicates their strength of feeling about those three factors relative to one another.
- 3.13. The further from a factor that the mark is, the less that factor played a role in the experience. This process of considering three factors together encourages respondents to utilise a more conscious and non-binary mode of thinking than, for example, separate 1 to 10 scales. It also reveals relationships between the three factors<sup>9</sup>.

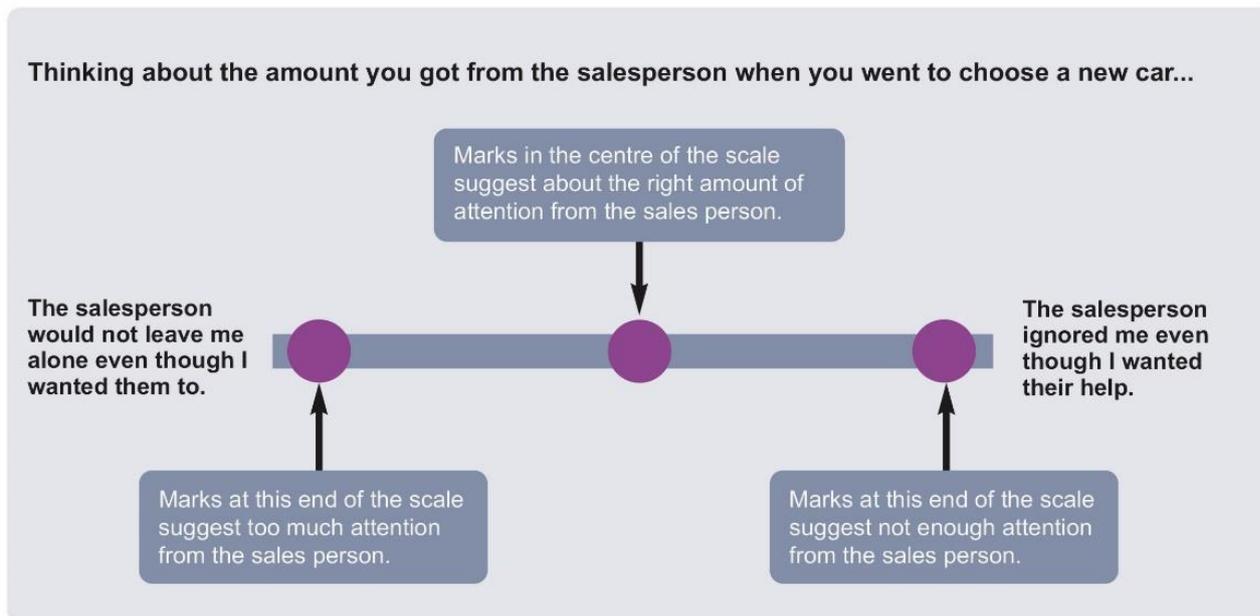
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<sup>9</sup> AcademiWales, 07.26.2016, *Dave Snowden - How leaders change culture through small actions* [online video], available at [https://www.youtube.com/watch?v=MsLmjoAp\\_Dg](https://www.youtube.com/watch?v=MsLmjoAp_Dg) [accessed 20.02.2019]

- 3.14. Trends emerge when marks cluster in areas of the triads and examining the stories that fall within those clusters provides the analyst with more understanding about underlying themes and relationships.
- 3.15. If, in the example below several responses clustered in the top corner, they would suggest that many people considered speed to be the most important factor in choosing a car. Analysis of the narratives in that cluster would, potentially, explain why.



- 3.16. The remaining three questions were sliding scales akin to a 1 to 10 scale in appearance and use. In this case, they have negative extremes at either end, so responses in the middle of the scale would suggest things had been about right.
- 3.17. This approach, of having 'bad' at both ends, minimises people evaluating if something was 'good' or 'bad' ('good' being the unlabelled central area) and instead encourages people to think more deeply about that element of their experience.
- 3.18. As with the triads, this type of sliding scale encourages a more conscious mode of thinking than a 1 to 10 version would.



- 3.19. The triads and sliding scales provided an opportunity to gather metric data, on a large scale, that could quickly provide a graphic rendering of key components of people's stories, and therefore, aspects of the early impact of the Act. The triads and scales were therefore used to test perceptions of elements of the Principles of the Act, and to do so using factors that would resonate with people.
- 3.20. Language was a fundamental factor in the refining of the triads and scales; ensuring that the questions could be understood, that the factors at the corners of the triads and the ends of the scales had a meaningful relationship, and that the questions retained a clear connection to the language of the Act whilst also being recognisable in the context of people's stories.
- 3.21. An important consideration when developing the questions was making sure that they related specifically to that individual's feeling or experiences and did not ask them to speculate on the feelings or thoughts of others.
- 3.22. The first two triads are a positive and a negative version of the same factors and provide an overview of people's experiences. The inclusion of the negative triad serves to validate the positive one (many people would need to respond to both, placing marks as mirror-images on the two) and enables those with less positive experiences to be heard and share their experience constructively.
- 3.23. The third, fourth and fifth triad, through the course of developing them, became neutral in tone, and while stories in the centre of these triads could reasonably be assumed to be

positive, those that lay elsewhere could have been anywhere from very negative to very positive. The neutrality of the questions suggests no 'right' answer to respondents.

3.24. The scales asked about information, being able to discuss matters with social care staff, and the extent to which social care staff acted upon things that had been discussed. These topics were identified as having important roles to play in the aspects of the Act related to information, prevention and early intervention and co-production.

3.25. The full question framework can be seen in Annex 1.



## 4. Delivering Phase 1 – Story-gathering

- 4.1. The story-gathering phase of MtM ran from March 22<sup>nd</sup> to December 10<sup>th</sup>, 2018. In this time 473 stories were collected, generating 45,000 words of narrative. A few approaches were used to gather stories, and the project was promoted via a range of channels. This section will outline the activity undertaken in relation to story-gathering.
- 4.2. The final version of the SenseMaker framework was produced in English and Welsh and made available as an online tool, accessed via a link on the MtM website. Paper copies of the framework were also produced for use in places without internet access or mobile data, and for use with, or by, individuals who were less confident about being online.
- 4.3. The website [mtm.wales](http://mtm.wales) / [mym.cymru](http://mym.cymru) was completed in April 2018. It was an information hub providing everything an individual or organisation needed to know about the project and how to get involved. The resources page contained a link to a three-minute YouTube video, produced by the project, that walked people through using SenseMaker, as well as documents to download that provided guidance on all aspects of the project. The project manager had access to the website's Content Management System (CMS) and maintained the pages to reflect current project activity.
- 4.4. The website went public on April 13<sup>th</sup>, 2018 and an initial email launching the project and inviting organisations to get involved was sent to 68 organisations across Wales. They included health-related charities, county voluntary councils, organisations that supported people with learning disabilities and housing associations.
- 4.5. Subsequent contact with those, and other organisations, created a core of 25 which supported the SenseMaker phase of the project enabling and promoting story-gathering using a variety of approaches. These approaches accommodated the varying capacity levels and needs that organisations had and broke down into three primary types:
  - Organisations hosting their own Listeners who gathered stories from people that organisation supported
  - MtM attending events, conferences and activities to gather stories from groups
  - MtM meeting with people face-to-face to gather more detailed experiences.

### Listeners

- 4.6. In the early stages of MtM it was identified that there would be people who would not want to submit their own story to the project. The Steering Group included people who had previously overseen or delivered story-gathering activity and their experience suggested that reaching everyone who might have a story to share would be challenging, and that some people would face barriers to sharing their own story.

- 4.7. MtM's focus on social care necessitated that stories be gathered from people with learning disabilities, physical and cognitive impairments as well as older people, people who were isolated and those that might struggle with technology.
- 4.8. Creating a network of Listeners, or citizen journalists, who would support individuals to share their story, addressed these issues, enabling the project to reach a larger number of people, a more diverse group of people and, at the same time, facilitate opportunities for people to have conversations.

## A Typical Listener...



- 4.9. 8 organisations registered with MtM to host Listeners and collected stories on behalf of the project. These organisations discussed their activities with MtM and received a walk-through of the project and story-gathering processes. This information was also available on the website, and organisations could host Listeners without needing to register with MtM or alert the project to the work they were undertaking.
- 4.10. Organisations with Listeners undertook story-gathering either through including the activity in the daily work of some of their staff or through including it at events they hosted as part of their annual calendar.
- 4.11. MtM partnered with Tempo (formerly Spice) to provide Time Credits to Listeners who undertook the role in a voluntary capacity. Time Credits are a recognised way of encouraging voluntary participation in activities<sup>10</sup>, and reward the time given with a

<sup>10</sup> 59% of people earning Time Credits say that they rarely or never gave time before earning Time Credits. Tempo, 2018 *Tempo 2018 Impact Report* available at <http://www.wearetempo.org/our-impact> [accessed 20.02.2019]

commensurate number of Time Credits that can be exchanged for activities, services or event tickets.

- 4.12. Listeners were the preferred approach for MtM to gather stories owing to the reach and efficiency of it. However, for many organisations, it was impossible to host Listeners as they did not have the capacity to devote staff hours to the role.

## Story-sharing at Conferences, Events and Activities

- 4.13. MtM ran 15 story-sharing activities at events, conferences and meetings of community groups. People would work in pairs, small groups or if they preferred, by themselves, to complete the paper surveys which were taken away and uploaded.
- 4.14. The activities provided an opportunity for people to be guided through the SenseMaker questions, supporting those who might otherwise have struggled, to understand how to complete each question, enabling them to submit stories more independently.
- 4.15. Working with groups of up to 18 and encouraging them to work together created opportunities for people to talk about their own experiences of social care and hear about the experiences of others. These conversations are valuable in their own right (*see section 16 for further discussion*), and hearing what others were sharing enabled individuals to identify their own stories, without needing prompts from the project team.

## 1-2-1 Story-gathering

- 4.16. MtM met with individuals at a variety of venues and events to hear their stories face-to-face. These discussions enabled detailed sharing of stories, often relating to a range of services, sectors or support, and facilitated the project to develop a better understanding of the complexity that prevails in many people's lives.
- 4.17. These longer, face-to-face discussions did more justice to the integral role of social care in people's lives, and the complexity associated with needing support from services and particularly, needing support from multiple services.

## Paper vs Digital

4.18. The SenseMaker questions were available online and as a paper copy. Approximately 80% of the stories were collected using paper copies, and uploaded by the project team after the event. Informal feedback, including the experiences of the project team, suggests that a combination of factors led to the paper survey being favoured over the online version:

- It can be easier, and less intrusive, to have a conversation with someone while taking notes than it is while typing
- Some venues did not have Wi-Fi available, or there were concerns about its reliability, and/or mobile data was not available to access the questions
- Many of the conversations the project had were wide-ranging, and covered several experiences which could more accurately be recorded, along with their corresponding question responses, on paper than was feasible with the online system where stories needed to be submitted one at a time
- The online survey does not include a mechanism for saving a story and returning to it later, as such, if someone with memory or cognitive difficulties is sharing a story, the paper version made it possible to take short breaks during the conversation.



## 5. SenseMaker Analysis

5.1. MtM gathered 473 stories, comprised of just over 45,000 words. The following section will present key information about these stories and the people who submitted them, outline findings and describe trends that have emerged. The section covers:

- A demographic breakdown of the people who submitted stories
- Overview information relating to respondents' perceptions of their stories
- A thematic breakdown of the main findings and emerging trends supported by data and narrative from the submissions.

### A Note on the Sample

5.2. Several approaches were used to gather stories, and, in all cases, aspects of self-selection were present in these approaches:

- Organisations identified for themselves whether they could host Listeners or if they wanted to invite MtM to attend events or meet their groups
- The decision to submit a story lay only with the individual whose experience it was.

5.3. These elements of self-selection, their necessity and possible ramifications are discussed in Part D, Reflections.

5.4. People could submit more than one story to MtM. Allowing this was an important component of facilitating engaging conversations and of emphasising that understanding people's experiences was the primary consideration of the project. To preserve people's anonymity and minimise the likelihood of personally-identifiable data being provided to the project, there was no mechanism to identify who had submitted experiences or, if someone had submitted several, which experiences related to the same individual.

5.5. Whilst submitting several stories was an option, it is unlikely that many would have done this given the time it would take, and the considerable length of some of the individual stories that were submitted (the longest was 4,500 words). This is supported by the data from the postcode prefixes: people were asked to provide the first four characters of their postcode, and 104 unique entries were submitted, this includes the densely populated post-code prefixes of Cardiff, Swansea and Newport.

5.6. Of the 473 stories MtM received, only 7% or 33 stories, were from people under the age of 25. Other aspects of the monitoring data show nearly twice as many women as men responding, and a higher than proportional response rate from the south east of Wales.

- 5.7. In 2016-17 there were approximately 150,000 adults receiving care and support services from local authorities across Wales<sup>11</sup> and there are an estimated 370,000 carers<sup>12</sup>. The sample of 473 stories therefore, is a tiny fraction of the number of experiences that could, potentially, have been submitted. It is important to acknowledge that the findings outlined over the coming pages are from these 473 stories and that much of what has been identified may warrant further, more substantial, exploration.

## A Note on the Numbers

- 5.8. Most of the SenseMaker questions were not mandatory, and of those that were, there was an option to tick 'not applicable' or 'too hard to say'. As such, throughout the analysis, where numbers are given, they do not total 473.



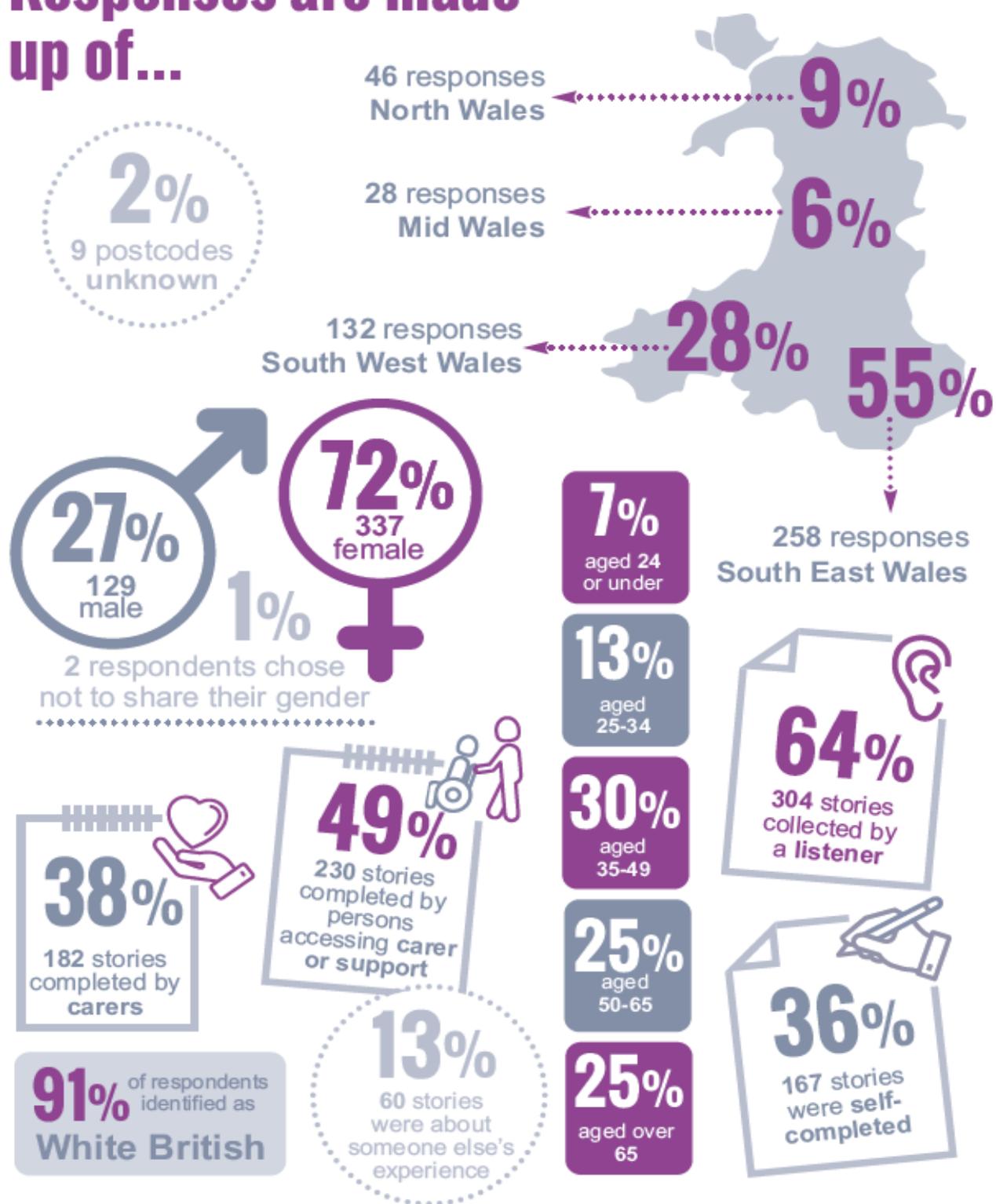
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<sup>11</sup> Welsh Government, 2018 *Adults receiving services by local authority and age group* available at <https://statswales.gov.wales/Catalogue/Health-and-Social-Care/Social-Services/Adult-Services/Service-Provision/adultsreceiving-services-by-localauthority-agegroup> [accessed 20.02.2019]

<sup>12</sup> Carers Trust, 2016 available at <https://carers.org/country/carers-trust-wales-cymru> [accessed 20.02.2019]

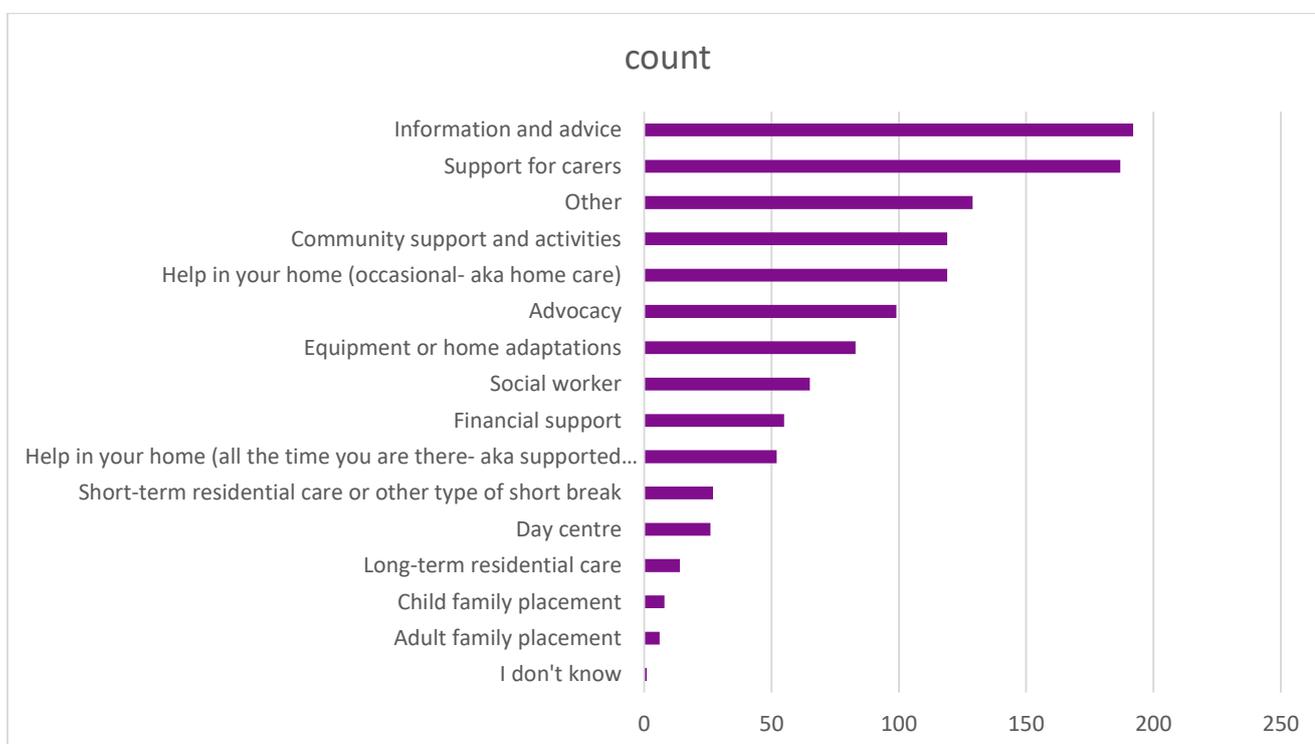
## Who Submitted Stories?

### Responses are made up of...



## Overview Information

- 5.9. After providing their narrative, respondents were asked a series of questions, 10 of these were multiple choice and covered the monitoring data as well as information about their story and perceptions of their story. These responses offered further means of analysing the narrative and aggregating responses to identify themes. They also provide a very broad overview of people's interactions with social care.
- 5.10. Respondents were asked to identify which services or settings, from a list of 14, applied to their story. They could tick as many as were applicable, and a 15<sup>th</sup> box for 'other' allowed them to list any additional, related services or settings.
- 5.11. Information and advice, and support for carers were the two most frequently selected services.

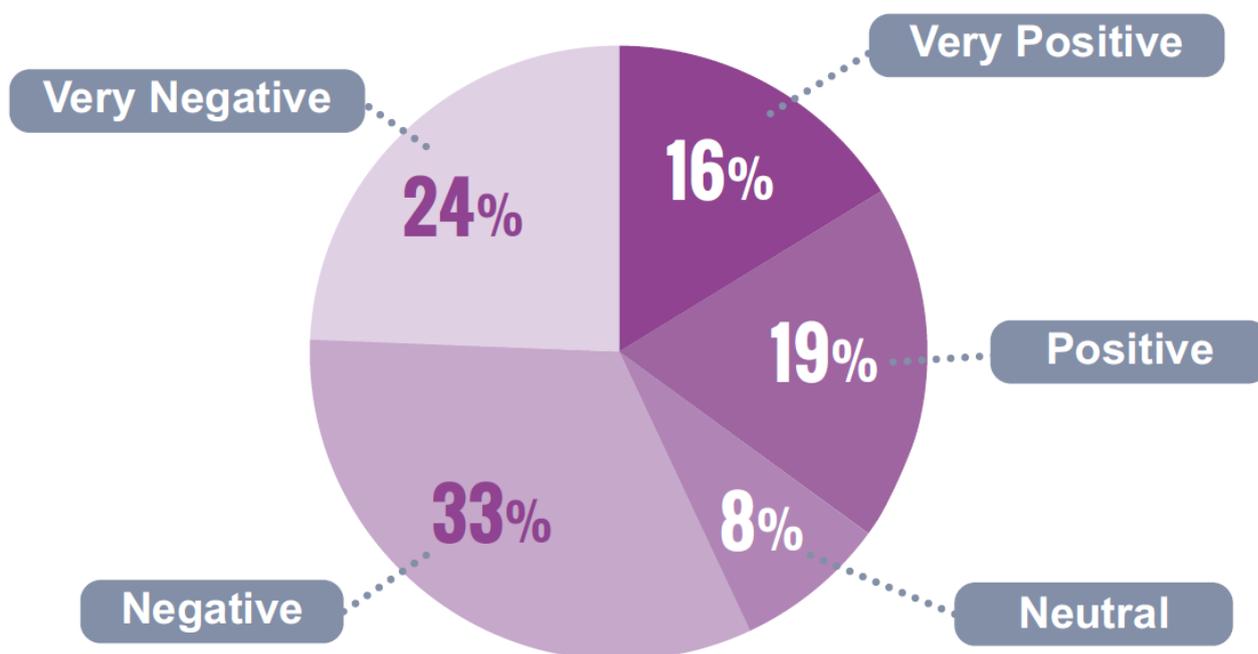


- 5.12. 129 stories were submitted with 'other' ticked. They related to:

- 59 - health or health services
- 17 - extra-care
- 8 - transport
- 7 - education
- 5 - mental health
- 5 – housing
- 3 – work or employment

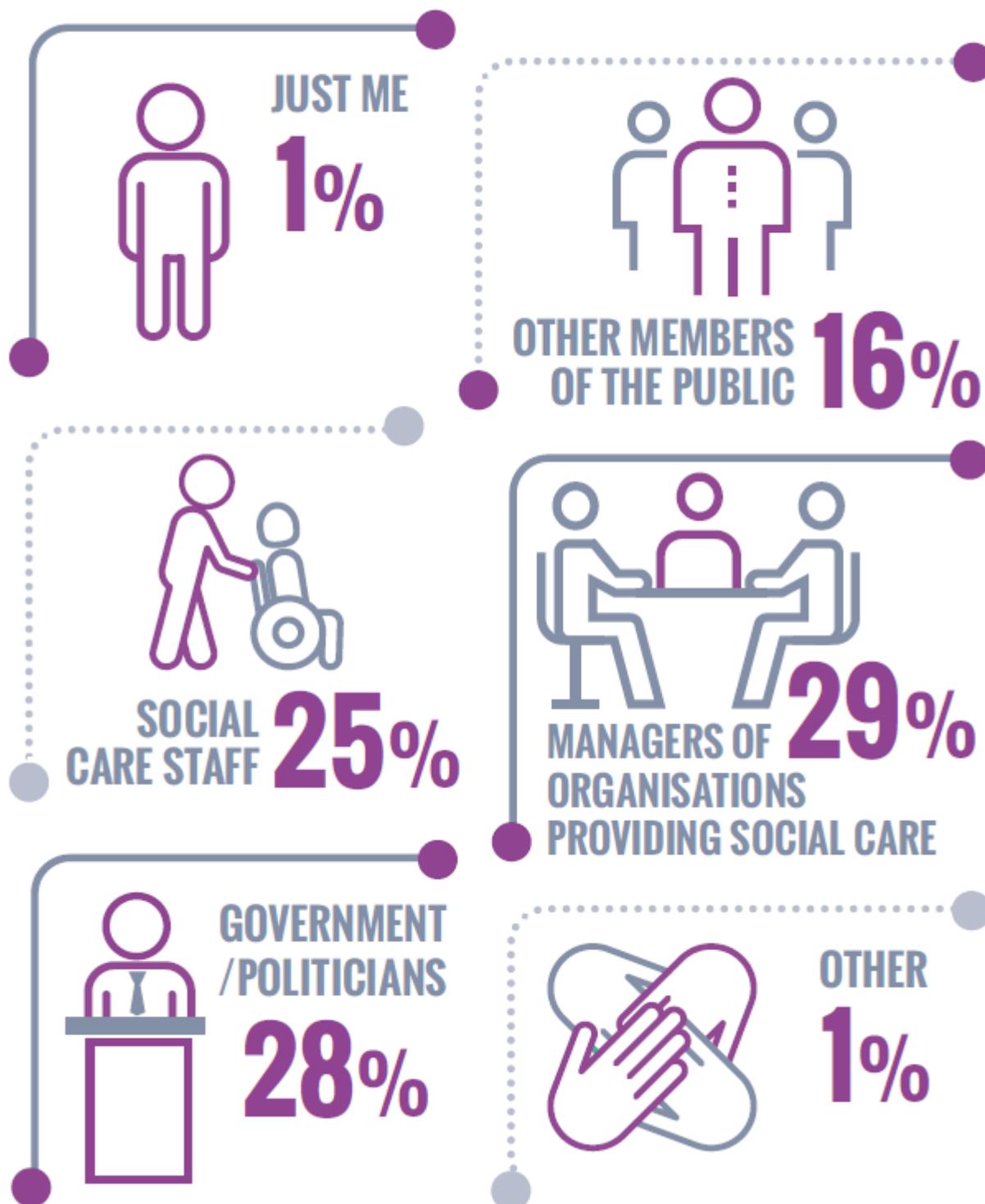
- 5.13. Respondents were asked to consider the experience they had just shared and identify how they felt about it overall.
- 5.14. The responses to this question indicate a leaning to the negative in people's experiences with 57% of the stories identified as being negative or very negative and 37% as positive or very positive.

## How do you feel about your story?



- 5.15. In relation to who else needed to hear what they had said, respondents could tick as many options as were applicable.

## Who should hear about my story?



5.16. Respondents of 405 of the 473 stories said that 'managers of organisations providing social care' should hear what they had said, and 387 thought government or politicians should hear it.

5.17. Among the 13 'other', five focused upon health professionals needing to hear their experiences, and two suggested human rights organisations.

## 6. Thematic Exploration of the Data

6.1. The stories submitted to the project were analysed using the metric tools built into SenseMaker and narrative analysis. These processes revealed themes and trends across the stories which have been used to group the findings:

- People and Well-being
- Voice and control
- Co-production / Working together
- Time-wasting
- Prevention and Information
- Carers
- Perceptions of the Act.

6.2. Each of these themes is discussed in the context of the positive and negative stories that relate to it, illustrated with depictions of the data, and accompanied by stories that illuminate, exemplify or add detail to those discussions. The factors that contributed to experiences being positive or negative will, in many cases, require further exploration, and the pressure, complexity and regulation of the social care sector will have played a role in the overall findings of MtM.

6.3. Triads show how experiences clustered in relation to particular topics. As discussed previously, people’s responses indicate their strength of feeling about particular factors in relation to their story. The further a mark is from a factor, the less significant it was.

6.4. The information provided in response to the sliding scales is presented as histograms, with the bottom axis representing the scale and the side axis the count. Each histogram has the mean response also marked as a dashed, vertical line.

6.5. Throughout, the stories used are **taken directly from the submissions to SenseMaker**. They are colour-coded with their title in a coloured bar, to indicate how positively or negatively the respondent viewed their story. These colours are fixed within SenseMaker:



6.6. The images of the triads, with two exceptions, show the stories *without* filters for how people felt their story (e.g. ‘positive, ‘neutral’) applied. As such, the stories are all marked with green dots. In these cases, the green does not indicate ‘very positive’; it is simply the default colour for the marks on the triads. In the two cases where the marks have been coloured, this is made clear in the text or image.

## 7. People and Well-being

### The Positive Triad

- 7.1. The first triad in the survey asked story tellers to reflect on the support they received and to consider whether they were listened to, had a choice in the support they received, and got what they needed.

Graph's Data Count: 223 NA Count: 249



- 7.2. 249 respondents chose not to complete this triad selecting the box marked 'not applicable' below the triad. Of those 249, 217 went on to complete the Negative triad (see section 7.7).
- 7.3. Across the triad, stories related to a variety of services and settings including equipment, family placements, advocacy, information and advice, help in the home, day centres, financial support and respite. Collectively they exemplify some of the excellent practice present in social care, often highlighting the significant contribution made by individual service providers who were well skilled/trained and committed to delivering the best possible outcome.

### Stress management

*"I attended a stress management course for carers a little while ago - I didn't think I was stressed and didn't think there was any point going but went along anyway. It was amazing. I realised how stressed I was and that the only reason I hadn't noticed was because of how busy I was caring for my mum. I'm so glad it was recommended to me and I've now qualified to deliver the course myself."*

### Life-line

*"I attend a group for people with the same health condition as me - it's a lifeline. The group gives me emotional support as well as providing me with invaluable information... Finding the group and getting involved has dramatically improved how I feel about myself and how I feel about living with a chronic condition."*

### Communal

*"The complex has lots of communal areas that I really like - I come to the cafe and the seating areas every day. I moved here from England and I've got to know people and feel settled very quickly. Being able to see people for meals and in the shared areas is nice and you can chat to people or not. Some people tend to stay in their flats and that's fine as well, I think we all like knowing that people are around if we want to see them."*

7.4. The central cluster framed on the triad containing 59% (131) of the stories is composed almost exclusively of positive and very positive stories. Two key themes emerge from those stories:

- the importance of connections and of people having relationships, friends, networks and activities in their lives
- the pivotal role one individual undertaking their job exceptionally can play.

## The Importance of Connections

- 7.5. 50 stories in the central cluster make specific reference to social activities, friends, community groups and spending time with others. They highlight diversity in the ways people feel connected and the value of service design that considers this and includes variety in the opportunities that facilitate and support a sense of community and being connected.

### Housemates

*"I live in supported accommodation with one other person. I have support from [a social care organisation] and there is someone around 24/7 if I need them. I'm very independent and like going to the pub, playing pool. I sometimes go to the pictures and I like walking."*

### Exercise

*"I go to several exercise groups that are aimed at people with the same health condition as me. I like the groups as I feel very comfortable and don't feel I have to apologise for moving slowly or feeling unsteady at times. The groups let me socialise as well which is nice and not something I would have sought out in the same way I looked for the exercise."*

### 5 star hotel

*"My son lives near Swansea so it's a very long way for him to come here and see me. This new complex though has guest accommodation so he can come and bring his family and they can stay in the same building. It's fantastic - he's booked already to come again in the spring. My grandson was trying to explain to someone where I lived and didn't really grasp the idea of flats or how to explain them so he said, 'Nain lives in a hotel' - and he's right, it's like a 5-star hotel."*

## The Pivotal Role One Individual Can Play

- 7.6. 16 stories in the central cluster make specific reference to an individual who was integral to the positivity of their story. They demonstrate the value of small acts, of listening to people, and of offering information or services rather than waiting for service users to request them. The role played by such individuals was pivotal in building a caring, human experience beyond the provision of a transactional service. Further evidence suggests the importance of treating others with dignity, respect and understanding to generate a positive experience.

### A piece of my life

*"My support worker is very important to me because she takes me to self-advocacy group meetings and picks me up. She also takes me to other social meetings which gives my mum and dad a break as they are retired now. If it wasn't for her support it would be too much for my mum and dad to do."*

### Amazing financial advisor

*“At the outset of the care needs assessment process as a carer with power of attorney for both my parents, I was able to arrange a financial assessment with the local authority. I have had the need to be reassessed 3 more times as my parents’ circumstances have changed. Each time I have seen the same financial officer, and each time been treated with kindness, dignity and respect. Each occasion the advisor has left me with a list of things to do - benefits to apply for, for my parents who both have dementia...without the financial support [facilitated by the advisor] the quality of life for my father, mother, husband and myself would have been dramatically affected...without those additional funds we may not have coped.”*

### Family support worker

*“...The service provided Dad with some support and harm reduction approaches to help his health, and vitally they assigned me a family support worker, who I think probably saved my life. Having someone who was an ally, who I could talk to and feel was there for me, was invaluable.”*



## The Negative Triad

7.7. In contrast, the responses on the second triad where people had experienced a combination of not getting what they needed, not being listened to and not having a choice, illustrate the barriers many feel exist between people as service users and the social care sector itself. The stories paint a picture of working at cross purposes, disconnection, confusion and isolation.

Graph's Data Count: 297 NA Count: 175



7.8. Three key themes emerge from the central cluster of 61% of the stories:

- People's need to fight for services
- Individuals feeling judged
- An expectation that people will accept, and fit in with, whatever support they are given.

## People's Need to Fight for Services

- 7.9. Many of the negative stories submitted to the project include references and inferences to needing to fight or struggle for services. In these cases, interactions with social care providers are characterised by difficulty, delays, frustration and confusion. Many of the examples shared relate to the systems and processes that govern social care provision and which frequently appear to add, rather than remove, obstacles to good support.

### Frustrated with social care

*"...Asked about a stair lift - told I was on a list, had to shuffle up and down the stairs on my bottom. Went out to buy one myself in the end. Cannot get into the bath and contacted [a third sector organisation] for support to get handrail, etc. Carers coming in but only able to have a wash not a shower. Waiting for a hip replacement - had 2 knee replacements. Husband and daughter both need caring for - I need to get support for my own needs as well as making sure they have what they need. I'm disappointed that I'm finding it so hard to get a response from social care."*

### Still missing the point

*"In October 2017, I asked for more time from the carers. We wanted an extra 10 minutes in the morning to make dad's morning routine more straightforward. We also suggested that these 10 minutes could come from other parts of the schedule, so a redistribution of the time to the points it was most needed. I was told that a meeting would have to be arranged to look at this. By January this meeting had still not materialised. And then we had 10 minutes cut from his reschedule without any redistribution."*

### Caring is the easy part

*"Caring for my son is the easy part. The difficult part, the part causes me so much stress and anxiety is interacting with social services and the local authority. In the last few months the stress of my son being transitioned from children's to adults' services has been so great that I've been put on medication for the first time. I don't want to be on it but the stress and anxiety is awful and I've been experiencing anxiety attacks for the first time in my life."*

## Feeling Judged

- 7.10. Within many of the negative stories, and associated with the need to fight for services, individuals often report feeling judged, or being made to feel guilty for asking for help, or they make inferences to being made to feel unworthy or a failure. The damaging emotions and low self-esteem characterising many of the negative stories suggest troubled relationships between providers and users, a breakdown of trust and a culture of challenging rather than believing those seeking help or support.

### I should do more

*"I asked for help from the social services team and was told that I needed to do more, that that 'is my job as a parent'. I have had no training on how to support children with autism, or how to provide the level of parenting this team seem to think I should be providing. I am told again and again by social care professionals that I should be doing more, trying harder, that I should know more, be better somehow. It feels really unfair but coming from people that I am inclined to believe because of their roles it starts to take its toll."*

### Guilt

*"I hate phoning up for anything - now that I have to ring a central number I don't know who's going to answer or what they're going to ask me. They often ask quite intrusive questions and the whole process makes me feel guilty for even getting in touch."*

### Made to feel horrible

*"...Throughout these processes, I was made to feel horrible. Even though I was asking for help, problems with my house were pointed out to me as though I had no idea they were there, and as though I should be the one fixing them. Whilst I do own the house, all of the issues with it had become much more urgent because Dad was living with me. All I wanted was some guidance, some advice and maybe some help with getting things fixed, getting the stairs made safer and keeping my Dad as well as could be."*

## Fitting in with Services

- 7.11. The third prevalent theme within these stories is the inflexibility of service providers and of individuals needing to accommodate the needs of the provider rather than the other way around. This includes expectations that people work to the schedule of the provider, that they accept whatever support is offered and be comfortable with any uncertainty attached to it.

### Working around them

*"My daughter attends a day centre service but if they have a training day, meaning she can't go in, then there is no replacement service provided or no additional carer to come to the house, I just have to find a way to accommodate it."*

### No notice

*"Yesterday I had a phone call from the care co-ordinator. She wanted to come over with a colleague to discuss some issues I have raised. She wanted to come over in the next couple of hours - I explained I had only just woken up and that I would prefer the meeting to happen in the next day or two instead so that I could arrange to have someone with me. This wasn't listened to and felt I needed to agree to the meeting take place there and then."*

### Apparently I should be home

*"Although my son's mum and I share custody, she is viewed as the primary care giver and, as such, manages 15 to 20 appointments a month in relation to our son. Among these appointments are the people who just show up - there is an assumption that she will be at home and that it will, therefore, be fine to just show up."*

## Voice and Control

- 7.12. Voice, control and co-production are pivotal themes within the Act and evident in the experiences service users shared with the project. As demonstrated in a number of stories, being listened to, being involved in decision-making processes and receiving appropriate support, advice or guidance are fundamental to many of the most positive stories and to the delivery of good social care. These factors help to ensure scarce resources are used to generate the best possible outcome for all parties engaged in social care.
- 7.13. To explore the degree to which people were able to exercise personal choice and power in the experience they shared, respondents were asked the question, *'In the experience you have just told us about, who influenced what happened?'*. Their responses illustrate the degree to which individuals often feel unable to influence decisions relating to their needs. Social care staff are perceived as having the most influence in decision-making, with 51% of respondents clustering in the bottom right of the triad.

In the experience you have just told us about, who influenced what happened?

Graph's Data Count: 409

NA Count: 63



- 7.14. The same triad, with a filter applied to show only the 'negative' and 'very negative' stories displays a clear correlation between social care staff being the primary decision-makers and negative experiences.

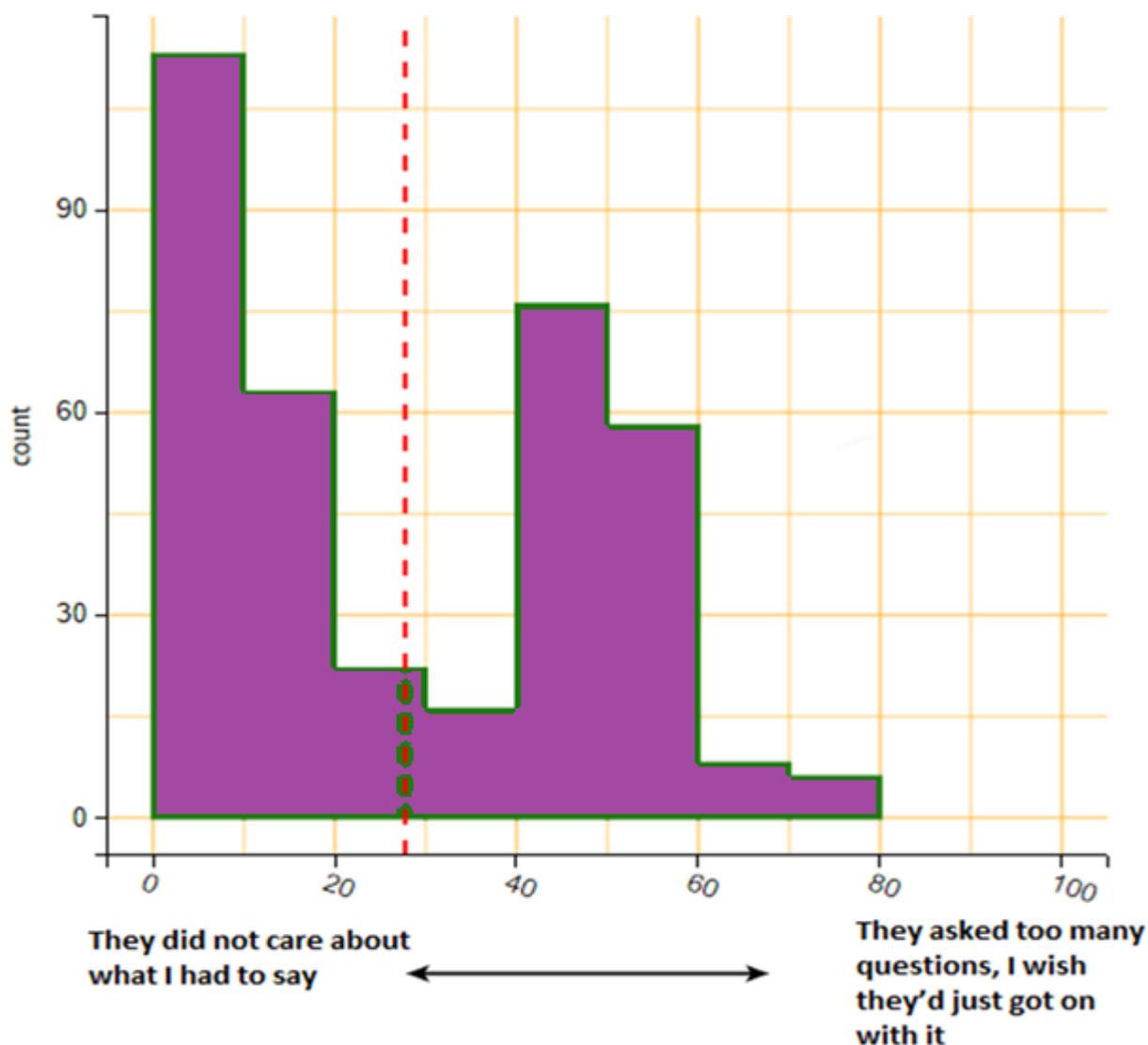


- 7.15. Further analysis compared the stories in the frame above with the stories in the central cluster of the Negative Triad i.e. those stories where people felt they did not get what they needed, were not listened to and did not have a choice. That comparison showed 71% of the stories to be the same. This suggests that social care providers are making decisions in relation to an individual's needs that are not generally considered, by that individual, to be good decisions.
- 7.16. This warrants further research with both people and service providers to explore what may be behind these findings.
- 7.17. While some stories refer to perceptions that systems and processes are limiting the decision-making capability of providers, in many cases, poor communication has played a significant role.

- 7.18. People feel unable to communicate their needs to social care staff, they are not listened to or the approaches to communication are inappropriate for that individual. Inevitably this means significant information is missed which could have improved the decision and outcome.
- 7.19. When asked the extent to which they were able to discuss what mattered to them with social care staff, data from the sliding scale showed that 49% fell in the range between 0 and 20, indicating that they felt staff did not care about what they had to say. 37% of respondents fell within the 'golden mean' range of 40 to 60 where they were able to discuss matters with social care staff.

I was able to discuss what mattered to me with social care staff...

Graph's Data Count: 362    NA Count: 110



## In Control

- 7.20. Within the central cluster of 41 stories (10% of the triad count) are examples of individuals being respected, included and treated well. Crucially, they are examples of individuals being able to discuss what matters to them with social care staff, and of them being listened to.
- 7.21. They demonstrate the simplicity of the approaches needed to create positive experiences.

### My sister, the carers and me

*“My sister has cerebral palsy – to help us we were given 2 carers. They come twice a day except for Saturday and Sunday because it’s our family time. The carers help with showering and dressing my sister, keeping tabs on her medication. My sister goes to day centre, the staff write a conversation log about my sister’s day. We and the carers work as a team – there’s always scope for meeting up in the middle.”*

### Good social worker

*“My older daughter got a new social worker and he’s really good – both my daughter’s needs and mine are now being looked at much better. He takes a properly collaborative approach to supporting us – he discusses when and where is best for us to meet, and supported me to complete my own carers’ assessment, ensuring my needs were fully identified.”*

### Nice things

*“I live with my mum and dad. I have a PA (personal assistant) and go out with him twice a week. We go to wherever I’d like. My favourite place is [on the coast] I like the breeze by the sea. And there is a cafe in nearby where I like to have hot chocolate. Sometimes I go out for dinner with my PA. When I’m at home I like to listen to music and watch football.”*

### Good family placement

*“I go to a family for adult placement to provide my granny with some respite. I go to the same family each time and we have gradually built up how much time I spend with them. I went for tea a few times, then had an overnight stay and a weekend stay. Throughout the process it was made clear to me that if I wasn’t happy that was fine and the placement could be stop or adjusted. The matching seemed to work very well and I like the family a lot.”*

## Out of Control

7.22. Social care experiences involving someone feeling out of control and not having a say in their own care were viewed negatively and often articulated with a sense of confusion, frustration and anxiety. From these stories emerged two key factors that contribute to when people are most likely to feel out of control:

- Working with multiple services or sectors
- Staff turnover

## Working with Multiple Services or Sectors

7.23. A recurrent theme within the negative stories is the challenges of moving between services and of needing support from several providers at once. Both circumstances are marked by uncertainty, communication difficulties and, very often, the responsibility for making progress is felt to fall to the individual or their carer.

7.24. All of the stories that related to moving from children's to adult services were negative. Many of the 92 responses that made a reference to health services and broadly relate to the interactions between health and social care were also described as negative.

### Beauty and the Beast

*"My son is 2 months away from transitioning from children's to adult services. He has good and appropriate support up to now, although it was a struggle to get that sorted initially. We are now facing a cliff-edge with provision as there is nothing in place for when he's deemed an adult. I was warned 6 years ago by other parent-carers that this would happen so I've been looking for solutions, services, and establishing what the law says. We're now really close to D-day, when all children's services will stop and nothing new is scheduled to start/take over. My son currently has 6 or 8 people support him every day, providing a range of services and in two months there'll be nothing. I've run parent-carer groups, I'm involved in lots of networks and am very active with local groups giving 70 hours a week volunteering to them. In 2 months, this will all have to stop."*

### No connectivity

*"Since my daughter transitioned to adult services the support she receives has declined enormously, particularly in relation to anything that would need health and social care to speak to one another...None of the health team came to the transition meetings, and it took two years to get back into the same room as the physio. In this time, my daughter's trunk has become unstable – she has dysphagia (difficulty swallowing) and this is made worse as her trunk weakens, and she can no longer straighten her legs as she doesn't have enough access to the standing frame. There was no interest in what had been in place previously and the benefit of that to my daughter. And there was no interest in her and making sure she has the right support."*

### Forgotten paperwork

*“My son has had a lot of interactions with health and social care services lately for a variety of reasons. He was going to be referred to a psychologist - something we had been trying to arrange for ages. After 2-months no appointment or letter had come through. I contacted the hospital who were making the referral and was told that they had forgotten to process the paperwork.”*

## Staff Turnover

- 7.25. Among those who have regular engagement with social care, either through a social worker or through carers coming into their home, the turnover of staff was a cause of uncertainty and anxiety. Individuals often did not know which carers they should expect or if they would have met them previously. Others reported multiple social workers in short periods of time, and several people reported issues with the availability of care workers.
- 7.26. Given the demonstrable value of building relationships and of feeling connected to support staff, often providing very personal services, continuity and familiarity were important to service users. Staff turnover not only creates immediate uncertainty for individuals but also undermines the development of meaningful relationships longer-term.

### Strangers

*“If I need something, I have a number to ring but I don't know who will answer and sometimes they aren't very nice and then the person that comes to see me is usually a stranger as well. I liked it more when I had the same person.”*

### Ever-changing carers

*“I have carers come to my home every day. I have no idea who they will be - sometimes I have the same person a few times in a row but not always. And although they have set times to come, they don't stick to them. I feel very unsettled all of the time.”*

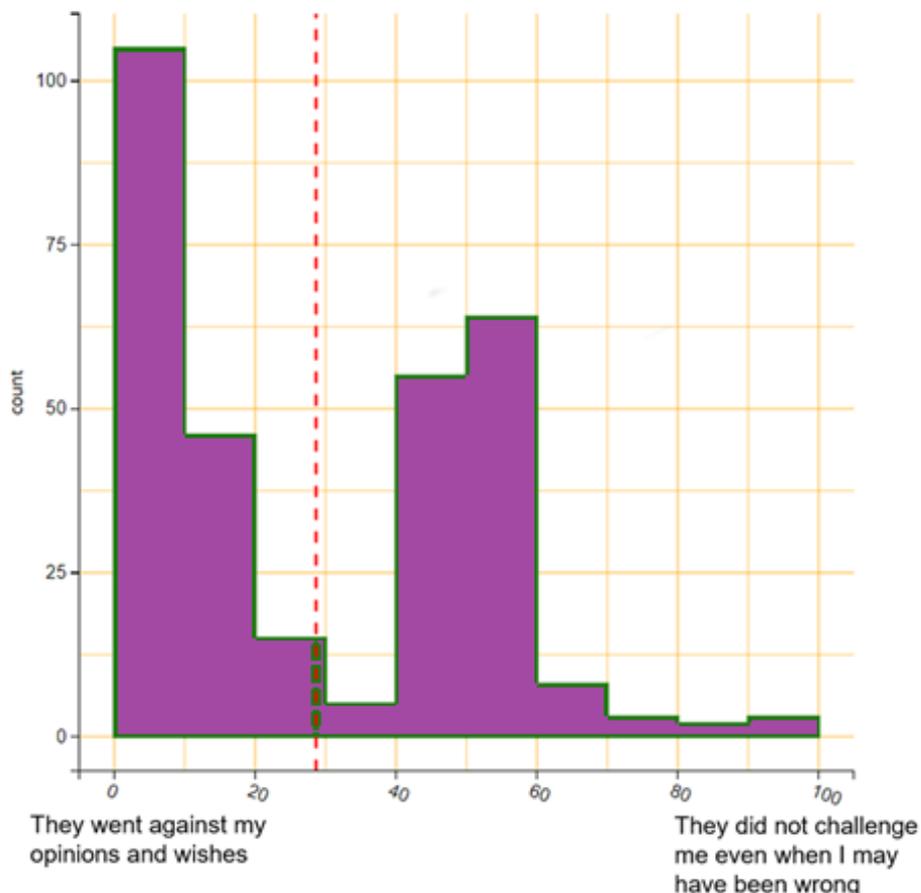
### Always changing

*“Social workers and social care staff change regularly – five social workers in two and a half years, for example. This leads to breakdowns in communication, poor handovers, disappearing paperwork and, more significantly, disruption and instability for us and our children. Building relationships takes time and my children don't want to meet new workers, increasingly now that's because they say there's no point, the worker will have moved on soon anyway.”*

## 8. Co-production / Working Together

- 8.1. Co-production is an asset-based approach to public services that enables people providing and people receiving services to share power and responsibility, and to work together in equal, reciprocal and caring relationships. It creates opportunities for people to access support when they need it, and to contribute to social change.
- 8.2. Working more co-productively is a theme throughout the Act and consistent with the ambition and aspiration of the social care sector itself. Current experiences however, demonstrate that co-productive approaches are not present in many circumstances although they are often espoused in the rhetoric of delivery.
- 8.3. Respondents were asked the extent to which social care staff acted upon discussions they had had about what mattered to them. 49% responded in the lower extremity, between 0 and 20, 40% in the 'golden mean' of 40 to 60 and 2% in the upper extremity above 80, where individuals considered that social care staff should have challenged them more.
- 8.4. **Social care staff acted upon those discussions...**

Graph's Data Count: 306 NA Count: 166



- 8.5. The stories at the lower end of the spectrum, where individuals' wishes were being ignored, echo themes examined elsewhere of not being listened to, not being included in decision-making and of needing to fight for support. Very few stories sat at the other end of the spectrum, but those that did included examples where individuals would have benefitted from social care staff providing them with more information or advice.

## Positive Challenge and Offers of Support

- 8.6. The experiences at the high end of the spectrum highlight the need for social care staff to bring their expertise and knowledge to situations, and to understand where the boundaries lay of what an individual knows, and what they may not know and could not reasonably be expected to know. In those latter cases, offering support and explaining why it was being offered would likely have addressed the situation.

### Cancelling appointments

*"...I cancelled [the carers attending] because [they were running late] I had people coming over and I didn't want it to all clash. But in morning appointments, I need a compression stocking putting on. Although I have documented memory issues, I wasn't reminded that the stocking is a medical need and must be put on every day. They just happily cancelled."*

### Wheelchair

*"I was given a wheelchair which took ages to sort out, and then when I got it, I wasn't really given any guidance about how to use it. They got me to use it a little bit in front of them, but I didn't really want them watching me, and I thought it would be quite easy to use so I said I was fine. They asked if I wanted more help, I said no, so they left but then it turned out it was actually quite hard to use. It would have been much better if they'd insisted or got me to use it more there and then so I could see that it was harder than I'd thought."*

### Direct payments, bit of a nightmare

*"I receive direct payments and use them to pay for care during the day as well as for someone to sleep over. I thought I was doing everything properly but then I was told I was being taken to court and being reported to HMRC because I haven't been paying enough for the overnight stays. I don't really know what's going on and getting help with this is proving really difficult."*

## Working in Partnership

- 8.7. In the middle of the spectrum, people's experiences describe being listened to and of feeling in partnership with the people supporting them. They echo sentiment expressed elsewhere about the importance of being listened to and of the pivotal role getting the right support can play for the individual and for those that care about them.

### Day Services for Adults

*"...I do XXX in the morning which is a day service. I enjoy XXX because they support me to cook and this helps me to cook for myself. I cooked a pizza recently. They listen to me at XXX. My overall experience of the services I go to is good and I like the range of activities. I told my social*

worker about XXX and she was able to help me go to this on a Thursday. I would tell my friends that I do a lot of different activities in XXX.

**Our Story**

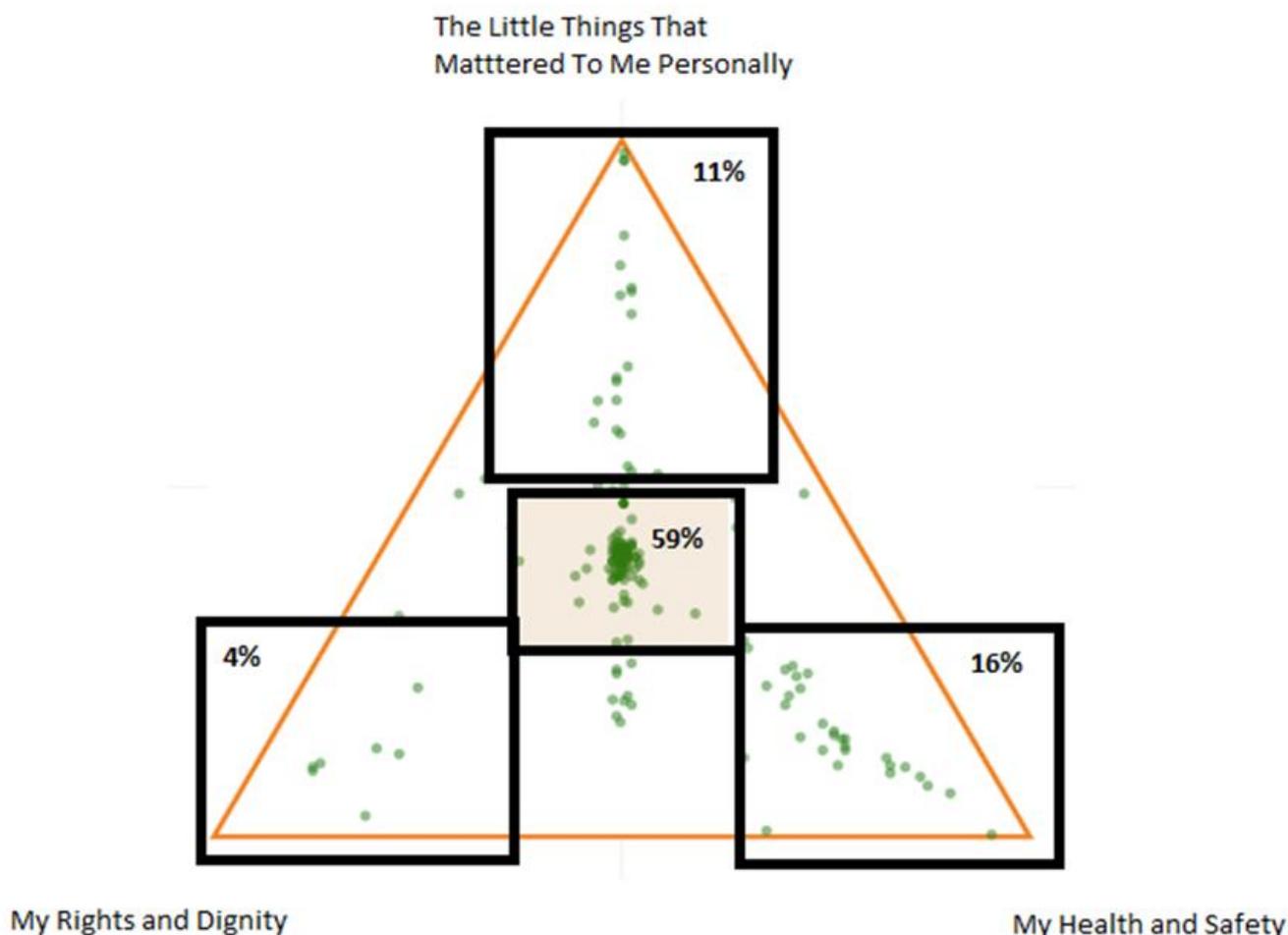
“In the last 12-months our daughter began to experience severe anxiety around attending school. We made various attempts to deal with the problem but felt our daughter required more professional support. Team Around the Family has been good in supporting our daughter to attend school with adjustments made at the school to reduce anxiety.”

**A say in staffing**

“I get support from a group of people who support me, my brother and another man...Once someone was doing some bad stuff and I talked about this so that he had to change jobs [disciplinary proceedings were undertaken] - I was brave and honest and told [the organisation that supports me] what was happening. I am going to be on the panel to help interview new people next time we need a support worker.”

8.8. People’s relationships with social care professionals were further illuminated by their responses to the final triad of the survey.

**Social care staff who provided support cared about:**



- 8.9. 190 responses were received to this question, one of the lowest response rates to a triad in the survey.
- 8.10. A majority of respondents (59%) identified that all three variables were taken into account in relatively equal measure. Of those 113 stories, 99 were positive or very positive and illustrate the value of holistic and more integrated approaches.

#### Good team support

*"I get regular visits from [a local organisation] to help support with my wife. I pay for some extra hours on top which I'm very happy to do. The District Nurse visits regularly to look for pressure points and sores. [the organisation] have been very good - well set up with slings and hoists. Their team system works well e.g. contact helped with finance information, good advice given. OT [occupational therapist] visit was good - they change slings that were worn, provided a ramp and a commode. I'm really pleased I can still look after my wife at home even though she has high care needs."*

#### Thoughtful design

*"I moved into a new complex a month or two ago - it's wonderful. My flat is at the end of a long corridor but there are no steps anywhere and there (sic) corridor has alcoves with chairs in and places you can take a little rest if you want. I feel very happy and safe here and my fitness is getting better and better."*

#### Help for The Others

*"Our youngest child is autistic; someone from school suggested we contact Social Services children with disabilities team. This has benefited my other children - got us in touch with N, this led to trips including Disneyland and weekends away that they wouldn't have been able to have otherwise. They also have time away with other children who understand. The Young Carers have been fabulous."*

## 9. Time-wasting

- 9.1. In at least 10% of the stories, respondents described situations that involved significant amounts of time being wasted, often at great financial cost to the local authority or service provider, and also at financial or emotional cost to the individuals involved.
- 9.2. They clustered primarily under several themes:
- Parents needing to escalate their children's needs
  - Meetings and appointments being poorly organised
  - Inappropriate support being provided.
- 9.3. Collectively, they illustrate sources of frustration for people accessing social care, and they raise questions about how social care services are organised as well as the attitude of providers to those requiring support.

## Parents Needing to Escalate Children's Needs

- 9.4. Several parents reported needing to escalate their child's educational requirement, a process that, the experiences submitted to MtM, cost thousands of pounds and was exhausting. In these cases, the decisions went in the parents' favour, in just a very few minutes, granting them the education for their child they had originally requested.

### Bonkers processes

*"It took thousands of pounds of solicitor time and countless hours of effort and arguing for my son to be able to get the right education. the process we had to go through was arduous and took a long time only for the final decision that was made to be the very one we'd asked for months earlier, and it was made in just 5 minutes despite the lengths, and costs, everyone had had to go to get there."*

## Meetings and Appointments Being Poorly Organised

- 9.5. Several submissions describe meetings that are arranged, often by the local authority, and often to be attended by several professionals, as well as the individual receiving support and/or their carer. These meetings then either fail to take place as those professionals do not attend or they result in a decision or form of action that requires yet further meetings, reviews or assessments. Similarly, respondents described appointments with providers that were poorly organised or unnecessary.

### Yet another failed attempt at a meeting

*"In April 2017, it was requested that we hold a review meeting. The meeting was attended by the memory nurse, social worker, district nurse, the carers' supervisor and myself – this was April 11th. The only outcomes of the meeting were some suggestions of minor changes to the morning routine. The social care professionals were adamant that this would need to be reviewed to establish what improvements these changes had led to. They were annoyed that I would be away for the date they wanted this review on. It was eventually agreed that we would meet again on June 6th. On that day, and in spite of their original assertions about how essential this meeting was, only the social worker and I showed up. None of the people who failed to attend contacted me – I had to ask them where they were, and then none of them rearranged this meeting suggesting it was a complete waste of time in the first place."*

### Waste of time

*"An appointment had been made by social care workers [at a non-local hospital] department which meant time off work. When I got there, I was told the appointment had been cancelled and I should have been notified. I hadn't been. Through a combination of getting upset – I was exhausted and frustrated – and knowing someone at the hospital, I was able to see the doctor. I was then told that the options open to us were to catheterise or keep things as they were. Catheterising is not an option for a number of reasons so this meeting was a complete waste of everyone's time - had I known that was what we would be discussing I would have cancelled the appointment myself."*

## Inappropriate Support Being Provided

- 9.6. Often in relation to the provision of equipment, a number of respondents outlined being provided with kit they did not want or was inappropriate to their situation. This meant that the correct support was delayed or never materialised.

### You need to work with us...

*“These included installing an H hoist at a cost of £5000 – we didn’t do this because we wouldn’t have been able to get dad into the hoist in the first place. They also suggested a hover mat – a very loud piece of equipment that requires a person to lay still while it’s in use; an elk and a camel – inflatable devices that require the person being raised to be compliant with this; and glide sheets that don’t work because you need to be able to drag the sheet. At one point they were supposed to demo these items to us, but the inflatables took 2 months to show up. By this time my dad had stopped falling out of bed because he had become largely immobile. In among these meetings and suggestions, I was told that I was being very negative, and that I needed to work with the social care practitioners to find a good solution. The fact that I had already provided a very good solution, that they refused to act upon, was not considered, and the expectation seemed to be that I should have endless patience with exploring pointless and inappropriate options. Surely, we all had better things to be doing.”*

## 10. Prevention, Information and Carers

- 10.1. Throughout the stories were examples of situations where opportunities to prevent someone’s circumstances from deteriorating were missed. Many of these relate to not being listened to properly, a thread that runs throughout the narratives and a recurring factor in almost all the negative stories no matter their topic.
- 10.2. Many respondents felt they needed to reach a crisis point before they would receive support; experiences echoed the narratives of being out of control, fighting for services and of staff turnover.
- 10.3. These themes allude to the complexity of people’s interactions with social care and the ease with which opportunities can be missed when services are seeking to act holistically but instead become fragmented. Further, they reveal the scope of the impact care has for people, and the role sectors and activities outside of social care can have in improving well-being and minimising the need for intervention.
- 10.4. To understand more about how the pressures on social care could be alleviated and people’s well-being supported more creatively and appropriately, it would be valuable to gather more data on these themes and explore them further.

## A Note on Mental Health



- 10.5. 17 stories make direct reference to mental health or mental health services, and suicide is specifically mentioned in five of those. They confirm findings already in the public domain about the need for more mental health support services, wider acceptance that many people experience mental health problems and the need for approaches among social care staff that are more mindful of the impact poor mental health has on people.
- 10.6. Several stories reiterate the need for people to listen, and the incredible, positive impact that can have. They also point out that, unless people know about a service, they cannot access it and that at times this may be a matter of life or death.

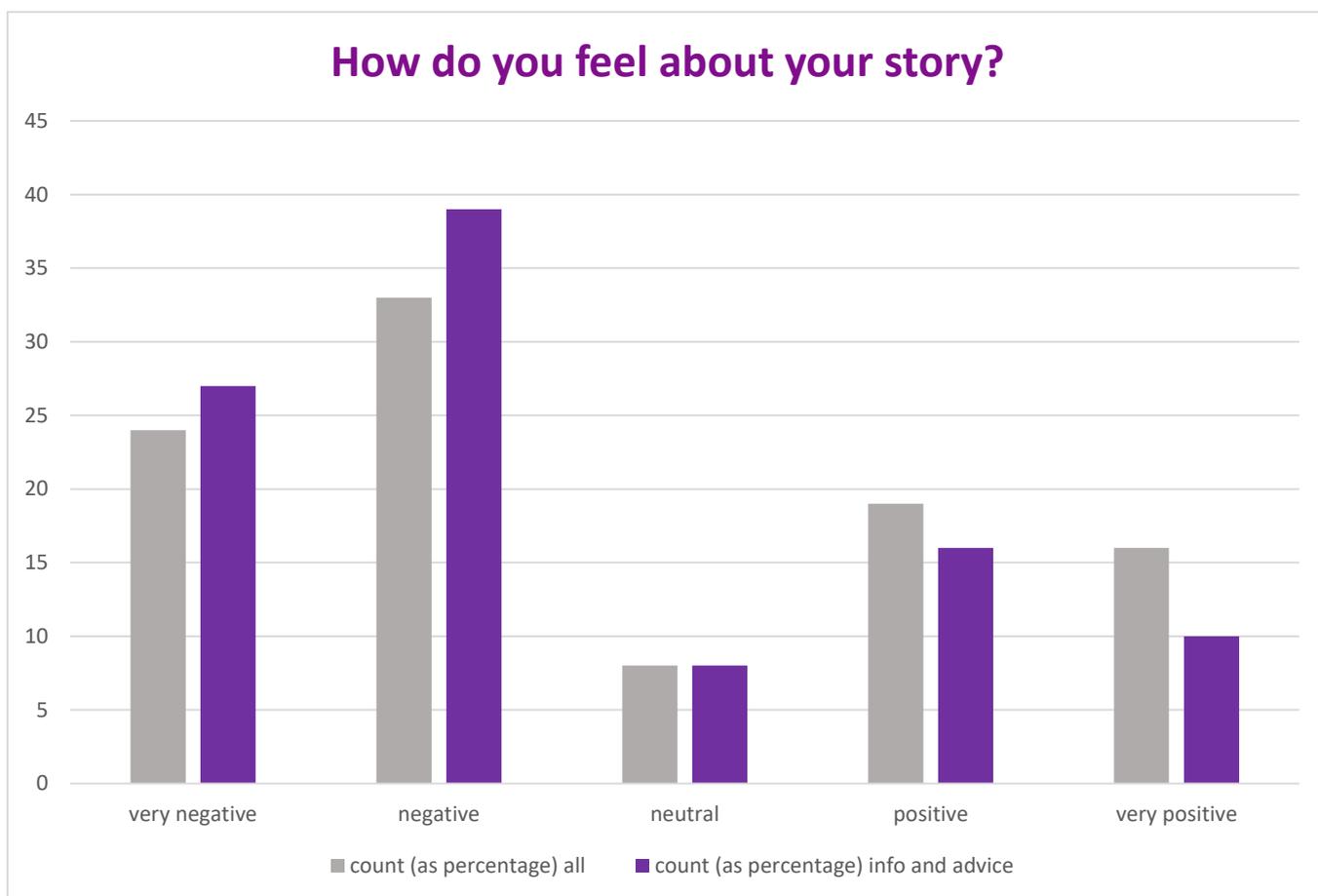
### In the know

*“My son has mental health problems and care for him when needed. Supporting someone who is suicidal is really difficult and distressing. I knew who to get in touch with for help because I work in the sector and I know people. If that weren't the case then I don't know what I would have done. The services that I contacted were a lifeline and I'm grateful that they were there and that I knew about them.”*

## Information

- 10.7. Across the data set, 192 responses related to information and advice and evidence the importance of providing good information, and the role it can play in preventing situations from deteriorating.
- 10.8. 66% of those responses were negative or very negative, and while that does not vary enormously from the rate across all stories, improving the quality and approach to providing information is one of the easier areas organisations can address.

Improvements in this area would likely create more positive individual experiences, and potentially improve people's opportunities to remain more independent.

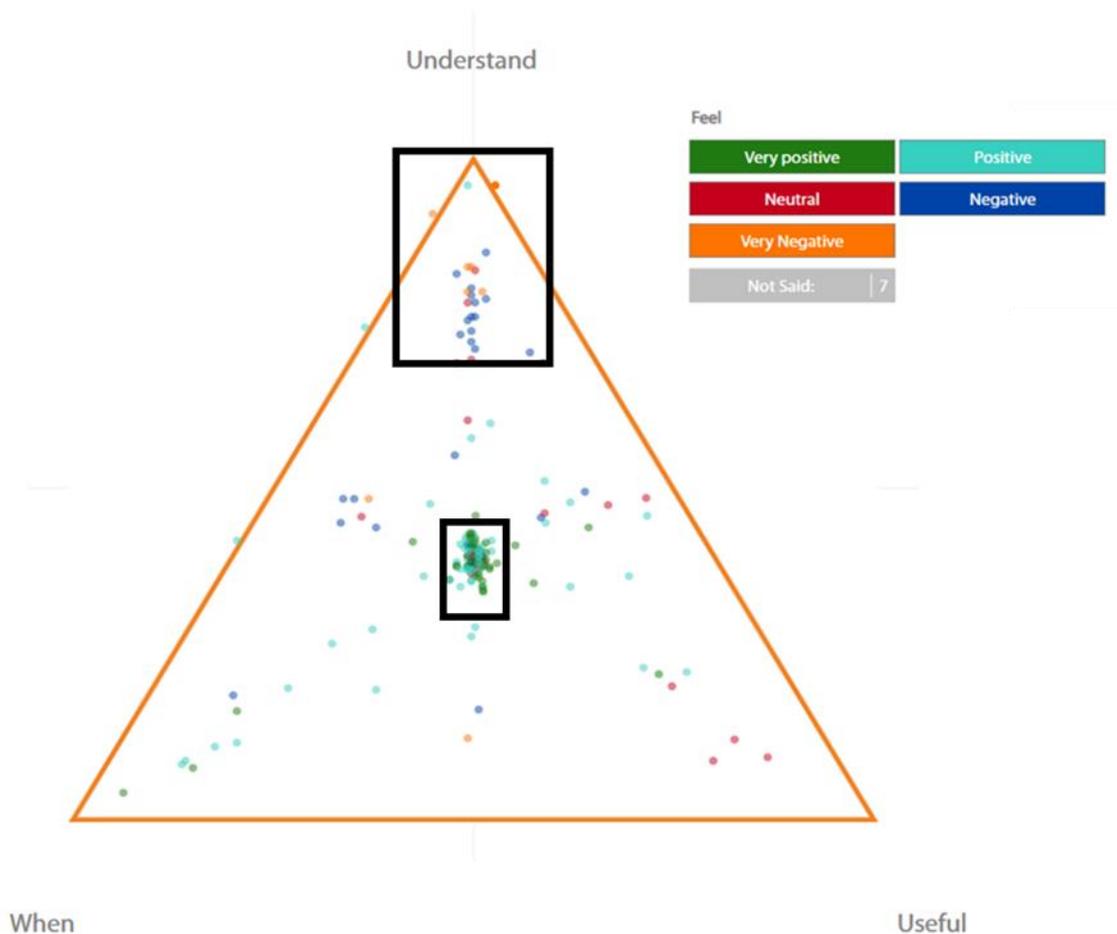


- 10.9.** The timeliness and accessibility of information have been raised across the experiences and highlight the need for service providers to be more active in offering information and ensuring it is available in a variety of formats and from a variety of sources.
- 10.10.** Only 38% of respondents completed the triad about information they had received. Of those that did complete the question, 69% rated their story as 'positive' or 'very positive' indicating the value of providing good information. 73% of the 'positive' or 'very positive' stories fell within the very compact central cluster where experiences related to information that was easy to understand, useful and provided when it was needed.

Thinking about the advice or information I received...

Graph's Data Count: 180

NA Count: 292

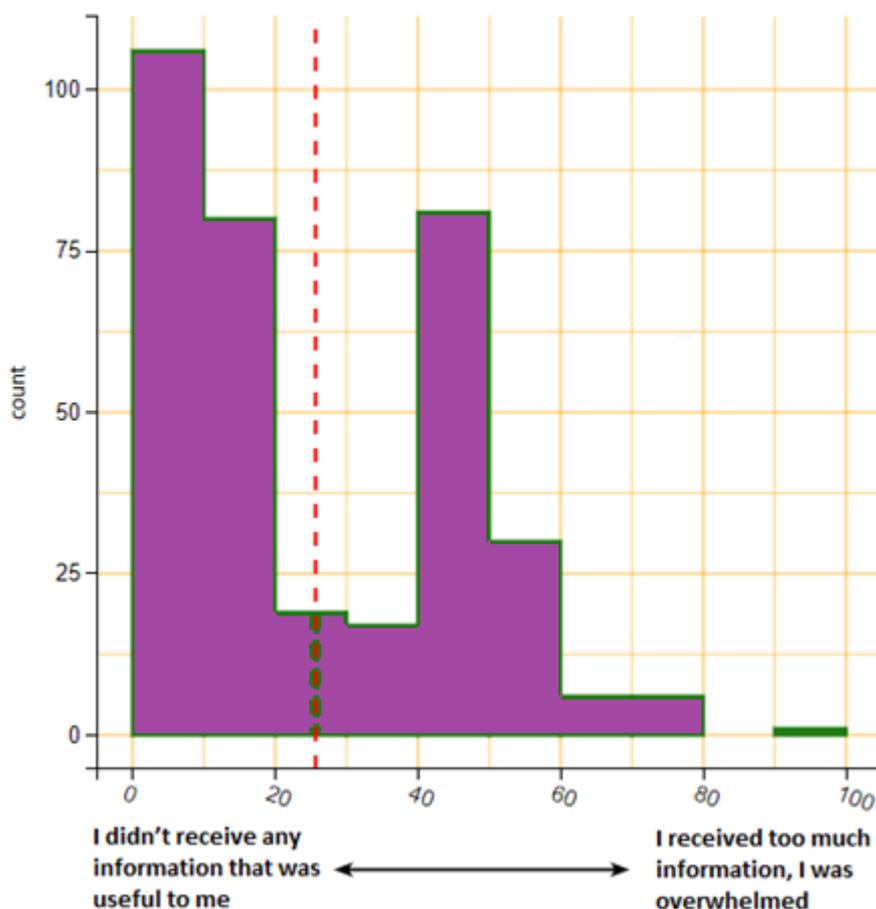


10.11. Almost one in five (19%) of respondents rated their story as ‘negative’ or ‘very negative’ and 57% of these are clustered towards the top of the triad where information was easy to understand but it wasn’t useful or provided at the right time.

10.12. A subsequent question asked respondents to place a mark on a scale to indicate how much information they had received. Responses were on a spectrum from having received no information that was useful through to having received too much information and being overwhelmed.

10.13. Just over half (55%) of respondents fell in the lower extremity of 0 to 20, indicating that they felt they did not receive any information that was useful to them. A third (32%) fell in the ‘golden mean’ of 40 to 60, and 0.3% (1 respondent) fell in the upper extremity, above 80, indicating that they felt they had received too much information.

Graph's Data Count: 346 NA Count: 126



10.14. Whilst narrative analysis adds some detail to this situation, it is an area that would benefit from further exploration, primarily to understand more about what 'useful' would look like for people and how best to ensure this is provided.

## Positive Experiences

10.15. The positive experiences focus on services that are responsive to their individual needs, that involve them being listened to and which help cut through the complexity that is present in much of the social care sector.

### Carers' strategy group

*"I am part of carers' strategy group which is tackling some of these issues and has produced an information book with lots of contact details and info about services people can access locally. And I'm involved in various pieces of work and activities that enable me, and others, to share our experiences with those that work in the sector and those that are new to being carers..."*

### People who listen

*“Having people (services) on the end of the phone that I can ring for advice, information and support has been so important. I am so grateful to them for everything they do for me, and for helping me and my husband. Being listened to and being able to speak is a lifeline...”*

### Seeking advice

*“XXX was having problems with accommodation, and suffering from depression or other mental illness. They sought information and advice from [local] information hub, but despite visiting twice, they had little help or support - with some advice being quite short and unhelpful. The person was left with a choice to pay for food or for a phone to make calls. Subsequently the person went to [local] library where they found staff to be both helpful and supportive, making a couple of phone calls on their behalf and signposting to services with a mental health charity’s local group.”*

### Large print prescription

*“My pharmacy provide my prescriptions and the all the dosage info to me in large print - they do this every time without me needing to ask. It’s very helpful.”*

## Negative Experiences

10.16. The negative experiences relate to information not being provided, offered or made available in appropriate formats. They highlight the damaging repercussions of this poor provision as well as the anger, upset and frustration that is caused when people are not kept informed.

10.17. These experiences overwhelmingly fell into one of three categories, relating to:

- People not being kept informed about changes to their own care or support
- Difficulties in finding information or knowing what information is available
- Information being inaccessible to those it is intended for

10.18. Exploration of these themes reveal the struggle many have to be independent, and the isolation that many people feel as they seek to navigate the social care system. They do, however, indicate straightforward approaches that could be used to radically improve people’s experiences.

## People Not Being Kept Informed

10.19. A number of people described not being kept informed about their care or matters connected to their care. This included the issues explored in Time-wasting, of people not being updated about changes to scheduled meetings or appointments, and of not being updated about the outcomes of meetings, as well as some of the issues related to staff turnover.

- 10.20. Other experiences echo this seeming disregard for people, and suggest an ambivalence towards the well-being and independence of people who should feel supported.

#### No warning

*"...I had received no information about this [change to incontinence supplies provided] despite the change having a huge impact on my son, and any changes or transitions needing time to adjust to. He is autistic and the change led to a meltdown and to him becoming temporarily violent. This lasted for a number of weeks and was a significant set-back for him, and extremely difficult for us as a family. There was no consultation on this matter and no advance warning..."*

#### Changes to direct payments

*"Recently a change was made to the way direct payments are issued so that the local authority provides pre-paid 'debit cards' for the payments to be loaded on to. This change was introduced with no warning and no explanation. It also seems to allow the authority to remove money from the card as well as put it on. These kinds of changes and the way they are communicated, or not as the case often is, only adds to the sense of uncertainty and unsettledness that prevails in our lives."*

## Difficulties in Finding Information

- 10.21. Many people described difficulties in finding information raising issues of not being offered information, it not being promoted in venues and using approaches that would be helpful, and emphasising that many felt they had to take responsibility for finding things out.
- 10.22. An element in many of these experiences was the idea that people cannot know what they do not know so that without being offered information or advice they would continue to assume there was none available. Related to this, a number of people suggested the language of the social care sector was confusing and inconsistent, the pressures on people's lives limited the time they had to search for solutions that might not exist and the overall complexity of social care created too many avenues of possibility for many to feel reasonably able to explore.

#### No information

*"The day service my daughter attends doesn't do anything to promote services or support mechanisms that might be useful to people. There are no posters, no information boards and there's no link up with health. Suggestions that these might be useful are met with blank faces..."*

#### Accountability?

*"There is no accountability and getting straightforward information is really hard. Unless you ask very specific questions you won't get the right info, and practitioners will arrange meetings, then seem surprised when the wrong people are there. At every turn the onus is on us to work out what we're entitled to, what is available, who we need to ask, how we need to ask, and then we have to know the legalese to actually make some of this happen, and when it doesn't work out, our only recourse is to complain..."*

## Different pads

*“When she became incontinent, for example, I didn’t know that there were different kinds of pads, and I didn’t know how to put them on properly. I wasn’t told about this, or shown what to do, I was just expected to get on with it, and you do. Because we had the wrong sort of pad though, we had to change them five times a day and they often leaked so I was needing to wash my wife throughout the day, make sure she was clean and launder her clothing repeatedly.”*

## Information being Inaccessible

- 10.23. The accessibility of information was raised most frequently by people with visual impairments. Without exception, people with visual impairments who contributed to the project had experienced multiple examples of information being in formats they could not access. There was particular frustration where the information was intended specifically for the respondent, such as appointments to attend the eye clinic, information about consultations on accessibility services and communication from providers with whom the respondent had a long-standing relationship.
- 10.24. Accessibility issues were also raised by deaf people, and by people with learning disabilities and cognitive difficulties.
- 10.25. Underpinning these experiences is a sense of disinterest on the part of providers to be more helpful which sets a poor tone for their engagement with people who need support. It results in communiques needing to be issued several times and may increase the likelihood of someone not seeking support.

## Welsh language act trumping the equality act?

*“I have real difficulty getting information in a format I can make use of - the priority seems to be adhering to the Welsh language act whilst keeping paper use to a minimum such that information is jammed onto one side of paper in one language, or printed in alternating languages, usually in tiny print, or in a format that won't work with my screen reader e.g. a pdf - screen-reader tech does not respond well to a mixture of languages. I would prefer there to be no Welsh in the information that I get so that it can be presented in a way that's actually accessible to me but that doesn't seem to be an option.”*

## Inaccessible

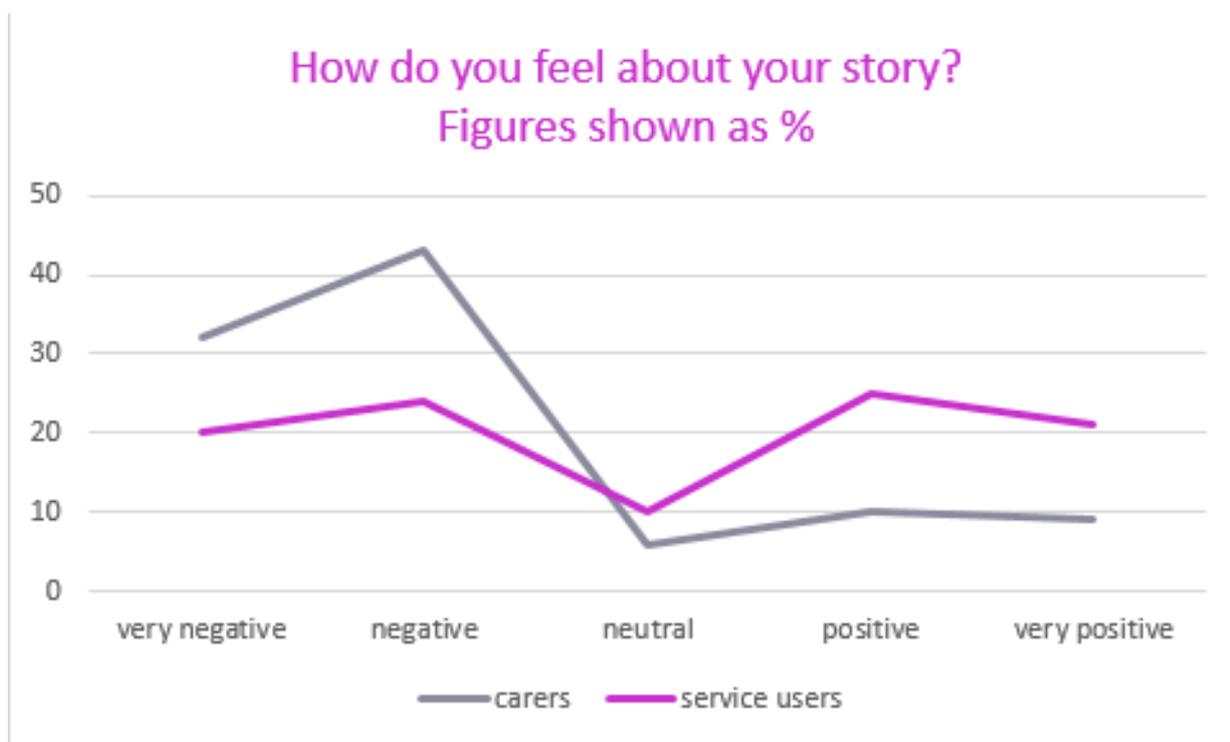
*“The way information is provided to me often isn’t accessible to me – for example, receiving an emailed pdf, which my screen reader tech can’t read, which, when I get someone else to read it, tells me I can acquire information in alternative formats by contacting X. Explaining this once is rarely enough - the same thing will happen again and again.”*

## Transport

*"I am usually given appointments at my local hospital which is quite easy for me to get to. I was recently given one at a hospital further away, I can't use the phone because I'm deaf [and the hospital will not use email], so I had to go down there to explain that the 9am appointment they had given me, I wouldn't be able to get to as there isn't an early enough bus. They said that transport could be arranged and directed me back to my local hospital to arrange this...In the end, the ambulance did not show up, and I was sent a letter saying that I had missed my appointment and been struck off their list."*

## Carers

10.26. Carers submitted 182 stories to the project, 38% of the total received. A comparison of the stories submitted by carers and those submitted by people who receive care or support shows carers reporting a far higher incidence of 'negative' or 'very negative' experiences than those who receive care or support. Carers rated 75% of their stories as 'negative' or 'very negative' in comparison to only 44% of the stories submitted by those who receive care or support.



10.27. 66% (121) of the 182 responses from carers **did not have the positive triad completed**. The negative triad was completed in 79% of carers' responses (143 times).

10.28. Stories from carers shared many commonalities with those submitted by people who receive care and support, identifying the need to fight for services, the challenge of

working with several sectors at once and the provision of information as significant barriers to well-being.

10.29. Parent-carers were notable in the extent to which they were affected by these issues. Contributing factors appeared to be the need for multiple sectors to be involved in their child's support (often education, care and health services); the language and imagery of support services for carers rarely resonating so that parent-carers were unaware of the services or felt conspicuous/self-conscious if they attended; and the awareness that the right support while their children are young could be transformative, while the wrong support could have long-term repercussions. These factors are present throughout the narratives received by the project but are particularly acute within the narratives of parents-carers.

10.30. Underpinning all the narratives submitted by carers were the experiences of the person they cared for. Many narratives submitted as 'My story is about being a carer' were, in fact, about the person they cared for. The lives of carers and their loved ones become inextricably entwined, with carers often taking a step back from their own lives to prioritise the needs of their loved one.

#### Good care

*"The care that my wife received was, overall, very good – we had regular contact with district nurses and support staff and services seemed to align well. We would, for example, have regular phone calls to check how things were going and if we needed anything additional that week. For me, the priority was always getting things right for my wife and if that was right then things for me were generally all right as well. Looking back, I do see the things that were more of a struggle and ways things could have been done differently to make caring for my wife easier, but her care and support was always good and that was the critical thing."*

10.31. The changing dynamic of people's relationships when one becomes the carer and the other cared for, was touched upon in a number of the narratives and is a theme that would benefit from further research, particularly in order to better understand how carers can be well supported. The experiences shared by carers, whilst echoing those shared by others, also brought to attention two topics specific to carers:

- Carers' assessments
- Respite services

10.32. Both carers' assessments and respite services are intended as forms of support for carers that should improve their lives and so the lives of those they support. The evidence from the stories gathered suggests that there is work to be done to move closer to this being the case more often.

## Carers' Assessments

- 10.33. Introduced as part of the implementation of the Social Services and Well-being (Wales) Act, carers' assessments still appear to be subject to confusion and inconsistency, and people's perceptions of them are very poor. Only one of the stories relating to them was positive.

### Being a carer is hard

*"I am a carer and had a carers' assessment for my husband who has dementia. My daughter and son in law arranged it and whilst I was fearful at first, it turned out to be a really positive experience and provided a great deal of assistance that I would not have otherwise accessed."*

- 10.34. Among the other, negative narratives respondents described asking for an assessment and not getting it, feeling that the assessment was being used as a tool to find fault and being told that the assessment, and any support that arose because of it, would relate to only some of the people they cared for. A process that is intended to be supportive is felt by many to be punitive.
- 10.35. More will need to be done to understand the processes employed by local authorities for administering and undertaking carers' assessments before recommendations could be made. Improvements to the process would appear to be necessary if these assessments are to facilitate the level of support many carers require.

### Poor support for carers

*"I had a carers' assessment - I look after my parents both of whom have dementia. All I was offered was a massage which when I tried to change the date of I lost. And training I had requested and booked as a carer was cancelled through lack of interest."*

### Can I take care of my children?

*"I had a carers' assessment, thinking that it might be useful and could lead to improved support for us as a family, but the whole experience was really alarming. I was sent a 12-page pre-assessment to complete...even though the whole thing is supposed to be more of a conversation than a form-filling exercise. I was asked 'do you feel able to continue caring for your children?' This is terrifying. They're writing these answers down and wanted me to say 'yes' or 'no'. Clearly, I don't want to create reasons why my children might be taken from me but at the same time I would like some respite. I was told that respite won't be available as my children don't have low enough IQs and that the assessment will take six weeks just to write up even before any action is taken or anything put into place."*

### Carers' assessment

*"Since their introduction I have made enquiries about a carers' assessment. I've been told that if I had a carers' assessment it would only be in relation to my caring for 2 of my 6 children, which makes no sense to me. On top of that, it feels to me that it's being approached as a safeguarding or child protection issue and the language associated with it is quite distressing."*

### No offers of help

*"I began contacting Social Service a while ago e-mailing and phoning letting them know my concerns about Dad and his living arrangements, and including my role in everything and the pressures I was under. Throughout that year I was never offered a carer's assessment..."*

## Respite

- 10.36. Respite is a vital form of support for carers but the experiences of respondents were mainly negative; some were described as damaging and others described the need for a greater variety of services and approaches than are currently available.
- 10.37. Many of these experiences illustrated the repercussions of being unable to access respite or having no suitable options available. They also highlight the wider impact of this deficit in services, and the longer-term implications of things going wrong.
- 10.38. Despite these concerns several positive experiences relating to respite were shared and touch upon the value of such experiences.

### Excellent support

*"Respite was arranged for my husband when I went into hospital and for when I came out as my operation meant I wouldn't have been able to take care of him. good bond with social worker and got the respite sorted which worked well - concern that if this needed to happen again the social worker could have been a different one and that relationship is so important. Respite was good and put in place in good time."*

### Fantastic - my son has a brilliant time

*"I am a parent of someone who receives care. My son has learning difficulties. He has a personal assistant. He has had the opportunity to get out and about and explore social activities that he otherwise wouldn't have done. It has also allowed me to have some respite. He has now gone to college and has been part of Shared Lives. He lives with people who treat him like family."*

### No respite options

*"There are no respite services for people with learning disabilities, the only option is adult family placement. Staying in a group environment, like a respite home, gives my son a peer group, people to socialise with, do activities with and gives me confidence that his routine, safety and well-being will be well taken care of. My son has had successful family placements previously but changes within the family meant they could no longer host anyone; finding a new family and building a relationship with them takes time and there is the constant knowledge and worry that something may happen to affect to the placement. It doesn't offer a sustainable, long-term option for us as a family."*

### Respite

*"Both my husband and I would benefit from respite and when I have asked about this I've been told that when my children are at their activities, youth club, for example, that is my respite time. I have several children who attend a variety of activities at different times and all requiring me to*

*drive them to/from them and that drive may be too far from my home for me to just drop them off. There is no opportunity for respite...*

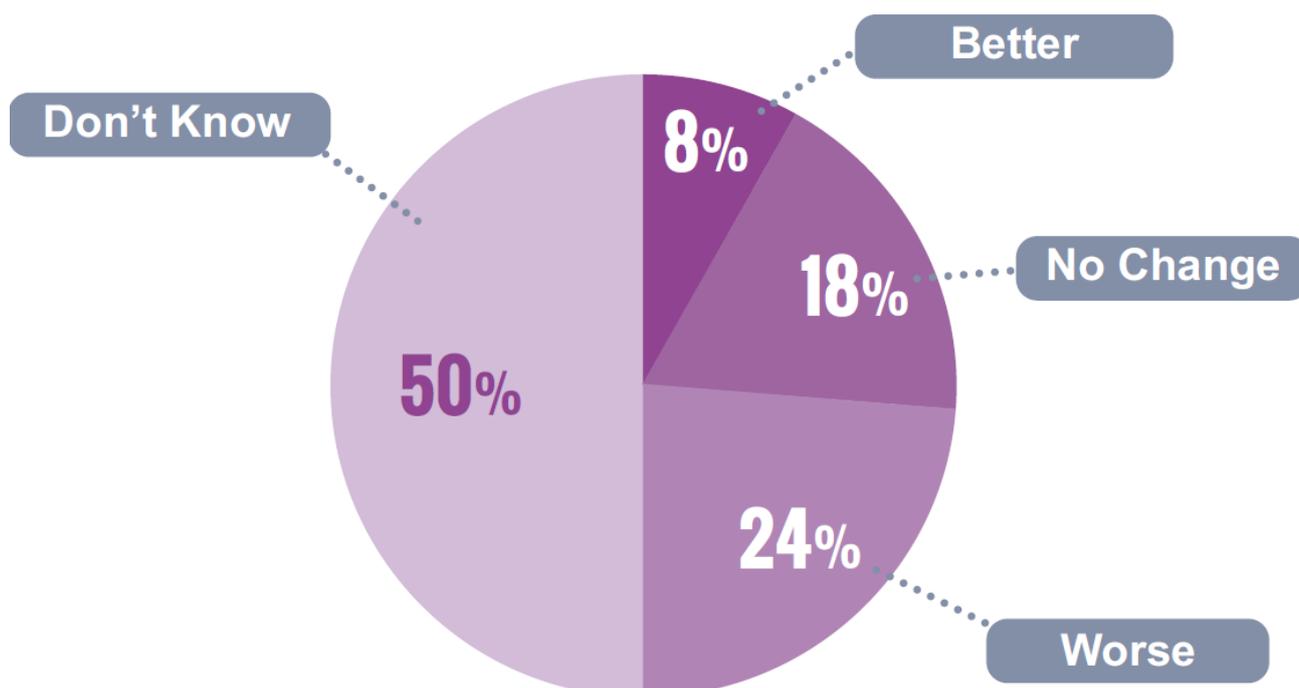
### **Terrible respite**

*“Now that my daughter is an adult (by just a few years) the respite homes she can stay at are for 18 to 65-year olds. They’re residential and can’t be group booked for younger people. We decided to try using one and did extensive prep with the home, putting a thorough care plan in place. When we arrived, they weren’t ready for her, and they later moved her to the back of the building as she was being noisy. My daughter is non-verbal, but using tech she can communicate very fluently and articulately – if she is distressed or upset or not able to communicate for some reason then she will make noises – this is a sign that something isn’t right. They didn’t get her ready for bed until midnight and didn’t support her to get settled. They left the light on and at 4am just switched it off. This scared her and she wet the bed. The next morning, they hadn’t washed her. She knows what her needs are and can communicate them but no-one enabled her to. Now neither she, nor I, want her to go back there, but that also means there are no respite options. Bad cases, like this one, need to be dissected and understood, and they’re just not.”*

## **11. Perceptions of the Act**

- 11.1. After submitting their story and responding to the metric questions, respondents were asked whether they thought that the 2016 change to social care delivery had had any effect on their experiences. The question was multiple choice, and 236 respondents (50%) selected ‘I don’t know’.

### **Since 2016, things are...**



11.2. The next question asked that, if they had noticed any change, what had changed and 84 responses were provided. Six related to 'no change' and provided only minimal elaboration on that response.

11.3. The 12 comments from people who did not know if their experience had been affected by the 2016 changes included it being too early to tell, having not used services prior to the introduction of the Act and difficulty in attributing any perceived differences to the Act specifically. Political and administrative changes, as well as changes in individual circumstances, made pre, and post-Act comparisons difficult.

11.4. There were 31 comments provided in relation to things being better, and 35 in relation to things being worse. In both cases, these are very small numbers and the question related to people's perception and did not seek corroborating evidence for their views. As such, even among those indicating that the Act had made things either better or worse, there is little certainty of any causation.

11.5. The comments from those who felt things were better included:

- *They asked what was important to him rather than just important for him*
- *I do lots of things I want to do*
- *The staff seem more concerned about being respectful and helping me stay independent, without pressing me to have more than I want*
- *I am treated better by staff and my son is happier now too*
- *The way this social worker engages with me is how it should be*
- *Better opportunity for a conversation - felt listened to and treated with respect*
- *In terms of being involved with services and having a voice is has got better.*

11.6. Less than third of the 113 respondents who felt things were worse provided comments, so there is not enough data to draw any conclusions. However, they loosely grouped into themes of accountability, expectations not being met, and capacity issues within services.

- *It is now much harder to understand your rights and challenge decisions*
- *The Act suggests holistic approaches and joined up approaches but instead there is just no accountability and fragmented services with silos of activity and people pointing the finger at other services*
- *There is no clarity about who is responsible for anything*
- *The Act suggests that approaches such as co-production should be the norm, and they just aren't*
- *The Act creates a lot of expectation and they're just not being met*

- *The Act brought with it suggestions of improved ways of working but these have not materialised, and the failure to live up to the expectation that was created makes things seem much worse - opportunities are being wasted all the time*
- *Social care workers not having enough time with client*
- *Budgets have been slashed help has been cut further*
- *Lack of money, too many risk assessments means there is nothing available. Too many departments looking after own budgets*
- *Far less money giving fewer opportunities.*

11.7. A causal relationship between the experiences of the individuals who made these comments and the implementation of the Act is impossible on the basis of this data. There may be merit in exploring some of these issues further though. Understanding more about people's perceptions of accountability and the extent to which clarifying chains of responsibility would be beneficial, could provide a straightforward way of improving people's experiences.

11.8. Similarly, identifying areas of increased expectation related to the Act could, potentially prove useful for piloting new approaches or developing co-productive activities with people.



## PART C – CITIZENS’ JURY

### 12.Phase 2 – Citizens’ Jury

- 12.1. MtM’s Citizens’ Jury, the second phase of delivery, was developed to enable lines of inquiry revealed during the SenseMaker phase to be explored in more depth. Employing the Citizens’ Jury methodology to conduct this phase facilitated the level of public involvement needed to understand the early implementation of the Act, and modelled a robust approach to engagement which yields tangible, productive results.
- 12.2. The key components of a Citizens’ Jury are creating the Jury, setting a question and developing a programme of witnesses, as well as the administrative and logistic work of organising a venue, finding a facilitator, ethics approval, the paperwork of the event itself and the report that is compiled afterwards.
- 12.3. A separate Citizens’ Jury report was prepared following the event. It documents, in summary, all aspects of the activity, focusing mainly on the days of the event, the recommendations from the Jurors and the evidence provided by the witnesses. This section of MtM’s final report focuses on elements not covered by the Jury report and elaborates on the relationship between the SenseMaker phase of MtM and the Citizens’ Jury phase.
- 12.4. MtM’s Citizens’ Jury report can be accessed on the website. This section covers:
  - Preparation for the Jury
  - Developing and delivering the programme
  - Recommendations made by the Jurors
  - The relationship between SenseMaker and the Citizens’ Jury.

### Preparation

- 12.5. Preparation for the Jury was the focus for July to September 2018, with work having been undertaken alongside story-gathering activity in the spring and early summer. Ethics approval for the activity was sought via the University of South Wales’ low risk ethics panel. This process helped ensure positive experiences for the Jurors and was the appropriate course of action given the role the Jurors would be taking on.
- 12.6. As part of the process, MtM developed robust approaches to recruiting Jurors, the provision of information, informed consent and maintaining the well-being of the Jurors throughout the experience. Ethics approval was granted by the Faculty of Life Sciences’ Ethics Committee at the University of South Wales on 6th August 2018.

- 12.7. The opportunity to be a Juror was advertised on mtm.wales from the launch of the site, and was included in the information on the submission screen of SenseMaker for anyone submitting a story. People could register their interest by completing a very brief enquiry form on the website or contacting the project manager directly. The opportunity was promoted further at events such as the Royal Welsh Show, and through online channels including Twitter and Facebook.
- 12.8. This approach to Juror recruitment was successful: a total of 42 people were initially interested in the role, and a random selection method was used to create the final Jury of 14.
- 12.9. The process of selection created a Jury that was knowledgeable and understanding of social care, with many Jurors having had personal or indirect experience of the sector. This brought several benefits as Jurors needed little to no briefing on the topics they would encounter, the language they would hear or the experiences that would be shared.

## Developing the Programme

- 12.10. In the first week of August an analysis was done of the 137 stories that had been uploaded to SenseMaker by July 31<sup>st</sup>. The stories presented a complicated picture of social care that included emerging trends and themes but did not immediately point to a specific question for the Jury.
- 12.11. Critical among the stories were matters that included the interplay between sectors and within parts of a sector (for example health, education and social care), the provision of information to carers and those seeking support, and the often competing roles of people, processes and finance.
- 12.12. It was important that the project did not prematurely draw conclusions or close potential lines of enquiry. Therefore, it was agreed to set the Jury a broader question than might typically be asked, and use the programme to explore the emerging trends in more detail. Jurors were set the question:

### *What really matters in social care to individuals in Wales?*

- 12.13. The witness programme was then developed to facilitate the discussion of these themes, as well as provide wider context of the social care sector. The final programme was organised such that each day had a broad theme: scene-setting on day one, services in practice on day two and innovation and best practice on day three. Each day included one panel of individuals who were in receipt of care and support, or who were carers, as well as the panels of social care professionals representing different perspectives or areas of work.

12.14. The people who made up the panels of individuals who were in receipt of care and support or who were carers were drawn primarily from the project's interaction with people submitting stories at events. Their experiences reflected and illustrated the trends that had started to emerge from the stories in SenseMaker.



12.15. The full programme can be found in Annex 2, and summaries of the witness statements can be found in the Citizens' Jury report which is available to download on the MtM website.

## Delivering the Programme

12.16. A pre-meeting was held for the Jurors on September 15<sup>th</sup>, 2018 so they could get to know one another, discuss queries they had, to become familiar with the process, the project team and facilitator. The pre-meeting was a beneficial ice-breaker and supported the Jurors to be more comfortable on day one of the Jury itself.

12.17. Following the pre-meeting MtM staff and the facilitator developed strategies for briefing the Jurors at the start of the day, supporting their discussions and de-briefing at the end, as well as agreeing processes for managing the smooth running of the days of the Jury.

12.18. The Jury had three public days (September 24<sup>th</sup>, 25<sup>th</sup> and 26<sup>th</sup> 2018) and a final in-camera half day on the 27<sup>th</sup> for the Jurors' deliberations.

12.19. The public days of the Jury required the presence of the facilitator plus a minimum of four of the project team to support the logistic and pastoral requirements of the event. Critical components which required managing throughout were timings and keeping to the schedule, the functioning of the audio-visual equipment, supporting witnesses as they arrived at the venue, and supporting the well-being of everyone involved.

- 12.20. The intensity of the process coupled with the personal experiences of care some of the Jurors had as well as the evidence presented by the witnesses, raised the possibility of someone becoming upset. Staff from Social Care Wales were present throughout the Jury to offer support and the venue had been organised to provide breakout spaces should people need them.
- 12.21. September 27th was the final day of the Jury and was a closed session for the Jurors to discuss what they had heard, draw conclusions and make recommendations. A half day, followed by lunch had been allowed for these discussions; however, the competency with which the Jurors approached their task yielded more information and discussion than could be accommodated within this time.
- 12.22. The recommendations that were produced were comprehensive and insightful; however, with more time, the Jurors would have had the opportunity to define, shape and prioritise these recommendations further.
- 12.23. The Citizens' Jury demonstrated the capacity of people to explore, consider and reach conclusions about a complex and emotive topic and illustrated the value of involving the public in debate.

### 13. Citizens' Jury Recommendations

- 13.1. The Jurors reached a number of conclusions in relation to *what really matters in social care?* These recommendations reflect the breadth of the issues that were explored and the complexity of the task the Jurors were set. They highlight the need for ongoing discussion and for considered action in successfully implementing the Act.
- 13.2. The Jurors expressed an admiration for the aspirations of the Act and its central tenets, but were frustrated at the systems and processes that hindered, rather than helped, practitioners to bring the Act to life. Acknowledging the enormity of the challenge of delivering good care, Jurors were concerned that respect and value for people were being lost from day-to-day experiences of accessing services.
- 13.3. Broadly, their conclusions and recommendations can be grouped under three of the four principles of the Act as defined by Welsh Government. The fourth principle, that of well-being, is achieved when the other principles are met. An additional set of recommendations relating to Scrutiny and Review were also felt to be needed to support the delivery of the Act.
- 13.4. These recommendations emphasise the role of people in Wales in shaping social care delivery, the value of meaningful engagement and the need for the development of social care to be an ongoing and collaborative process.

## People

- 13.5. Jurors agreed that the social care system is complicated and difficult to navigate, making it hard for people to have voice and control; for them to get the right support, and for them to feel confident that decisions are being made in their best interest. Additionally, they felt that carers are under-valued and that the language of systems there to provide support does not resonate with them.

The Jury recommends that:

1. **Each person approaching the social care system and related sectors whether child, adult or carer, should receive the support of an impartial, well-trained and knowledgeable key worker who will advocate and stand alongside them:**
  - It should not be a battle to get the right support: processes should reduce stress instead of produce stress
  - Access to financial resources should be straightforward and easy to understand
  - Whoever is best placed to deliver a service should be the one to do so: 'best' may vary from person to person.
  
2. **Care and support plans need to respect an individual's desired outcomes, and be more holistic, so that services fit the person and not the other way around:**
  - Focus on what people can do, and want to do, and not what they cannot do
  - Relationships, whether intimate, familial or community friendships, are paramount to well-being and support. Their importance needs to be embedded in social care delivery at all stages
  - Greater effort needs to be made to engage with people, particularly those with additional needs and those that are housebound, to find ways to better include them in communities.
  
3. **Greater consideration must be given to carers so they are recognised, supported and valued, as the vital assets they are:**
  - Greater diversity should be employed in the methods, language and imagery used to promote services and support for carers
  - Support for carers should continue to be made available after they have ceased to be a carer as this is a significant and difficult adjustment.
  
4. **The transition between children's and adult services must be made less disruptive and should better prioritise the young person:**
  - Children in residential care should be able to access transition support to ease their move to live more independently

- Services should provide greatly flexibility in their offer and approach to young people enabling greater support that promotes ‘normality’.

**5. Individuals and service providers should work collaboratively as equal partners, promoting good decision-making and minimising the need to challenge decisions:**

- Independent legal help should be provided to those who wish to challenge decisions
- Statutory services must be supported to learn lessons arising from legal challenges and the decisions that result from them.

## Partnership and Integration

13.6. Jurors were clear that approaches to partnership and integration could be improved and should have a renewed focus on the individual and ensuring the best service for them. They felt that partnerships tend to be limited in scope, and that tendering processes hinder, rather than support, collaboration and creative working. Whilst best practice is recognised across social care, Jurors considered that more needed to be done to share, learn from and emulate it.

13.7. Social care should not be a fight between those that need services and those that provide them, nor should it be a fight between service providers. The holistic provision of services that many need, and that the Act aspires to provide, requires sectors across Wales to be supported and guided to look upwards and outwards far more.

The Jury recommends that:

**6. Greater consistency is needed in strategic and operational delivery of social care across Wales with better facilitation of partnerships and collaboration:**

- Portable services that travel with the individual across localities if required
- Services, such as foster care and specialised schools, should not be different if someone moves across the invisible boundaries of Local Authorities.

**7. Regional Partnership Boards need to be made more transparent and accountable, and need to be more open to the public:**

- Increased, and more meaningful, citizen representation and engagement
- Mandated, and consistent role across Wales, publicising their function, activity and how to get involved.

**8. Co-production needs to be defined and embedded as a practice which is understood and utilised by all who are involved in the creation, delivery and evaluation of social care services:**

- It must be easy for service users and carers to understand how they can contribute and the value of their contribution
- It must be accepted that all statutory and voluntary bodies have to share power for the well-being of users
- Service providers must regard citizens as stakeholders and provide accessible approaches to engagement by looking at transport, the location of meetings and covering all costs for service users and carers.

**9. Tendering and commissioning processes need to ensure they focus on delivering high quality services that provide exactly what is needed for people in the short, mid and long term:**

- 'Races to the bottom' where low cost triumphs, no matter the longer-term consequences to people, need to be stopped
- Very short service delivery contracts need to be avoided as they create uncertainty, and lead to people reinventing the wheel for the sake of securing further funding
- As innovation requires risk, pilot projects need to be given some leeway to demonstrate their achievements
- The administration of 'saving' money should not be more expensive than the savings made.

**10. Processes and tools need to be developed and utilised effectively to embed good partnership and collaborative working:**

- Develop platforms to share best practice and to demonstrate how that practice is achieved
- Share learning and understanding from other sources, including from co-operatives, social enterprises, failed schemes, the corporate world and other countries
- Identifying strengths and weaknesses around collaboration and sourcing complementary organisations will enable productive partnership and consortium working.

## Prevention

- 13.8. Jurors agreed that greater priority should be given to preventative services and measures. Accessible information, a motivated and supportive workforce and a focus on supporting people's independence were considered vital to early intervention, minimising the risk of issues escalating and promoting trust of, and within, social care.
- 13.9. Jurors considered that too many aspects of social care created a need for people to fight for services or information, and that simplified systems would promote ease of access as well as transparency, trust and accountability.

The Jury recommends that:

**11. Statutory bodies should provide clear information about their services and about the Act, ensuring it is easy to access and understand, no matter what someone's circumstances, background or needs:**

- Pride should be taken in creating clarity for people and the onus for understanding what a person is entitled to is removed from individuals and returned to services
- Common sense should be applied, and communication needs stated once (and only once), for example, those that are registered blind receive information in a format appropriate for their screen-reader technology
- The Act must respond to the diverse, and multi-cultural, communities of Wales and facilitate diverse ways of communicating, for example teaching British Sign Language in primary schools.

**12. Improvements should be made to the overall system so that people's experiences are not complicated, and getting the right support is easy:**

- Complex processes and large quantities of information need to be made simple and easy to understand
- People's mental health should not be adversely affected by their interactions with social care.

**13. Frontline workers need to be recognised as critical assets within the social care sector and their status, professional development and pay should be enhanced to reflect this:**

- Training, and the opportunity to attend it, needs to be provided properly to support professional development
- Trust should be encouraged amongst workers in the sector, motivating them and allowing them to challenge the status quo
- Better marketing of social care professions that reflects the diversity of roles within the sector and appeals to more people
- Better remuneration and terms and conditions for frontline social care workers.

**14. All those who are involved in social care should be encouraged to embrace new technology:**

- Many innovations could enhance care and promote independence, supporting people to live longer with less intense service provision
- Providers may need to be creative in cultivating multiple sources of expertise in relation to their understanding of technology and its applications.

## Scrutiny and Review

13.10. Throughout their discussions, Jurors identified that scrutiny and review processes needed to be enhanced and that they required more meaningful citizen involvement. They were concerned that reports from Commissioners in Wales on aspects of social care, as well as treaties that inform the Social Services and Well-being (Wales) Act 2014, including the UN Convention on the Rights of Persons with Disabilities, were ignored or not well understood, and that it was difficult to see their impact in service delivery.

13.11. They agreed that scrutiny and review processes needed to result in tangible outcomes, and that robust and transparent approaches would support effective implementation and delivery of the Act.

The Jury recommends that:

### **15. Citizens should be formally involved in greater and deeper scrutiny of the Act to build confidence in the sector and ensure the proper delivery of the Act:**

- A 'You Said, We Did' process in social care
- All levels of governance to develop local, citizen-based critical friendships, strengthening their relationships with communities and formalising their approach to citizen input and public engagement
- An annual Citizens' Jury to be broadcast live to the public across Wales.

## 14. The Citizens' Jury and SenseMaker

14.1. The SenseMaker and Citizens' Jury phases of MtM were complementary elements of the same fundamental process: understanding people's experiences of social care in Wales. The stories submitted to SenseMaker in the first half of 2018 were used to inform the question that the Jury were set, as well as the programme of witnesses, and many of the themes that emerged from the stories were also present in the Jurors recommendations.

14.2. The Jurors noted that social care is difficult to navigate, that moving between services is disruptive and that information could be presented more clearly. They further noted that co-production, as an approach, could be better understood and utilised, that carers are undervalued and collaboration between organisations, and between organisations and those they support, needed to be improved.

14.3. These ideas are found throughout the SenseMaker data, and many of the recommendations made by the Jurors have the potential to address the associated issues raised in those stories. Undoubtedly, there is further work to be done to confirm the veracity of the Jurors' recommendations and transform them into approaches to delivering social care. The consistency between the Jurors' recommendations and the

SenseMaker data suggests this work would be beneficial to the social care sector as a whole.

- 14.4. The Jurors' recommendations also included ones relating to Regional Partnership Boards, tendering and commissioning processes, terms and conditions for social care workers and scrutiny and review processes. These were not topics that explicitly arose in the stories submitted to SenseMaker as they relate more to the experiences of social care workers and those that oversee the sector.
- 14.5. Despite this, there are correlations between these topics and the themes of the SenseMaker findings. Issues relating to staff turnover, time-wasting, working with multiple agencies and the concerns about accountability raised in relation to changes the Act may have led to, could all be seen to be related to these topics and potentially improved if the recommendations were developed and implemented.
- 14.6. Similarly, much of what was recommended by the Jurors would likely create more examples of the positive stories that were submitted and highlight the importance of many of the same approaches or behaviours. Jurors recommended a number of approaches that would support providers to work more closely with those that they support, to work more co-productively, to work more collaboratively with other providers and to create more of a culture of learning and trust within social care.
- 14.7. These elements are at the core of many of the positive stories that were submitted (see section 7.1 to 7.6), and would be further supported by the more strategic and delivery orientated recommendations made by the Jurors.



## PART D – REFLECTIONS

### 15. Reflections

- 15.1. Measuring the Mountain was a new and innovative approach to evaluating the impact of legislation in Wales. The project utilised methodologies for undertaking this work that had not previously been used together, and which were new to many of the participants involved in the project.
- 15.2. The following pages will outline key reflections and things that were learnt over the course of delivering MtM, and will cover SenseMaker, the Citizens' Jury and the project overall.

### A Note on Self-selection

- 15.3. Self-selection was an element of individuals submitting stories, organisations getting involved in the project and of people becoming Jurors. The project created its own relationships and built on contacts the Steering Group had, as well as cultivating connections through word of mouth once the project was more established.
- 15.4. This lay the foundation that anyone with a story to share could participate, that they did not need to be part of a particular group, in receipt of a particular service or registered on any particular list. Circulating information in newsletters of organisations like Carers Wales and WCVA, presenting at conferences like the Age Alliance Wales Conference and attending events like the Royal Welsh Show helped the project reach a range of different communities.
- 15.5. Selection bias may have led to people with more polarised experiences or views submitting stories. Overall, the stories showed a leaning to the negative but not a significant one. 268 stories were negative or very negative, and 175 positive or very positive.
- 15.6. Organisations contacted the project to discuss getting involved and the ways this could be facilitated. In a very few cases, organisations suggested that the project was seeking, or that they would gather on MtM's behalf, 'good news stories'. The resultant conversation about the project's interest in any and all stories related to social care, and the need for the story to be one the individual wanted to submit, often led to the organisation not being involved.
- 15.7. Of the organisations that hosted Listeners and invited MtM to events, approximately half were organisations that do not deliver social care, rather they operate in sectors that are linked with or are adjacent to care. Of those that do deliver care, and invited MtM to

events, the project was able to lead its own activities, and engage with people without interference from the host.

- 15.8. The final area of self-selection was that of becoming a Juror. Primarily this brought advantages to the project and the knowledge and experiences the Jurors entered the process with varied from person to person and did not manifest as any obvious biases for the group as a whole. The question that the Jurors were set was broad and complicated, and their collective skills enabled a substantial exploration of the question and the topics that underpinned it.

## 16. Story-gathering

- 16.1. The story-gathering phase of MtM presented several challenges and opportunities for the project to adapt its approach, learn rapidly from conversations with partner organisations and develop a flexible, responsive delivery method. These adjustments created a project that was engaging, that people were interested in and that, ultimately, has produced a detailed picture of people's experiences of social care in Wales.

### Listeners

- 16.2. The Listener network did not become as extensive as had originally been hoped. A combination of factors meant many organisations, while very happy to support the project and be involved in other ways, could not host their own Listeners.
- 16.3. Capacity was the primary issue, with many organisations having limited time or no time to gather stories as part of their current activity and no time to organise specific events or create slots in the agendas of pre-planned 2018 events. Further, a few organisations had recently completed their own story-gathering activity and did not want to duplicate this by now asking for stories on behalf of MtM.
- 16.4. The role of Listener could be undertaken by both paid staff and volunteers, and Time Credits were available for anyone who was a Listener in a voluntary capacity. They were intended as an incentive for becoming involved, and a means of recognising the time people would give to the project. In discussions with organisations, the same capacity issues existed whether it was paid staff or volunteers who would have been story-gathering.
- 16.5. Among those organisations that did have volunteers who could gather stories, the opportunity to earn Time Credits posed some issues. Often organisations had more than one volunteer and they were not always in roles that would enable story-gathering. As such, to have one volunteer earning Time Credits because of their activity, and not the others, would have been inappropriate.
- 16.6. This was significant for the project to have learnt and highlighted the considerable thought and energy that goes into managing volunteers. Without a dedicated volunteer manager as part of the MtM team, the project could not create or support its own network

of volunteers and collaborating with other networks was a sensible approach but one that did not benefit from the availability of Time Credits.

- 16.7. The support of Listeners with gathering stories was a valuable component of MtM and enabled the project to hear from groups who, for reasons related to geography, demography and vulnerability, it would otherwise have been very difficult to gather stories from.

## Engaging with the Project

- 16.8. Some elements of the project were less accessible than would have been ideal, and while the project took what actions it could to address them, with the time and resources available, they were not fully resolved.
- 16.9. Aspects of the version of SenseMaker used by MtM (the most up to date version available at the time), were not compatible with screen reader technology, and owing to the inclusion of the triads in the questions it was not possible to create a Word version (which would be compatible with screen readers) that would produce data that could be validly combined with the other data gathered.
- 16.10. Due to this, people with visual impairments could not get involved in the project unless a Listener was able to support them. People who used adaptive aids to address other cognitive issues also reported some difficulties and required support from others to fully complete the questions.
- 16.11. Although Listeners were able to provide support and so overcome these issues, among the stories a number raised issues relating to a reliance on other people. A significant theme was services assuming that people have someone available to support them and considering that this was a suitable alternative to creating accessible services that could be used independently.
- 16.12. It is unclear what impact the inaccessibility of the questions may have had on the data collection. However, in terms of people's experiences, creating a more accessible means of becoming involved, would have greatly enhanced them.
- 16.13. As was discussed previously, the sample of people who submitted stories to the project was not wholly representative of the people of Wales or those accessing social care, with younger people being particularly under-represented.
- 16.14. Understanding more about why this was would be useful for future public engagement work. While some elements likely lay with the engagement methods of the project, coupled with the capacity of the project team and the time frames of MtM, other elements may be subtler and warrant further exploration.

- 16.15. The language of social care was raised by several of the witnesses at the Jury as being an area of confusion or disconnect, with definitions and use varying between services and locations. Members of the service user and carer panels said that when seeking services, the language used to describe those services, or describe the people they might be beneficial to, did not resonate with them. Many people reported not identifying as a 'carer' or a 'parent-carer' even though they undertook those roles and responsibilities.
- 16.16. In early discussions, the issue of what the project meant by 'social care' was raised a number of times and proved to be a term that created some confusion for people. There is a likelihood that language prevented some people from realising the project was aimed at them, and that MtM wanted to hear about their experiences.
- 16.17. A further issue arose relating to what stories the project wanted to hear. A number of people, in conversation with Listeners, expressed surprise at the mundanity, as they saw it, of the experiences MtM was interested in. Experiences that were day-to-day occurrences for people did not necessarily feel significant enough to be of value to the project.
- 16.18. In these cases, that perception was addressed, and those individuals submitted stories. Work was undertaken to include example stories in the Listener Toolkits, and to promote the breadth of experience the project was interested in. However, it is likely, that some people still did not submit stories as they did not think they would be interesting enough for the project.

## 17. The Citizens' Jury

- 17.1. The Citizens' Jury methodology was new to many involved in MtM and the Jury. The feedback and reflections on the next pages have been drawn from those who were involved in the activity as well as observers who attended the public days of the event. These reflections fall, broadly, into two areas: the challenge and the opportunity of the process.
- 17.2. Approximately 30 people observed the Jury, several of whom provided feedback on their experience. Jurors, witnesses, the facilitator and project team also provided feedback and reflections.
- 17.3. The Citizens' Jury report outlined the hopes and fears of the Jurors in relation to their involvement in the Jury and the recommendations they identified, as well as aspects of their knowledge of, and attitude towards, elements of social care. These have not been reproduced here to avoid duplication.

## The Challenge of the Process

17.4. The breadth of the question set for the Citizens' Jury was a challenge in itself. Owing to the lack of a singular, clear direction for the question from the SenseMaker data, setting a narrower question would have been inappropriate. However, this created the need to address a large quantity of information from several perspectives, and to do so in relation to the somewhat subjective matter of evaluating the Act.

17.5. One observer, noted that the task, overall was challenging, and that clarity of purpose and expectation was essential:

*“One of the key points that resonated for me came from Mark Llewellyn about what ‘evaluation’ means, which involves establishing whether the outcome is attributable to the intervention. For me that not only explained in a very helpful way exactly what the jury are tasked with, but also highlights just how difficult that task is likely to be. As Mark also said, there will be no absolute answers and no perfectly robust and objective evidence, but the jury will have to form as good a judgement as possible using the evidence they have.”*

17.6. Developing a thoughtful programme had been essential. Ensuring that the witnesses were well briefed and understood the format of the event, their role, and specifically what was needed from them in terms of information sharing was critical. Each witness was there because of a particular aspect of their work and they needed to convey relevant information to the Jurors succinctly, in very limited time.

17.7. Keeping to time was critical because the programme for the Jury needed to run to a very tight schedule to enable all the information Jurors needed to hear to be shared with them. Organising the quantity of information needed, provided by 22 witnesses, in three days was a challenge, and some of the Jurors expressed frustration at not having as much time as they would have liked to ask the witnesses questions.

17.8. The Facilitator, commented that:

*“Some of the Jurors were frustrated by the time available to question the excellent witnesses... at times, witnesses may not have truly answered the question, and an opportunity for a rebuttal or further questioning would have been appreciated.”*

17.9. Certainly, the time constraints Jurors faced, were a source of frustration but this frustration also illustrates the commitment, thoughtfulness and responsibility with which they approached their task.

## The Opportunity of the Process

17.10. The Jury method brings together people with diverse perspectives, enabling heads of service, front line workers and carers the same platform for sharing their thoughts and experiences, and a similarly diverse group to listen and process those thoughts. This diversity offers new ways of looking at issues and provides people with understanding of aspects of situations with which they may previously have been unfamiliar. The platform of the Citizens' Jury also offered more neutral ground for discussing social care, where people's presence was in a representative and enquiring capacity.

17.11. The breadth of topics discussed was commented on by the Facilitator:

*“Working with the group for a sustained period of time was a real privilege and an excellent experience...I also thought the range of topics discussed was a fantastic experience from which I learned a great deal about the Social Care system in Wales...”*

17.12. The process also afforded opportunities for people to reflect on their own practice and ways that their work could be developed. An observer noted that:

*“The opportunity that being supportive offers sectors is enormous, and individuals being alert to the needs of people they're seeing, irrespective of their remit, will facilitate better prevention services, reduce a person's need for interventions, and foster positive relationships between individuals and service providers, and across sector and between providers.*

*The patient journey, and the various causes of delays in patients being enabled to return home after being treated in hospital, is something that is discussed a lot at the RCN. I thought it was interesting that [one witness] said that she had managed to hold onto her social care team that work in hospitals whilst many local authorities have lost theirs, and I wondered how much that has contributed towards their good performance in the areas that were mentioned”*

17.13. Significantly, one of the recommendations made by the Jurors was that there should be an annual Citizens' Jury, suggesting that the opportunity to be more involved in policy debate was a welcome one, and one that indicated a valued interest by Welsh Government's in the opinions and expertise of people in Wales.

## Measuring the Mountain – Overall Reflections

17.14. MtM was about really listening to and understanding people's experiences of social care. The work of the project has highlighted the benefit that meaningful conversations bring for people, and the lack, in some cases, of opportunities for them to take place.

- 17.15. Creating opportunities for people to have conversations appears increasingly vital, and this year of delivery led to conversations that were useful beyond the immediate project. Discussion with a group of visually impaired people in south Wales, for example, led to people finding out about sources of financial support they had not been aware of as well as approaches to applying for it.
- 17.16. In north Wales, a group of women in a residential complex were sharing experiences of their new living arrangements and were discussing their fall alarms. This conversation led to several of the group realising they were not always wearing them when they should and deciding to wear them more often.
- 17.17. A housing association in south Wales organised a one-off meeting for their staff to meet with MtM's project manager. The discussions at the hour-long meeting covered the project, the roles of the people present and the value of story-gathering. The manager who had arranged this commented that meetings were often about performance or aspects of delivery, and that it was good for the team to have an opportunity to reflect more broadly on their practice and their roles in people's lives.
- 17.18. By asking people to share their own stories, the project asked people to do something straightforward and, in principle, enjoyable. Social care, as discussed elsewhere, is a complex topic that can be upsetting, but the act of talking and being listened to is considered more positive.
- 17.19. Further, sharing stories did not require anyone to identify how or why an experience was good or bad, or how or why it could have happened differently. Those questions are difficult to answer and can lead people into rote responses or no responses. More than 200 stories referenced experiences of not being listened to, and provide evidence of the need for genuine engagement and meaningful, human conversations.



## PART E – CONCLUSIONS AND RECOMMENDATIONS

### 18. Conclusions

- 18.1. The analysis of the stories coupled with the recommendations made by the Jurors provide insight across several areas of social care. People's experiences varied enormously and underlined the complexity of people's lives, and of delivering social care services. Significantly, they revealed the relatively minor elements of someone's experience that can make it very positive, and the harm that can happen when an experience is negative.
- 18.2. Many people's experiences showed them feeling side-lined in some way and the presumption stipulated in the Social Services and Well-being (Wales) Act, that the adult is best placed to judge the adult's well-being, is not well considered. Many respondents indicated that social care staff had been the primary influencers in the experience they shared, and those experiences were negative ones.
- 18.3. The evidence gathered by this project suggests that co-production needs to be better understood and that further work is needed to explore how it, and the values that underpin it, can be better embedded in people's interactions with social care. Negative stories raised issues of the need to fight for services, of feeling judged when accessing care and support, and of needing to fit in with service provision no matter how inconvenient. Marked by a lack of connection, these stories revealed experiences of lives made more complicated by care, of declines in mental health and of individuals who were resigned to the hard work, frustration and occasional indignity of needing support.
- 18.4. Positive stories contained examples of balances in decision-making power, thorough and reliable communication and flexibility in approaches from social care professionals. They demonstrate the importance of connections and the pivotal role one individual can have; they underline the value, both financially and from a humanitarian perspective, of listening to people, treating them with respect and believing what they say.
- 18.5. Several experiences related to individuals' time, and the time of social care professionals being wasted in some way. They were all negative and came with high financial costs attached to them, primarily in the form of wasted salary hours. They revealed social care professionals missing meetings, inappropriate forms of support being organised for people, and of decisions being made without proper consideration for the longer term.
- 18.6. At a time when resources are increasingly scarce, salary hours need to be viewed as cash, and their use considered as carefully as the use of money. Ensuring that social care professionals have a clear and valuable sense of purpose, and are working in partnership with those they support, would lead to good decisions about the use of their time.

- 18.7. Similarly, improving the provision, availability and accessibility of information would support people to remain more independent, reduce the need for interventions and promote well-being. Too often information is not being offered, is not easy to find, is too complicated, or is in formats that make it inaccessible; improving all this would streamline people's interactions with social care services.
- 18.8. The most urgent conclusion however, is the need to provide better support for carers. Three in four of their experiences were negative, and their stories demonstrated more than any others, the impact of not treating people as partners and of not recognising their views, expertise or needs. With an estimated 370,000 carers in Wales saving the economy £8billion a year<sup>13</sup> carers need to be well-supported.
- 18.9. The stories showed that carers' assessments and respite services are often not providing the support that's needed. Carers' assessments need to be more supportive and their delivery should reflect the value of the role played by carers. Similarly, respite services can support carers by becoming more creative and flexible and working more effectively with carers and their loved ones.
- 18.10. The social care sector is complicated, pressurised and necessarily highly regulated. It would be disingenuous to suggest that the issues people experience could be ameliorated entirely or easily. However, below are some adjustments and considerations that would go some way to improving the experiences of people accessing care and support. Undoubtedly there is greater complexity yet to be revealed and the origin of these issues is likely steeped in cultural, political and systemic concerns, but the starting point is clear, and simple:

### **People need to be viewed as partners in social care delivery**

- 18.11. The implementation of the Social Services and Well-being (Wales) Act 2014 will take years, decades even, and change will only come about if those in the social care sector are supported to evaluate and understand what is important in social care delivery and how to take the best approaches. Creating partnerships between service providers and the individuals they support will require two core principles:
- People must be listened to, and they must be believed
  - There must be a common purpose that is shared by both parties.
- 18.12. Facilitating these two things will be aided by many activities and approaches, outlined below. Many of these will be present in people's interactions already, and others will not. Where they are present, there may be opportunities for sharing this information with colleagues and modelling approaches with them.

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<sup>13</sup> Carers UK, available at <https://www.carersuk.org/wales/about-us/facts-and-figures> [accessed 20.02.2019]

## 19. Recommendations

- 19.1. Listen to what people say, and believe them. Start conversations from the stand point of wanting to understand someone's circumstances and needs, not a stand point of wanting to challenge or disbelieve them.
- 19.2. Discuss arrangements for meetings and appointments with the person being supported; recognise that they have commitments and often complex lives, and agree a mutually suitable time and location.
- 19.3. Make sure that the reason for a meeting or appointment is clear to everyone involved and they agree it would be useful. This includes referrals to other services, and ensuring that those appointments are similarly purposeful.
- 19.4. If meetings need to be rescheduled, or missed for some reason, let everyone who was attending know.
- 19.5. Greet everyone at someone's house, and ask them how they are. Many social care workers visit homes to see an individual; greeting others who live there, especially if they are carers, will build rapport, and offer better opportunities for early interventions, should they be needed.
- 19.6. Offer carers' assessments to carers. Do not wait for them to say they are struggling, or for them to indicate that they need something; being a carer is hard and offering assessments to them is an easy way to provide support.
- 19.7. Develop an approach of offering information, advice and support without people needing to ask. Although the Act seeks to provide individuals with voice and control, this should not be interpreted as individuals needing to understand everything that may be available to them, and also being comfortable asking for it. Offering appropriate services, even occasionally, will support an agenda of early intervention and prevention.
- 19.8. Anticipate people's needs and offer them information in alternative formats where that would be useful. Registers of people with impairments and disabilities (section 18 of the Act<sup>14</sup>) provide a starting point for identifying needs. If someone asks for documents or information in an alternative format, ensure that they only need to do this once.
- 19.9. Discuss personal connections and social lives with people and work with them to identify ways these could be maintained, strengthened or expanded. Recognise that people's needs in this area vary enormously and that options may take time to identify. In relation

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<sup>14</sup> Welsh Government, 2014, *Social Services and Well-being (Wales) Act 2014*, available at [http://www.legislation.gov.uk/anaw/2014/4/pdfs/anaw\\_20140004\\_en.pdf](http://www.legislation.gov.uk/anaw/2014/4/pdfs/anaw_20140004_en.pdf) [accessed 21.02.2019]

to carers seeking respite, respite is not respite unless that person is doing something they want to do, for a length of time and in a location which suits them.

- 19.10. People who are new to being a carer will be facing emotional and practical challenges they may struggle to navigate successfully. Offering them easy to understand support and guidance, using the expertise that working in the sector affords, will minimise these challenges and build an understanding that the social care is there to help. Consider creating a small packet of information for people, or appointing someone to a role to provide support to and build links with carers.
- 19.11. Consider if the work that is being undertaken truly brings benefit for the person being supported. If it does not, give thought to why that might be, and work with colleagues to identify the rationale for carrying out that work and whether it could be achieved more productively in another way.
- 19.12. If a process will involve a number of individuals, for example, fitting a hoist in a home which may require multiple visits, seek to have as many of those visits at the same time as is appropriate. Combining visits, or meetings, minimises the time burden on the person being supported, and improves communication between the parties involved.
- 19.13. Where someone requires a range of support that is inter-related, work with that person to identify ways this support could usefully be streamlined. For example, if a child requires splints and special shoes, try to arrange for both of these to be measured for and delivered at the same time.
- 19.14. Provide individuals with a named point of contact that they can reliably get in touch with. Explore options that would meet this need, for example, a two-tier system so that individuals know who they will speak to when they phone up each time, even if that person is not their named case-worker.
- 19.15. Provide a range of ways that people can communicate with services; ensure that they are all free and ensure that they all offer the same continuity of relationship that the two-tier phone system would.
- 19.16. Work co-productively with people. Use the expertise of people accessing services to develop useful information, efficient routes through provision and to improve the delivery of preventative measures. Make use of the knowledge and experience of people accessing social care.
- 19.17. The Social Services and Well-being (Wales) Act 2014 is about improving well-being outcomes for people who need care and support and carers who need support. These recommendations illustrate approaches which would support the social care sector in Wales can move closer to providing the best possible well-being outcomes for the people it supports.

## PART F – NEXT STEPS

### 20. Next Steps

20.1. The findings from both the SenseMaker phase of the project and the Citizens' Jury indicate several areas that require further research either through gathering more stories and continuing with public involvement approaches, or through exploring the perspective of social care providers and staff. The next steps below are split into those that relate to individuals who need care and support and carers, and those that relate to other parts of social care.

### Individuals and Carers

20.2. As has been discussed earlier, aspects of the project's accessibility and inclusivity would have warranted improvement. It would be beneficial to continue to gather stories, using the same broad prompts as MtM used this year, from groups, communities and areas of Wales that were less well represented in this year's data.

20.3. This would generate useful data in relation to areas that were missing this year, and start to build a year-on-year sample that would support the monitoring of progress, and the ongoing understanding of people's experiences. From the current findings, two topics stand out as needing more specific work to be undertaken:

- Providing information
- Supporting carers.

### Providing Information

20.4. The narratives reveal numerous experiences where people have not been given information, where information is not useful or where it is inaccessible. The critical role that information plays in preventing people's circumstances from deteriorating and enabling them to plan effectively, suggests that these missed opportunities may be negatively contributing to wider issues in the social care sector.

20.5. Of the recommendations made by the Jurors one is specifically about providing good information, and two-thirds of them relate to information and/or would involve the provision of information. Talking to people will identify the factors that contribute to information being useful, well-timed and accessible and so enable social care providers to improve what is available.

## Supporting Carers

- 20.6. The experiences of carers that were submitted to the project were mostly negative and reveal how isolated and unsupported many feel. Understanding more about the experiences of carers is vital and urgent. Work needs to be undertaken to expand the issues already identified and look, on a much bigger scale, at carers' assessments, respite services and other provision intended to support carers.
- 20.7. Current indications are that these forms of provision could function more successfully and provide higher levels of support. Gathering more stories will enable these issues to be explored thoroughly, facilitating a deeper understanding of people's perspectives and ways services could be delivered more effectively.

## Perspectives of Social Care Providers and Staff

- 20.8. Much that has been revealed by people's experiences of social care needs to be explored from the perspective of social care professionals to better understand the factors that contribute to people's experiences, both negative and positive.
- 20.9. The constraints that social care staff work within, the policies and processes that govern the sector and cultural norms will affect how a service is provided and what any one staff member feels able to do. Conducting research with the work force would reveal the pressure points that contribute to the gaps between what social care should be providing and what it is providing.
- 20.10. Significantly, that information would clarify the reasons for many of the concerns that were revealed in the stories that relate to the themes of People and Well-being and Voice and Control. Understanding those reasons would enable recommendations to be identified that would improve service delivery in the social care sector.
- 20.11. Talking to social care professionals about their reasons for entering the sector, their expectations and ambitions, examining the opportunities for professional development, as well as exploring the circumstances under which people are expected to undertake their role, will build a more complete picture of the staffing challenges within social care, and identify areas to be addressed.
- 20.12. Facilitating the social care work force to share their perspectives on their role and the activities associated with it would also illuminate why co-production and more co-productive approaches are sometimes missing. At the same time, these discussions will generate examples of best practice and the approaches that are needed to facilitate it.

- 20.13. Information and the experiences of carers also need to be examined from the perspective of the work force. By understanding the processes by which information is produced and shared opportunities to enhance them will emerge.
- 20.14. Finally, the experiences of carers are informed, in large part by the processes and attitudes within social care that govern how support mechanisms are offered and delivered. Examining both sides at once will create a clear picture of what needs to be improved and how best this can be done.



## PART G – THANKS AND ACKNOWLEDGEMENTS

### 21. Thanks, and Acknowledgements

21.1. Measuring the Mountain would not have been possible without the incredible contributions made by people in Wales. The 473 stories are a pivotal starting point in understanding people's experiences of social care, and in supporting the social care sector to flourish.

21.2. MtM would like to thank everyone who submitted stories to the project, everyone who supported others to do so, and all the organisations that supported and promoted the project throughout 2018.

21.3. MtM would also like to thank everyone who participated in, and supported the Citizens' Jury: special thanks to the Witnesses, the Facilitator and Observers, and especially to the Jurors, without whom the event could not have taken place.

21.4. MtM was made possible by the guidance and support of the Steering Group:

- Neil Wooding, chair Ministry of Justice
- Rachel Iredale, vice-chair University of South Wales
- Rich Williams, secretariat Office for National Statistics
- Sue Evans Social Care Wales
- Simon James Interlink
- Adrian Roper Cartrefi Cymru Co-operative
- Catriona Williams Children in Wales
- Sara Woollatt Good Practice Wales, Wales Audit Office
- Emma Sullivan Children in Wales
- Beth Smith Interlink
- David Williams Greater Gwent Partnership
- Nick Andrews University of Swansea
- Alwyn Jones Anglesey County Council
- Wayne Jepson Public Health Wales
- Maria Gallagher Public Health Wales
- Owain Williams Tempo
- Ruth Nortey Disability Wales

21.5. This report was written by Katie Cooke (Project Manager), Dr Rachel Iredale (Co-Chair), Rich Williams (Secretariat) and Dr Neil Wooding (Chair) of Measuring the Mountain, March 2019.

## ANNEX 1 – SenseMaker Framework

### Measuring the Mountain - understanding experiences of care

#### Consent

I confirm that I understand the information on this sheet and agree to take part in this project. I understand that I have the right to withdraw from the project. If I later decide to have my data removed or if I have any concerns, I will contact: BSmith@interlinkrct.org.uk

All information is handled and stored in accordance with the General Data Protection Regulation (GDPR 2018)

If you agree to take part please tick the appropriate box:

I understand that you may publicly share my story as part of Measuring the Mountain, but my story will be anonymous.

I understand that you will not share my story publicly, but you will use the data from the questions I answer, as part of Measuring the Mountain.

First 4 characters of post-code

**1. What experience of social care have you had in the last 12 months? This could have been advice, care, or support for you, or someone you know. Please tell us about an experience that stands out to you.**

**2. Please give your experience a title**

**3. Which best describes the story you have just told? Please mark one option.**

- My story is about care or support I have received
- My story is about being a carer
- This story is about someone else's experience

**4. What setting, service, or provider does your experience most relate to? (Mark all that apply)**

- |  |   |  |
|--|---|--|
| Information and advice                       | Help in your home—all the time you are there (aka supported living) | Day centre   |
| Advocacy                                     | Community support and activities                                    | Adult family placement                                   |
| Support for carers                           | Financial support   | Child family placement                                   |
| Equipment or home adaptations                | Social worker   | Long-term residential care                               |
| Help in your home—occasional (aka home care) |   | Short-term residential care or other type of short break |

Other:

I don't know

Please put a mark in the triangle in the position that best describes the experience you just shared.

**5. Reflecting on the support I received...**



**6. Reflecting on the support I received...**

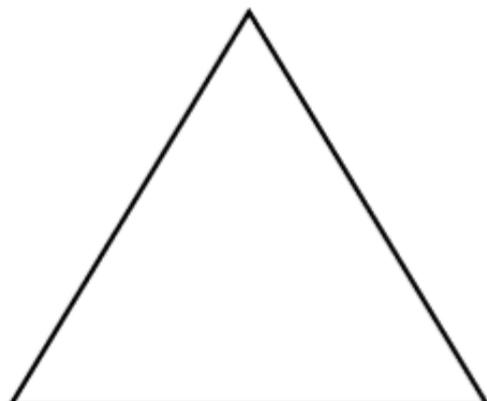


**7. In the experience you have just told us about, who influenced what happened?**



**8. Thinking about the advice or information I received...**

It was easy to understand



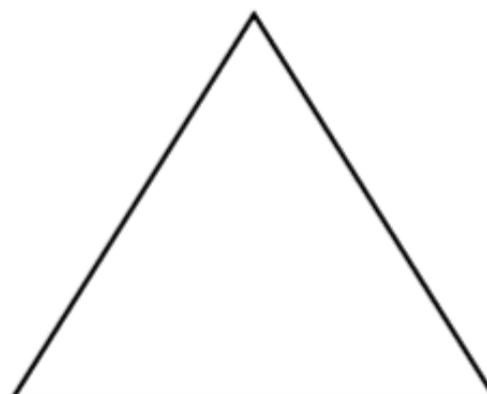
I got it when I needed it

It was useful to me

None of these

**9. The social care staff who provided support cared about...**

The little things that mattered to me personally



My rights and dignity

My health and safety

None of these

Please place a mark on the bar that best describes the experience you have just shared.

**10. The information I received allowed me to make the best decisions**

I didn't receive any information that was useful to me



I received too much information, I was overwhelmed

Too hard to say

**11. I was able to discuss what mattered to me with social care staff**

They didn't care about what I had to say



They asked too many questions, I wish they'd just got on with it

Too hard to say

**12. Social care staff acted upon those discussions**

They went against my opinions and wishes



They did not challenge me, even when I may have been wrong

Too hard to say

13. The way social care is delivered changed in 2016. Do you think this has had any effect on your experiences? Since 2016 things are:

Better      No change      Worse      I don't know

13b. If you have noticed any change, what has changed?

14. Do you think that other people would have had a similar experience to what you have described in your story?

No other person  
Some people  
Lots of people  
All people

15. How do you feel about your story?

Very positive  
Positive  
Neutral  
Negative  
Very negative

16. Who needs to hear what you have said?

Just me  
Other members of the public  
Social care staff  
Managers of organisations providing social care  
Government/politicians  
Other

17. What is your sex?

Male  
Female  
Other  
Prefer not to say

18. How old are you?

Under 16  
16—17  
18—24  
25—34  
35—49  
50—65  
Over 65  
Prefer not to say

19. What is your ethnicity?

White British/ Welsh/ English/ Scottish/ Northern Ireland  
Irish  
Gypsy or Irish Traveller  
Any other White background  
Mixed/Multiple ethnic background  
Indian  
Pakistani  
Bangladeshi

Chinese  
Any other Asian background  
African  
Caribbean  
Any other Black/African/ Caribbean background  
Arab  
Any other ethnic group  
Prefer not to say

Do you have any further comments?

This questionnaire was completed by:

Myself  
A Listener

If collected by a Listener please enter your ID number and/or organisation's ref below:

## Citizens' Jury - Liberty Stadium, Swansea, September 2018

Monday 24			Tuesday 25			Wednesday 26		
<b>09.15 arrival</b>	<b>Dr Neil Wooding</b> , Chair of Measuring the Mountain's Steering Group	<b>Geraint Jenkins</b> , Assistant Director, Catreif Cymru	<b>Adele Gilmour</b> , Information and Support Manager, MS Society Cymru					
<b>09.45</b>	<b>Albert Heaney</b> , Director of Social Services and Integration, Welsh Government	<b>Julie Boothroyd</b> , Chief Officer for Social Care, Safeguarding and Health, Monmouthshire County Council	<b>Nick French</b> , Chief Executive, Innovate Trust	<b>Marisa Moon</b> , Assistant Director, Barnardo's Cymru				
	<b>Mark Llewellyn</b> , Professor of Health and Care Policy, University of South Wales							
<b>11.00</b>	<b>BREAK</b>	<b>BREAK</b>	<b>BREAK</b>					
<b>11.15</b>	<b>Sheila Lyons</b> , Improvement and Development Manager, Social Care Wales	<b>Changing needs, changing services</b> – service user and carer perspectives	<b>Meilys Smith</b> , Senior Transformation Manager, Gwynedd County Council	<b>Joanne Bartlett</b> , Cooperative Development Advisor, Wales Co-operative Centre	<b>Niki Williams</b> , Manager, Hengoed Park Care			
	<b>Jenny Williams</b> , Strategic Director of Social Care and Education, Conwy & President of Association of Directors of Social Services							
<b>12.30</b>	Jury discussion and deliberation.	Jury discussion and deliberation.	Jury discussion and deliberation.					
<b>13.00</b>	<b>LUNCH</b>	<b>LUNCH</b>	<b>LUNCH</b>					
<b>13.30</b>	<b>Finance, integration and accessibility</b> – service user and carer perspectives	<b>Sally Jenkins</b> , Head of Children's and Young People Services, Newport City Council	<b>Alex Williams</b> , Head of Adult Services, Swansea Council	<b>Networks, support and independent living</b> – service user and carer perspectives				
		<b>Dave Street</b> , Corporate Director Social Services & Housing, Caerphilly County Borough Council						
<b>14.30</b>	Jury discussion and deliberation.	Jury discussion and deliberation.	Jury discussion and deliberation.					

## ANNEX 2 – Citizens' Jury Programme

