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Expectations and Experiences

Service User and Carer perspectives on the Social Services and Well-being (Wales) Act

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Evaluation of the Social Services and Well-being (Wales) Act 2014

Expectations and Experiences

Service User and Carer perspectives on the Social Services and Well-being (Wales) Act

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The full report from which this document is drawn can be found here:

[Evaluation of the Social Services and Well-being \(Wales\) Act 2014: Expectations and Experiences](#)

Views expressed in this report are those of the researchers and not necessarily those of the Welsh Government

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Glossary

Acronym/Key word	Definition
Advocacy / advocate	Advocacy services can help people to access information and services, get involved in decisions about their lives, explore choices and options, and express their wishes and needs.
Assessments	Assessments are undertaken with individuals to focus on what the individual needs and try to meet those needs, and carers to identify the support they need. The Act states a local authority must offer an assessment to any adult, child, and carer where they may have needs for care and support.
BSL	British Sign Language
CAMHS	Child and Adolescent Mental Health Services
Co-Production	The Act aims for people to be more involved in the design and provision of their care and support. It means organisations and professionals working with them and their family, friends and carers so their care and support is the best it can be.
Direct Payments	Direct Payments enable individuals and/or their carers assessed as having eligible social care needs to source care that is tailored to their needs, rather than using existing statutory providers. They are intended to provide greater flexibility, independence, and choice and control over the support people receive.
IMPACT	Independent evaluation of the <u>Implementation of the Social Services and Well-being Act</u>
LAs	Local Authorities
Multi-Agency working	The Act aims to strengthen joint working between care and support organisations to make sure the right types of support and services are available in local communities to meet people's needs.
P-FE	Principles-Focused Evaluation
Prevention and Early Intervention	The Act aims to ensure that people can ask for the help they need when they need it to prevent their own situation from getting worse, and carers can access support to assist them in their caring roles and maintain their own well-being.
Sensory loss	Sensory loss is an umbrella term to describe the loss of the distance senses i.e. sight and hearing. There are four types of sensory loss; hearing, visual, deafblind, deaf British Sign Language (BSL) user.
SERG	Study Expert Reference Group
Voice and Control	Voice and control aims to put the individual and their needs at the centre of their care and support, using their 'voice and control' over the outcomes that can help them achieve well-being and the things that matter most to them.
Well-being	The Act aims for people to have well-being in every part of their lives. Well-being is more than being healthy. It is about being safe and happy, having choice and getting the right support, being part of a strong community, having friends and relationships that are good for you, and having hobbies, work or learning.
'What Matters' conversation	'What Matters' conversations are a way for professionals to understand people's situation, their current well-being, and what can be done to support them. It is an equal conversation and is important to help ensure the voice of the individual or carer is heard and 'what matters' to them.
WIHSC	Welsh Institute for Health and Social Care

1. Introduction and Background

- 1.1 The Welsh Government commissioned a partnership of academics across four universities in Wales and expert advisers to deliver the evaluation of the *Social Services and Well-being (Wales) Act 2014* (hereafter referred to as ‘the Act’). Led by Professor Mark Llewellyn, Director of the Welsh Institute for Health and Social Care (WIHSC) at the University of South Wales alongside Professor Fiona Verity, Professor of Social Work and Social Care, Swansea University, the partnership also includes colleagues from Bangor University and Cardiff Metropolitan University. PRIME Centre Wales and the [Study Expert Reference Group](#) (SERG)³ with its three citizen co-chairs support the evaluation.
- 1.2 The Act sets out the Welsh Government vision to produce ‘transformative changes’ in social service policy, regulation and delivery arrangements across Wales. It has 11 parts and is informed by five principles that set out a vision to produce transformative changes in public policy, regulations and service delivery. Aligned to it are structures, processes and a series of Codes of Practice.

Study activities, outputs and findings to date

- 1.3 The independent national evaluation, referred to as the [IMPACT study](#),⁴ has been running since November 2018.
- 1.4 The evaluation examines the implementation and outcomes of the Act through its five principles (and the financial implications of each). These are being evaluated through a consideration of how the Act has impacted on five domains, and is informed by Michael Patton’s (2018) Principles-Focused Evaluation (P-FE) approach which we are using as the framework for the study.⁵
- 1.5 The domains are where the principles of the Act meet the people or organisations for whom the Act should be having an impact – for individuals in need of care and support, for their carers and family members, for the communities in which they live,

³ For more on the SERG, see: [Study Expert Reference Group | University of South Wales](#)

⁴ A bilingual introductory film explaining the structure of the study can be found here: [Ffilm gwerthuso'r Ddeddf / Act evaluation film – WIHSC - YouTube](#)

⁵ For more on P-FE see paragraphs 1.22-1.25 below, and the section on ‘Approach’ in Chapter 2.

for the workforce that supports them, and for the organisations who have responsibilities and duties to discharge as outlined by the Act and associated Codes of Practice:

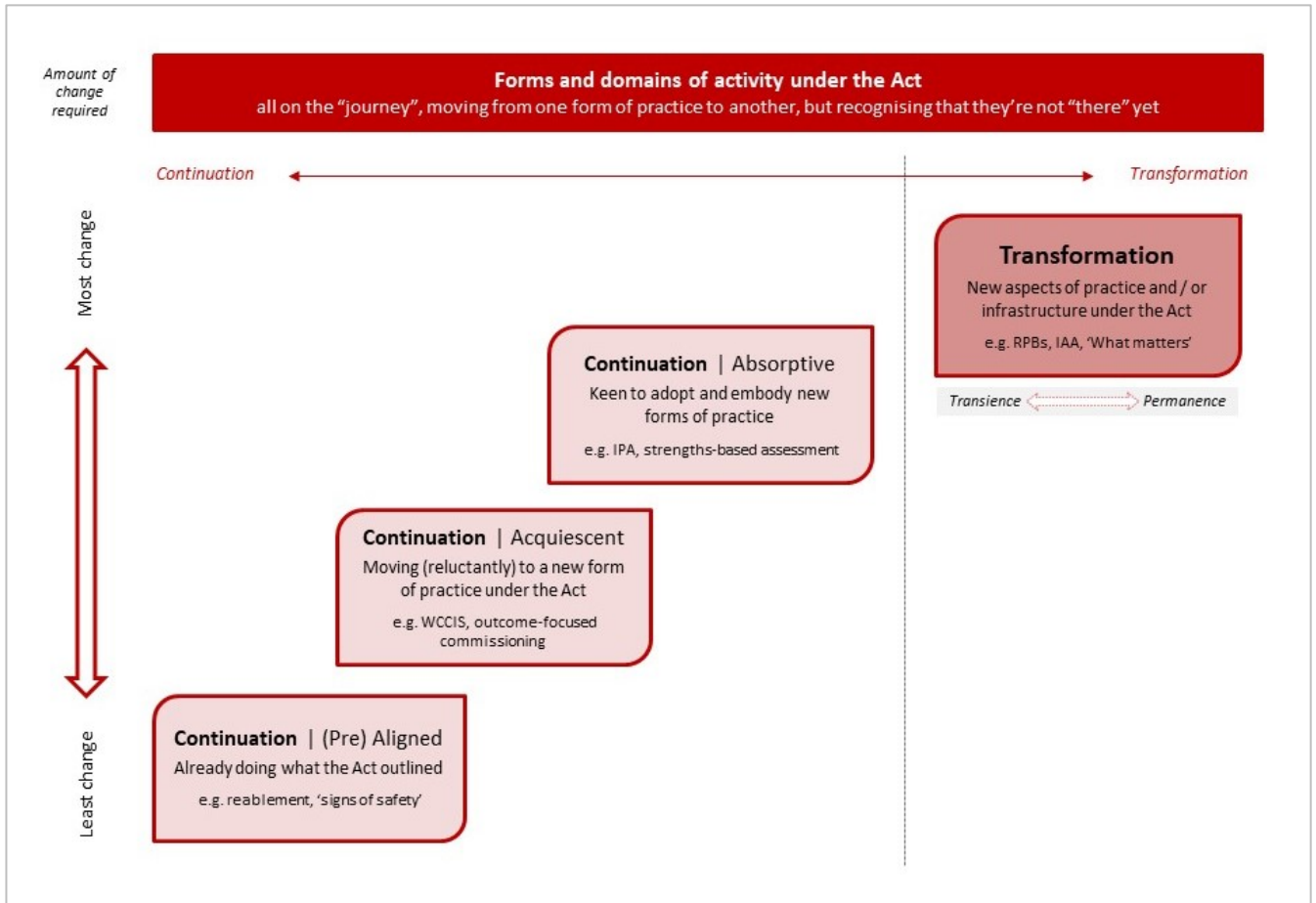
Table 1.1: Five principles of the Act, and the five domains of the study

Principles	Domains
- Voice and control	- Citizens
- Well-being	- Families and Carers
- Co-production	- Communities
- Multi-agency working	- Workforce
- Prevention and early intervention	- Organisations

- 1.6 During the first three years of the study, the team have produced three principal outputs:
1. [Framework for Change](#) (published in September 2019) – in effect the ‘theory of change’ for the implementation of the Act, describing the ways in which the legislation was designed to achieve its desired outcome;
 2. [Literature Review](#) (published in September 2020) – a detailed consideration of the published literature organised around the five principles of the Act; and
 3. [Process Evaluation](#) (published January 2021) – an extensive fieldwork exercise to gather data on the workforce perspective on the implementation of the Act.
- 1.7 The Process Evaluation is the companion piece to this report and its corollary in many ways – this report provides the service user and carer perspectives on the evidence provided by the workforce.
- 1.8 It is worth noting that the Process Evaluation (data for which were gathered immediately prior to the COVID-19 pandemic in early 2020) emphasised the incomplete ‘journey’ that the workforce perceived towards the full implementation and realisation of the underlying aims of the Act.
- 1.9 The evidence from the workforce was complex, with a degree of internal tension in many of the findings presented in that report. In response to that, Figure 1.1 (below) was produced to try and rationalise the complexity we saw. It offered a

conceptualisation of the feedback received into two principal domains: a transformation modality, and a continuation modality (which has three forms itself).

Figure 1.1: Continuation and transformation forms of practice in response to the Act's implementation



1.10 In Figure 1.1, change is taking place in two ways. The first is within the forms of activity and practice that 'continue', where things to a greater or lesser extent had already been established prior to the Act's implementation. The second concerns forms of practice that in order to meet the duties and requirements of the Act, required an element of 'transformation'. It suggests that due to a range of factors, including the differential starting points of all of the localities in Wales, four different forms of practice have been embodied which have required different amounts of change to realise the ambition of the Act:

- 'Continuation | (Pre) Aligned' encapsulates the views of those professing that they were already doing what the Act outlined ahead of implementation;

- ‘Continuation | Acquiescent’ describes those (reluctantly) moving to a new form of practice under the Act;
- ‘Continuation | Absorptive’ reflects continuity with extant practice simultaneous with those keen to adopt new forms of practice; and
- ‘Transformation’ presupposes the greatest amount of change, reflecting new aspects of practice or infrastructure under the Act.

1.11 It was also clear from the Process Evaluation that the Act has legitimised change. It has been a catalysing force in the development of social services, and local authorities’ relationships with key partners in health, the voluntary sector and the independent sector. The Process Evaluation report pointed to considerable evidence of the difference made, but also to the difference still to be made.

Scope and remit

1.12 In relation to the evidence previously gathered, it is important to reflect on the scope and remit for this work, being clear about what this report is, but also what it is not. As the title suggests, this report is solely concerned with reporting service user and carer perspectives on the Act, and in particular their expectations and experiences of their care and support under the auspices of the Act since April 2016.

1.13 The evidence provided in this report does not claim to be ‘representative’ in any quantitative methodological sense of the word. Whilst we were privileged to hear from 170 participants, this is a small proportion of the total number of service users and unpaid carers in Wales. Our hope is that those reading this report will value how we have presented and communicated their perspectives. They are not, however, the totality of experiences of service users and carers in Wales, and it would not be sensible to think that they are.

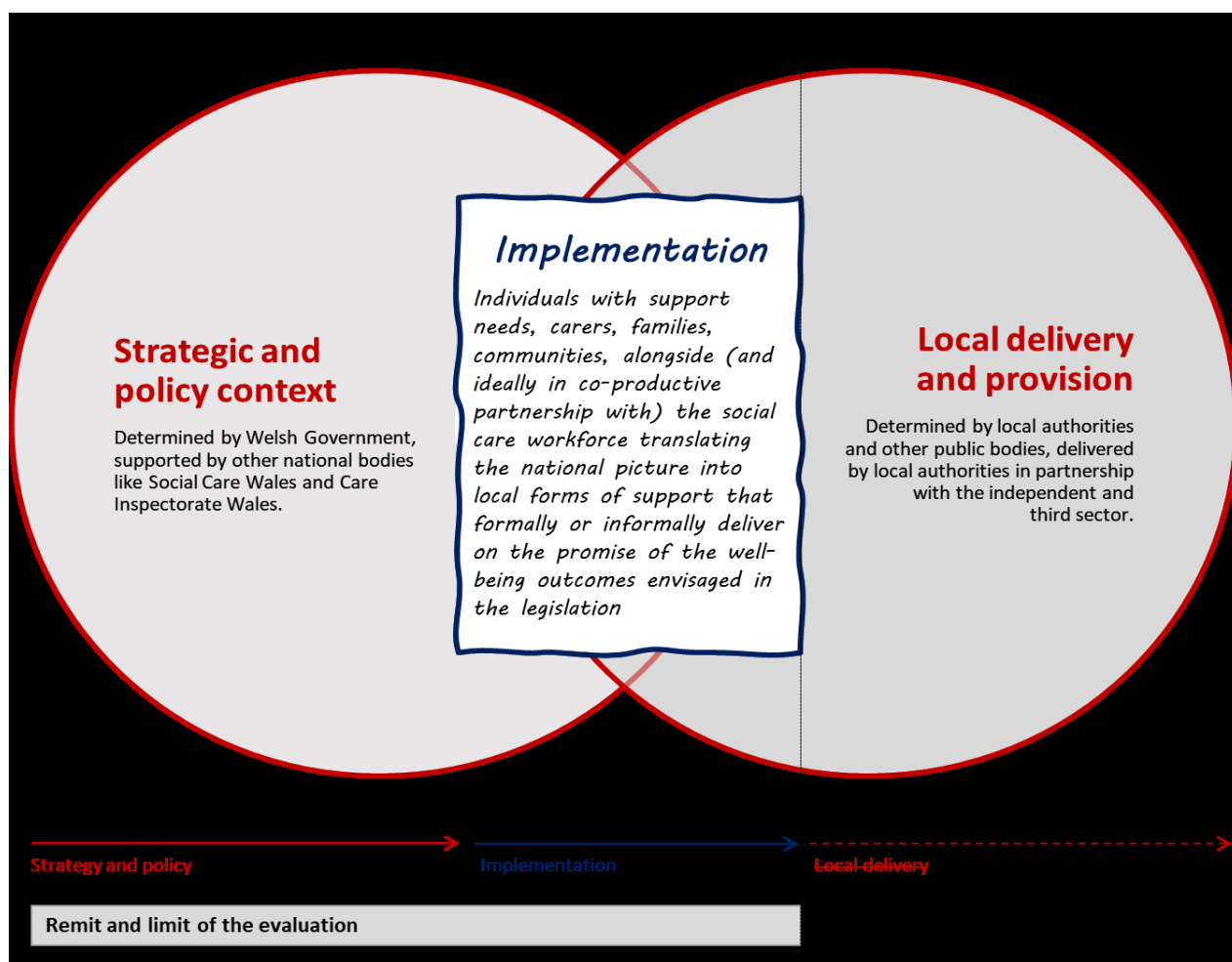
1.14 However, we did not set out to do anything other than gather detailed evidence on the expectations and experiences of the people that are on the face of the Act – those that need care and support and their carers. The evidence provided here is personal, it is local, and it speaks to the circumstances and challenges of their lives.

1.15 Our task in this report is not to evaluate the impact of the way in which local services are delivered on the experiences of service users and carers *per se*, but it

is to use those experiences to tell us something about the difference (or otherwise) that the Act has made to them. These are subtle but important distinctions.

1.16 To that end, Figure 1.2 provides a representation of the remit and limit of our study:

Figure 1.2: Remit and limit of the IMPACT evaluation study



1.17 This diagram is deliberately not written from the top down. Policy making in Wales is much more collaborative than such a model would imply, hence the three domains within the diagram have been arranged side by side. The vertical line represents the remit and limit of our work, highlighting the previous point – that this is not a ‘super-inspection’ of local delivery of services. That is a role for others.

1.18 We do however seek to understand the ‘local delivery and provision’ domain only insofar as it tells us something about the other two domains within Figure 1.2: the strategic and policy context, intersected by the ‘fuzzy frontiers’ of implementation.

- 1.19 The implementation domain is consciously represented between strategy and delivery, with ‘unsteady’ and ‘wobbly’ lines and font indicating its moving, fluctuating and changing shape. Implementation is a fluid process that does not remain static for long, and constantly forms and re-forms.
- 1.20 It is important to note that this is not the final report of this study which will consider the overall difference the Act has made – that document, which will be produced in Autumn 2022 will be the Impact Evaluation.
- 1.21 This report considers three specific issues for service users and carers that were raised in the original Welsh Government project specification for the evaluation – namely:
- to what extent they feel that services worked in partnership with each other, were fully integrated and were streamlined to ensure the best possible care was provided to them (covered in Chapter 4);
 - to what extent they feel involved in decisions about their care and support (covered in Chapter 5); and
 - their quality of life and their well-being (covered in Chapter 6).⁶
- 1.22 Our evaluation study as a whole – and this report in particular – represents an independent and objective assessment of the implementation of the Act and the way in which it has impacted the well-being of people who need care and support and their carers. In order to bring this about, we draw upon the approach espoused by Michael Patton (2018) in his ‘Principles-Focused Evaluation’ (P-FE) framework which we are using as the theoretical and conceptual underpinning of our study. Further detail on P-FE is provided in Chapter 2. Here though it is useful to reflect on Patton’s three core questions (2018, pp.27-29):
1. To what extent have meaningful and evaluable principles been articulated?

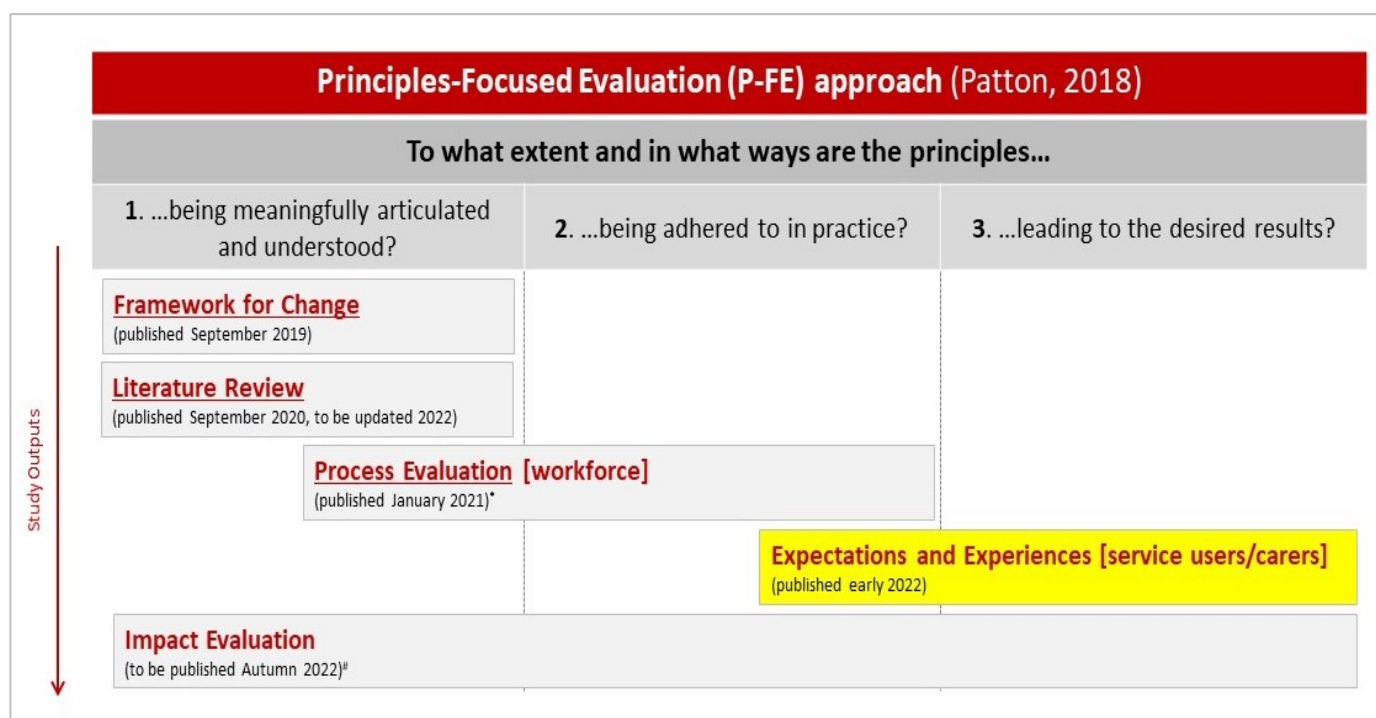
⁶ Given our previous Process Evaluation report wherein we focused extensively on the workforce perspective of the implementation of the Act, it was agreed with Welsh Government officials that this report would focus exclusively on the service user, carer and family perspective. In addition, the final phase of our data collection (Winter/Spring 2022) will revisit the [Process Evaluation](#) phase where we will gather data, among other things, on the impacts of COVID-19. It is also important to note that we do not imply any causal links between the ‘activities’ (or process outcomes) and short-term outcomes for people. The circumstances that the data was drawn from are far too complex to make such ‘straight-line’ assumptions of causality.

2. If principles have been articulated, to what extent and in what ways are they being adhered to in practice?
3. If adhered to, to what extent and in what ways are the principles leading to the desired results?

1.23 There is a clear connection between Patton’s questions and the areas for inquiry as described in paragraph 1.21. The expectations and experiences of the service users and carers that we have engaged with – in respect of their experiences of services working effectively alongside one another, their experience of feeling involved, and their quality of life and well-being – are the means through which we are able to gather evidence to allow us to answer Patton’s questions.

1.24 In order to provide some clarity on this, we have produced Figure 1.3:

Figure 1.3: Principles-Focused Evaluation questions and study outputs



* The study team will ‘Revisit’ the localities that took part in the original Process Evaluation during Spring 2022, to consider the post COVID-19 impacts on the workforce implementation of the Act.

The Impact Evaluation (Final Report) will take account of all of the publications on this diagram, plus seven working papers across all of the themes and principles undertaken by the study team.

1.25 In Figure 1.3 we indicate the ways in which the various study outputs – including this one – map onto Patton’s three key questions. It is useful to note that this report (the yellow block in the diagram) covers Q2 and Q3 of Patton’s framework:

Key contexts

- 1.26 It is also important to consider two contexts which are key to understanding the point in time at which this report was written.

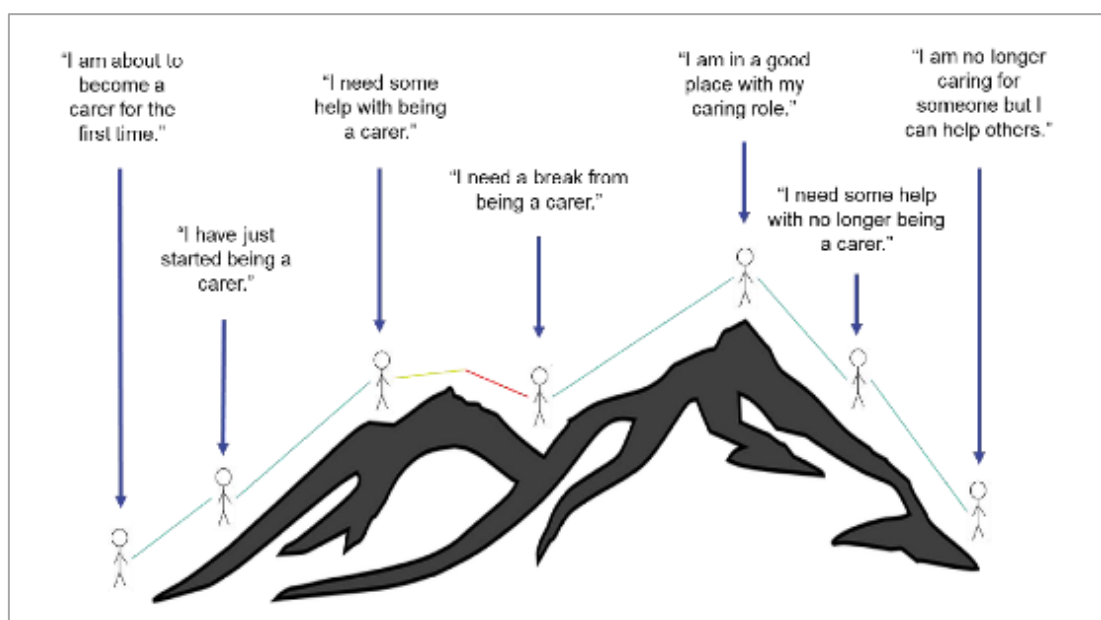
COVID-19

- 1.27 The fieldwork was undertaken through the pandemic, 14-20 months after the initial lockdown (between May and October 2021), and sufficiently long enough after the initial arrival of COVID-19 for participants to be significantly impacted by that experience.
- 1.28 It is evident through their responses that the pandemic exposed some of the underlying frailties that existed in the system, but it also exposed the significant amount of determination and resilience present within individuals and in families to try to cope at a most challenging time.
- 1.29 It is important to reflect on the nature and tone of the discussions and conversations that we held. Many of the people who engaged with us found the experience a very emotional one, speaking from the heart about the difficulties that COVID-19 had placed upon them over and above the everyday, long-term challenges they have faced. These were difficult things to hear, but they were much more difficult to experience and to say, and we are very grateful to those people who took time to share their experiences.
- 1.30 One of the implications of this is that we need to reflect on the extent to which participants were able to dissociate their experiences of care and support under the Act as a whole from the specific and powerful experiences that many of them had under the pandemic. This is too complex an issue to make simplistic statements about, but in many ways our qualitative approach provides us with insights that are useful and valid without the need to consider formal 'controls' on the 'noise' in the data that a more positivist approach would have had to address.
- 1.31 That having been said, we have been mindful to refer to COVID-19 in the Chapters below wherever it was a major factor in people's experience, and have been careful when forming conclusions, that the experiences associated with COVID-19 are noted and referenced.

Pressure within the social services system

- 1.32 It is also important to note that the social services system (not least because of additional challenges brought about by COVID-19, but also associated with workforce challenges, some of which are linked to Brexit) is a system under considerable pressure, a situation it has been in for some while.
- 1.33 Respondents reflected on financial pressures impacting social services, and workforce issues such as the pressure on social workers, care workers and support workers. These reflections are anchored in examples where problems and challenges in the broader system had consequences for the day-to-day experiences of care and support.
- 1.34 To complement this system perspective, Figure 1.4 below (from the 2021 West Glamorgan Regional Partnership Regional Carers Strategy) is instructive in providing a glimpse into the world of service users and their carers and how their pressures mirror those within the system as a whole:

Figure 1.4: A Carer's Journey



- 1.35 The imagery of mountain climbing is apt – the peaks and valleys provide a useful way of thinking about the experiences that people have each day, and which are reflected in the evidence of this report.

1.36 It is certainly the case that the pressure within the social service system has served to deepen those valleys and elevate the peaks, so that traversing from one to another is even more challenging than it once was. It is also interesting that this representation uses the same central metaphor – that of being on a ‘journey’ – that was in evidence from the workforce perspective on the implementation of the Act in the Process Evaluation.

Towards the final report

1.37 The study is not yet complete. This is the latest in a series of outputs which continue to build a picture of the extent to which the Act is having the ‘desired results’, to use Patton’s phrase.

1.38 The findings in this report are the perspectives of service users and carers – the document does not include perspectives from the social care workforce, partner organisations, local authorities, or other stakeholders. Our [Process Evaluation](#) report is the source for that evidence, and this report should be read in conjunction with that one.⁷

1.39 The analysis undertaken within the context of this report has consciously tried to do no more than organise and structure the dataset against key themes, and allow the voices of the participants to be heard. By the time the study finishes in Autumn 2022, these detailed qualitative perspectives will be triangulated with a number of data sources and evidence, including:

- a time-series analysis of nationally collected well-being data;
 - narratives on the costs associated with implementation of the Act;
 - additional reports picking up on issues pertaining specifically to the five principles underpinning the Act;
 - an update to the previously published literature review;
 - a review of evidence gathered from a range of secondary data sources (largely from stakeholders in Wales) to help provide context for our analysis;
- and

⁷ It is useful to know that in early 2022, we will be re-engaging the four localities that we worked with to undertake the Process Evaluation to update our work, and to take account of the legacy of COVID-19 on their journey towards the full implementation of the Act.

- all of the other data that has hitherto been collected and analysed.

- 1.40 Ahead of that final report stage, all of the people who have participated in the study – whether service user, carer, workforce or stakeholder – will be invited to hear from us in Spring 2022. We will be running a series of data validation workshops which will allow us to sense check the emerging findings with participants and to gauge their views on the important messages emanating from the study before moving towards our overall conclusions and recommendations.
- 1.41 Therefore, by the time we conclude this study in Autumn 2022, we will be able to be more definitive in our conclusions about the strategic and policy context, the process of implementation, and the experience of service users and carers, and what this means for the Welsh Government and all of those with responsibility for social services in Wales.
- 1.42 That is to follow, and by the time we reach the end of the study we will address the central aim of the Impact Evaluation which is to understand what impact the legislation has had, primarily, on those who receive care and support and carers who receive support but also consider the impact the Act has had on local authorities, practitioners, health organisations, third sector organisations and other key partners.
- 1.43 We are not yet at that point, and this report as a stand-alone document does not allow us to draw simplistic conclusions about the overall impact of the Act – but it was never going to be able to do that at this stage. However, it does provide a set of very clear signals as to where the expectations of services users and carers are being met in a way that is commensurate with the aims of the Act, and importantly where their experiences fall short of the overall aspirations of the legislation.
- 1.44 In the following pages, Chapter 2 outlines the approach and methodology. Chapters 3, 4 and 5 present the findings, the first of which focuses on how service users and carers have experienced the provision of social services. This is followed by two chapters picking up on two of the key principles of the Act – one on experiences of multi-agency working, and a second on voice and control. Chapter 6 provides a

discussion on the unifying principle of the Act – well-being. Chapter 7 draws conclusions from the evidence presented in the previous chapters.

2. Approach and Methodology

Approach – Principles-Focused Evaluation

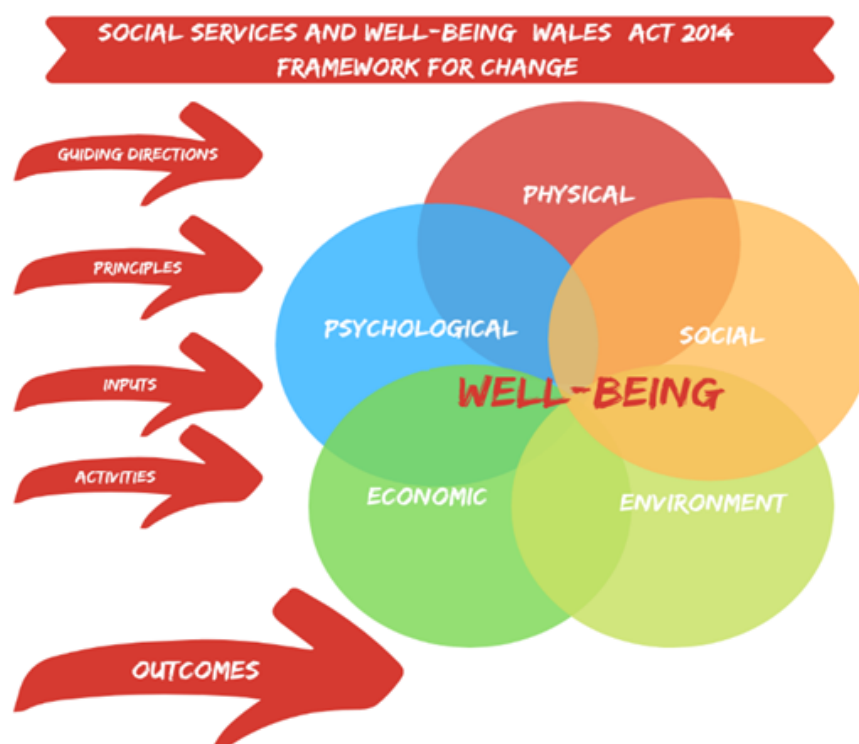
- 2.1 The study follows Michael Patton's *Principles-Focused Evaluation* (P-FE),⁸ an approach for the evaluation of principle-based initiatives in environments he describes as becoming '...ever more complex' (2018, p.4). P-FE is informed by understandings from complex adaptive systems theories and developmental evaluation with an eye to '...addressing complex problems in a rapidly changing and turbulent world' (2018, p.viii). Accordingly, the P-FE approach is sensitive to the dynamic and complex environments in which an intervention occurs.
- 2.2 What is being evaluated in P-FE are the principles used in an initiative, and how they guide actions and adaptations in changing environments. Patton (2018, p.12) writes that principles are the '...rudders for navigating complex dynamic systems'.
- 2.3 In practical terms, P-FE offers a scaffolding to traverse and connect evaluation data on processes, utility, and impact of principles-based developments. Patton writes:
- ...principles-focused evaluations can evaluate processes of implementing principles, outcomes associated with principles, longer-term and broader impacts that result from principles-driven programming, and innovative approaches to principles adaptation.*
- 2.4 There are three central questions in a P-FE evaluation (2018, pp.27-29):
1. To what extent have meaningful and evaluable principles been articulated?
 2. If principles have been articulated, to what extent and in what ways are they being adhered to in practice?
 3. If adhered to, to what extent and in what ways are the principles leading to the desired results?
- 2.5 A tenet of P-FE is the use of evaluation for learning and improvement. The rationale for adopting the P-FE approach for this revolves around four factors, each of which say something about the complexity of what is being evaluated (i.e. the Act) and the context of its implementation.

⁸Patton, M. Q. (2018). *Principles-Focused Evaluation - The GUIDE*. New York: Guilford Press

1. The Act is a multifaceted piece of public policy, covering all areas of social services, which sets out key principles

- 2.6 The Act is a principle-based public policy. What is being evaluated is the implementation and the associated impact of the Act, a consolidated legislative framework for the social services functions of local authorities and partners in Wales, repealing previous Government legislation. Codes of Practices are established under Section 145 of the Act.
- 2.7 Together with legal duties, there is explicit pronouncement of key and interconnected principles to inform social service provision; ‘well-being’, ‘voice and control’, ‘co-production’, ‘prevention’, and ‘multi-agency working’. This emphasis enables social services to act to deliver on things that must be done, framed by values and ways of working which follow these principles. The Act has also been introduced in parallel with other significant Welsh legislation, for example the Well-being of Future Generations (Wales) Act 2015. The purpose, architecture and desired results of the Act is described in the [Framework for Change](#) document, an earlier output of the evaluation – see Figure 2.1.

Figure 2.1: The Framework for Change as envisaged by the Act



- 2.8 The principles of the Act introduce a further modicum of complexity to the implementation process. The [Literature Review](#) prepared for the evaluation, explored the published and grey literature for each of the five principles of the Act. Common to all five discrete reviews is that the principles can be amorphous and slippery with implications for gaining a shared meaning of them, and for how they translate into practice. Following the P-FE approach, exploring how these principles are interpreted and enacted by key actors throughout the social service system can support an understanding of how, and if, the desired results are attained.
- 2.9 For example, the principle of well-being is central to the Act, encompassing the contributions made by social services to the well-being of people, but also going well beyond that to the contributions made by wider societal institutions, the third sector and people themselves, alongside their families, carers, friends and communities. As canvassed in the [Literature Review](#) (Anderson et al, 2020, p. 4⁹) well-being is conceptualised in two ways. ‘Eudemonic Well-being’ includes the components of well-being rooted in human relationships and social life more broadly, and ‘Hedonic Well-being’ relates to ‘...emotional and embodied aspects of well-being, such as pleasure and enjoyment’. Any changes to well-being take a very long time to become visible in population-level data.

2. The Act is being implemented across 22 diverse Welsh local authorities with the third sector, health partners and the independent sector

- 2.10 The Act is being implemented nationally, across Wales’ diverse geographic and socio-economic environments. Organisations with a role in implementation include 22 local authorities, the third sector and independent and health partners, each with distinctive histories, cultures, practices and values.
- 2.11 Differences can be especially pronounced when comparing local authorities across Wales – some are a mix of urban and rural settings and others primarily rural or urban.

⁹Anderson P., Lyttleton-Smith J., Kosnes L., Read S., Blackmore H. and Williams Z (2020). Chapter 2: Well-being literature review. in Llewellyn, M., Verity, F. and Wallace, S (eds). (2020). *Evaluation of the Social Services and Well-being (Wales) Act 2014: Literature Review*. Cardiff. Welsh Government, GSR report number 60/2020.

3. Implementation is occurring within a changing social, demographic and economic context which will impact on the implementation of the Act

- 2.12 One of the hallmarks of P-FE is understanding the contexts in which a principles-focused initiative is being implemented and how adaptation to this context/these contexts is taking place.
- 2.13 The Welsh Government document, *Sustainable Social Services – A Framework for Action* published in 2011, set out the immense challenges for the provision of social services in times of social change. Population trajectories of people living longer, quick paced technological developments, uneven impacts of austerity and poverty, and the pressures on services were all significant in shaping policy.
- 2.14 There are marked inequalities in UK society, with implications for how the wider context is experienced. Public Health Wales identifies that groups more likely to experience poverty are ‘lone parents, minority ethnic groups, families in which there is someone with a disability, and people living in rural and coastal regions’ (Azam et al, 2021, p.11).¹⁰
- 2.15 The devastating impact of the COVID-19 pandemic on people’s health and wellbeing and needs for care and support, further brings into sharp relief the ‘turbulent’ context (Patton, 2018) in which social services are delivered.

4. All of the above have implications for attribution; that is, making a judgement about the outcomes and impact for individuals, carers and communities as a result of the Act

- 2.16 As Patton (2018) writes, in a less complex and simpler initiative or project, there can be higher predictability about the causation chains between an input, output, and an outcome. For instance, a project with a tightly defined population group, fewer elements to the intervention and an environment of more certainty, can allow for evaluation judgements to be drawn in more clear-cut terms. This is not the case with the evaluation of the Act where context matters, as does the interpretation of the principles of the Act.

¹⁰ Azam, S. et al, (2021). *Brexit and Poverty in Wales: A Public Health Lens*, WHO Collaborating Centre on Investment for Health and Well-being, Public Health Wales.

2.17 Mindful of this complexity, the rationale for using a P-FE approach is to ensure that there is an appropriate and robust framework in place within which the primary and secondary data will be analysed. The P-FE approach involves both the collection of evaluation data about the process of implementing principles-focused initiatives, and the results. The expectations and experiences of those who receive care and support, and their carers is a key part of this data collection, and the focus of this report.

Methodology

2.18 In describing the overall methodology for this part of the study, we have sought to provided information on the ethical review and approval processes that were undertaken, a description of the data collection activities, information on data analysis and a reflection on some of the limitations of the method.

Ethics¹¹

2.19 Ethical approval was secured from the University of South Wales Ethics Committee to undertake the data collection with service users and carers as described below. This was processed as a ‘high-risk’ ethics application which acknowledges the potential vulnerability of the study population, and involves a thorough and rigorous review of the application via the ethics panel before recruitment and data collection can commence.

Data collection

2.20 Data collection used a mixed methods approach with three distinct strands: a Wales-wide bilingual on-line questionnaire, qualitative data collection via interviews and focus groups, and a closed Facebook Group.

2.21 The primary philosophy of mixed methods is pragmatism (Johnson et al, 2007),¹² focusing on ‘what works’ through the use of whichever methods are best suited and advocates a more holistic understanding of the topic (Creswell and Poth, 2014).¹³

¹¹ Further detail on the ethics process that was followed can be found in Annex A.

¹² Johnson, R.B, Onwuegbuzie., A.J. and Turner, L.A. (2007). ‘Towards a definition of mixed methods research’, *Journal of Mixed Method Research*, 1(2), pp. 112-133.

¹³ Creswell, J.W. and Poth, C.N. (2014). *Qualitative Inquiry and Research Design: Choosing Among Five Approaches*. 4th edn. London: Sage Publications.

Implementing multiple approaches to data collection ensured prospective participants were able to choose which approach best suited them. For example, the questionnaire and Facebook Group ensured that those seeking to have their views and experiences represented but preferring to do so without speaking directly to the study team directly could still take part.

2.22 Each of the three core data collection elements are detailed below:

Wales-wide bilingual pro-forma

2.23 Four versions of the questionnaire were available: Welsh, English, Welsh Easy-Read, and English Easy-Read. Questionnaires could be accessed online¹⁴ or could be downloaded as a MS Word document and returned via email to the study team.¹⁵ The English-language copy of the questionnaire is available in Annex B.

Qualitative data collection

2.24 Qualitative data collection comprised of a mixture of interviews and focus groups, conducted online (via Microsoft Teams), by telephone, or face-to-face.¹⁶ Interviews and focus groups are particularly useful for greater depth and understanding of participants' experiences around a topic (Creswell and Poth, 2014). Topic guides helped frame questions in an open form (Smith et al, 2009),¹⁷ and were based on the principles of the Act. They were developed in collaboration with the wider study team and the SERG and reviewed/approved by the Welsh Government (see Annex C).

Closed (private) Facebook Group

2.25 A closed Facebook Group was a new approach adopted by the study team following discussion with our SERG co-chairs. The aim was to offer an alternative means for service users and carers to take part in the study and provide an additional source of data that complemented and augmented the other strands.

¹⁴ Using the online survey platform JISC [Online surveys | Jisc](#), which is approved for use by USW.

¹⁵ No hard copies of questionnaires were returned, all were completed online via the JISC survey platform.

¹⁶ Due to ongoing COVID-19 restrictions, the majority of qualitative fieldwork took place online or via telephone.

¹⁷Smith, J.A., Flowers, P. and Larkin, M. (2009) *Interpretive Phenomenological Analysis: theory, method and research*. London: Sage Publications Ltd.

2.26 Social media platforms provide an information-rich opportunity to reach diverse populations (Franz et al, 2019)¹⁸ and increasing numbers of studies have incorporated data from Facebook, and recruited from and included Facebook users as study participants (e.g. Abramson et al, 2015; Kent et al, 2016).^{19,20} Whilst Facebook is emerging as a viable method of reaching populations who may be hesitant to participate in person, limitations such as a lack of internet and/or computer/mobile phone access are barriers to participation (Pederson et al, 2015).²¹ Hence, the Facebook Group was only one of three means through which social care service users and carers could choose to take part.

2.27 Participants requested to join the group, and were approved by the study team subject to confirming their status as a service user and/or carer living in Wales, and agreement with the group rules. A timetable of fortnightly bilingual polls (eight cycles in total) based on the Easy-Read questionnaire, followed by regular reminders were posted to the group. Members responding to polls were issued a follow up question via private Direct Message, which they could choose to reply/not reply to.

Participants and sampling

2.28 Information was sought from the key informants – who in this instance were service users and carers. This is particularly important as Patton (2015)²² argues that when brought together these key informant groups can highlight characteristic and important patterns of data.

2.29 Using purposeful sampling, a technique which involves identifying and selecting individuals or groups of individuals who have in-depth knowledge and/or experience

¹⁸ Franz, D., Marsh, H. E., Chen, J. I., and Teo, A. R. (2019). Using Facebook for Qualitative Research: A Brief Primer. *Journal of Medical Internet Research*, 21(8), e13544. <https://doi.org/10.2196/13544>.

¹⁹ Abramson, K., Keefe, B., and Chou, W.Y. (2015). Communicating about cancer through Facebook: a qualitative analysis of a breast cancer awareness page. *Journal of Health Communication*, 20(2):237-43, doi: 10.1080/10810730.2014.927034.

²⁰ Kent, E.E., Prestin, A., Gaysynsky, A., Galica, K., Rinker, R., Graff, K. and Chou WS. (2016) Obesity is the new major cause of cancer': connections between obesity and cancer on Facebook and Twitter. *Journal of Cancer Education*, 31(3):453–9.

²¹ Pederson, E.R., Helmuth, E.D., Marshall, G.N., Schell, T.L., PunKay, M. and Kurz, J. (2015). Using Facebook to recruit young adult veterans: Online mental health research. *JMIR Research Protocols*. doi: 10.2196/resprot.3996.

²² Patton M.Q. (2015) *Qualitative Research and Evaluation Methods* 4th Ed. Los Angeles: SAGE Publications.

of the phenomenon of interest (Creswell and Plano Clark, 2018),²³ participants were recruited via a range of gatekeeper organisations.²⁴ Primarily these were through organisations that are members of SERG e.g. third sector organisations, local community groups, LAs, and others.

- 2.30 To be eligible to take part in the study, participants had to be a social care service user and/or a carer.²⁵ The minimum age required to take part in qualitative data collection was 11 years old. To take part in the questionnaire or Facebook Group, participants were required to be 16 years and over.
- 2.31 The intention was that the recruited sample would cover service users and carers from a variety of different places in Wales, across a range of ages, living in a variety of different circumstances.²⁶
- 2.32 Several routes to the recruitment of service users and carers (all of which were via gatekeeper organisations) were implemented:
- One-to-one virtual meetings between the study team and gatekeepers and email correspondence to provide information about the study, the ways in which prospective participants could take part, and a request to share information with their networks and members;
 - A request to gatekeepers to share recruitment information posted to social media e.g. WIHSC Twitter and LinkedIn; and
 - Study team members attending organisations virtual events/meetings to share information about the study and the ways to take part.

²³ Creswell, J.W. and Plano Clark, V.L. (2018) *Designing and Conducting Mixed Methods Research*. 3rd edn. Los Angeles: Sage Publications.

²⁴ A gatekeeper is described as someone who controls access to an institution or an organisation such as a school principal, managing director or administrator. Singh, S. and Wassenaar, D. (2016, p.42). Contextualising the role of the gatekeeper in social science research. *South African Journal of Bioethics and Law*, 9(1), 42-46.

²⁵ It is of course possible that in addition to being either a service user or carer, participants could also have a professional role within the social care workforce. Where quotations quotes are used that come from employed care workers or support workers, these are cases either when they were speaking about their caring role or their experience as a service user. In addition, there are a very small number of occasions where a care worker supported a service user to be able to take part in the study.

²⁶ Annex B provides a copy of the questionnaire and Q23 to Q30 within provides an insight into the demographic sampling that we wanted to achieve. Tables 2.1 to 2.4 then indicate the extent to which the range within the sample that was achieved.

- 2.33 Subject to the above-mentioned inclusion criteria, participants chose their preferred method through which to take part. Participants were advised they could have a supporter present at interviews/focus groups, and telephone interviews were offered where online interviews were problematic i.e. connectivity issues.
- 2.34 It is important to note that the data collection took place during the COVID-19 pandemic, between May-September 2021.²⁷ Prior to the pandemic, qualitative data collection had been intended to take place largely face-to-face. However, lockdown restrictions at the time of commencing data collection meant that all face-to-face data collection was suspended and instead moved online or via telephone.
- 2.35 Despite a small number of face-to-face focus groups taking place following a move to Welsh Government 'Level 0' restrictions, the move away from planned face-to-face engagement and data collection may have had implications in accessing and hearing from some care service users and carers.
- 2.36 Throughout the data collection period, the study team engaged with a range of different groups from different parts of social services provision. However, there were also groups, for example Welsh language speakers and care experienced young people, that the study team did not hear from extensively.²⁸
- 2.37 Groups the study team heard from in depth include:
- Older people
 - Carers
 - Black, Asian, and Ethnic Minority community members
 - People living with learning disabilities
 - People living with sensory loss
 - Parent carers

²⁷ Anecdotal evidence from gatekeeper organisations highlighted the issue of potential research burden on prospective participants with the target population receiving high numbers of requests to take part in interviews and surveys over the past 18 months

²⁸ The study team are continuing their engagement with gatekeeper organisations in order to hear from these groups. The team are also collating a range of secondary data and reports from organisations who represent these groups in lieu of primary data to help ensure their perspectives are included. The sources will be triangulated alongside all of the other study data in the final report.

- Young carers/young adult carers

2.38 Gatekeeper organisations were pivotal within the data collection process. The study team are grateful for the support of these organisations for raising awareness of the study through various channels, enabling access, and identifying prospective participants, to help ensure the voices of individuals and carers receiving care and support were heard and included in this report.

Total number of service users and carers engaged

2.39 Table 2.1 (below) provides the total number of social care service users and carers who engaged with the study (n=170).

Table 2.1: Total number of service users and carers engaged

Participant type	Interviews / FGs	Facebook Group	Pro-forma	Total
Service User	33	8	6	47
Carer	42	41	18	101
Both	2	15	0	17
Other	4	0	0	4
No Response	0	0	1	1
Total	81	64	25	170

2.40 Overall, across the data sets, carers were the most frequent type of participant who engaged with the study (n=101), followed by social care service users (n=47) and individuals with a dual role of service user and carer (n=17). 'Other' (n=4) represents individuals from a gatekeeper organisation who provided anecdotal evidence via their experience of working with and supporting a specific service user group.²⁹

2.41 Tables 2.2-2.4 below present the demographic profile of service users and carers who engaged with the study via the qualitative data collection and the questionnaire. Due to the private status of the Facebook group, demographic information was not collected.

²⁹ The study team took advice from the gatekeeper organisation about concerns over sensitivity of material and safeguarding if seeking to speak directly to the service user group.

Table 2.2: Age profile of service users and carers

Age	Interviews and FGs	Pro-forma	Total
<25	6	1	7
26-49	21	7	28
50-64	16	7	23
65-84	17	8	25
85 or older	0	1	1
No response	21	1	22
Total	81	25	106

2.42 The most frequent age profile of individuals who took part in interviews, focus groups, and the questionnaire was 26-49 (n=28), 65-84 (n=25), and 50-64 (n=23). Age groups least heard from were 85 and older (n=1) and 25 or younger (n=7). 22 participants did not provide a response.

2.43 Table 2.3 below shows most participants identified as female (n=77), compared to male (n=27). Two participants did not provide a response.

Table 2.3: Gender profile of service users and carers

Gender	Interviews and FGs	Pro-forma	Total
Male	23	4	27
Female	58	19	77
Non-binary	0	0	0
Prefer not to say	0	0	0
Prefer to self describe	0	0	0
No response	0	2	2
Total	81	25	106

2.44 Table 2.4 below demonstrates representation across all of the regions in Wales.

Table 2.4: Area of residence of service users and carers engaged

Region	Interviews and FGs	Pro-forma	Total
North Wales	10	3	13
Mid Wales	8	2	10
South West Wales	14	2	16
South Central Wales	27	5	32
South East Wales	22	10	32
No response	0	3	3
Total	81	25	106

2.45 The highest number of participant responses were received from South Central Wales and South East Wales (n=32) respectively. Sixteen participants took part from South West Wales, 13 from North Wales, and 10 from Mid Wales. Three participants did not provide a response to their area of residence.

2.46 In terms of identifying the type of respondent in the Chapters that follow, descriptions at the end of each quotation indicate the participant's status (service user, carer, both), the region they are from, their age group³⁰ and gender. As much information as is available for each participant is provided. All names and any other identifying information have been removed for purposes of anonymity and confidentiality.

Data analysis

2.47 Data from all three methods were considered in their entirety. Interviews and focus groups were audio recorded and qualitative data was transcribed verbatim and anonymised. Transcripts were analysed using thematic analysis (TA) (Braun and Clark, 2006).³¹ NVivo 12 was used to organise and manage the data and a

³⁰ 25 years or younger (Young person/Young adult), 26-64 years (Adult), 65 years or older (Older person).

³¹ Braun, V. and Clarke, V. (2006) 'Using thematic analysis in psychology', *Qualitative Research in Psychology*, 3(2), p.77-101

framework of codes was developed. Free text responses from the questionnaire and Facebook Direct Message replies were entered into NVivo 12 and coded against the framework.

- 2.48 Data analysis was an iterative process; using TA, the development of the coding framework was undertaken by the authorial team for this report, and included a series of discussions to review, iterate and refine.
- 2.49 High-level initial findings were shared with the Welsh Government and the SERG in October and November 2021 for feedback and comment ahead of the production of this report.

Limitations

- 2.50 As with any study of this size and complexity, there are limitations to note.
- 2.51 We have limited feedback from those who are older than 85 years. It is not possible to be certain as to why, but gatekeepers noted that it may be linked to the extensive use of IT – the questionnaire was hosted online, and due to restrictions of COVID-19 most of the interviews and focus groups had to take place online. In terms of not hearing extensively from those under 25, and again accepting that it is not possible to be certain, this may be due to a lack of awareness of the opportunity to contribute to the study despite our use of multiple approaches to recruitment.
- 2.52 As commented elsewhere in this Chapter, there are gaps in some service user and carer experience in this report – like Welsh speakers, and care experienced young people for example – which will hopefully be mitigated as described above in advance of the final report.
- 2.53 It is also worth noting that we have heard from many more women than men during this report. It is not possible to be certain as to why this is, but it may be due to the larger proportion of women who identify as carers than men within the Welsh population.

3. Findings: Experiences of the Provision of Social Services

Introduction

- 3.1 This is the first findings chapter. The focus is on presenting an analysis of participants' expectations and experiences of social service provision under the remit of the Act. As outlined in the Framework for Change document, the Act sets out guiding directions, principles, inputs, and activities which are intended to support well-being outcomes.
- 3.2 This chapter covers participants' knowledge of the Act, experiences of assessment processes, relationships with social care workers, continuity of care, access to information, and use of social services. There is also analysis of participants' perspectives on the social care system, which includes issues about the impact of limited resources in social care, staffing levels and pressures, performance systems and measures, and pressures arising over the time of the COVID-19 pandemic.

Knowledge about the Act

- 3.3 Knowledge, understanding and awareness about the social service provisions under the Act was seen by some participants as pivotal to being and feeling informed. This was key to knowing what to expect in engaging with social services, and the support available, points made in the extracts below:

...education is really important, if people are not aware of the Act and its authority and powers etc., then they're not going to know and they need to be informed [...]. [The Act] needs to be, I don't know advertised or, you know, people who are in a caring role, whether unpaid or not, need to be told it's there and maybe a webinar or something like that arranged for people, or some meeting somewhere so that it could be explained to them (Carer, South Central Wales, Male, Older person).

I think just more access to information. [...]. ...an information pack to say, you know, this is what to expect from us, these are the policies or the guidelines we follow, this is what you may be able to look at to help you along this journey (Carer, South East Wales, Female, Adult).

- 3.4 For some participants accessing information about the Act was a challenging experience. They spoke about feeling uninformed and examples were recounted of having to seek out the information for themselves:

...that information isn't getting out there to carers and also the jargon that's around (Carer, North Wales, Female, Adult)

...unless somebody knows or you've got this inside knowledge, nobody wants to tell you about it. So it's a constant digging around looking for information, Googling all sorts of things and trying to find out things for yourselves. [...]. Unless you actually hunt for them yourself, nobody tells you about it. So yeah, as far as this Act is concerned, I don't really know anything about it to be honest (Carer, South East Wales, Female, Adult)

- 3.5 The difficulties of locating and then comprehending an abundance of information, whilst trying to manage their caring responsibilities, was raised by some participants:

I have not got time to be sat down reading through stuff that I know I probably won't understand. A small section I will and it's just frustrating because probably like everybody else you've got so much on your plate, what with struggling with appointments, caring and everything, you just want something simple (Carer, South East Wales, Female, Older person).

I actually looked at it, scrolled down to the amount of pages and then just closed it cos I didn't have the time to read it (Carer, South West Wales, Female, Adult).

...if you've got the time, obviously, if you're a full time carer really it's another thing. So that's added into that basket that's already overflowing with everything else you're trying to do (Carer, South East Wales, Female, Adult).

...there's not only the Act, there's the guidance on the Act that you get if you go to Social Care Wales's website [...]. I very much doubt whether the average carer a) understands how to do that b) has the time to do that and I certainly think c) they shouldn't have to do that. Nobody should have to be wading through that kind of stuff in order to get a decent basic service through their local authority (Carer, South West Wales, Female, Adult).

- 3.6 There was an emphasis on the importance of ensuring social care users and carers are provided information about the Act (or where to go to retrieve it) and what it means for them in a place that is easy to locate (e.g. signposting via professionals, online), and information being available in a range of accessible formats:

There's so much in the [sic.] Health and Well-being Act, it's never simplified enough for some parents cos of course a lot of parents who've got disabled

children, do have disabilities whether it be learning or just mild themselves (Service User and Carer, South West Wales, Female, Adult).

...you could really do with something that is a cross between the easy read version and the Act itself that made it easy for families to understand that as a result of the Act what they could expect, almost even in bullet points. I think I'm quite up to speed with things really but the Social Services and Well-being Act itself is a nightmare. I mean I've got it downloaded anyway and I sort of looked through at various times but ended up reading the easy read version (Carer, South West Wales, Female, Adult).

'[I'm] drown in information, but not the key things that you actually need to know' (Carer, South West Wales, Female, Adult).

- 3.7 The perceived complexity of accessing information related to the Act highlights the importance and value of not just the provision of information in a range of formats, but for professionals to be well versed and confident to communicate information to help ensure understanding and offer reassurance:

...it's all things like your minimum income and all that sort of thing, they don't give you the clear policies, they just refer you to the Social Services and Well-being Act and don't explain it. They make it very complicated as well you know cos I've been asking them for simple terms for years about my care costs 'cause I still don't understand that and I'm not a stupid person (Service User and Carer, South West Wales, Female, Older person).

- 3.8 Intrinsically linked to the extract above was the expectation that it is the responsibility of professionals working with service users and carers to share, signpost, provide support to access, and explain information, and not leave this for the service user or carer to locate by themselves:

I have had to inform myself of my own rights rather than what I would've expected that the so-called professional would inform me of this (Service User and Carer).

...the way that [LA] do things is they tell you all about direct payments, well they give you an awful lot of marketing waffle. They don't tell you information, not real information, and then they give you a link to the Social Services and Well-being Act. So rather than giving you a summary you have to read the Social Services and Well-being Act, which is absolutely ridiculous (Service User and Carer, South West Wales, Female, Older person).

There's too much of a broad spectrum information that is given to everybody. Whereas what you really want is targeted information, things that are relevant specifically to you and it doesn't seem to be anybody's job whether that's within the local authority or some of the third sector agencies to kind of narrow it down for you and I really think that would help. [...]. ...there are very specific things that would be very useful to know and I don't need to be buried under a load of stuff that isn't useful to me (Carer, South West Wales, Female, Adult).

- 3.9 Some carers spoke about their knowledge and understanding of the Act being related to previous paid employment roles, rather than being due to their carer status. However, there were participants with no knowledge of the Act and the supports that might be available, as was the case with the following service users in a focus group:

Researcher: How many of you are actually aware of the Act and what it means?

Service User 1: Never heard of it

Service User 2: No

Service User 3: No (Service Users, South Wales Central, Older people).

Assessments

- 3.10 Under the Act are clear duties in respect to assessment for adults, children and carers. Moreover, the Act outlines the need for implementation of a proportionate assessment process that focuses on the individual and personal wellbeing outcomes (The Act, Part 3).³² Co-produced 'what matters' conversations are required under the Act and associated Codes of Practice.³³
- 3.11 Matters about assessment processes were raised in interviews and focus groups. There were positive stories about assessments and the subsequent care that resulted, and contrary accounts of negative experiences. In the two extracts below

³² [Assessing care and support needs of individuals: code of practice | GOV.WALES](#)

³³ As defined in the Glossary, 'what Matters' conversations are a way for professionals to understand people's situation, their current well-being, and what can be done to support them. It is an equal conversation and is important to help ensure the voice of the individual or carer is heard and 'what matters' to them.

the significance of the Carer's Assessment³⁴ is evident, with positive outcomes for feeling recognised, supported and empowered:

[My Carer's Assessment] was just that chance, I think it was the first chance I'd had really as a carer all the way through my daughter's childhood to be able to go, 'oh I'm here, hello!' I found that really empowering (Carer, Female).

This [a new Carer's Assessment] is proving to be of great value. Instead of mapping ad hoc services to meet the needs of those I look after with a view to my caring role benefiting by proxy - this assessment is looking at what I need to support my needs and well-being as a person. This reduces the frustrations I feel at having to constantly juggle piece meal services to meet my households' needs but instead gives me the tools I need to be swimming and not drowning (Carer).

- 3.12 The next extract also recounts a positive experience where the carer felt that the professional took their time to understand the issues being faced and to engage with the family throughout the assessment process:

This one was professional, every question was explored, there was considerable effort made to be absolutely sure that she understood the question and there were other questions around it. She took her time, there was no rushing at all. She asked the question after about 10 minutes 'is everything OK'? 'Are you OK to continue?' Yeah, it was just what I would call a very professional activity and it was obvious that she was knowledgeable about autism and experienced as well (Carer, South East Wales, Older Person).

- 3.13 In contrast, some participants expressed their frustration that assessments felt like a 'tick box' exercise with the priority being the completion of forms and paperwork. There were experiences recounted where carers had not been able to gain an assessment, despite being eligible and wanting one. This was the case for the two carers below, as seen in extracts from their interviews:

...the Act specifically says that you know, carers have a right to an assessment and that assessment should be, is carried out by law to ensure

³⁴ 'A Carer's Assessment assesses a carer's needs for support and what those needs are likely to be. It includes an assessment of the extent to which the carer is able and willing to provide the care and to continue to provide the care; the outcomes the carer wishes to achieve both in terms of themselves; and, if a child is a carer, the outcomes the person(s) with parental responsibility for that child wish(es) to achieve for them': [Handout 4 Carers Assessment Guidance.pdf \(socialcare.wales\)](#)

that carers have the same outcomes and treatment that the person that they care for has. I think what has happened is the Act and the actual carers assessment has become, uh, disfranchised. It's become just a loose thing that happens, that possibly happens, when you become a carer (Carer, South West Wales, Male).

I mean just to give you an example, under the Act we are legally entitled to a Carer's needs Assessment and let me tell you my experience of carers needs assessment and I can tell you a great deal of other people, you can't get them ok (Carer, South East Wales, Adult).

- 3.14 Some carers had experiences of assessment processes and 'what matters' conversations which they felt to be disempowering and unsupportive:

...I mean if they actually put more energy to putting in the support they are paid to do instead of judging your parenting, threatening you and blackmailing you, it would be a much more wonderful thing (Carer)

...it is really worrying because if anything happens to me, well who's going to look after [my son]? I mean he's two to one, he's got complex needs, he can't just go to a foster home you know, but they just won't discuss it with me (Carer, South East Wales, Adult).

- 3.15 Participants had suggestions for how assessment processes could be improved, including a closer link to well-being outcomes and conducting assessments face-to-face, rather than on the telephone:

Some people don't know, they are not sure. They want the social worker to say to them 'well look, this is what we've got on offer, this is what I can suggest', that's never been my experience, you've got to have a clear idea of what you want and then it goes to panel. It's not really linked to well-being, its more about concrete plans for the young person which is understandable you know, but it's not linked to well-being, no-one ever says 'what would make your life easier', it's not really like that, it's centred around care packages for the person (Carer, South West Wales, Adult).

I've seen too many assessments being done over the phone and they should never have been, you know, they should be face to face [...]. ...you just can't do it that way, you need to go around and see somebody, see the state of their house, or you know, all sorts of things, it's just no good. (Carer, South Central Wales, Male, Older person).

Provision of care and support

- 3.16 Throughout the evidence base that was provided were stories and insights about experiences of the impact of improvements in social services since the Act was introduced. The carer below gives an example of such improvement in social services:

...I got the impression that they had their act together a lot better in social services. Visits were better, if we asked the hospital could they ring us back they rarely did, or ever did really but if we left a message for social services to ring us back, they would come back to us within a day or two (Carer).

- 3.17 In another example, the Act was described as making 'a huge difference' and a 'huge shift'. Positive changes referred to by other participants included:

- a discernible openness and responsiveness in how social services communicated with and supported them; and
- feeling valued and recognised in their role as a carer.

...before you always felt like you were walking on eggshells around social services, you were always going to them cap in hand to ask them for whatever you wanted and it was always a case of 'are you sure?' 'We can't really afford that, are you sure you want that?' You kind of almost had to justify anything that you were asking for and I'm finding that very different now. [...] ...any issues I'm having, I'm going to them with the smallest things and I'm finding that they are opening doors rather than creating more barriers and I'm finding that really useful (Carer, Female).

- 3.18 Several participants recounted positive stories of the service delivery arrangements in response to COVID-19, such as the use of direct payment hours, which allowed for flexibility in care responses, and the care and support enabled by technology:

Our son was deemed too vulnerable to attend a nursery due to COVID so he has been given extra direct payment hours by Social Services to allow us to hire a Personal Assistant (Carer).

... was actually fantastic in the pandemic, she was the only person who ever bothered to ring to check we were all still alive and did we need anything (Carer).

Yes, I mean thank goodness for COVID, organisations did change in the way they supported people. [Organisation] is where she gets her support worker from and they agreed to do WhatsApp with my daughter (Carer).

3.19 In contrast, other participants commented on the disconnect between their initial impressions formed via the content and wording of the Act and subsequent experience of the provision of care and support.

3.20 For many who participated in this evaluation, the Act was not delivering a tangible difference to their experience of care and support. There was expressed disappointment that expectations of improvements in care and support had not eventuated. This included the limited availability of early intervention and prevention support, and dissatisfaction with their care package post the Act's introduction:

I remember reading it and that and I thought there's good stuff in this. I was thinking 'oh yeah brilliant, they are really focussing on early intervention and that seems to be the crux of this' and I thought that's the way it should be because early intervention prevents people getting to me basically, but the reality has not been that (Carer, North Wales, Male, Adult).

...it's hard to say whether it's a result of anything to do with the Act but from a personal level there's been no improvement whatsoever (Carer, South West Wales, Female, Adult).

...the Social Service and Well-being Act doesn't work, it doesn't. Not in my case anyway (Carer, Female).

When social services were implementing the Social Services and Well-being Act, a lot of services stopped or changed and they couldn't find my Mum alternative care and support. So the day centre closed, which was very traumatic for a lot of people and the alternatives couldn't support my Mum's needs so we were you know, I think we felt vulnerable (Carer, South West Wales, Male, Older person).

[LA] had a brilliant team, this was before the Social Services and Well-being Act, a superb team which was the carers' team with its own dedicated social worker. I was recommended to have a carer's assessment which I did from the social worker, and they set up support for my daughter, they pushed for extra support because she was living at home then, to go for independent living, they did loads of things. Then LA completely revamped their social services operational strategy and plan for workforce development and said that all the

social workers had to be responsible for carer's assessments and the carers' team was scrapped (Carer, South East Wales, Female, Older person).

- 3.21 Some respondents had opposing interpretations to social service staff on what they were eligible to receive under the Act. The first excerpt below illustrates this point through an experience of direct payments, where the offer from the social service department contrasted with the respondent's own wishes for the provision of support as noted in the excerpts below:

I think the way that social services interpret the Act is very, very different to how an individual would interpret it. They're often using it to shut things down rather than open them up because their argument is 'ok you could find a personal assistant for £12.66 an hour therefore that is a reasonable direct payment to give you', whereas I'm saying 'a) I can't find one and b) I don't want one'. So it was easier for them to then contract the agency themselves and pay them directly which closes the whole thing down (Carer, South West Wales, Female, Adult).

...they're [LAs] just not doing what you know, those things that they say that they are supposed to do. They're just not doing it (Service User and Carer, South West Wales, Female, Older person).

I think to be honest it is since lockdown everybody is using excuses [...]. ... there's so many more excuses used about COVID as a reason not to do things now and that's in all aspects of disabilities full stop (Service User and Carer, South West Wales, Female)

- 3.22 There were also experiences of assessments not translating into any practical support for them. In the third extract below, the carer expresses the dispiriting impact of the experience of sharing what matters to them, but not receiving any support services:

They say 'what do you need'? And you tell them but nothing happens. You say you need more help or you need this or you tell them what you're going through and they just look at you, it's usually a social worker, and that's it, nothing changes (Carer, South West Wales, Adult).

After a lot of nagging I finally had a "what matters to you" discussion. Sometime later, I received an e-mail to say that none of the things I asked for help with were available. I was just left to get on with it as normal. If they

councils have a statutory duty, then they need the funds to be able to back up requests for help (Carer, Female).

...they do this 'oh yes that matters to you', 'oh yes that matters to you', 'oh yes', 'oh yes, yes, yes' and then it's like they've done the box and then it's like the reality of it is a hundred miles away from that [...]. ...that has to stop because there's nothing worse for carers, with reasonable expectations only then to have it taken away. Do you know what if there's any message I want to say here is 'being raised in your expectations about how the system is going to help you, only for you to then find out that it's way above what they are able to deliver' is really a problem (Carer, North Wales, Adult).

- 3.23 However, efforts amongst LAs to implement the Act were acknowledged, and some participants had seen the signs of improvements. Nonetheless, as the second extract below highlights, there was a sense that LAs were not fully aligned with the duties as required by the Act:

...there is a hell of a long way to go before they actually do the spirit of the Act', but people are trying (Carer, North Wales, Female, Adult).

It isn't all negative, things have improved and things have changed [...]. ... but they [LAs] are still not following law and that's what's so frustrating. They are not following what the Act's say, they are not following what it's promised by our Government [...] what should be happening just isn't (Service User and Carer, South West Wales, Female, Adult).

Specific issues for service users with sensory loss

- 3.24 The need for the provision of accessible information, communication, and support was particularly pertinent amongst service users with sensory loss. Yet, numerous experiences were relayed about missing information or not recognising an individual's communication needs, services not adapting/identifying solutions to communicate information, and a distinct shortage of interpreters and British Sign Language (BSL) trained professionals.
- 3.25 Central to experiences for these service users with sensory loss was the impact of services not adapting to meet the communication needs of respondents; namely a loss of their individual agency through an expectation that family members could communicate on their behalf:

I go to the doctors and I say to them 'I need an interpreter', they say 'Ok no problem', and then I went back a week later, there was no interpreter. So the doctor is worried about my mental health so what's happened then is my doctor has to phone my mum and my mum went through the roof and she was really angry because she said 'they shouldn't be phoning me they should be talking to you via an interpreter'. You know, I keep telling them and telling them and telling them and they don't take any notice. They think I can lip read them but they don't understand, lip reading is really difficult especially if a person mumbles or talks too fast and they've got to understand my voice. I can't understand them so I'm having to ask somebody else what did they say (Service User).

- 3.26 The excerpt below highlights inconsistencies with some services refusing to speak to family members on their behalf, which contrasts the experiences of individuals above, where there appears to be an over-reliance within services on communicating through family members rather than providing an interpreter or an alternative form of accessible communication:

We used to have a social worker for the deaf called [name] but they retired and they've never replaced them. But the good thing about [name] was they would come in and would check up on us, would see if our equipment was working, see if our needs have changed, but we don't have that now. We used to have [name], based in [LA], but they didn't tell us that they were retiring and we all panicked because we needed things like a pager system for the doorbell and the smoke alarm and we've got PIP forms and DSA forms to fill in. I've asked family to help but then we are told that the family can't help because they are third party, they want to deal with us direct, so I find it very frustrating (Service User).

- 3.27 The availability of interpreters for participants was inconsistent, with participants reporting access in some cases, but overall a lack of their provision was an issue. Where interpreters were provided, participants reported more positive outcomes. Another issue affecting the experiences of service users with sensory loss was the absence of a dedicated social worker to support and enable them to have greater independence and access services.

Lack of formal support and reductions in care packages

- 3.28 More generally, participants often indicated that they had been left with very few options other than to provide unpaid care; the provisions under the Act for considerations around their well-being exist but are often overlooked. The example below draws on an experience pre-pandemic when educational provision for the complex needs of this carer's son was limited to part of the week:

I remember going to a meeting with social services and they were absolutely flabbergasted when I said 'well if my son is coming to this school for three days a week, what's going to happen on the other 2 days, as I work?' And they said 'well people don't work, you'll have to stay home or is there a helpful Granny or something?' There really isn't as we are in our 50s, our parents are in their 70s, mine are hundreds of miles away anyway. But it was expected and I think that impacted hugely on us. It's huge, it's huge, you have no choice in it (Carer, South West Wales, Female, Adult).

- 3.29 Several of the participants gave examples of the lack of respite care, with implications for the service user and family:

I haven't had respite really, as respite was stopped straight away, we are supposed to have 42 nights a year, that was stopped immediately, and we didn't get any respite at all. COVID has had an impact but it shouldn't be used that things would be that much better because I don't think they'd be that much better usually anyway (Service User and Carer, South West Wales, Female, Adult).

We had one really good social worker but even when I say a really good social worker, all I mean is that we booked our respite through her. She'd say to me, and I used to think this was good, 'if you don't book your respite in a year in advance for the whole year, then you won't get it for your Dad'. That's disgusting really but at the time I was saying 'oh I'm glad she's telling me that, she's a good social worker'. Now I think 'hang on', do you know what I mean? When I look back now, I think that's crazy but I used to think she was really good because she was telling me that (Carer, North Wales, Female, Adult).

What you're left with is situations where you're trying to ensure that (my wife) gets all the attention and you don't. I'm fully aware that you know, (my wife) wouldn't survive here if something happened to me, yet the safeguarding and the responsibility that the health board have seems to be far less for me. That's not me being sort of jealous in any way, but it's me saying if I couldn't

care for (my wife) for a fortnight, she'd have to go into respite and it would cost you a fortune. But no they don't look at it that way, they can't see beyond that (Carer, South West Wales, Male, Adult).

And the last time we got you some respite it was during COVID wasn't it? But what we made them say it was, it was a holiday for you wasn't it and we made them do craft things for you and we wrote what matters to you so it wasn't being put in respite...it was a real holiday for you (Service User, Mid Wales, Female).

- 3.30 There were comments from participants about experiences of service gaps. In a focus group with carers, the issue was raised about a lack of specialist refuge provision for individuals accompanied by children with additional needs and carers. This service gap can greatly exacerbate the challenges and obstacles for those in abusive relationships as evidenced in the quotations below:

...when you are talking about refuge, survivors who have children with disabilities feel they are unable to make that move into refuge. It can be a huge barrier from physical disabilities to things like autism, it can play a big role and the survivor having to stay within that abusive relationship because it would be too disruptive, and the needs of the children wouldn't be met as effectively within the refuge (Carer, North Wales).

...somebody was in need of refuge but the person that they needed to take with them was an adult who was registered as their carer. So trying to find a refuge that is able to have the space or able to adapt the space to be able to take in two adults is really difficult because a lot of them it's like, well they are used to the binary of what they are used to. Trying to find ones where they are able to be flexible with what they are able to offer, can offer its own barriers you know (Carer, North Wales).

- 3.31 Other participants talked about service gaps for people with autism with learning difficulties and children newly diagnosed with conditions, and gaps in training for areas such as supporting Black, Asian, and Ethnic Minority people living with dementia:

There's a huge gap that autistic people without learning difficulties fall through and they don't meet the criteria for any services (Carer, South West Wales, Adult).

...we've got a very active Facebook page and there's a wide range of parents on there whose children are newly diagnosed. I feel for them because what the social worker was actually saying was unless they are harming their children or neglecting their children, there will be no service for them at this time (Carer, South West Wales, Adult).

...if you look at the home, the staff there wasn't qualified to look after people with dementia, they didn't have enough staff there, the staff that were, wasn't trained in that (Carer, Female).

- 3.32 Participants identified the consequences for them caused by the unpredictability and inconsistency of the paid care worker visits that they rely upon.³⁵

He is not a well man so he would probably have had a heart attack eventually anyway but that stress of being there 24/7 for my mum you know. If my mum was having a toilet emergency and the care workers weren't there and I wasn't there, my dad was having to deal with that and that happened a lot. There's no communication, there is very rarely a 'sorry', and if it's out of their office hours then it's even harder to get in contact with somebody. If it's the 9 or 10 o'clock call at night and they haven't turned up then yeah my dad is doing it by himself. I've reached a point where I'm having to stay there every other night with [family member] who will stay there every other night. My dad's giving money to [family member] to cover any losses she has for work just in case the carers don't turn up. It shouldn't be like that (Carer, North Wales, Male, Adult).

- 3.33 This above experience is instructive, and reminiscent of others. It would be fair to say that the pandemic has catalysed this issue such that the lack of care workers available is causing home care providers to hand back contracts to their respective local authorities.³⁶ This is especially troubling given the huge pressure placed upon service users and carers, and the consequent challenges to well-being that participants identified:

Dad was sent home and his catheter broke and no one had shown me how to use a catheter. I didn't know what to do with a catheter on my dad do you

³⁵ It is important to note that home care providers can be both 'in-house', provided by the local authority itself, or outsourced, provided by agencies commissioned by local authorities. We did not ask individuals details about who provided their care, so it is not possible to determine who comments like this one relate to.

³⁶ As an example of this see this news article from 13.1.2022: [Social care providers 'turning away new care requests and closed to admissions' | South Wales Guardian](#)

know what I mean? The catheter broke and apparently it was a temporary one they'd put on so I think, thinking I'd phone up the surgery, phone up the district nurse, who said, 'well can't you go to a care home and borrow one?' Well I said, 'I don't know what I'm doing with it, I don't know where to stick it.' And again you couldn't, you just couldn't write it could you? (Carer, North Wales, Female, Adult).

- 3.34 The carers cited below readily identified the fact that constantly juggling a set of needs, priorities, people and relationships was impactful on their well-being. If this could be managed successfully, participants were positive about their well-being, but all too often, circumstances and situations led to a much more negative impact. These examples highlight the considerable pressures faced by carers, and the potential value of support provided by social services, given the role of the Act "...to seek to promote the well-being of people who need care and support and carers who need support" (*The Act*, 2014, p.2):

My wife has barely seen me the last month because every other night I'm not here and there is that impact as well and it would be the same for my sister. My sister has got a younger child as well. My sister is meant to be off this week on a trip away with her daughter and her partner and that's not happened because we are both running around after me mum and dad. Mum's not going to last forever. We can do it but how much it's taking out of me, my sister, my wife you know even my kids they miss me not being there, as much as I didn't think they would but they do, it's had a huge impact on our day to day life. I can't remember the last time I did something with my wife because I can't because my weekends are taken up at my parents (Carer, North Wales, Male, Adult).

I didn't have care for him so I've had to resign from my job now. So now I'm a full-time carer and my wife has managed to keep two little admin jobs going largely from home due to the pandemic but one of those is finished now due to redundancy. So, we are both kind of caring at the moment and juggling things between us (Carer, South West Wales, Female, Adult).

I was working full-time as well, my mum was living with me and I would do anything for my mum. I was only happy to look after her, a privilege and an honour to look after her, if I could have given up work you know, I just felt like saying in the end 'look everybody just go away, I'll give up work and I'll do it all

on my own' you know. I don't want to ask anybody for anything cos I felt a sort of a burden to people (Carer, South West Wales, Male, Older Person).

Interpretations of the Act

- 3.35 Examples were given of inconsistencies between LAs in the way that they interpreted the requirements and duties of the Act and how it was applied, leading to service users and carers pointing out variation between different authorities in Wales:

I've read the easy read version of the Social and Well-being Act, it is really strong, but [my LA] aren't adhering to it. I think different councils, I've been to a few of these meetings, and what I'm seeing is different councils act in different ways unfortunately. I've heard a few people from [another LA] and they seem to have it together and [my LA] haven't. They need more training; they just don't want to work with you. Everything you ask for, they just want to do everything their way, rather than listen to you to provide you with something that suits your home better, that costs less sometimes. It's do what we say unfortunately, they don't want to work with you (Carer, Female).

- 3.36 Some participants felt an inconsistent application of the Act was linked to a lack of knowledge, understanding and training amongst professionals, as was highlighted above:

[The social worker] came out, they said they'd never done one [an assessment] before, hadn't a clue how to fill in the form, which is like the Magna Carta by the way. She sat here and told me that she had no clue what happened afterwards and that was in February 2020 and I've never heard anything since. So I can absolutely tell you, all they are is a tick box exercise (Carer, South East Wales, Female, Adult).

...we were educating the officers about co-production and the Social Services and Well-being Act, you're having to repeat all the time and they ignore it because they don't understand it and they just say, 'oh right OK but I need to tick this, this, this and this' (Carer, Female).

I think they [social services] need to go back to universities to have a look at their curriculum and how they engage with their students, and then look at the lectures and how they deliver a service (Carer, Female).

- 3.37 More widely, a lack of knowledge and the responsibilities of services under the Act was highlighted as extending beyond social services to other professionals and

organisations. The particular example below refers to the use of interpreters for individuals with sensory loss (which follows on from the points being raised in paragraphs 3.24-3.27) and a lack of understanding amongst professionals of their responsibilities under the Act to provide an interpreter:

Most organisations out there think it's the deaf person's responsibility to book an interpreter but we know it's in the Act. That message is something that I carry everywhere I go and I explain it to people in [town in LA] there's a dentist, there's a doctors, the people that interact with [service user], they know it's their responsibility to book an interpreter but only because they've met me. The message is not understood, the services do not understand their responsibility under the Act (Service User, Mid Wales).³⁷

- 3.38 Some carers felt that a lack of support in line with the Act was partly a lack of oversight and leadership from Welsh Government to 'drive' the Act 'in the right way':

I think there has been a significant lack of guidelines from Welsh Government. They wanted to push on things which is fine and the Minister has been involved and written letters and said, 'you will collaborate', 'you will show partnership working', but a perfect example is the first population needs assessment that was required by Welsh Government for every single local authority in Wales. [...]. ...you know what I'm going to say about population needs assessment, there are 22 different documents. Some are narrative, some are lists, some are aspirational. You can't measure that. [...]. ...you cannot measure that can you? You're not comparing like with like. [...]. I think there is a real lack of expertise in Welsh Government to actually drive the Social Services and Well-being Act in the right way and that's why things have happened so slowly I think. We still haven't got, one of the key objectives was to really focus on low level prevention, preventative services, and its hit and miss still, very poor (Carer, South East Wales, Female, Older person).

- 3.39 Another carer found the speed of change because of the implementation of the Act had the effect of making their experience of care and support 'out of control', and felt their mother's care had 'suffered' as they explain below:

I think they tried to make too many changes, too quickly and for some people maybe they were having like for like but by mother's care suffered and was inferior due to the changes. I think because we were having as I said the care

³⁷ These comments were made by a BSL interpreter on behalf of one of the participants.

package, the day centre, the sitters, it sort of everything that we were having, changed. [...]. I've got to be honest, I know this is a big word but I felt a bit bullied by social services and the council because we were out of control and I wanted to speak to them, I was writing to them and it was just 'no its got to be done because of the Social Service and Well-being Act'. I think they sort of hid behind (Carer, South West Wales, Male).

Interactions and relationships with social services staff

- 3.40 Experiences were shared about interactions and relationships with social services staff. These cover the full gamut from relationships that are experienced as helpful and 'working well' to ones that were frustrating, disempowering, intimidating and where people felt misunderstood.
- 3.41 The extracts below illustrate this spread of experiences, which can change over time with different episodes of care and support. The first participant recounts both positive and negative experiences of interactions with social workers over time. The second extract is a carer who experienced social workers as not listening to the family.

...my son's social worker is an absolute gem, he's brilliant, he really does, he really cares. He rings up he makes sure that everything is well, he does everything he can, I would give him a gold star as a social worker. The other social workers I've got, I've just argued with half of them because they don't listen to me and I tell them what the problem. I remember when it first all came up about this direct payments because I was saying I'm both a carer and a disabled people and they wouldn't have it (Carer).

The social workers were not listening to us. The first placement that she sent us to have a look at we came back to say it's not suitable and she said 'how do you know?' And I said 'well there are no downstairs changing facilities, she has to climb into a shower, it needed to be level, the staircase is too wide she can't go up and down it, we told you she would prefer somewhere with no stairs'. It was implied that we were just making excuses we don't really want her to go there (Carer, South West Wales, Adult).

- 3.42 A participant with a dual role as a service user and carer described 'a very unequal relationship' with their LA and the LA as having 'no understanding that people can be both a carer and have a disability' (Service User and Carer, Female).

3.43 Continuity of care is a theme emerging from the data, both its importance and people's experience of its absence in a lack of a consistent social work contact person. In the first extract below a carer laments not having a 'named social worker', recounting cycles in their mother's care journey over a period of six years. The second participant also referred to not having a 'named social worker', which they see as problematic for monitoring progress of their mother's support:

...while Mum has a problem or her care needs change I get in contact with the common access point. They contact a social worker who contacts me, they deal with that issue and then the case is closed and you have to go all the way through the same rigmarole again next time you need something. You don't have a named social worker. We've probably seen about maybe 8 or 9 social workers in 6 years (Carer).

...that's another thing, the [locality] keep on taking my social worker away. In my care plan, I didn't even realise that it's the social worker who is supposed to make sure that my care plan has been alright and it hasn't been updated since 2018. The social worker isn't named so they can get away with it sort of thing, you know, but then they don't give me a social worker so I'm just stuck. The amount of times we've done assessments, the amount of times we've done the social care assessments with the social worker, it's never been and the adults, when he first went to adults, it was more about what are the outcomes, what would you like, it was much more than it was with the children's. However, we only had one good social worker who did a lovely plan, did a lovely assessment, what happened...two weeks later she disappears off the earth (Service User and Carer, South West Wales, Female).

3.44 It was common to hear that people had had numerous social workers over time, which meant people needed to repeatedly tell their stories anew; 'no-one knows you', as one participant said. This led to service users and carers feeling frustrated, desperate, stressed and weary, which is evident in the language used in the following accounts:

...she had a very good assessment by a social worker who was quite knowledgeable but she then moved so we had to start the process all over again (Carer, South East Wales, Older Person)

...nobody knows you, you have to tell your story to a new person every single time [...]. [I've had] eight or nine social workers but two of them were really,

really good and really did their job incredibly well, understood what I was asking for Mum and gave me an assessment in my own right as a carer. But the other six or seven you know, bless them, trying to do their best but you can't fight against a system like that (Carer, South West Wales)

- 3.45 A crucial element, from the viewpoint of some participants, was the importance of various agencies and professionals including and working with them and sharing information more regularly about their care and support. This was especially significant in the second extract wherein a carer relayed an experience where their mother's assessment was conducted without their involvement and not in Welsh, her language of choice:

I would like to be much more in control of looking at the way Mum's dementia is managed (Carer, South West Wales, Female, Adult).

... the first [Continuing Health Care] assessment had been done without even involving us at all, without even being aware that my mother's preference was Welsh language, without even being aware that she couldn't communicate only through us. (Carer, North Wales, Female, Adult).

I think the managers of the organisations [NHS and Council] talking to us more frequently about what's happening would be a big help. Everything seems to be reviewed every 12 months, yet with a severely disabled child things change week-by-week (Service User and Carer, Male).

- 3.46 Despite the importance of this point, participants often communicated a lack of meaningful involvement. This was defined in terms of the extent to which they felt informed and included in discussions, and sometimes it was down to simple things such as professionals not following up on an agreed telephone call:

They [social services] were saying, I wouldn't say they were evasive but I got the impression that we weren't being told everything at that point about medical, the reasoning for him going into a care home rather than a nursing home (Carer, North Wales, Male, Adult).

...they offer [a care planning meeting] like once a year, but that's it then and that's the sort of only time that you all come together in one room, or zoom actually, but that's the only opportunity for everybody to sit down in a room and discuss things all together and make a proper plan. Whereas ideally I think it should be every month or every few months or something (Carer, South East Wales, Female, Adult).

I think a lack of communication for all carers with agencies is a biggy [...]. ...they say 'I'll phone you next week' and you don't want to be awkward so you don't say 'oh when are you going to call me next week' you just say 'ok, next week'. But you are still waiting on a Friday night (Carer, North Wales, Female, Adult).

- 3.47 There was a sense in the evidence collected that respondents felt that they needed to be increasingly firm in their interactions with social services about what they need and when, for fear that otherwise they will be ignored:

I was always quite gentle with social services but now if I want something for one of the children what I've learnt to do, and this has been very effective for me, is I will phone and say for example 'my son needs [this thing], I'm going to have this for him and I will phone every day until it's put into place and I will never go away so you may as well just save yourself the time and give it to me now'. And generally they do, but you shouldn't have to be like that. It's terrible, it's almost like a kind of bullying on my part you know, but you have to be incredibly strong and not take no for an answer and very creative in your thinking. You know, make big life plans for each of the children and plan out what's next, what are they going to need in 6 months, 12 months, 5 years. It's a life's work (Carer, South West Wales, Female, Adult).

- 3.48 A Black, Asian, and Ethnic Minority carer commented on their experience of social services acting in a 'superior way', and another carer outlined their experience of 'fighting everything' with the council which was a very common theme in the evidence:

But they certainly don't want to, don't want to look at themselves, within themselves, the problems that are going on there they do seem to have some superiority complex, my experience anyway with many of them (Carer, Female).

[We] just fight everything. Everything since, I had no real involvement with social services until the transfer, and since the transfer it's been four years of hell. You can question them, you can quote things out of the Social Services and Well-being Act and they just ignore you. I'm going through my second formal complaint (Carer, South West Wales, Female).

- 3.49 Professionals taking the time to fully prepare individuals for attending care planning meetings was seen as an important to alleviate potential anxieties:

...as good as it sounds on paper having somebody who already has all those issues going on and is anxious and hasn't got much self-confidence and doesn't like speaking in front of people to then sit in a room full of professionals, as they are called, and have people glaring at you and asking you questions. So the one time actually when they were going to do it in person we did say 'can you go through it all with [Service User] first, have like a pre meeting of what to expect, what it will look like, who'll be in the room, how many people there will be'. Just to take all that uncertainty away (Carer, South East Wales, Female, Adult).

Perspectives on the changing environment and its impact on social services

- 3.50 The impact of reduced budgets and financial pressures, the pressures on the workforce and the impact of the COVID-19 pandemic on social services is a thread throughout the responses from service users and carers.

Lack of system-wide capacity and budgets

- 3.51 There were many insights about the wider context in which the Act was being implemented and how limited budgets and workforce challenges were impeding the sector's capacity to deliver on the intentions of the Act:

...you've got an external system who is totally under resourced and totally not able to deal with it, being forced to somehow do this major culture shift when they are under so much stress themselves personally. So to be honest in one way, the Act is fantastic, it's a fantastic piece of legislation but trying to shoehorn it into the current thing whilst pulling resources away is insane (Carer, North Wales, Adult, Female).

...there is a drive to give people more choice, which I absolutely appreciate [...]. It's lovely to write an Act that kind of in a sense makes people feel they are entitled to lots of bells and whistles when that's absolutely not the case, social services do not have budgets for that (Carer, South West Wales, Female, Adult).

- 3.52 Echoing the sentiment above, limited resources/budget constraints amongst LAs were highlighted as being at odds with the spirit of the Act and limited the ability to offer choice to individuals about their care and support:

...they [social services] will quote 'we can only do the bare essentials', what's essential and I don't think the Act actually says what's essential because is

that what's statutory or not what's statutory? I think that's where we've got a real issue at the minute where people are being drawn into 'oh that's not essential' (Service User, Mid Wales).

...even when they turn round and tell you it's not cost, it's not budget then I find agencies, alright they might be more expensive than the others, I find carers who could come in that could be more expensive and yet 'oh no they are not allowed'. For some reason they keep hurdles all the time so tell us how to use this Act (Service User and Carer, South West Wales, Female, Adult).

- 3.53 Experiences were relayed where participants perceived that the social services managers were making care and support decisions based on the money available, not the assessment process:

...the social workers don't decide on you know what support you get, the managers do. I think it just depends on how much money they've got in the budget at that particular time you know and basically whether you're eligible in inverted commas or not (Carer, South East Wales, Adult).

As far as we know this request was turned down by a panel of middle/senior managers. To date, we have not been formally informed of this decision. This to me suggests that our views and wishes, as a family, in respect of the type of care and support we need are listened to at a ground roots level. Unfortunately these views can be overridden further up the decision making chain. These decisions and the reasons behind them are seldom communicated to the service users. These are factors that I believe are contrary to the aims of what is on the whole a good and empowering Act (Carer).

- 3.54 Some participants felt the COVID-19 pandemic had served to expose existing problems within the social care system. The quotation below situates these problems in a historical context; a social care system that has '*been creaking*' for decades. They especially highlight systemic issues such as insufficient numbers of paid care workers, low wages for formal care workers and a poor public perception of social care:

...the whole system has been creaking, probably for decades but it's been creaking so badly over the last few years that COVID was probably just the final straw [...]. ...there are not enough carers coming into the job that the whole kind of issue over they are not paid enough, the profession is not really professionalised, all of those pigeons are coming home to roost at the worst possible time. If the health and social care act is being looked at, it absolutely

cannot be looked at through rose tinted spectacles of what would be nice to have in an ideal time because this is the worst time after many, many years of it being quite a bad time (Carer, South West Wales).

Many families in [LA] have felt abandoned by the council during the pandemic, some families (that don't come to our provision) have had more correspondence with myself over the past year than they have with their council run service or clubs (Carer).

As soon as COVID hit, all of a sudden I was given these medicines to give to my son if I needed emergencies to drug him up when he's having challenging behaviour, first time ever. That shouldn't be the answer but that's what they do and that's where again what happens to the Health and Well-being Act, it's not being followed (Service User and Carer, South West Wales, Female, Adult).

- 3.55 The data collection took place well into the second year of the pandemic and issues arising from COVID-19 related service changes pepper the responses. The double-edged nature of online support with positive and detrimental aspects, and reduced services because of priority setting are themes raised in the interviews:

One of the major problems has definitely been COVID related, in so far as the direct support we received from our social worker had moved online. While our social worker has always tried to support us, she has had to prioritise [sic.] more needy families. That said I understand her need to prioritise [sic.]. On a more service/agency level most supports were closed down (Carer).

...for my daughter it got a lot worse because she really needs that face-to-face, so phone calls just don't work at all. [...] ...that's been really really hard. Again with social services I think they did, they did stop seeing the people they were working with for a while in the first lockdown, but maintained that, the contact and the relationship is a lot more friendly, even though it's professional it's more accessible. So she would be if you text her and said, 'oh [name] is struggling can you give her a call', she would (Carer, South East Wales, Adult).

- 3.56 For some respondents, the shift to online and/or telephone communication by agencies as a consequence of COVID-19 was described as 'fantastic' and services that had explored alternative preferred means of communication with service users had a 'positive impact':

They [autism support team] quickly recognised that it would be good for her to talk to her support worker via WhatsApp, whereas that hadn't happened before. But they recognised that was really important and it was effective and so that was a positive impact as well (Carer, South East Wales, Older person, Female)

- 3.57 Benefits to online or alternative communication methods were tempered by the recognition that it is not accessible to all and for individuals unable to access and use IT equipment meaning there was 'no way of accessing the service':

...everything has gone online, which is fantastic if you are online, but I mean for the ones that can't look at a screen, they can't cope with doing something over Zoom [...]. ...and there's no other way of accessing the service at all (Service User, Mid Wales)

- 3.58 The impact of reduced face-to-face contacts and home visits, together with the closure of supports like day centres and an inability to be able to travel to take up alternative care and support options, were noted by participants:

...during COVID the day centres shut and mum used to go to the day centre two days a week so eventually after a while I said 'look 'you haven't opened the day centres'. That's about 12 hours a week of kind of socialisation that Mum wasn't getting. [...]. Mum hasn't seen a social worker at her house since COVID started (Carer, South West Wales).

Day services got stopped completely, that was it for a while and eventually they came back after a couple of months of care, in a different place so she had to attend a different centre and everything like that, different staff, it wasn't a one to four (Carer, South West Wales).

Service User: At the moment it's getting on my nerves at the moment, I can't even go on the buses or nothing

Interviewer: So when you mentioned [service user] that you used to go to the embroidery centre...

Service User: It is open but I can't go there until they say (Service User, South Central Wales).

She is not getting the full day services that we used to. She used to have five days, it's still only four days because of COVID, so still trying to tell her she can't go on a Monday because the centre is closed to her, she won't be able to go. Even though her routine changes a little bit she still knows exactly what

should be happening on certain days and so if it does change she does get quite agitated (Carer, South West Wales, Adult).

Social care workforce pressures

3.59 Social care workforce challenges were articulated in various ways. A carer with a social work practice background talked about the stress levels across the social care sector, which they specifically linked to the inherent complexity of children's social care, and in particular child protection. They viewed stress in this practice context as 'incredibly high' and queried whether social workers were sufficiently trained to respond to complex and urgent situations in social care.

3.60 Carers also comment on matters of complexity in social care. These include the multi-dimensions of personal care and support needs, and complexity in the social care provider landscape. The latter theme is taken up more thoroughly in the chapter on multiagency working. The two examples below illustrate these points:

...my mum's needs were quite complex in a generic type of way [...]. ...we had the day centre, the care package, the sitters, equipment and things. Everything we had was changing and I felt they didn't care to be honest but it felt as if they hadn't thought you know, the more complex somebody is the more services they've got, the more it's going to change for them (Carer, South West Wales, Male)

I thought I understood, I've worked with family carers, I've worked with foster carers, I've worked with families since I was 21, I thought I understood but when you're inside the system, you realise that you don't understand it, but it takes that experience to happen before you realise (Carer, North Wales, Female, Adult)

3.61 There were insights about the implications of turnover in the social care workforce and significant recruitment difficulties. Carers commented on a shortage of social workers in their local authority, and the implications for assigning social workers to work with children and young people. They saw need for closer analysis of the underlying causal factors that are impacting on social work recruitment to identify solutions:

They are working I think to 40% capacity within the social workers team at the moment [...]. ...in the social services department's defence, if they haven't got

any social workers, they can't allocate children or young people to them and that's the problem (Carer, South East Wales, Adult)

...it's not a matter of not wanting to help and not wanting to help families, they have a big recruitment issue so I suppose it would be looking really at why that is and where that problem stems from to solve that (Carer, South West Wales, Adult)

- 3.62 Another carer observed that '*all the social workers are exhausted*'. They understood this situation to be related to insufficient financial and human resources in social care. Sickness levels amongst social care staff and the obstacles this creates for contact and access to social care support were commented upon. It was however noted that the workforce often brought a compassionate approach to their work:

Half of the [organisational] team are off sick or have left. It is very hard to contact and get support from them recently. Though the staff they do have are very caring (Carer, North Wales, Adult).

...you've got people leaving because the stress, I know the stress of my role and talking to the healthcare professionals that come out to my mum I've seen stress and how beat they are especially in the last 18 months (Carer, North Wales, Adult)

- 3.63 Workforce shortages and employee churn and the implications for care and support provision was a recurring theme. Participants recounted how these issues generated problems in accessing services; communication and relationship formation with social care professionals; care assessment and planning processes; and in the delivery of care.

- 3.64 Some participants linked the social care workforce constraints mentioned above to the time and capacity available for undertaking preventative work. This was the experience of the following service user, which is counter to what is needed to build strategies for longer term prevention:

Yeah, but they don't, they don't intervene until last minute when it's too late you know and this is always going to be a problem and it shouldn't be (Service User, South West Wales).

Chapter conclusion

- 3.65 This chapter has presented key themes about aspects of the functioning of social services in the environment since the implementation of the Act. These are developed from an analysis of the evaluation data from both service users and carers who have diverse reasons for engaging with social services. As discussed throughout this chapter these themes are: engagement with social services, the importance of knowledge about the Act for access to care and support, assessment processes, service provision, continuity of care and relationship based practice, service gaps, and systems pressures.
- 3.66 Broadly speaking, the evidence from service users and carers provides insights into people's experiences of a social care system undergoing considerable pressures (i.e., workforce issues and budgetary constraints), pressures that preceded the implementation of the Act and have been exacerbated during the COVID-19 pandemic. These insights about the systemic realm highlights the challenges of implementing principles based public policy (i.e. 'The Act') in a context where historical resourcing and institutional practices issues come face to face with the strains and constraints of the current times.
- 3.67 There are penetrating insights from service users and carers about barriers to accessing services, financial considerations rationing service delivery, and implications of workforce churn for continuity of care and relationship-based practice. Looking across the evaluation data there were numerous examples where the ambition and improvement agenda of the Act was not the experience of respondents. For several respondents there was no discernable change in the experience of care and support, and for some things were more difficult, including limited availability of early intervention and prevention support.
- 3.68 Some respondents had little to no knowledge of the Act, which had implications for them in respect to how they could access care and support. Others still experienced the delivery of social services as operating from a 'tick box' culture in performance reporting and accountability. There were also experiences of carer assessments falling short when it came to facilitating the follow up provision of care and support. Gaps and shortfalls in service availability were raised. Service users and carers

spoke of having to manage alternative interpretations of the principles and entitlements under the Act, with a juxtaposition between their views and those of staff within social services. Notable is the negative impact for wellbeing of these encounters with social services.

- 3.69 Whilst not the dominant story, from this evaluation data there were also positive encounters with social services, and stories of improvements. This was the case for some carers who recounted positive outcomes in carer assessments and the implications for feeling recognised, supported and empowered. Experiences of social services being flexible in instigating service adaptations during the pandemic were noted positively, for example the delivery of online and remote support. Some respondents commented about their experience of social services being open and responsive, and that this had been different since the implementation of The Act. There were examples of respectful interactions with social care staff, and from some respondents an empathic consideration of the stresses experienced by the social care workforce.
- 3.70 The evaluation data points to areas where improvements could be made, and this includes in the ongoing training of staff about the Act, public communication of information about the Act, and ensuring this information is relevant to a diverse group of service users and carers and is available in a range of accessible formats. The need for the provision of accessible information, communication, and support was particularly pertinent amongst service users with sensory loss. Service gaps were identified in areas such as support for individuals with children in leaving abusive relationships, specialist services for children, and support for Black, Asian, and Ethnic Minority people. Moreover, attending to systemic issues (resources, staffing, institutional performance reporting) and managing the consequences of staff turnover for relationship-based practice are pressing areas that emerge from the discussion in this chapter.

4. Findings: Experiences of Multi-Agency Work

Introduction

- 4.1 Building on the previous chapter which provided a broad spectrum of the range of issues that are experienced by service users and carers in their interactions with social services, this chapter focuses specifically on their experiences of multi-agency working amongst the professionals providing their care and support.
- 4.2 As one of the five principles of the Act, multi-agency working places an emphasis on partnership and integration in the delivery of services for individuals with care and support needs. The Act envisages that improvement in well-being outcomes for people will in part be achieved through better co-ordination and enhanced collaboration between public bodies, including local authorities and the NHS, the third and independent sectors, working together through and across regional partnerships.
- 4.3 It is important to note that work between different parts of the public sector, including between local authorities, is covered under the principle of multi-agency working.
- 4.4 Three areas were reflected on by participants when raising issues around multi-agency working:
- Relationships and partnership working between and within sectors;
 - Variations in approach to multi-agency working; and
 - Transitional planning from children to adult services.

Relationships and partnership working between and within sectors

- 4.5 When discussing multi-agency working with participants, a recurring theme was the relationships amongst professionals within and between the statutory sector (including the NHS), the voluntary sector and the independent sector.
- 4.6 From the perspectives of participants, their ability to work efficiently together was a requisite to positive experiences of care and support. Notably, the COVID-19 pandemic and the need to adopt to online working was seen as facilitating more effective multi-agency working and communication amongst organisations:

I think the positive impact [of COVID-19] was the fact that online use has improved. Professionals from all agencies and organisations have had to work in a different way. My experience is that this has made people a little bit more effective (Carer, South East Wales, Older person).

4.7 Participants identified that a key enabler of effective inter-agency relationships was whether LAs knew and recognised the role that different agencies could play, and could fund them accordingly. Service users and carers referred to a tendency that they detected in LAs looking inwards and focusing primarily on their own resources, offering LA-run services and provision as the first option. This led to a perception that service users and carers were not being given the option of being supported by services provided by the third or independent sector, even though these could have been more appropriate for them.

4.8 In the excerpts below, carers highlighted 'barriers' to accessing other services they had identified:

There is little or no recognition of new service provisions and when the service are identified by parents/primary carers there are often unacceptable barriers put in the way of accessing these services. One of the key barriers centres on the level of contributions the carers are told they will have to pay towards the service they have identified. Paradoxically there are no "charges" for accessing many of the services offered by the LA's day service (Carer, South East Wales, Female, Older person).

[LA] talk about 'Direct Payments and individuals having a choice' but it's only council run services that are advertised. Anything other than that it goes to panel where it is turned down (Carer).

Third sector

4.9 Recognition and knowledge of local third sector community assets were perceived to be lacking in Welsh Government, social services and the NHS in general. This led to families missing out on valuable support as noted by the following respondents:

They [social services] need to listen to the smaller charities on the ground, you know, it's the missing links, we keep missing those links to those other agencies. I remember working in [LA] and we actually arranged for a networking meeting within the area because we had so many agencies but we were all missing things that could really help a family, and I feel with the

Government it's the same, they are missing those charities (Carer, North Wales, Female, Adult).

...with Child and Adolescent Mental Health Services there is no signposting to other services or where you might be able to get help or charities [...]. ... there's not much there to say 'this is actually what's going on for your child, this is where you can go to get more help and advice and what we've identified is we can go here or here to get help and advice'. There's nothing like that (Carer, South East Wales, Female, Adult).

I mentioned [third sector provider] and you know, 'what's [third sector provider]?' [...] they hadn't heard of them and that surprised me [...] to not even know who [third sector provider] are and they've got, you know, children maybe in their 30s, who could have definitely benefitted from some advocacy at a certain point but they just don't know that that help is there for them (Voice of service user via gatekeeper organisation).³⁸

- 4.10 Where service users and carers had been supported by the third sector, participants placed significant value on the provision and spoke positively about the support they had received:

...there was a volunteer that used to sit with my Mum on a Friday afternoon who was excellent, you know, if I needed to go anywhere in the evening or something, they could sit with my Mum for a few hours. [...] when I rung the [third sector organisation], I always got a feeling that they would do their best, they were on my side in a way and they would find someone to be with my Mum if I needed someone, they would do their best to find someone (Carer, South West Wales, Male, Older person).

The staff are amazing. Honestly, I'm being serious, they are amazing people. [...] Like I call [youth worker] twice a week and have like a 30 minute conversation, all the drama in my life and it's nice to have that little vent. [...]. ...it's the little things that make a change or having little events, like trampolining yesterday (Carer, South East Wales, Young person/Young adult).

[Organisations' nurses] are nurses who are trained in dementia and support families, really properly trained in dementia, but their role is not specifically to look after the person with dementia but it's to support the family of the person with dementia. So to offer advice and for me she was the only person that ever

³⁸ Gatekeeper organisation providing anecdotal experience of a specific service user group, as described in Chapter 2.

had that continuity of understanding (Carer, South West Wales, Female, Adult).

- 4.11 An issue raised by participants was in respect of the financial challenges facing the third sector. The majority view was that such important services which support and augment the work of the public sector, should be better supported financially by the state:

...there are a couple [of hospices] in this area [...]. I can't fault them but they are charity and things like that should not be a charity. A service that good shouldn't be reliant on charitable donations and I know they struggled through COVID because their charitable shops were not open so their revenue was down, yes they'll get a certain amount of revenue from the health service but it won't cover everything (Carer, North Wales, Male, Adult).

Relationships with health services³⁹

- 4.12 The Act was perceived to have positively placed a greater emphasis on the need for health and social care services to work together:

I think one thing that has come out of the Act is that I think it's made the health service aware that there is such a thing as social care, and they have to work with social services in a much better way. [...]. I think they've had to think differently (Carer, South East Wales, Female, Older person).

- 4.13 Nevertheless, respondents described partnership working between social services and health services as problematic at best, and in some cases non-existent. This also applied to integrated health and social care teams that social services work with. Ineffective working relationships were felt to be to the detriment of service users and carers:

...the social worker really I don't know how much they communicated with the integrated autism team, I think it was more the other way around, that the integrated autism team tended to respond immediately, sort things out, contact the social worker, it was them doing the work and not the other way around (Carer, South East Wales, Female, Older person).

³⁹ These experiences relate to health services in general. Specific interactions with mental health services – both for children and adults – were reflected on in more depth by participants and will be considered in a separate sub-section below.

We couldn't get them [social services] to work together with health care at all, and we do still struggle with that, even though things are better, they are still terrible at working together (Carer, South West Wales, Female, Adult).

- 4.14 Given that the downside of organisations not working together effectively is often felt by service users and carers, participants identified that they felt a sense of responsibility to try to ensure the two sectors work more effectively together. These experiences point to some common tropes of poor multi-agency working, namely needing to repeat the same information multiple times to different professionals, and being forced to seek out support without assistance:

I have tried to get them [social services and health] working together but the biggest struggle is getting health to work with the other services. So far, I have not accomplished this! If my family had multi-agency support, we wouldn't be in the situation we are. Not only would our needs be met and understood I wouldn't have to repeat myself over and over to the different people (Carer).

They literally just don't work together at all, it's not how well they work together, they absolutely don't. The only contact they have between each other is if for example, say I wanted something from social services that they were denying me, I might get one of the nurses from the older person's service to give the social worker a call and explain. [...]. But I would have to do that, I would have to instigate that joining up of the services, it wouldn't happen without me (Carer, South West Wales, Female, Adult).

When I came to [the health department] for appointments and [tests] and everything, they don't seem to liaise with the social work care of it all. I had to do all the legwork myself to get help with assistance with things in the house and years ago, it was much better when we actually had a social worker (Service User, South Wales Central, Older person).

- 4.15 Additional effects of poor multi-agency working, especially between social care and the health service were identified by participants. These included a lack of responsiveness between partner organisations, leading to service users and carers feeling that the professional who should know about the circumstances of service users were actually poorly informed about them:

...we've had multi-disciplinary team meetings and the paediatrician has actually given social services tasks to do and they just haven't done them. Quite recently, the paediatrician has asked my social worker to 1) look into a holiday play scheme options for [Service User] and also to up my Direct

Payments [...]. I actually spoke to my paediatrician the week before last and they said they can't get anywhere with social services, they won't return their calls, so again they're hitting the same brick walls that us mortals down on the ground are (Carer, South East Wales, Female, Adult).

Supporter: Health is absent...

Service User: Absent yeah. They are not listening...

Supporter: They are not communicating it to you are they?

Service User: No, not listening. I've only got my Mum and I've got you [supporter] (Service User, Mid Wales).

[Social worker] is an excellent social worker but if I said to them 'who is [Service User's] epilepsy nurse?', 'Who is their epilepsy consultant?' [Social worker] would have a better idea actually of [Service User's] education. [...] ...with regards to health, I've never seen any evidence of any link or joined up thinking between health and social services in all the years I've had children (Carer, South West Wales, Female, Adult).

- 4.16 Issues were also raised about health professionals not working or communicating effectively with each other to share information about the individual being cared for. The case below provides two separate examples of health services not sharing information with carers/relatives in relation to hospital discharge nor with social services professionals. The first relates to the family not being informed of their relative being placed in isolation due to COVID and the second is the family not being provided information in advance of their relative's discharge from hospital:

...what we were never told until the day before he left [hospital] was that he had been in close contact with someone who had COVID and had been placed in isolation for the whole of the three weeks that he was in [hospital]. [...] They hadn't told us that he was in isolation, they hadn't told us that there was any COVID linked concern, we knew nothing at all about that. [...] ...it was purely by accident, the nurse rung my sister and told her and realised that we didn't know and was hugely apologetic and clearly concerned (Carer, North Wales, Male, Adult).

...all of a sudden in the middle of December, we get a phone call saying he's being discharged tomorrow. We had no warning of that, we had no opportunity to speak to social services about it, so it was a mad scramble. [...] I had to take half a day off work in the end to be able to ring around and make sure that we could get an OT to visit him at home because we needed to think about this wet room and all of that type of thing. [...] ...it was suddenly

decided and we had a day's notice and he was brought home on a community ambulance. [...] There was no kind of you know, 'we need to start planning now', 'are you ok', 'are you going to be home on that day', 'are you away', you know, there was none of that checking with us (Carer, North Wales, Male, Adult).

- 4.17 Participants also shared examples of a lack of multi-agency working between social services and other areas within the health system which require close partnership working, in particular Continuing Healthcare (CHC) and primary care. In terms of the relationship between CHC and social services, 'the funding issue' was one aspect cited as a major barrier to effective multi-agency working:

...as soon as a person you care for is then fully funded by the NHS as in the Continuing Healthcare team, the social services just take one step back and don't help at all and do not intervene when even though they are supposed to be there [...]. This is a big problem and what I found, as soon as my son hit the adult years of going into the team, the social services just wanted to wash their hands of him full stop, by trying to get him over to the CHC's simply because of the funding issue (Service User and Carer, South West Wales, Female, Adult).

- 4.18 Within primary care, whilst recognising the need for patient-confidentiality, carers expressed concerns over a lack of knowledge amongst GPs about how their partners in social services operate:

From memory, I think the person I spoke to checked PARIS⁴⁰ and said 'yes there is a note here that a social worker is being assigned to [Service User]'. So I'm assuming and if my memory is correct, the hospital had involved the hospital social workers who were a separate team and a separate location out of county really. So we didn't really have any kind of link with them until [Service User] was at home (Carer, North Wales, Male, Adult).

The social worker wouldn't talk to the nurse and I suppose that's for confidentiality reasons that that's actually ok, you don't want every Tom, Dick and Harry and social services having, you know, direct access to someone's medical records, that's not ok. But, I don't know, the fact that the GPs don't really know how social services work but they always get surprised when you tell them things you know as if it's unusual (Carer, South West Wales, Female, Adult).

⁴⁰ PARIS is a local government-based record, case management and reporting system for social care.

4.19 In contrast to the data presented in the section detailing 'relationships with health services' above, a feature that had worked well in the view of participants was the 'single point of access' team, which acts as a 'front door' to services to ensure people receive the right care, in the right place by people who have the right skills at the right time:

...we contacted the [third sector organisation] and the [health] team through the single point of access... [...] I must say the single point of access team, they were really quick putting them in, there was no hint to me of there being any elements of kind of trying to get away with giving [Service User] the minimal. They wanted to put in the right stuff for [Service User] at the time they visited and get it done quickly. They were very good with timescales, if there was going to be a delay I'd have regular phone calls or my sister would. So the single point of access side of it was very good (Carer, North Wales, Male, Adult).

Mental health services, including Child and Adolescent Mental Health Services

4.20 Individuals with experience of Child and Adolescent Mental Health Services (CAMHS) relayed similar issues to those presented in the preceding sections. In the extract below, a parent-carer explains their experience of ineffective multi-agency working between social services and CAMHS, describing a 'blame culture', with neither sector taking responsibility:

I think the relationship between the social worker and CAMHS, you know, the local authority and health board is horrendous. It appears to me that CAMHS will always say that's for the local authority to deal with, that's the local authority responsibility, where are the local authority why aren't they in this meeting that we called an hour ago sort of thing [...]. It's almost like it's some sort of blame culture it feels like and we are the piggy in the middle between the CAMHS system and the social worker. One of them saying 'oh well that's not good enough the local authority should be doing that' and then the local authority is saying, 'no that's not within our remit that's for CAMHS to do we're not trained in mental health that's what they need to be doing' (Carer, South East Wales, Female, Adult).

The same participant referred to a perceived disparity between the greater provision of care and support for physical health needs when compared to mental health needs, identifying an issue of variation across partner organisations, points expanded upon in the section below.

- 4.21 Other service users and carers discussed challenges in accessing mental health services, citing long waiting lists as a detriment to their mental health. Despite having been part of the social care system, their feelings of frustration and exasperation at a lack of effective partnership working were evident:

...you can ask a hundred different social workers, teachers, health care, GPs whatever for access to CAMHS, the waiting list, it's come down don't get me wrong, but the waiting list is monumental (Carer, North Wales, Male, Adult)

I've talked about my mental health, how long we've got to wait for it and mental health and waiting lists are very important because your mental health gets worse. [...]. Like I said I've been experiencing problems for three years and they are getting worse, I'm going downhill and I've tried to talk to the doctor cos he's concerned about me and they've said you need counselling for mental health. Three times I've gone to a counsellor but it hasn't worked, they didn't have a Cognitive Behavioural Therapist, so how long will I be waiting? (Service User).

Variations in approach to multi-agency working within and between LAs

- 4.22 In the view of respondents, variations clearly exist between and within LAs in Wales in how they work, communicate and share information with each other to support service users and carers. This is particularly important for those moving between different LAs in Wales. Delays in information being shared between LAs had led to disruptions in the provision and seamless continuation of care and support.
- 4.23 Challenges were highlighted when transitioning a care package from one LA to another, a key aspect of multi-agency work in Wales, and an issue that the Act tried to address in facilitating the portability of assessments:

...[Service User] is still waiting for contact from [current LA] Social Services. [Service User] moved I think it was March, and the social worker in [previous LA] took ages to pass all the information over to and contact [current LA]. In the end, the support worker had to contact [current LA] Social Services to ask whether they had heard anything from the [previous LA] social worker and they hadn't so it's not their fault. Eventually, they have now and [Service User] is just waiting to hear from them but goodness knows when that will be (Carer, South East Wales, Female, older person).

- 4.24 A further example was provided by a carer who described their experiences of accessing Direct Payments in two different LAs. Whilst the eventual outcome was a

positive one (awarded an 'extra 5 hours' Direct Payments), the process of transitioning their Direct Payment entitlement had been hampered by a lack of joined up, cross-LA working. This was described as the LAs '*not singing off the same hymn sheet*' due to variation in each of the individual LAs' interpretation of the legislation. Delays in information being shared between LAs led to disruptions in the provision and seamless continuation of care and support.

- 4.25 Furthermore, there were concerns noted in the context of different LAs sharing information between their social services teams:

I don't understand, it just feels to me like that that is an accident waiting to happen. Sooner or later someone will fall massively through the gaps because there was nobody with an overview, there was nobody doing actual case management or understanding individual people. [...] I've spoke to a lot of different departments in social care at LA and it did not in any way fill me with confidence that the individual departments talk to each other (Carer, South West Wales, Female, Adult).

Transitional planning from children to adult services

- 4.26 In the context of multi-agency working and the transition from children to adult services, improvements in transitional planning since the introduction of the Act were acknowledged by a minority of participants, yet accessing such services was felt to be dependent on factors that related less to the circumstances faced by people, and more to do with how vociferous people were:

The only thing I will say which might be slightly better than has been since the Act has come in is the fact of maybe slightly better transitional planning from child and adolescent services into adult services and that again is a lottery dependent on which parent is shouting (Carer, Mid Wales, Female, Adult).

- 4.27 A lack of appropriate planning and preparation was seen as hindering a seamless transition between children and adult services. The excerpts below refer to a shifting of responsibilities between the two services and the impact of not having a social worker to provide support through the process:

It didn't even happen properly, forget that. I mean, you know, transition just doesn't exist, it's supposed to happen at 14, it just does not exist full stop. [...]. Children's Services tried to put him, 'oh he's 16 now, let's move him over to Adult's Services now, we are not going to wait until he's 18'. They tried to do

that, which didn't really help at all (Service User and Carer, South West Wales, Female, Adult).

...it's a process that you need, you actually need a social worker's help for this to, for it to be effective, to plan that transition over a period of years and when the social worker just vanishes and they don't replace them, your plan is scuppered really, you've almost got to start again (Carer, South West Wales, Female, Adult).

- 4.28 Other concerns focused on services bringing a halt to support in the lead-up to the transition leaving carers in a difficult place between services, and facing a reduction in provision within adult services compared to what had been provided via children's services:

...it's almost like CAMHS have pressed pause on what they are doing they don't want to do or start anything else because we are leaving that service soon. So you are almost too old for one type of service but you're too young for the other service, so we'll just leave you dangling in this middle bit for now (Carer, South East Wales, Female, Adult).

It wasn't a good transition because they couldn't offer any day care facilities really and I was pushing, you know, 'why can't you see the bigger picture, why can't the care he gets stay until he's 25?' Developmentally he's not an adult, why can't they see what he has, what's working well with his carers? So I did make quite a noise of why can't he stay until he's 25, why change what isn't broke? (Carer, North Wales, Female, Adult).

- 4.29 However, positive developments to improve the experiences of transitioning for service users and carers by social services were highlighted, for example, the introduction of dedicated 'transition workers':

You hear a lot of horror stories about the transition and that it takes around about six months when a child is 18 to actually be accepted into adult services, just like on waiting lists and things. But they have started very recently with these new transition workers who work with the child around about six months before and six months after to transition. I think my daughter is one of the first ones to have this set up, so it's very early days and the transition worker is lovely but it's about as much as I don't know about that this is very new. [...] A lot of people have said it was needed and they have had an awful lot of issues in the past so this was something new, but I don't know whether it's been brought in in a hurry maybe or I don't know but we'll see how it goes (Carer, South East Wales, Female, Adult).

Chapter conclusion

- 4.30 Overall, there was a shared perspective on the importance of agencies not only working well together with each other, but also with the people in receipt of care and support.
- 4.31 Yet, across the interviews and focus groups, there were frequent experiences of a lack of effective multi-agency working within and between LAs, and between different sectors. In particular, poor multi-agency working practices between social services and health featured heavily in the accounts of participants.
- 4.32 Further, despite a significant value placed on third sector support, it was felt these services are not fully recognised by statutory services, which is especially problematic given that there were a number of positive examples of third sector support cited by participants.
- 4.33 As demonstrated in this chapter, an absence of effective multi-agency working in the provision of care and support was the norm rather than the exception for the service users and carers we heard from.
- 4.34 Their evidence focused on issues of variation like disparities of care and support between LAs and other agencies, differing interpretations of the Act, and delayed information sharing. Ineffective working, communication and information sharing between and within LAs, and between and within sectors, were all identified as issues to the detriment of service users and carers. For example, disruptions to the continuity of care when moving between LAs, and repeating information and experiences to multiple professionals, leading to feelings of frustration and distress.
- 4.35 Whilst there were few positive experiences of multi-agency working, aspects seen as supporting effective multi-agency working included the introduction of dedicated transition workers for those moving between children and adult services, and single-point of access teams.

5. Findings: Experiences of Voice and Control

Introduction

- 5.1 Having a strong voice and real control is central to the Act as it optimises everyone's opportunity to achieve well-being and an appropriate level of independence. Under the Act, everyone has a right to be heard as an individual and as a citizen. Citizen engagement is a central theme of the Act and advocacy has an important role to play in underpinning the wider requirements of the Act in terms of well-being, safeguarding and prevention. It can assist people with expressing their views and making informed choices.
- 5.2 The Act posits that to have voice and control, an individual must be able to feel that they are a genuinely equal partner in their interactions with professionals. It is a principle of the Act that a local authority respond in a person-centred, co-productive way to each individual's particular circumstances.
- 5.3 Individuals and their families must be able to participate fully in the process of determining and meeting their well-being outcomes through a process that is accessible to them. The process must ensure that people are empowered to express their needs and are able to participate fully as equal partners. This must include enabling an individual to indicate if they want to have someone supporting them when weighing up options and making decisions about their well-being outcomes.
- 5.4 It is important to note that there are connections between this chapter and the section in Chapter 3 concerning the 'communication with and from service users and carers'. The difference and reason that they appear in this chapter rather than in that section is that the experiences relayed here serve to impact positively or negatively on the extent to which service users and carers feel they are able to truly express their voice, and exercise control over their care and support.
- 5.5 Participants identified two principal issues. They identified ways in which they were sometimes able to, but more often unable to, exercise voice and control. Secondly, they recognised mechanisms and approaches that are a means for achieving voice and control. One of these key approaches is another of the fundamental principles of the Act – co-production.

Being able/unable to exercise voice and control

5.6 In positive terms, respondents were able to recognise and point to a number of ways through which they were able to exercise control having been heard by those within the system. On occasion, this had occurred when groups of service users and carers had come together to express their voices on a collective basis.

5.7 Most positively given the context of this evaluation, some respondents noted a marked change over time, comparing favourably the current situation with that of the pre-Act era:

I've seen a huge difference in the approach from social workers since the Act came into being - previously I felt that I was blamed for my situation and made to feel that any support requested was a burden to the system. This has vastly changed and continues to change. I now feel that my role as a carer is valued and I'm also listened too. In fact when I had a new member of the social services team become our case worker a couple of years ago the first thing he said was 'I'm here for you, you're the most important person I need to look out for here'. I actually cried, I'd been caring for about 22 years and I had never heard anyone say this to me in all that time. Most often carers put themselves last in the queue for everything including sleep, showers and food, so this was a huge shift. Again having the right to a carers assessment recognises my role as important, it's helped me to realise just how much I do and that it's not only ok to look after myself but hugely important for those I care for as well 😊 (Carer, South West Wales, Female, Adult).

5.8 Often when positive experiences of being able to exercise voice and control were identified, they centred on good practice at an individual-to-professional level. This reflected the excellent practice of some social workers and social care professionals in enabling the dialogue to lead to service users and carers realising voice and control over their circumstances:

I don't know, in terms of the support from a certain social worker it has been really good...through all of this she has been really sort of, on my daughter's side. There for her and for us and so you know you do hear as soon as you think social services, social worker, you're like 'ooh they are going to take my children away' and it's not that at all, they are supporting you as a family and what you are going through so that you can stay together as a family and yeah she has been really, really good (Carer, South East Wales, Female, Adult).

We've now got the integrated autism team involved with her since early last year, who have been absolutely brilliant, I can't speak too highly about them, but of course they don't fund care packages or anything but they've seen her, they've assessed her, they've talked with the mental health team as well who have now at long last...assessed her (Carer, South East Wales, Female, Older Person).

5.9 For others who were able to reflect positively on making their voices heard, they had to rely much more heavily on their own agency in order to achieve the outcome they wanted than they had envisaged would be necessary.

5.10 One further positive was the example of a multi-agency team who were perceived to be effective given that they had open dialogue with those they were supporting:

I'd say communication is just so important, especially over COVID to reassure, people are quite understanding and it's just reassuring people, 'yes I have had your email I'll be back to you soon as I can.' And you get that from the integrated autism team which is a newish team, you get that, there are social workers, psychologist and nurses all work together and they really do communicate very well where as social services are not so good (Carer, South East Wales, Female, Older Person).

Tokenistic approach to listening

5.11 Whilst some service user and carer experiences had been positive, many more reported that they unfortunately had not benefitted from being able to exercise voice and control. A number of participants identified that their dealings with social services had been characterised by professionals going through the motions and 'ticking the box' in respect of voice and control (as first identified in Chapter 3), but not acting on what was said:

I think actually that we do sometimes get asked it in the way of, 'oh this is working really well isn't it,' in that sort of way. And if you say 'well actually I don't really think that's appropriate' or 'that's not going to work what about this' then you don't actually ever get a reply to that or it's 'oh yes I'll pass it on to my manager and get back to you' and you are still waiting for somebody to get back to you (Carer, South East Wales, Female, Adult).

I would like people to listen and act on what we actually say. For instance the OT rung me the other day and her opening question to me about my daughter that she said 'how are you today', and I thought 'oh this is great she is asking me how I am, brilliant'. So I said 'I'm really not very good at the moment, my

mother in law is ill, my mother has fallen in hospital and my daughter, my other daughter that I rely on a lot has fallen and is on crutches'. Her next sentence was, 'Moving on then...' (Carer, South West Wales, Female, Adult).

Because you know, you can hear it in people's voices when they are on the phone, I can hear that somebody is not listening to me, I can hear that they've got a tick box that they are going through you know and just knowing that that support isn't there anymore. (Service User, South West Wales, Female, Adult).

- 5.12 Crucially, this centred on the ability of those involved to get beyond hearing what was being said, to an understanding of what was being said, especially for those with additional communication challenges like people living with dementia:

It's the understanding that lies behind asking those questions that's important, it's no good just doing a tick box 'yes I have listened to this person' but have you understood what level of need there is? I don't know, it makes me think 'well even if my voice is being heard you don't understand what I'm saying' (Carer, South West Wales, Female, Adult).

Power imbalance

- 5.13 Sitting behind some of the challenges in respect of service users and carers being truly heard and exercising genuine control, was an inequality in the power of the respective parties as expressed by respondents:

They met with me which was good you know, I had about half an hour with them but I think there was two of them there, they were quite powerful people, they looked powerful, they were behind the desk, they didn't make it easy for me I didn't feel, you know and I'm not an aggressive nasty person you know, I was doing my best to fight my mum's cause but I think they just, it was just sort of the business line coming back at me all the time, they weren't friendly and reassuring to me (Carer, South West Wales, Male, Older Person).

It's very different when you then become a very lowly voice with very little support behind you, you are already adjusting to the loss of [a parent] ... you are already adjusting to the impacts of the family dynamics, which families have whether they are open about it or not, you are already adjusting to all that and on top of that you have to actually battle, it's bad (Carer, North Wales, Female, Adult).

- 5.14 Part of this power imbalance centred on who holds the key to the information that is needed in order to take conversations forward. All too often in the evidence provided were occasions when service users and carers perceived that they were

being kept away from information that they need which disempowers them in respect of their ability to exercise voice and control:

I don't think people are given correct information to work with, we're kind of kept in the dark so...that adds to the feeling of a lack of self-control because you can only feel a sense of control if you've got knowledge and that needs to be given to you and you have to take responsibility for getting it too, but I wouldn't say people feel empowered or have a sense of control at all (Carer, South West Wales, Female, Adult)

Because often you'll have 'oh we've had a professionals meeting together'. And I'm like 'well the most professional person in the room who knows about my child is me, not somebody who has met her for an hour a week for six weeks, you know, you don't know that child at all' (Carer, South East Wales, Female, Adult).

- 5.15 One of the reactions to this from service users and carers was the building of a sort of 'siege mentality' within families, pitting them against social services, rather than collaborating or working together more co-operatively.

Fighting with or chasing social services for support and/or recognition

- 5.16 Following closely on from this previous point was a very strong sense that came through in the evidence that as a consequence of not being listened to, service users and carers took to chasing and battling with social services departments to ensure that their voices were recognised and indeed heard. All the while this ran the risk that they would be seen as 'challenging' for doing so:

But as an example then I emailed straight back with some details she'd asked for and she was meant to email me back the same day and she didn't and this is a common experience of families that you have to chase and chase and chase for anything to be done. That's part of the full-time job of being a carer, endless phone calls and nagging and you have to get to know what services are available and I really fear for some families who may be and I mean this in the nicest possible way, they haven't got the intelligence, haven't got the resilience that they will just fall through the net (Carer, South West Wales, Female, Adult).

But, I have asked, 'what happens now'? And people say 'ooh, I don't know, oh we haven't been asked that before', you know those sorts of things, and I want to say, 'well you are being asked it now so please find out', but I can't, I'm not

that confrontational sort of thing so you just sit back and think, 'oh here we go again' (Carer, South East Wales, Female, Adult).

Now once you have raised your heads above the parapet and I don't know if this is true, I suspect it is but then carers are not finding people to raise their heads about the parapet, that's the problem but once you do that you are, you are labelled. So from the very beginning I'm afraid, we became a difficult family (Carer, North Wales, Female, Adult).

- 5.17 The lack of voice and control came up in respect of children and young people with autism, whose parent carers perceived that there is a sense in which they have to fight for the recognition and support of their children's needs. Why that was is hard to say, other than perhaps this was a reflection of the ongoing pressures and responsibilities of having to support children with complex needs:

You know just because, and you see it all the time, a young person who is in a wheelchair or has limited mobility or has Down's Syndrome sometimes receives more understanding than autistic, non-verbal for their actions that they, because there is no visual. No visual, no issue. You know, and we know that that's not right (Carer, Mid Wales, Female, Adult).

We've got to learn about autism, we've got to learn about ADHD, it's a whole new ball game again and there is no support for that again as a parent you've got to find all that out yourself. So yeah you know being a carer is not just about caring for your child's needs it's all that other stuff that goes on in the background (Carer, South East Wales, Female, Adult).

My wife and I are also on the [local] committee of the [national voluntary organisation] so we hear a lot of similar stories, I know I probably can't speak on behalf of other people but it's a general consensus that if you are not strong enough and you haven't got tenacity then you won't get services for your children, your young people, your family, you've got to keep on it (Carer, South West Wales, Female).

- 5.18 Respondents spoke about a requirement to be constantly challenging, constantly 'on it' to ensure that their voices are heard and how this is difficult to sustain. It is instructive to note the following participant's view that, due to the challenges being faced by carers, they felt unable to contribute to this study as a means of exercising voice and control:

I am trying to encourage other families to take up the offer to give them a voice and a sense of control, you know even if they were part of a very small

change, it's small changes that make a big change, but I've hardly had any responses and the reason is people are so broken and tired you know (Carer, South West Wales, Female, Adult).

Cultural insensitivity as a barrier to being heard

- 5.19 The final issue that was raised as a barrier to enabling effective voice and control for service users and carers by some respondents was a perceived lack of cultural sensitivity on the part of social services and their partners. Black, Asian and Minority Ethnic respondents identified a number of ways in which their cultural and ethnic identities were appropriated in discussions about their care and support packages:

There are ongoing communication challenges. People who work in social care have often no ways of communicating with older people from ethnic minority communities. Many of the older people I know also have hearing problems even though they pretend that they can hear which means that the communication challenges are even harder...Under COVID, we are still experiencing some cultural insensitivities. One example is people refusing to remove their shoes as they come into the house. I can't understand how people are allowed to wear their uniforms in and out of work especially in hospitals. There is often an unwillingness to listen to our worries about things like shoes being removed from houses, we don't have a very positive outcome from those conversations (Carer, South East Wales, Female, Older Person).

- 5.20 For other Black, Asian and Minority Ethnic respondents, these issues went beyond cultural insensitivity towards explicit prejudice and stereotyping. Their perspective was that when being assessed, some social services staff made judgements about them in respect of their family life, the traditional roles ascribed to women, and their skin colour, which were clearly felt to be negative:

I did ask my social worker one day whether the way that I've been treated has got anything to do with the colour of my skin and she just said to me 'no, why would you think that?' I was receiving, or not receiving the help that I needed, that my son needed. And when complaining to those higher up, the managers there didn't return phone calls. And I did think it might be because of my name and the colour of my skin (Carer, Female).

So as a family, we are a big family so she was brought down to stay with a relative, and that relative was an older relative that couldn't look after children, and there was no support given, there was no help, there was no checking up...And I think race has a big part to play in it because I often think that when

it comes to bigger families, it's assumed that they are self-sufficient, that they don't need help, that they can do everything, that they can fit these cultural social needs of this particular person (Carer, Female).

I believe that we do get alienated very often by certain organisations, because all they do is they just kind of judge you off how you look and like what colour your skin is and how you are able to articulate words, it's never about what the actual problem is...it's always excuses when it comes to us and that's just my opinion on it you know, everyone's story is different but that's just how I see things (Carer, Female).

Race does play a huge part – I think we are judged as soon as we are seen. You can't tell from my name or my mum's name but as soon as the social worker turns up to my mum's home there was like a fear on her face. And the way, when you live with racism all your life you can just pick it up from a nuance from the way that they look, from the way people look at you. From the tone in the voice, the way they ask, the way people ask you questions, because you've lived with it you can pick it up. And as a professional as well as an unpaid carer most of my life, it is really, really challenging. It's absolutely challenging (Carer, Female).

Mechanisms for achieving voice and control

- 5.21 The second substantive issue within this theme related to the extent to which effective mechanisms were in place in order that service users and carers could exercise voice and achieve control.
- 5.22 Four such mechanisms were discussed: the role of legislation and the rights 'agenda'; using the complaints process to register voice and regain control; the importance of Direct Payments providing more say for service users and carers; and the way in which co-production has been supporting voice and control since its introduction as one of the fundamental principles of the Act.

Legislation and Rights

- 5.23 There was much positivity about the ways in which legislation has been developed in Wales (thinking about the Social Services and Well-being (Wales) Act 2014 alongside the Well-being of Future Generations (Wales) Act 2015) and the extent to which the fundamental principles under the Act were supported. However, there was a recognition from respondents that there was a real need to self-educate if service users and carers were going to be able to use the legislative landscape to challenge decision-making, ensure that their rights were upheld and their voice heard:

I have had to inform myself of my own rights rather than what I would've expected that the so-called professional would inform me of this. I had to challenge the service that I am supposed to get. It is a very an unequal relationship that I have with the council. There is no understanding that people can be both a carer and have a disability. This is not taken account of (Carer).

No, and they didn't tell me that and it and like the fact that I know about the Equality Act now about the Social Services Well-being Act about the Human Rights Act. All these things I've had to sort of educate myself, they tell you nothing about it, nothing (Carer and Service User, South West Wales, Female, Older Person).

- 5.24 Despite this self-education, and the support of independent advocates mentioned by several respondents, the majority of participants described the need to 'battle' with social services to realise the ambition of the various relevant pieces of legislation that have been produced over recent years. However there was a general sense of improvement identified, but with some distance still to travel:

We've got the BSL Act but we haven't seen any changes for it, still going through the process, they should have sorted all of this 50 years ago, nothing has happened over the last 50 years. I feel really sorry for people years ago when there weren't any interpreters (Service User).

I do agree that things are slowly, slowly improving over the years in general but it's just still not meeting what is promised and what legally should be in place, what the rights of carers, what the rights of disabled people are, it just isn't implemented (Service User, South West Wales, Female, Adult).

You've got Equality Act 2010, so my niece is explaining it to me and said, because historically deaf people didn't have interpreters so hearing people would be speaking and a deaf person would be sitting there not knowing what

was going on but since 2010 we have the right to an interpreter for meetings or doctors or for I don't know if you were involved with the fire or police we are supposed to have equal rights but we don't (Service User).

- 5.25 More negatively, there was a degree of cynicism expressed about the fact that these rights seem somewhat illusory to a number of service users and carers which serves to undermine their status:

But why are they a long, long way away? Because the reality is they were never enforced. We have rights, dad's human rights, the barrister for the [organisation] said dad's human rights had been breached and which part of the human rights had been breached, but there was no enforcing, nothing happened. Just because he has human rights, what does that mean if they are never enforced or there's no legal system to support a carer who is battling for human rights or whatever? There is no way to access any legal funds (Carer, North Wales, Female, Adult).

...when I've quoted the Social and Well-being Act to [LA] and say 'this is what the Social and Well-being Act says' they just ignore you, they don't even bother replying. So I'm on day 13 of the response to our formal complaint (Carer, Female).

- 5.26 Echoing this point, participants with a good understanding of the Act felt that when attempting to ensure that LAs complied with their duties, their rights as social care service users and carers were not recognised. In the face of this situation, some questioned the meaningfulness of the legislation:

The (sic.) Social Services Act 2014 is supposed to give people like me legal rights isn't it? I'm a carer ok, I've got a disabled child and I also look after my Mum, so I care for two people. The Act is supposed to protect us; it's supposed to give us rights, so basically in a nutshell it's a law to say that it's a legal right of ours to be able to access support like respite and all kinds of things. Under that umbrella, things like working carers come into it, it's quite a big umbrella isn't it but, in actual fact we don't have any rights and the reason is because even if it's written in law there is no way for people like us to actually force local authorities to adhere to any of these laws. So actually, they might as well be written in toilet paper (Carer, South East Wales, Female, Adult).

Complaints

- 5.27 Some respondents had instigated formal complaints processes, borne out of a sense that they had been discriminated against by social services, and were trying to seek redress in a variety of different ways.
- 5.28 More generally, comments were made about the complaints process itself, with some voicing a reluctance to complain because they fear the consequences, and others expressing a frustration with complaints processes. They provided evidence of the barriers to being able to regain their voice and subsequent control through the complaints process, and their frustrations because of this:

I tell you what, it is beyond frustrating because you are constantly banging your head against a brick wall and how they deal with it is they just ignore you, you know, complaints and things are just totally ignored...and of course what people don't realise is with complaints basically you've got to go through stages with a complaint ok, so basically this is how they get away with it, this is why you can't escalate a complaint you see because they just don't respond to you so you can't escalate the complaint, you see what I mean because they've got to actually acknowledge they've received the complaint and they don't, so you can't escalate it and this is what happens (Carer, South East Wales, Adult).

When you make complaints [...] nobody does take responsibility even if gave them the Act word for word, this is what's meant to be in place, this isn't in place for my son, this isn't in place for me as his carer who's supposedly got as much rights as him, it doesn't happen so where are you supposed to go, what are you supposed to do? (Service User and Carer, South West Wales, Female).

Yes it is when you are at your most vulnerable and you need the support from a professional and then they say you have to go through the complaints procedure and you're still not listened to or actions followed it is very soul destroying because [...] I've been a carer most of my life but with my mum and she is living with dementia and knowing how proud she is and when no one listens for a vulnerable person the impact just ripples right across the family, not only for my mum but for my children, the grandchildren as well. There seems to be, there's nowhere to complain and have those concerns listened to and acted upon it seems so that everybody closes ranks on you, and that's it you can't go any further than you making that complaint and that's it (Carer, Female).

Direct Payments

- 5.29 Direct Payments have been a key mechanism through which service users and carers have been able to exercise greater control over their care and support for many years. Direct Payments are a way that LAs can help to meet eligible individuals' need for care and support, or a carer's need for support, and they are a way for people to arrange their own care and support. Direct Payments are not a form of income but are paid specifically to buy services or equipment, and are intended to improve choice, control and independence for people. Individuals can work with the local authority to decide how their care and support needs will be met, and they decide who provides that support and they control how, where and when it is delivered.
- 5.30 Direct Payments pre-date the Act, but they remain an important, and perhaps increasingly important, route through which the voice and control principle may be realised.

Flexibility / inflexibility of approach

- 5.31 Respondents provided much detail on the operation and ambition of Direct Payments, reflecting first on the flexibility and inflexibility of the approach. There were a range of contrasting, and somewhat contradictory views expressed, providing little consensus on the role and impact of Direct Payments as the following quotations exemplify:

I have support three times a day to help with my meals. I don't always realise I need this help because of the effects of the dementia. I often go out at night and have become very confused and upset. I have flagged down traffic and knocked on strangers' doors because I felt lost and confused. I would like a Direct Payments allowance so I can employ someone to come for a walk with me which is what I have always done. None of my family live locally so they can't help during the week. I want to go out for a good walk – up to 5 miles a day. I asked for Direct Payments but have been declined. The support I have is carers calling to complete specific tasks, it doesn't help with my need to exercise and do what I usually do in my daily routine (Service User).

Yeah, I kinda hate Direct Payments to be honest. Like they sell them as you have this pot of money and you can decide whatever you wanna do with it. Well, one, that's a lie cos you can only decide within their, you know, reason. Also they like say you can have this money but you have to pay the person,

you have to sort out whatever the CRB check is called now, you have to do these things on top of my 24 hour care for my son (Carer, South West Wales, Female, Adult).

However, now that we receive Direct Payments, we are able to access the support we need outside of LA provisions. The independent company we use has been a godsend and is fully meeting [her] needs (Carer).

The actual, the process of getting a Direct Payment has been easy really, I've never had any struggle with proving that we needed the hours, they seem quite happy to push that through because you are doing a lot of the work, you've got to try and find your worker, that's the hard part, getting somebody. We both have managed accounts with the council, so the money side of things and sorting out wages and leave and things, I find that relatively easy because it's dealt with via [locality] (Carer, South West Wales, Female, Adult).

But trying then to find a provider out of the pool that was available within [locality] it was a challenge, alright they haven't got anybody they've got to try and match to the child. By the time they've matched to that child it was about eight or nine months down the line and then that person left so you kind of, you're stuck in that scenario. It may work for some families but the majority of families have a huge battle on their hands you know (Carer, North Wales, Male, Adult).

Unable to get provision due to confusion over 'rules'

- 5.32 Coupled with the arguments about flexibility and inflexibility, a number of respondents noted their concern and confusion over the rules around Direct Payments which has meant that certain service users and carers have been unable to get the care and support provision that they have wanted:

Unfortunately, it was not easy to get the LA to agree to Direct Payments to enable her attending this provision. Our application went before a LA panel, who turned down our application because, in their view, it did not meet my daughter needs. When we were turned down for Direct Payments we were not informed of this decision or the reason for the rejection in a timely manner, as required by the Act. However for this to be effective, social worker and their managers need to ensure they have an up-to-date knowledge of all types of service provision (Carer).

My sister was laughed at during her review when she told them what she wants to do. The council and social services rejected her application for Direct

Payments to access the private provision that she wanted to attend that would help her achieve those aims (Carer).

Need for transparency in describing the 'pros and cons' of Direct Payments

- 5.33 Respondents were concerned that there is a lack of openness in the Direct Payments process, with some worrying that there was a degree of deliberate obfuscation about some of the realities:

The [locality] website is awful, it's far too much information. I've got a friend who's disabled in [locality] and if you look at their website, they talk about Direct Payments, ah God its lovely, it's one page, you go to 'Direct Payments;' and it gives you like a sentence and big words and all that sort of thing and you choose a thing and then it goes to the next bit and so it's not, there isn't this information overload that [locality] give you. But it's also, I don't know, I get a funny feeling that they do it on purpose, so you get confused and don't ask (Carer and Service User, South West Wales, Female, Older Person).

- 5.34 Having clear and accurate information around Direct Payments was identified as an issue for service users and carers, who were concerned that they do not always get the correct information. In order to help with this, there were suggestions that social workers or independent advocates should always be available to help interpret all the permutations and options around Direct Payments.

- 5.35 Respondents identify that at times there appear to be contradictory messages in the ways in which Direct Payments are 'pitched' to service users and carers. They are promoted as one optional means of gaining additional control – *it was on the booklets as well, big glossy booklets you know, 'we'd like people to go over to Direct Payments' on the Social Service Well-being Act booklets (Carer, South West Wales, Male, Older Person)*. However, for some, Direct Payments were 'mandated', undermining that sense of choice: *everything was Direct Payments that they wanted and I felt forced to do it (Carer, South West Wales, Male, Older Person)*.

- 5.36 There were also concerns expressed about the extent to which people were really free to use Direct Payments to suit their needs and well-being outcomes which they had been told was the point of Direct Payments when they had been informed about them:

The other thing that has come about since then is the fact that Direct Payments do not see my PA as being an extension of me. They see my PA

purely to sit and watch my wife and therefore they said she cannot feed my wife, she cannot administer any medication, she cannot change her stoma, she cannot empty her catheter bag, she cannot wipe her face. She can't do anything. I then have to turn to health and say to health 'can you provide this?' (Carer, South West Wales, Male, Adult).

Sufficiency of budget and capacity within the PA workforce

- 5.37 Finally in respect of Direct Payments and employing personal assistants (PAs), there were significant concerns raised over the extent to which PAs were available within the workforce to employers. This is a continuation of the broader issues of workforce availability raised in Chapter 3, but more 'focused' in the sense that if people on Direct Payments do not feel that the overall budget that they have is sufficient, this can lead to them not being able to employ PAs, and be left without anyone to support them:

However, then what happened was the care package we had in place initially when he was under social services was Direct Payments. I struggled to find care [workers] full stop, lousy wage, basic wage and the bottom lines...we've had care workers lie, we've had care workers literally just sit there not do anything and then as soon as my son holds them tight or just excited, never mind being challenging, they just leave, walk out and that's it...so it's a struggle with Direct Payments (Service User, South West Wales, Female, Adult).

There were discussions around upping his Direct Payment hours for example but again the reality of that situation is that...due to poor care workers' wages it's incredibly hard to find PAs and we are extremely fussy as well as you should be so it can take a year really to find a good match for your child, your young person (Carer, South West Wales, Female, Adult).

It just kind of went on and on but their response is you know 'well the Direct Payment is £12.66 an hour', to get specialist dementia care costs I think it was £23.95 an hour for the agency that I did use. So you know 12 hours a week extra, that extra payment that I was then paying was huge and I think that eventually they contracted the agency directly in a way to shut me up shouting about the fact that a Direct Payment is not enough for what it's intended for because you know the bit they did keep saying 'you should have a personal assistant', I kept saying 'I don't want one and the Act says I don't have to have one' you know (Carer, South West Wales, Female, Adult).

We couldn't find a PA to be honest, they just weren't out there...people would apply for the job but then when you shortlisted them, they would withdraw their

applications and maybe not turn up, so yeah extremely difficult and then [name] came into contact and said she could do it and obviously we knew her and actually funnily enough she used to work in the day centre that my mother went to which was great (Carer, South West Wales, Male, Older Person).

Co-production

- 5.38 The fourth mechanism centres on another of the fundamental principles of the Act – co-production. 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.
- 5.39 At an individual level, the Act sets out overarching duties in relation to well-being, and fundamental to the whole approach and system is that practitioners co-produce with children, young people, carers and families, and with adults, carers, families.
- 5.40 Co-production is distinct from ‘voice and control’ as a principle under the Act, but is on the same spectrum. It is an extension to the ideas of voice and control such that power sharing and equality between all of those involved in the care and support of individuals is achieved.
- 5.41 There was relatively little mention made of co-production across the evidence gathered in this part of the study.⁴¹ To an extent, as noted by respondents, this has been influenced by the pandemic, and the lack of recent face-to-face co-production activity that has been ongoing.
- 5.42 Respondents did however identify two key issues. The first touches on the difficulty of grasping the concept and delivering on it as expressed by service users and carers:

Co-production can sometimes be seen at times as a fantastic aim but often is more aspirational than a tangible reality. For real co-production, service users must be given access to information about all the services that could meet their need. As new services come online, I recognise that this is a difficult task. My experience is that my local authority are not as proactive as I would like in

⁴¹ Importantly, additional work is being carried out on co-production which will feed into the final Impact Evaluation report in Autumn 2022.

making service users aware of the full range of provision, they tend to direct you to their own provisions and in many cases are not aware of new private services (Carer, Female)

You know even this co-production that's supposed to be in place and working with one another, the meetings you go to for that, there's great ideas and great on the day you think 'oh, something is going to change', then when it goes to who makes decisions, it doesn't happen and I think for me as so active over the years that you lose face in doing it and it becomes so tiresome and you do get a name for yourself (Service User, South West Wales, Female, Adult).

- 5.43 The second relates to the largely sub-optimal experiences of co-production that people have had. This tends to focus on things not being quite right:

The only experience I've had of co-production, I know that (name) from the Independent Living team has started, we're trying to work co-productively. It doesn't really work because he's doing it, and he's from the Council, so I don't think that's co-production (Carer and Service User, South West Wales, Female, Older Person).

It's not her at the centre of things, they should be putting her needs there, and nobody has even asked her, I know she has huge, huge communication issues but if they spent time with her she would be able to tell them which centre she prefers. But nobody has even take five minutes to sit with her and ask her (Carer, South West Wales, Female, Adult).

Chapter conclusion

- 5.44 Overall, there were challenges for service users and carers when it came to realising the prospects offered by the principle of voice and control.
- 5.45 For some people, there was an ability to be heard and to influence largely driven by the work of individual social workers rather than being supported by the ways in which systems operate.
- 5.46 However, for the majority of respondents, their experience was one of much greater frustration.
- 5.47 They identified barriers around a relatively 'tokenistic' approach to listening; power imbalances between themselves and professionals; the need to chase social services for support and recognition; and around cultural insensitivity. These all served to militate against the full experience of voice and control.

- 5.48 In respect of mechanisms for achieving voice and control, the range of legislation and rights available to Welsh citizens, the complaints process, the availability of Direct Payments, and the role of co-production as a principle of the Act were identified as means to achieving voice and control. It has to be said, however, that shortcomings in all four were identified.
- 5.49 The Act outlines that realising voice and control means that an individual must be able to feel that they are a genuinely equal partner in their interactions with professionals. There is some evidence that service users and carers feel that their experience is moving towards this, but in terms of genuinely being able to exercise voice and control, this remains very much a work in progress.

6. Discussion: Impacts on Well-being

Introduction

- 6.1 Well-being, in many ways, is the unifying principle at the heart of the Act. The Act provides a focus on the well-being of people who need care and support and carers who need support, on rights and entitlements, on empowering people to have a new relationship with social services.
- 6.2 Well-being underpins and connects all of the other principles, linking through from the role that early intervention and prevention can play in promoting well-being, to how people can be empowered by information, advice and assistance and by being involved in the design and operation of services.
- 6.3 This chapter continues to use the evidence gathered through this part of the study, but rather than just directly reporting the findings (as in Chapters 3, 4 and 5) it is more discursive in tone. The purpose is to understand the ways in which individual-level well-being has been impacted during the lifetime of the Act, recognising that there are very many contextual factors – not least of which is COVID-19 – which have had a significant influence over people’s sense of individual well-being.
- 6.4 In many ways, however, the point is to identify what can be learned about the implementation of the Act, and what else might need to be done to move closer to the aspiration that it has for the five principles, through people’s reflections on well-being. The chapter is broken down into three sub-sections.

Mental well-being, anxiety and stress

- 6.5 People talked about the impact on their well-being in relation to the support received, but also the lack of support received from social services, particularly during COVID-19. As noted in Chapter 3, despite the best intentions of all parties, there are often barriers – like the pressures across the whole system – in being able to find capacity for support within the workforce, which have been especially acute during the pandemic. This led to a range of issues around anxiety and stress for participants.
- 6.6 Well-being impacts were often described in fairly stark terms, and from the perspective of service users and carers, stemmed in part from a lack of openness and honesty in discussions with professionals, as seen in Chapters 4 and 5.

Concerns over an unwillingness on the part of some social services departments to discuss contingency plans that would be needed if, for example, the carer had to be hospitalised due to COVID-19, brought unnecessary stress into people's lives. This lack of 'peace of mind' had negative well-being impacts for respondents.

- 6.7 The well-being impacts that were described were often done so in emotional terms – both in the sense that they described how participants' interactions with social services had made them feel, but also in that they were often very emotional in re-telling their experiences. These feelings were heightened by people's perceptions that the stress that is experienced could be alleviated to some degree.
- 6.8 The impact of being a carer – especially for young people and young adults who are acting as young carers – was described as more than just stressful, in that it caused in some cases a fundamental reconsideration of the nature of the relationships within families, to negative effect. The perception of some respondents that this was a role that 'had' to be done without any real discussion of whether the young carer wanted to undertake it or not. This sense of duty was also at the centre of a number of negative well-being impacts, especially in respect of mental well-being.
- 6.9 Being to an extent 'forced' into a situation where individuals had to live with relatives and act as carers, precipitated by the lockdown, also brought about negative impacts on well-being for respondents. These impacts often weren't immediately apparent at the time, but with the benefit of time to reflect, respondents identified feeling additional pressure as carers. The negative mental well-being impacts for some were profound, and this was exacerbated when they were unable to find care workers to provide the hours of respite they had been granted.
- 6.10 Two other issues that caused stress and negative impacts on mental well-being within families were present in the evidence. The first concerned the nature of the personal care that was required of carers, and the extent to which they often felt anxious and stressed in having to undertake very intimate care for their parents or relatives. The second centred on the 'battle' that fell to the family when care workers did not turn up for scheduled calls, leading to a very stressful conversation with care agencies and LAs.
- 6.11 All of the factors identified above have combined – along with system pressures like additional demands on budgets and workforce sustainability challenges, alongside

the global pandemic – to leave service users and carers feeling anxious, uncertain about their position, and that their mental well-being has been very negatively impacted.

Isolation, distress and feeling like a burden

- 6.12 Respondents also reflected on the ways in which their interactions with the system could lead to feelings of anger and frustration on one hand, and desperation, distress and feeling helpless on the other. Either way, these were expressed in negative well-being terms.
- 6.13 Strong feelings of anger were linked in the narratives of service users and carers to being emotionally and physically exhausted. Respondents noted that the amount of effort that is required to sustain their caring role can lead to excessive tiredness and exhaustion, which has been amplified and exacerbated by the forced isolation brought about by COVID-19.
- 6.14 The result of this for a number of people in well-being terms was a loss of control and a growing sense of desperation and helplessness about their situation. Feelings of distress and disempowerment were common, and whilst participants readily acknowledged the role of COVID-19 in enhancing these issues, some also reflected that the Act had not brought about the changes in their circumstances for the better that they had expected or hoped.
- 6.15 Participants suggested that simple things – like the fact that all too often social services departments did not return telephone calls or emails – contributed to a growing sense of isolation. This had led to them feeling like they were a burden and a drain on resources, with negative consequences for their well-being.
- 6.16 In addition to this, participants who were caring for people living with dementia, suggested that in their view these issues of isolation and feeling like a burden were heightened, due to the additional challenges of dealing with dementia. The carers in that situation expressed that they felt additionally vulnerable.
- 6.17 There was an overall sense – in the views of the participants – that in their interactions with service users and carers, there was a lack of empathy from social services to their situations and circumstances, and a tendency of the paid workforce

to reflect more on the pressures that they were experiencing themselves, than those of the service user, carer and family.

- 6.18 Service users and carers reflected that this lack of empathy led to a disconnection with social services at a time when it was most needed. People described a sense of 'disdain' from some social workers, whilst others simultaneously recognised that there are a significant number of thoughtful and compassionate social and care workers across Wales.
- 6.19 The impact that greater empathy could have was linked to a potential increase in well-being, such that people could feel much more positive about the instability and impermanence of their care and support packages.
- 6.20 There was, however, a sense in which the lack of empathy that people felt had a series of unintended consequences. One of these was that people often felt compelled to raise issues that they believed were not being given sufficient attention by social services. This in turn caused some of them to feel that certain social services departments 'labelled' them as troublesome.

Resilience and peer support

- 6.21 The resilience to continue with caring roles and responsibilities – especially during the extreme experience under COVID-19 – was remarked upon as being particularly noteworthy. Carers described the considerable strength they need to deliver the 'duties' they feel they have to undertake, which has had positive well-being impacts – less for them, but more for those that they are caring for.
- 6.22 Similarly positively, and of especial value during COVID-19, a number of participants identified the contribution that their peers had made to maintain their well-being. It was suggested that the sort of peer support that carers receive from others, alongside the support of key voluntary sector organisations, has improved their quality of life and feeling of well-being just for knowing that there is someone to talk to if it is needed.
- 6.23 This was particularly valued by carers who were supporting a person living with dementia for, as some indicated, they had few others to talk to. Being able to share with others in the same sort of situation had served to empower a number of them.

6.24 This was also the case for young carers who found the opportunity to spend time with their peers – albeit in a different form during the pandemic – enhanced their sense of well-being, and was both valuable and sustaining.

Chapter conclusion

6.25 As noted at the outset of this chapter, it is important to recognise the central role that well-being plays in the Act. Participants in this study have identified some positive well-being impacts relating to their contact with social services, but more ways in which their experiences have led to negative impacts.

6.26 The pandemic has clearly played a key role in shaping people’s feelings about their well-being – whether as a service user or carer. That is not to overlook the issues that exist within the ‘system’ that many of them have reported, but it is to recognise that from their perspective, COVID-19 has served to ‘reveal’ and bring to the fore some of the underlying pressures that were impacting on well-being that existed before the pandemic.

6.27 It is overly simplistic to draw straight-line connections between people’s self-reported well-being, and their experiences with social services – it is much more nuanced and complex than that as our P-FE framework and approach recognises. However, it is important to note that the evidence provided here offers an insight into what people think about their well-being, and the role that social services can play in trying to support and improve it, as envisaged by the Act.

7. Conclusions

Introduction

- 7.1 Very many hours of social care and support are provided on a daily basis across Wales to people in need of that care and support and their carers. This study has tried to capture and understand the extent to which the Act's principles are driving the experiences of those service users and carers.
- 7.2 Many of those services are being delivered and experienced in line with the aspirations laid out by the legislation. However, there is ample evidence from this study that the experience of service users and carers is sub-optimal. There are a number of significant structural factors that help to explain this, not least of which are the global pandemic, budgetary pressures and growing demand, challenges over workforce sustainability, and the relative 'newness' of the Act.⁴²

Answers to key questions

- 7.3 In moving towards conclusions at this stage of the study, in the following section, we have brought together the three areas of focus for this report⁴³ and then mapped these against the questions from Patton's P-FE framework that are germane to this report (see Figure 1.3 in Chapter 1).

To what extent do people feel that services have worked in partnership with each other, were fully integrated and were streamlined to ensure the best possible care was provided to them?

(Covering P-FE Q2: To what extent and in what ways are the principles being adhered to in practice? and Q3: To what extent and in what ways are the principles leading to the desired results?)

- 7.4 An absence of effective multi-agency working in the provision of care and support was the rule rather than the exception for service users and carers who participated in the study. Variations in the way in which agencies work together exist, and in the

⁴² This point about the relative 'newness' of the Act was made in passing by some service users and carers, but was reflected on extensively by the workforce – see the [Process Evaluation](#) report. It has been brought in here as a point of connection between the two datasets.

⁴³ Taken from the WG specification, these are the extent to which services are being delivered in partnership with each other; the extent to which people feel involved in decisions about their care and support; and the impact on quality of life and well-being.

view of service users and carers, this is often to their detriment meaning that some people do not have access to services and support that others are receiving.

- 7.5 In particular, poor working practices between social services and health featured heavily in the accounts of participants, and despite a significant value placed on third sector support, it was felt these services are not fully recognised and valued by statutory services.
- 7.6 Acknowledging the overlap with issues around voice and control below, service users and carers expressed a desire to be more involved in multi-agency decision-making, and be informed with information and guidance about their care and support. This has not often been the experience of our participants – on the whole, respondents spoke of experiencing a lack of meaningful involvement when multiple agencies are involved in their care.
- 7.7 Participants are clear in their view that they want professionals to more confidently relay and explain information to them, especially when those professionals are working in close partnership with each other.
- 7.8 Respondents also noted the importance of continuity in the relationships that they have with professionals in social services and their partner organisations. They identified the difficult consequences that follow from staff turnover, and the negative impact that losing trusted relationships has for meeting their needs and maintaining good communications.
- 7.9 In respect of multi-agency working therefore, much remains to be done. There is evidence from service users and carers that the challenges of moving to new ways of working remotely under a situation of considerable stress precipitated by the pandemic has stalled, and in some places reversed, some of the progress towards the co-location and integration of professional multi-agency teams that was being made.

To what extent do people feel involved in the decisions about care and support?

(Covering P-FE Q2: To what extent and in what ways are the principles being adhered to in practice? and Q3: To what extent and in what ways are the principles leading to the desired results?)

- 7.10 Typically, service users and carers identified challenges when it came to realising the prospects offered by the principle of voice and control and being involved in decisions about their care and support.
- 7.11 Some participants noted that they had an ability to be heard and to influence, and where this occurred, it typically centred on good structures in place locally – around Direct Payments and taking control of employment relationships for example – or was down to excellent social work practice.
- 7.12 The majority of respondents, however, felt stymied by the number of barriers they encountered around:
- ‘tokenistic’ approaches to listening;
 - power imbalances between themselves and professionals;
 - the need to chase social services for support and recognition; and
 - cultural insensitivity.
- 7.13 These issues were exacerbated by shortcomings identified by service users and carers in being fully able to access the rights available to Welsh citizens enshrined in legislation, complaints not being taken forward to their satisfaction, challenges in the ways in which Direct Payments operate, and the ways in which potential benefits associated with co-production have not yet been realised.
- 7.14 Overall, there are some, but a small proportion, who reported that being listened to allowed them to exercise control over their care and support in the ways that the Act envisaged. For the majority however, this was not the case, and they felt a long way from the vision as proposed by the Act. A matrix of structural barriers, and too little power sharing, around issues of co-production for instance, led to people feeling that their voice was not heard. From the data collected for this report, questions emerge about whether the current practices supporting the voice and control principle, on the whole, are leading to the desired results.

What impact has the legislation had on the quality of life and the well-being of those who receive care and support and carers who receive support?

(Covering P-FE Q3: To what extent and in what ways are the principles leading to the desired results?)

- 7.15 It is important to recognise the central role that well-being plays in the 'life' of the Act, and as outlined in Chapter 2, the complex structural and interpersonal factors that influence well-being. Any changes to well-being take a very long time to become visible in population-level data. However, participants in this study identified relatively few positive well-being impacts linked to their experiences with social services. As with elsewhere, where these positive impacts occurred, they were often down to good relation-centred care and support, practised by excellent social workers and social care workers.
- 7.16 Factors reported to impact negatively on well-being included the perceived lack of empathy shown to service users and carers, leading to a series of undesirable feelings –frustration, distress, feeling helpless, isolation, stress and perceptions of being a burden. Peer support groups were notable in the positive role that they have reportedly played to bolster and maintain service users' and carers' well-being.
- 7.17 Demands associated with undertaking caring relationships were also identified as a material factor impacting negatively on well-being. The constant need to juggle caring responsibilities alongside work and family pressures was reported to be challenging, and feelings of being 'boxed-in' in part due to shortages in the paid workforce, also impacted on how people felt about their well-being.
- 7.18 In line with the other sections of this concluding chapter, the well-being impacts experienced by service users and carers in this study, are not commensurate with the vision laid out in the Act. At this stage and based on the evidence provided by service users and carers, it is not possible to conclude that the principle of well-being, and everything associated with it, is leading to the results that the Act desired.

Implications

- 7.19 This closing section brings together some of the evidence in order to consider the implications of this dataset. These perspectives serve in the place of formal

recommendations, given that it is too early to provide these. They are an insight into the most important implications of this data.

7.20 Twelve statements and a commentary on each are provided below. The statements are paraphrased from quotations from study participants. They are an amalgam of perspectives from multiple service users and carers, and should not be seen as ‘universal’ – they do not apply to everyone in every circumstance, but they do speak to elements within the dataset. They reflect the evidence provided in the sense that there are some elements of positivity, but with much that is negative.

7.21 The commentary that accompanies the statements relates each back to the Act, its principles, and its implementation, thereby making connections with the key questions under our P-FE approach.

	Statement	Comment
1	<i>I feel more visible after the Act than before it. I have a different relationship with social services after the Act than before. I no longer feel that I have to justify everything I used to have to.</i>	For some service users and carers, the implementation of the Act has provided them with a presence that they struggled to achieve previously. More focus needs to be given to how this can happen for more people, more systematically and consistently.
2	<i>The fight is just draining. I don't want to be exhausted all the time. You have to chase and chase and chase before anything is done. How do you constantly find the energy to fight? I can't be bothered to argue.</i>	Too many people feel that the organisations that they are dealing with are unresponsive to them and their needs, undermining any attempts to deliver on the promise of the voice and control, and well-being principles. The simplest things, like keeping to appointments or answering emails in a timely fashion, would make a great difference to a great many people.
3	<i>People's lives don't fit into neat outcome boxes.</i>	The structures around social care and what is offered to whom, and under what circumstances, is not felt to be sufficiently nuanced to reflect the complex and messy realities of daily life. Well-being outcomes cannot be easily captured nor contained, and the implementation of the Act has left room for improvement in this regard.

	Statement	Comment
4	<i>You cannot separate out the service to the cared for person from the carer. If my son is unhappy, I'm unhappy. Unpaid carers know the cared for person better than anybody. I am the bridge that makes the situation manageable.</i>	Carers too often feel that they are unable to have their voice heard, listened to and acted upon. There is a priority that emerges from this evidence base that more needs to be done to bolster them in the role they play in preventing escalating need and spiralling cost, a key principle at the centre of social work and social care practice within the Act.
5	<i>As we are not in crisis, we are ignored. I would like people to listen to what we say. As the carer, you have to find the strength to find a voice.</i>	The need to be resilient in the face of the hourly and daily responsibilities is draining for very many carers. Great comfort would be taken from the knowledge and reassurance that when they need to reach out, their voice will be heard and responded to, as the Act envisaged.
6	<i>We don't fit the script of what a family in need looks like. We weren't the template and we had a bad experience because of that. It became easier for our family only when we decided to work outside the system.</i>	Thinking that your family doesn't 'fit' a 'template' that may be on offer is not in line with the vision or the principles of the Act, nor is feeling that someone would rather go without the support that social services can offer, than be within the 'system'.
7	<i>There was absolutely no warning ahead of hospital discharge. We were kept out of the multi-disciplinary team meeting where all of the key decisions were taken.</i>	Multi-agency working is an area that was identified as especially problematic. The feeling of being on the outside when a multi-agency meeting is happening and important decisions are being taken is a symptom of sub-optimal working relationships. The Act requires that people are at the heart of the decisions about them, but there is distance to travel before this is consistently achieved.
8	<i>The reason that they feel so far away is that the principles and people's rights are never enforced. Are there sufficient avenues for redress under the Act? Do people know how to challenge?</i>	There is a considerable concern that despite the promise of rights in the Act, the process by which these can be achieved is not working for service users and carers. It is not clear how they can realise their entitlements in the Act or challenge decisions that are made.

	Statement	Comment
9	<i>If we had also had to fight for care in the Welsh language we would have gone under.</i>	Limited as it may be to date in the evidence of the previous pages, there is an important point to be made about receiving services in the language of choice. ⁴⁴ The issue is about how this could positively impact upon people's well-being given that in many cases doing so is 'what matters' to people.
10	<i>The system constantly raises your expectations, and then disappoints. It was sad to see how it really works. I want honesty in the conversations. Just tell us what you can and what you can't do.</i>	Having an open and honest dialogue is one of the key things that people want from those who are there to support them, as enshrined in the Act. Too often people were identifying that they feel they are not being given the full picture in their dealings with the social care system.
11	<i>Under COVID, it has shown how isolated people are. People's support networks are really pretty thin. Will the Act be able to cope with the groundswell of unmet need that COVID will have created?</i>	The additional pressure that COVID-19 has brought on an already stressed system has exposed some of the underlying frailties in our communities, relationships and services. There may therefore be a need for a national and local time of 'renewal' for the Act – such that the purpose of the legislation is restated to catalyse its further implementation.
12	<i>I think a lot of what is in the Act is aspirational rather than actually achievable at this point in time and any legislation shouldn't really be aspirational, that's not the point of legislation in my opinion.</i>	The evidence presented in this report points to a disconnect and gap between some people's expectations of what the Act could achieve for them, and their experience which fall short of those desired results. This should not be the prevailing condition of our social care system.

Closing comments

7.22 The process of implementing the Act continues to evolve, responding to changing circumstances that service users and carers face every day. Five years into that process, the evidence presented in this report – albeit impacted by the COVID-19

⁴⁴ We recognise that in only one place in this report (paragraph 3.45) does this issue arise. That said, this is an area that is at the heart of the [Welsh Language Standards](#), and [More Than Just Words](#), the Welsh Government's Action Plan to strengthen and develop Welsh language services in health and social care, and as such deserves attention.

pandemic – suggests that service users and carers feel there is still a distance to travel before the aspirations of the Act are fully realised.

- 7.23 It is interesting to contemplate the extent to which the work undertaken to date to embed and implement the Act has helped during the nation- and system-wide stress test that COVID-19 represents. It is also important to consider whether the expectations on organisations to make transformational change when social services are overstretched is realistic.
- 7.24 It is equally important to recognise the value of hearing directly about the lived experiences of others as one of the key foundations for improvement which is at the heart of the Act.
- 7.25 This report paints a complicated picture. Whilst we present in this document the perspectives of many people who have not had positive experiences, it is crucial to note that this data cannot formally ‘represent’ all of those in receipt of care and support. What it does, however, is suggest powerfully that the ‘journey’ towards the full implementation of the Act is not yet complete.
- 7.26 The system clearly needs to work more effectively to fully realise the potential of all of the principles working together in harmony. Given the additional challenges that the pandemic has brought, the principles have never been more important for people to hold onto. Similarly, they have never exerted such influence – despite the enormous pressures brought about by COVID-19, the principles still feel relevant and resonant to service users and carers.
- 7.27 Nonetheless, there is an irony in that for some people during the pandemic, the principles have never felt further away from their day-to-day experience of social services. Moving these closer to people will be difficult to achieve, but there has never been a more important time to do this than now. There is pressure on the system in order to get this right for those people who have been living under unprecedented challenge over the last two years.
- 7.28 Some service users and carers, however, are growing increasingly impatient for change. Recognising and valuing this is now key to the work to further embed the Act and its principles.

Annex

A. Ethics

Whilst not an exhaustive list, groups considered vulnerable in the context of research ethics include children, the elderly, single parents, learning disabled, ethnic minorities, and those who are homeless, economically disadvantaged, poor, illiterate, or unemployed (Allen, 2017).⁴⁵ In cases where studies may involve potentially vulnerable groups the [UKRI Economic and Social Research Council](#) advises that 'every effort should be made to secure freely given informed consent that participants have actively provided'.

Informed consent is one of the founding principles of research ethics,⁴⁶ and is based on the provision of full and accurate information (Bulmar, 2008).⁴⁷ In this study, the ethical review laid down the terms under which participants were to be recruited and the consent process that was to be followed.

All potential participants received an information sheet (available in Welsh and English and as an Easy-Read version in both languages) that provided details of the study and what their participation would entail (Silverman, 2017).⁴⁸ Easy-Read information sheets and consent forms were developed following consultation with the University of South Wales' [Teaching and Research Advisory Committee](#).

A key component of informed consent is ensuring participants are aware of the limits to confidentiality and are advised of any mandatory reporting requirements following disclosures of harm to self or another (Btoush and Campbell, 2009).⁴⁹ As such, the information sheets outlined this and the use of anonymised information in publications, yet noted that full confidentiality could not be guaranteed. For example where unexpected disclosures were made that suggested harm to self or others.

⁴⁵ Allen, M. (2017). *Vulnerable Groups. The SAGE Encyclopaedia of Communication Research Methods*. Available at: [Vulnerable Groups - SAGE Research Methods \(sagepub.com\)](#)

⁴⁶ [Informed consent | Research Support \(ox.ac.uk\)](#)

⁴⁷ Bulmar, M. (2008). 'The ethics of social research', in Gilbert, N (ed.). *Researching Social Life*. 3rdedn. London: Sage Publications Ltd, pp. 145-162.

⁴⁸ Silverman, D. (2017). *Doing Qualitative Research*. 4th.edn. London: Sage Publications.

⁴⁹ Btoush, R. and Campbell, J.C. (2009). 'Ethical conduct in intimate partner violence research: Challenges and strategies', *Nursing Outlook*, 57(4), pp. 210-216.

Participants were given time to consider the information and invited to ask questions of the study team ahead of agreeing to take part. Information sheets and advised of their right to withdraw from the study at any time without having to provide reason and without consequences to their care and support (Henn et al, 2009).⁵⁰

The informed consent processes linked to the three data collection methods (more detail on which is provided in Chapter 2) as follows:

- Wales-wide bilingual online questionnaire – to access the online questionnaire, participants were asked to confirm they understood that completion implied consent as defined by the University ethical review process;
- Qualitative data collection (interviews and focus groups) – written or verbal consent was confirmed before interviews/discussion groups commenced and signed consent forms were retained; and
- A closed (private) Facebook Group – consent forms were uploaded to the Group and members notified via a bilingual post, with regular reminders.

All participants were made aware of the privacy notice approved by Welsh Government for the study.

⁵⁰ Henn, M., Weinstein, M. and Foard, N. (2009). *A Critical Introduction to Social Research*. 2nd edn. London: Sage Publications Ltd.

B. Questionnaire

PRO FORMA: for service users who need care and support and unpaid carers

For more information about the IMPACT study, visit:

<https://wihsc.southwales.ac.uk/evaluation-implementation-social-services-and-well-being-wales-act-gwerthuso-gweithrediad-deddf-gwasanaethau-cymdeithasol-llesiant-cymru/>

If you want to access this pro forma online please go to:

<https://southwales.onlinesurveys.ac.uk/impact-proforma>

PLEASE COMPLETE AS MANY QUESTIONS AS YOU WANT TO. ONCE YOU ARE FINISHED, PLEASE EMAIL YOUR RESPONSE TO PROFESSOR MARK LLEWELLYN: mark.llewellyn@southwales.ac.uk

Introduction

The following questions are about the care and support you receive, or the care and support the person you care for receives. They have been structured around the five principles of the Act: well-being, voice and control, prevention, co-production, and multi-agency working.

Please try and answer in as much detail as possible so that we can understand your experience. Your answers are important and will help us understand what is good and what needs to change. After each question are some points that may help you to think about your experiences.

Please do not complete these questions if you have already taken part (other than if you intend to complete this pro forma from the perspective of both a service user and a carer if that applies to you), or plan to take part in any of the other activities within this study.

You can withdraw from completing the pro forma at any time simply by closing the window and your data will not be saved. Your data will only be saved if you submit your responses at the very end.

Before starting, it is important that you read through the Participant Information Sheet (PIS). The PIS can be accessed by clicking here:

<https://wihsc.southwales.ac.uk/evaluation-implementation-social-services-and-well-being-wales-act-gwerthuso-gweithrediad-deddf-gwasanaethau-cymdeithasol-llesiant-cymru/impact-evaluation/>

About you

Q1. Are you...?	
a. A service user	
b. A carer	
<p><i>We recognise that it is possible to be both a service user and an unpaid carer. You are welcome to complete the pro forma from both perspectives should you want to. Please complete both columns (from Q9 onwards) on the pro forma.</i></p> <p><i>If you are neither a service user or carer but want to contribute to the study, please contact Professor Mark Llewellyn – mark.llewellyn@southwales.ac.uk</i></p>	

Consenting to take part	
Please answer the following questions to confirm that you are happy to take part in the study by completing the pro forma.	
Q2. I confirm that I have read and understand the information sheet dated 13.4.21 (version 1) for the IMPACT study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
a. Yes	
b. No	
Q3. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without any consequence to myself.	
a. Yes	
b. No	
Q4. I understand that accepting the informed consent statements at the beginning of the pro forma implies consent to participate.	
a. Yes	
b. No	
Q5. I agree to anonymised quotes being used in any publications that arise from this research.	
a. Yes	

b. No	
Q6. I give permission for my data to be stored and processed in accordance with the General Data Protection Regulation (2018).	
a. Yes	
b. No	
Q7. I understand that anything declared concerning illegal/unprofessional activity or suggesting potential of actual harm might arise to an individual or group will be reported to the appropriate authorities.	
a. Yes	
b. No	
Q8. I agree to take part in the above study.	
a. Yes	
b. No	

FOR THE REMAINING QUESTIONS, PLEASE USE THE LEFT HAND COLUMN IF YOU WANT TO PROVIDE FEEDBACK FROM THE PERSPECTIVE OF A SERVICE USER, AND/OR USE THE RIGHT HAND COLUMN IF YOU ARE RESPONDING FROM THE PERSPECTIVE OF A CARER.

Your situation	
<i>Service user perspective</i>	<i>Carer perspective</i>
Q9. What sort of care and support do you receive, and who provides it for you?	Q9. What sort of care and support does the person you care for receive, and who provides it for them?
Well-being	
<p>The Act seeks to ensure that people who need care and support, and carers who need support, enjoy well-being in every area of their lives.</p> <p>Well-being is about more than just being healthy, it can also include:</p>	

- being safe
- having somewhere suitable to live
- being involved in decisions that impact your life
- having friends
- being part of good, strong communities
- having every chance to do well in education
- feeling good about your life
- For adults – being able to work
- For children – being able to grow up happily and successfully, and being well-looked after.

Assessments are undertaken with individuals to focus on what the individual needs and try to meet those needs, and carers to identify the support they need. A ‘what matters’ conversation helps to carry out the assessment. It is a way for professionals to understand people’s situation, their current well-being, and what can be done to support them.

It’s about identifying with the person:

- How they want to live their life
- What might be preventing that
- What support might be required to overcome any barriers

It is an equal conversation and is important to help ensure the voice of the individual or carer is heard and ‘what matters’ to them.

<i>Service user perspective</i>	<i>Carer perspective</i>
<p>Q10. To what extent do you think the care and support you receive is based around ‘what matters’ to you?</p> <p><i>(Think about what was good, what wasn’t as good, what difference it made to you)</i></p>	<p>Q10. To what extent do you think the care and support the person you care for receives is based around ‘what matters’ to them and you?</p> <p><i>(Think about what was good, what wasn’t as good, what difference it made to them)</i></p>
<p>Q11. Thinking about the care and support you receive, what could be done to improve your well-being?</p> <p><i>(Think about the support you receive, or your relationships with friends, family, the community)</i></p>	<p>Q11. Thinking about the care and support the person you care for receives, what could be done to improve their well-being and yours as their carer?</p>

	<i>(Think about the support you receive, or your relationships with friends, family, the community)</i>

Voice and Control

Voice and control aims to put the individual and their needs at the centre of their care and support, using their ‘voice and control’ over the outcomes that can help them achieve well-being and the things that matter most to them. This could be:

- Having a safe and permanent home
- Taking part in activities
- Being able to plan and cook a meal
- Remain or become part of their communities

Advocacy is an important tool to support people’s voice and control, and well-being. Advocacy services help people to:

- Access information and services
- Get involved in decisions about their lives
- Explore choices and options
- Express their needs and wishes

<i>Service user perspective</i>	<i>Carer perspective</i>
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<p>Q12. How much voice and control do you feel you have over the care and support you receive?</p> <p><i>(Think of an example about when you have talked about what is important to you with a person or agency who is providing your care and support)</i></p>	<p>Q12. How much voice and control do you feel the person you care for has over the care and support they receive?</p> <p><i>(Think of an example about when you have talked about what is important to you with a person or agency who is providing your care and support)</i></p>
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<p>Q13. Has the amount of voice and control you feel you have changed in the last year?</p>	<p>Q13. Has the amount of voice and control you feel the person you care for has changed in the last year?</p>
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<i>(What has changed, what was it like before it changed? Has that been a good thing or a bad thing for you?)</i>	<i>(What has changed, what was it like before it changed? Has that been a good thing or a bad thing for them?)</i>

Prevention

The Act is designed to make sure that:

- People can ask for the help they need when they need it to prevent their own situation from getting worse
- Carers can access support to assist them in their caring roles and maintain their own well-being

<i>Service user perspective</i>	<i>Carer perspective</i>
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<p>Q14. In what ways do you feel the care and support you receive impacts on your life?</p> <p><i>(Think about whether there is anything that makes it harder or better - what helps or hinders. Can you think of any examples?)</i></p>	<p>Q14. In what ways do you feel the care and support the person you care receives impacts on their life and yours as their carer?</p> <p><i>(Think about whether there is anything that makes it harder or better - what helps or hinders. Can you think of any examples?)</i></p>

<p>Q15. How far do you feel that the care and support you receive has stopped you from facing unexpected moments of difficulty in your life?</p>	<p>Q15. How far do you feel that the care and support the person you care for receives has stopped them from facing unexpected moments of difficulty in their life?</p>

Co-production

Under the Act, people will be more involved in the design and provision of their support. It means working WITH them and their family, friends and carers so their care and support is the best it can be.

It recognises their strengths and the expertise they can bring, too.

This will make sure our care and support services are designed around what matters most to people.

<i>Service user perspective</i>	<i>Carer perspective</i>
<p>Q16. To what extent do you feel that decisions about the care and support you receive are taken with you?</p>	<p>Q16. To what extent do you feel that decisions about the care and support the person you care for receives are taken with them?</p>
<p>Q17. Can you give an example of what co-producing your care and support means to you?</p> <p><i>(Think about what was good and what wasn't as good, did any changes happen, what difference it made to you)</i></p>	<p>Q17. Can you give an example of what co-producing your care and support means to the person you care for?</p> <p><i>(Think about what was good and what wasn't as good, did any changes happen, what difference it made to you)</i></p>

Multi-agency	
<p>The Act wants to strengthen joint working between local authorities and other relevant partners, such as health, housing and the voluntary sector.</p> <p>This is to improve people's well-being and the quality of services and support people receive.</p> <p>This will make sure the right types of support and services are available in local communities to meet people's needs.</p>	
<i>Service user perspective</i>	<i>Carer perspective</i>
<p>Q18. How good do you think the agencies that provide the care and</p>	<p>Q18. How good do you think the agencies that provide the care and</p>

<p>support you receive are at working together?</p> <p><i>(Think about what is good about it and why, and what isn't as good and why)</i></p>	<p>support for the person you care for are at working together?</p> <p><i>(Think about what is good about it and why, and what isn't as good and why)</i></p>
<p>Q19. Thinking back to when you first started receiving care and support, has the way in which the agencies work together to support you changed?</p> <p><i>(If yes, what has changed, what was it like before it changed? How has this affected you?)</i></p>	<p>Q19. Thinking back to when the person you care for first started receiving care and support, has the way in which the agencies work together to support them changed?</p> <p><i>(If yes, what has changed, what was it like before it changed? How has this affected you?)</i></p>

Overall	
<i>Service user perspective</i>	<i>Carer perspective</i>
<p>Q20. Over the past year, has anything about the care and support you receive got better?</p> <p><i>(If yes, think about what this is and why it is better. Can you give an example?)</i></p>	<p>Q20. Over the past year, has anything about the care and support the person you care for receives got better?</p> <p><i>(If yes, think about what this is and why it is better. Can you give an example?)</i></p>
<p>Q21. Over the past year, has anything about the care and support you receive got worse?</p> <p><i>(If yes, think about what they are and why it is worse. Can you give an example?)</i></p>	<p>Q21. Over the past year, has anything about the care and support the person you care for receives got worse?</p> <p><i>(If yes, think about what they are and why it is worse. Can you give an example?)</i></p>

<p>Q22. To what extent are you able to achieve the outcomes that matter to you?</p> <p><i>(Think about how you know your outcomes are being met, what does it look like?)</i></p>	<p>Q22. To what extent are you able to achieve the outcomes that matter to them and to you as their carer?</p> <p><i>(Think about how you know their outcomes and your outcomes are being met, what does it look like?)</i></p>

About you	
Q23. In which local authority area do you live?	
a. Anglesey	
b. Blaenau Gwent	
c. Bridgend	
d. Caerphilly	
e. Cardiff	
f. Carmarthenshire	
g. Ceredigion	
h. Conwy	
i. Denbighshire	
j. Flintshire	
k. Gwynedd	
l. Merthyr Tydfil	
m. Monmouthshire	
n. Neath Port Talbot	
o. Newport	
p. Pembrokeshire	
q. Powys	

r. Rhondda Cynon Taff	
s. Swansea	
t. Torfaen	
u. Vale of Glamorgan	
v. Wrexham	
Q24. How old are you?	
a. 16-18	
b. 19-25	
c. 26-49	
d. 50-64	
e. 65-84	
f. 85 or older	
Q25. Which of these best describes your gender?	
a. Male	
b. Female	
c. Non-binary	
d. Prefer not to say	
e. Prefer to self-describe (please state)	
Q26. Which of these best describes your ethnicity?	
<i>White</i>	
a. Welsh, English, Scottish, Northern Irish or British	
b. Irish	
c. Gypsy or Irish Traveller	
d. Any other White background	
e. Mixed or Multiple ethnic groups	
f. White and Black Caribbean	

g. White and Black African	
h. White and Asian	
i. Any other Mixed or Multiple ethnic background	
<i>Asian or Asian British</i>	
j. Indian	
k. Pakistani	
l. Bangladeshi	
m. Chinese	
n. Any other Asian background	
<i>Black, African, Caribbean or Black British</i>	
o. African	
p. Caribbean	
q. Any other Black, African or Caribbean background	
<i>Other ethnic group</i>	
r. Arab	
s. Any other ethnic group	
Q27. How would you describe your use of Welsh?	
a. I can read Welsh	
b. I can write in Welsh	
c. I can speak Welsh	
Q28. Are you or the person you care for able to receive care and support through the Welsh language if you or they want to?	
a. Always	
b. Often	
c. Sometimes	
d. Rarely	
e. Never	

f. This is not relevant to me	
Q29. Who provides the care and support you or the person you care for receives?	
<i>[Tick all that apply]</i>	
a. Local authority	
b. Independent sector care agency or organisation	
c. Voluntary sector care agency or organisation	
d. NHS	
e. Other (Please state)	
Q30a. Which of the following statements best describes where you live?	
FOR SERVICE USERS ONLY	
a. I live in my own home on my own	
b. I live in my own home with others who support me	
c. I live in a residential or nursing care home	
d. I live in a children's residential home or foster placement	
e. I live in another form of accommodation (like extra care, supported living or others)	
Q30b. Which of the following statements best describes where you live?	
FOR CARERS ONLY	
a. I care for an adult or older adult in their own home	
b. I care for an adult or older adult in their own home living with a disability	
c. I care for an adult or older adult in another setting	
d. I care for an adult or older adult in another setting living with a disability	
e. I care for a child in their own home	
f. I care for a child in their own home living with a disability	

And finally...

Q31. Is there anything else that you want to say?

--

Thank you!

Thank you for taking the time to complete this pro forma.

Once you have finished, please email it to Professor Mark Llewellyn:

mark.llewellyn@southwales.ac.uk

C. Topic guide – Interviews and Focus groups

Introduction

1. How much do you feel you know about the Act?
(Prompts: what information have you received? Have you had conversations about the Act with professionals, and what it means to you? Were there any parts you feel you didn't understand?)
2. Can you tell me about the care and support you receive/the person you care for receives?
(Prompts: what type of care and support is received? How long has it been received? What agencies are involved?)
3. Over the past 12 months, can you tell me whether there have been any changes in the care and support you receive/the person you care for received?
(Prompts: if so, what brought about these changes? What does the care and support you receive/the person you care for receive look like now? What role does COVID-19 play in this?)
4. What impact (if any) have these changes had on you as an individual/carer/family member?

Well-being

5. What does good well-being look and feel like for you?
6. Do you recall having a 'what matters' conversation as part of your assessment? If so, can you tell me about your experience?
(Prompts: what was helpful/unhelpful, what (if anything) could have been done differently?)
7. How do you think that well-being should be measured?
8. Are there ways in which your well-being and care could be improved? If so, how?
(Prompts: think about services, support you receive, connections with friends, family, community)

Voice and Control

9. How do you know when you are really being heard?
(Prompts: what are the key signs that people respond to you having your say?)
10. Thinking about the care and support you/the person you care for receives, how much voice and control do you feel you have?
(Prompts: can you give me an example where you feel you have/haven't had voice and control over the care and support you/the person you care for receives – what worked well, what didn't work as well?)

11. Has the amount of voice and control that you feel/the person you care for feels changed?

(Prompts: if so, what has prompted these changes? How does it compare to what it was like before the change? What impact have these changes had?)

12. To what extent do you feel listened to when discussing your/the person you are caring for care and support?

(Prompts: has this changed, what (if anything) could be done differently?, any examples?, power balance between you and the professionals supporting you)

Prevention

13. Do you feel there have been any changes in how social services have worked with you over the last few years? If so, what have they been?

(Prompts: How, if at all, has the support from social services changed for you in this time?)

14. How, and in what ways, do you feel that the support you receive from social services makes life better for you? Is there anything about it that makes life harder?

(Prompts: In what ways, if any, do you think social services help your situation from deteriorating? If so, can you say more about what helps?)

15. In terms of care and support, can you think of any examples of this being delivered by groups within your local community?

(Prompts: Have you had contact with any community-based services support happening in your area? If so, what might they be?)

Co-production

16. Do you feel you/the person you care for have an equal stake in your care and support?

(Prompts: if yes, can you give me an example, e.g. what worked well, who was involved, what happened. If no, can you tell me about the reasons you think this is, and what could be done to help ensure you feel like you have an equal stake?)

17. Can you tell me about any experiences of co-production you/the person you care for have had?

(Prompts: in what way have you been involved in co-producing your care and support?, what worked well, what didn't work as well)

18. What good or bad changes have come about as a result of attempts at co-production?

(Prompts: can you provide an example?, what could be done differently?)

19. Which of these changes as the result of co-production are most significant?

(Prompts: what difference has it made? How does this compare to what it was like before?)

Multi-agency

20. When you/the person you care for first started receiving care and support, can you tell me what it was like to access help and advice?

(Prompts: was the support available from different agencies explained to you? Were you signposted to different agencies? Did you have to repeat the same thing to different agencies?)

21. How well do you feel that the agencies that support you/the person you care for are working together to support you?

(Prompts: for example, health, social services, and the third sector. If it is working well/not so well, can you tell me why? What (if anything) could be done differently?)

22. From the time you have been receiving care and support, has the way in which the agencies work together to support you/the person you are care for changed?

(Prompts: if so, in what way? What led to these changes? What impact have the changes had on you/the person you care for? What does it look like now?)

Financial

23. What (if any) improvements have you/the person you care for experienced in the services you have been receiving?

(Prompts: How would you describe these improvements?, What impact have these improvements had on your/the person you care for life? When did these improvements start?)

24. Have you/the person you care for experienced any change/decline in the services you/the person you care for usually receive? If so, what were they?

(Prompts: What impact (if any) has this had on you/the person you care for?)

25. Can you tell me whether the coordination of services for the care you/the person you care for receives now has changed? If so, in what way?

(Prompts: What impact (if any) has this had on you/the person you care for? What (if anything) could be done differently?)

Overall

26. To what extent are you able to achieve the outcomes that matter to you?

(Prompts: how do you know these outcomes are being achieved?)

27. Is there anything else that you would like to talk about that we haven't covered today?

D. References

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