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

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Evaluation of the *Social Services and Well-being (Wales) Act 2014*: Literature Review

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1. Introduction

- 1.1 This document is a summary of the extensive review of the literature undertaken to inform the evaluation of the *Social Services and Well-being (Wales) Act 2014* (hereafter referred to as 'the Act').¹ The Welsh Government has commissioned a partnership between academics across four universities in Wales and expert advisers to deliver the evaluation. The Act sets out a government vision to produce 'transformative changes' in social service public policy, regulations, 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 codes of practice. The Evaluation of the Act – a study called IMPACT – is organised around each of the five principles together with a focus on the financial and economic aspects of the Act's implementation.
- 1.2 The approach to undertaking this evaluation research is to structure the evaluation by using the fundamental principles of the Act as the scaffolding. These principles are:
- Well-being
 - Prevention
 - Co-Production
 - Multi-agency working
 - Voice and control
- 1.3 There is also a focus on the financial and economic considerations of the implementation of the Act and this area constitutes the sixth evaluation study theme.
- 1.4 This approach to the evaluation is complemented with a focus on the following five domains:
- **Individuals** – whether these are people in receipt of support and/or care, or not;
 - **Family and carers** – those people who provide unpaid support to people with needs;
 - **Communities** – place-based communities and other forms of social relationships;
 - **Workers** – whether these are 'frontline' paid care workers, social service and third sector paid workers, team managers or those care managers arranging support and care for others;
 - **Organisations** – whether these are the strategic leaders of public sector bodies like local authorities and health boards (including finance officers), or leaders of key stakeholder organisations.
- 1.5 Each evaluation study theme has a set of research questions. The literature review positions the evaluation of the Act in the wider academic and policy literature in order to build on the existing knowledge base and debates pertaining to each of the study themes.
- 1.6 This literature review is an update to the original literature review published in 2020. It combines findings from the first literature review and the findings from a literature search and review performed in 2022. Therefore, this report provides the most up-to-date references. The updated review also includes a new chapter focused on the subgroups of

¹ The Technical Report can be accessed from: [Technical Report](#)

service users and carers in Wales most relevant to our study, i.e., children and young people (CYP), adults and older people, disabled and learning-disabled people, and Welsh language speakers.

2. Methods

Fiona Verity, Sarah Wallace, Mark Llewellyn, Pippa Anderson and Jennifer Lyttleton-Smith

- 2.1 A comprehensive literature search of academic and grey literature was conducted across five of the six themes: prevention and early intervention, co-production, multi-agency working, voice and control, and financial and economic implications. Details of the literature searches and reviews performed are within the content of the Technical Report².
- 2.2 The PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-analysis (Moher et al., 2009), informed the action plan/steps for the literature search and review. A combination of search terms agreed and refined by the Evaluation Team individual leads and advisors, were entered into online databases, for example, Scopus, ASSIA, and Social Care Online.
- 2.3 For the well-being theme, leads used systematic mapping to source relevant literature. A systematic map is a database of academic, grey, and policy literature published on a specified topic that is coded by categories such as subject area, methodology, population of interest or study, and theoretical approach.
- 2.4 Search terms used for the 2020 review were replicated for the 2022 search and review for all principles, including terms used within the well-being systematic mapping exercise.
- 2.5 The numbers of papers included in the 2020 review, the additional papers included in the 2022 update, and totals are as follows:

THEME	NO. PAPERS IN 2020 REVIEW	NO. ADDITIONAL PAPERS IN 2022 UPDATE	TOTAL NO. PAPERS
Well-being	50	13	63
Voice and control	52	27	79
Prevention and early intervention	50	9	59
Co-production	52	17	69
Multi-agency working	48	19	67
Financial and economic implications	16	12	28
TOTALS	268	97	365

² [Technical Report](#)

- 2.6 In addition, 24 papers were included in an additional area for the review – namely drawing on papers and reports on the experiences under the Act of subgroups of service users and carers in Wales (Chapter 9).
- 2.7 The key messages from each of the individual theme reviews are presented below.

3. Well-being

Pippa Anderson, Jennifer Lyttleton-Smith, Liv Kosnes, Simon Read, Heulwen Blackmore and Zoe Williams

- 3.1 This review explores the conceptual coherence of well-being as it is applied within the Act and its associated guidance. Well-being is a multi-dimensional construct, often inspiring a selective approach to definition and measurement, and holding the risk of utilisation in nebulous or purely polemical forms. Conceptual coherence in application is therefore crucial to support effective and transparent government policy aims and evaluation. To understand the application of well-being in Wales, we reviewed the current debates around definitions and measurements of well-being as applied to people who need care and support. While we discovered some conceptual coherence around well-being criteria, such as rights and agency, we also found a greater weight allocated to subjective interpretations of well-being and ‘happiness’ within the literature than is observable within the current Welsh application of the concept. This offers substantial support to the Welsh approach to defining and measuring well-being, while also suggesting a clear path to improvement.
- 3.2 There are two broad conceptual spheres of individual well-being emergent within the literature:
- **Eudemonic Well-being:** Relational and social aspects of well-being, such as access to rights, contribution to society, respect and agency as a citizen, access to positive activities, education and work. Converges with related concepts of ‘quality of life’ and living standards.
 - **Hedonic Well-being:** Emotional and embodied aspects of well-being, such as pleasure and enjoyment. Converges with mental health concepts of happiness and life satisfaction. This sphere is currently characterized as ‘subjective well-being’ (i.e., measurable only by an individual’s own assessment, rather than by evaluating contributory factors such as physical health or living standards).
- 3.3 The two spheres, while sometimes applied separately, generally complement one another (Henderson and Knight, 2012). For instance, receiving social respect (eudemonic well-being) often leads to personal pleasure (hedonic well-being). Using both perspectives is referred to as the “flourishing” model of well-being by some researchers. Huppert & So (2011) offer a conceptual framework that combines the hedonic and eudemonic approaches.
- 3.4 For application of these concepts in policy and measurement, two dominant approaches are defined and evidenced within the literature. Note that each approach may include both eudemonic and hedonic aspects of well-being.
- **The Components Approach:** The components approach is the current dominant discourse for well-being, breaking it down into a series of components or independent elements as commodities for the individual to achieve (Atkinson, 2013; Ruggeri et al., 2020). Policies based on this approach seek to enable people to attain these components to enhance their well-being, such as relationships, health, activities of work/leisure, financial stability, and education.
 - **The Capabilities Approach:** This approach claims that well-being can be assessed by understanding individual’s capabilities to do or be something and that individuals

should be evaluated within the context of available and feasible opportunities, not their achievements (Alkire, 2015; Sen, 2009). The uptake of these opportunities are the essence of 'flourishing lives'.

- 3.5 For each of these approaches, localized domains of well-being relevant to cultural and historical location should be determined and applied to best define and apply the concept in policy and measurement. These may require personalization to different groups within a population. It has been noted by many that for the purposes of evaluation and monitoring, policy-makers should seek to measure impact of policy (life satisfaction), experience (momentary mood) and eudemonia (purpose).

Determining domains of well-being for groups covered by the Act

- 3.6 Conceptual well-being literature focused directly on people covered by the Act is sparse. The evidence base we found generally focused on whole adult population measurement or was focused specifically on children or older people.
- 3.7 Adult population determinants of well-being reported in the literature include health, personality traits and socio-economic circumstances including financial, income and employment status. For children, it is recognised within recent literature that children's views and experiences – particularly those who are vulnerable, must take precedence in determining their domains of well-being.
- 3.8 Within the UK, four domains central to the well-being of children and young people in care have been identified through such participatory research: relationships; rights; resilience building; and recovery (Selwyn et al., 2017). These sit alongside broad child population indicators of education, protection, and economic stability.
- 3.9 For older people, health, living standards, and agency emerge as the key aspects of well-being within the literature, though there is some critique that measurement of well-being for older people has failed to effectively capture both eudemonic and hedonic spheres, with an excess of focus on the former at population level.

The Act and well-being in Wales

- 3.10 The Welsh Government definition of well-being within the Act and National Outcomes Framework (NOF) is largely eudemonic, with the hedonic sphere only briefly represented. This is reflected in the Welsh Government approach to well-being measurement, which is identifiable as a components approach with an emphasis on eudemonic determinants of well-being such as housing or employment statistics, rather than hedonic elements such as happiness or emotional state.
- 3.11 While the Well-being Statement and NOF reach towards this by locating attainment as, at least partially determined by an individual's own satisfaction, the boundaries placed around personal well-being outcomes and the measures currently established to evaluate the Act's impact remove the possibility to locate well-being in other spheres of life that it does not cover. The extent, therefore, to which the Welsh approach to well-being, and specifically people who need and receive care and support incorporates subjective, hedonic perceptions, remains debatable.
- 3.12 This review found that inclusion of both eudemonic and hedonic spheres, alongside objective and subjective measures is regarded as important to accurately reflect the

potential and actual impact of public policy on the well-being of individuals. In this way, the Welsh Government application of well-being requires further refinement – substantively, a broadening of the degree to which it incorporates subjective hedonic elements and measures, to cohere with the conceptual literature.

- 3.13 In addition, we found greater strength in the arguments presented to support a capabilities approach to measurement, therefore going forward we will consider whether the evidence is strong enough to recommend an adjustment to the current strategy.

Next steps

- 3.14 The well-being team have explored the conceptual framework of well-being with people in need of care and support, and carers in need of support, from a range of backgrounds and ages. This is allowing us to build on the sparse conceptual literature relating to specific groups and will inform the ongoing refinement of the evaluation strategy.
- 3.15 Having established through the literature review that there is a gap in the meaningful measurement of well-being for people covered by the Act, the team will explore effective and efficient strategies to improve measurement. We will produce recommendations based on practice and policy needs, mindful of the need to minimise the administrative burden on local authorities, balanced with the need to demonstrate the conceptual coherence of well-being in Welsh social care policy.

4. Prevention and early intervention

Fiona Verity, Simon Read and Jonathan Richards

- 4.1 Preventative approaches to social care incorporate a variety of distinct-yet-related aims informed by assessment and planning processes, co-production and multi-sector working. In this sense, many of the themes reported elsewhere in the Review notably overlap with the design and delivery of preventative services.
- 4.2 Alongside understanding the results and impact of preventative work in social care, the broader focus of this review of the literature is to explore the preventative frameworks being deployed, how the underlying concepts are understood and the manner in which interventions are implemented and evaluated. This is done through four sections:
- concepts and definitions in prevention and early intervention;
 - contemporary drivers for the preventative focus in social care;
 - state of the evidence about prevention in social care; and
 - prevention approaches in social care.

Concepts and definitions in prevention and early intervention

- 4.3 Social care literature on prevention and early intervention more typically identifies a three-tiered framework consistent with a public health paradigm (Gough, 2013; Miller & Whitehead, 2015). These three levels are:
- tertiary / downstream – where interventions target urgent, existing issues;
 - secondary / midstream – targeting identified problems and preventing escalation; and
 - primary / upstream – targeting entire populations with support before problems set in.
- 4.4 Each stratum requires the provision of different initiatives aimed at differing audiences. Some authors (e.g., Warin, et al., 2015) view these strata in terms of temporality, suggesting preventative agendas divorced from everyday reality may be less effective than those grounded in lived experiences.
- 4.5 While there is broad agreement on the three-tiered framework, there remains considerable variation in how the term ‘prevention’ itself is used (Curry, 2006; Marczak et al., 2019). Terminology overlaps and disparities are reportedly common, encompassing a diverse range of activities and interventions (Allen & Glasby, 2010; Marczak et al., 2019). Within this loose application of prevention concepts, there is a general view that social care has predominantly focussed on tertiary and secondary approaches rather than primary, upstream work (Gough, 2013).
- 4.6 There are growing calls for the varying levels of a three-tiered framework to be implemented more collectively than independently, and a more nuanced social care preventative framework (Marczak et al., 2019).

Contemporary drivers for the preventative focus in social care

- 4.7 As with its historical development, contemporary strides towards prevention have parallel and sometimes conflicting drivers (Gough, 2013; Clark, 2019; Marczak et al., 2019; Tew et al., 2019). Alongside economical, cost-saving imperatives, prevention is widely conveyed in

policy discourse to reduce service demand, as well as a means of enacting social justice and inequality reduction. These various focal points have implications for the interventions that are considered for commissioning, planning and decision-making.

- 4.8 Authors have highlighted the need for ‘interdisciplinary, interagency, and interdepartmental’ local commissioning frameworks more aligned to community-specific needs (Kerslake, 2011; 16). The discursive emphasis on prevention as a cost-saving exercise has also drawn critique. While community energy and resources are largely regarded as untapped, there are concerns that top-down approaches are less effective in harnessing these than smaller-scale, bottom-up, community-led projects.
- 4.9 Recent developments with community businesses, social enterprises and cooperatives have offered a burgeoning evidence base comprising measurable cost-saving benefits alongside indicators of community strengthening and development (Hull et al., 2016; Bedford & Harper, 2018).

State of the evidence about prevention in social care

- 4.10 The scientific evidence base on social care prevention is perceived to be limited. This is attributable to a ‘paucity of longitudinal studies’ (Curry, 2006; 1) that track implementations of preventative programmes over time (Marczak et al., 2019). This limitation arguably complicates the positive value that such approaches are anecdotally felt to offer.
- 4.11 However, recent efforts to contextualise prevention work outcomes through cost benefit analysis have indicated that there is potential for evaluations that may aid understanding of their economic impact (Knapp et al., 2013).
- 4.12 Beyond this, the viewpoint of an ‘evidence deficit’ has been increasingly unpicked. Assessing prevention requires a long-term perspective and consistent interventions. Yet, the social conditions that preventative measures aim to change are complex and dynamic. Furthermore, the diverse remit of prevention work means that methods for assessment may vary dramatically. There is a considerable evidence base around the lived experience of social services users and practitioners, and from community developers, which is often disregarded relative to empirical studies, as well as potential to better use routinely collected data to understand effectiveness of initiatives (e.g., Emerson et al., 2011; Shapiro et al., 2013).

Prevention approaches in social care

- 4.13 Prevention approaches in social care mirror the framework outlined above, with a predominant focus on secondary and tertiary interventions. One overriding emphasis is the need to identify and respond to individual needs through re-enablement programmes, information provision and self-directed support (Allen & Glasby, 2010). These are generally entwined with aims to maintain independence and social connectedness. Another focus has been on community development, particularly with recent growth in community businesses and social enterprise research (Abrams et al., 2019; Bedford & Harper, 2018; Hull et al., 2018). Many of these initiatives adopt a ‘strengths perspective’ and use ideas of social capital and asset-based community development (ABCD) while also being principled in terms of community control and co-production. Consequently, in the context of contemporary drivers, numerous authors are contributing to the evidence base about most appropriate means to encourage participation, highlighting the importance of sensitivity to

diverse local contexts and the need for further commissioning support in order to aid ongoing evaluation of the process, impact and outcomes of such work.

Literature review themes

- Definitions of prevention in social care are contested with a range of approaches that span the individual, community, and wider social structures.
- Prevention is inextricably linked to co-production, voice and control and multiagency working.
- Prevention in social care can be implemented for many reasons. These relate to the fulfilment of social justice principles and/or a view that prevention is a way to save money and slow demand for services. Some argue prevention is not a cost neutral activity but requires long-term investment.
- There is a need for stronger commissioning frameworks that support evidence-based decisions about where resources should be allocated for preventative purposes.
- There are a range of sources of evidence for the effectiveness, and impact of preventative social care (lived experience, practitioner wisdom, and scientific evidence). However, the scientific evidence base for prevention in social care is 'underdeveloped', and where there is evidence, it can be underused in practice.
- Recent work in the field of community businesses, social enterprises and cooperatives offers potential solutions to measures of impact and effectiveness in relation to specific local community needs.

5. Co-production

Nick Andrews, Gideon Calder, Noreen Blanluet, Sion Tetlow and Sarah Wallace

5.1 This summary of literature reviewed on the theme of co-production is divided into three sections. In the first, we summarise key aspects of the changes required in the successful promotion of co-production in social services. In the second, we identify lessons for policy in Wales, gleaned from evidence around the implementation of co-production in different countries and settings. In the third, we highlight key enabling factors, relevant to the practical achievement of co-production in the sectors addressed by the Act.

Organisational strategy

5.2 Organisational structures and strategy was highlighted within the literature as being key in co-production. Changes in organisational strategy which will enable successful co-production have been highlighted below, structured around key issues to be tackled, key changes required, and key aspects of learning needed to facilitate change.

5.3 *Key issues that need to be tackled*

- Potential incompatibilities between co-production, and dominant managerial approaches (Parry-Jones & Soulsby, 2001; Keinhans, 2017).
- What makes co-productive projects sustainable (Denbighshire Voluntary Services Council (DVSC), 2018; Meerkerk, 2018).
- Power-sharing in sensitive services, e.g., those where safeguarding duties are paramount. (Munroe, 2011; Clarke et al., 2011).
- Tensions are to be found between:
 - policy imperatives and organisational/workplace constraints (Gunasakera et al., 2017; Pearson et al., 2017; Pilgrim, 2018; Thom & Burnside, 2018);
 - co-production of relevant knowledge about particular services and established requirements of research funders and organisations (Allen et al., 2018; Baines, 2018; Pilgrim, 2018);
 - service user and provider perspectives on appropriate services (McCarry et al., 2018; Wharne, 2015); and
 - service-centred and wider social imperatives (Vaeggemose et al., 2017).
- Gauging the savings and costs involved in co-production, and the value added (Bovaird & Loeffler, 2012; Harlock, 2014).

5.4 *Key changes that are required*

- ‘Culture change’ in order to allow for genuine co-production (Bradley, 2015; Patterson et al., 2011).
- Adaptation to legacies of spending cuts affecting services (Keinhans, 2017; Pearson et al., 2017; Milson, 2018).
- New forms of public management conducive to co-production (Keinhans, 2017).
- Revision of priorities of services historically run on separate, non-co-productive lines (Gunasakera et al., 2017).

- Forms of language which translate across different professional and service-user perspectives (Patterson et al., 2011).

5.5 *Key aspects of learning to facilitate change*

- Better use of evidence in service development (Andrews et al., 2015).
- Integrated, pluralistic and hybrid approaches to relations between stakeholders (Schlappa & Imani, 2012; Nandram & Koster, 2014; O'Leary et al., 2012).
- Acknowledgement of stages of development of co-produced services (Freeman et al., 2016).
- Insights from the full range of academic disciplines (Ellis, 2017; Allen et al., 2018).
- Incorporating professional and non-professional insights (Vaeggemose et al., 2017).

Participation

5.6 The literature also presented some key findings relating to participation and what issues, changes and enablers were identified relating to co-production.

5.7 *Key issues that need to be tackled*

- Different barriers to participation facing different groups (Beresford, 2013; Cree et al., 2015).
- Historic lack of consultation with certain groups (Bradley, 2015).
- Risks around over-protective practice undermining agency of service-users (Sanders, 2006; Smale et al., 1993).
- Barriers to participation posed by factors beyond a service's control (Doran & Buffel, 2018).
- Risks around overlooking some forms of organisation (DVSC, 2018).

5.8 *Key changes that are required*

- Finding workable approaches which genuinely accommodate all parties (Andrews et al., 2009; Smale et al., 1993).
- Recognition of specific expertise embodied in local practice (DVSC, 2018).
- Development of supporting infrastructure to enable participation by all groups (Milson, 2018).
- Finding ways of working with or around risk-/deficit- based practices (Gale et al., 2018).
- Reform of potentially exclusionary aspects of organisations' established working cultures (Andrews et al., 2015).

5.9 *Key aspects of learning to facilitate change*

- Promoting democratic processes in negotiating relationships (Budge et al., 2019).
- The role of relationship-centred and person-centred approaches (Andrews et al., 2009; Andrews et al., 2015; O'Leary, 2012; Nandram & Koster, 2014; Maurits et al., 2018).
- The role of social capital (Meerkerk, 2018).

- The different roles and impacts of co-produced services for different groups (Ford, 2015) .
- New/adapted forms of assessment (Miller & Barrie, 2016; Andrews, 2009).

Lessons for Welsh policy

5.10 From comparative evidence, we can identify clear value in:

- The Act's pluralistic specification of the key features of co-production, echoing policy in Norway (Askheim et al., 2016);
- Prioritising learning from existing projects using co-production (Lowe & Plummer, 2019);
- Focusing on what matters to people at 'ground level' (Miller & Barrie, 2016; Weaver, 2018; Vrangbaek et al., 2019);
- Being realistic about what is required by way of support and incentives to achieve the Act's stated aim of 'building the local economy of people exchanging their skills, interests and time' (Voorberg et al., 2018); and
- Accepting and working with the expectation that service transformation will be – 'multi-layered, messy, fluid and emergent' (Dougall et al., 2018).

5.11 Alongside this, there are clear challenges in:

- Achieving the 'culture change' required to enact genuine co-production (Miller and Barrie, 2016);
- Bridging the gulf between different scales of co-production relevant to the provision of care and support (Bovaird et al., 2014);
- Genuine involvement of specific groups in the design and management of services (Duner et al., 2019); and
- Avoiding any impression that co-production has been promised but not realised (Flinders & Wood, 2018).

Enabling factors

5.12 The enabling factors identified below are conclusions drawn from an overview of points emerging from across all literature reviewed.

5.13 *Knowledge, understanding and planning*

- Thinking wide to gain a clear understanding of the potential for co-production across the design, delivery and evaluation of public services.
- Ensuring clarity on the distinction between co-production as such, and related ways of working such as collaboration.
- Importance of combining different kinds of evidence in evaluating co-productive projects.

5.14 *Recognising and responding to challenges*

- Recognising and grappling with the challenges for co-production within the complex multi-level governance of public services.

- Recognising and addressing the tension between the discourses of individual rights/consumerism and mutuality/compromise.
- Challenging existing approaches to planning and performance that call for predictability and control and thus allowing for emergence.
- Willingness to confront what's at stake when co-production does *not* work in the expected ways and considering the implications of this for future practice.

5.15 *Fostering a supportive and enabling culture and environment*

- Developing a culture and way of thinking in professionals and organisations that truly values the worth and knowledge individuals and communities.
- Providing supportive environments and embedded systems that enable co-production, which come at cost.
- Developing a common language and meaningful relationships through caring dialogue and deliberation, which creates trust.
- Overcoming risk aversion in decision making in the face of hostile media coverage and litigation.
- Leadership that devolves power and promotes agency at the frontline.
- Listening to, and amplifying seldom-heard voices.
- A greater focus on the outcomes of co-production.

6. Multi-agency

Carolyn Wallace, Alison Orrell, Tony Garthwaite, Sion Tetlow and Sarah Wallace

- 6.1 Working together across agencies is challenging but it provides opportunity to problem solve and address the fragmentation of service delivery aggravated by organisational autonomy, competition, and choice (King's Fund, 2019, 2013; Leichsenring et al., 2016). It achieves this by sharing each other's knowledge and skills, coming to some mutual understanding through providing time and space for people to come together thereby benefitting individuals, families and communities, but not necessarily health or social care organisation economics (Fernandez et al., 2018) and are dependent on many variables.
- 6.2 In recent years the focus of how we work together has been moving away from its main concern regarding health and disease (NHS specifically) to an understanding that health and wellbeing have multiple determinants and that working together should be people centric through empowering people and their communities to work with professionals, organisations and policy makers in order to ensure that people receive 'the right care, at the right time, in the right place, in accordance with their needs and local context' (WHO, 2018).
- 6.3 The Act itself uses words such as 'cooperation', 'integration of care', 'partnership', 'joint arrangements' to describe its expectation as to how we should work together. Regulations such as 'The Care and Support Partnership Arrangements for Population Assessments (Wales) Regulations 2015' and 'The Partnership Arrangements (Wales) Regulations 2015' specify terms such as 'partnership' which include specified functions and arrangements such as partnership boards, sharing information, pooled budgets and referral procedures.
- 6.4 The term 'multi-agency' in the literature is often used interchangeably with inter-agency (between agencies) and partnership working. Peckover and Golding (2017) have acknowledged this multi-level approach in their definition and we are using it for this literature review:
- 'Multiagency working includes work undertaken by different professionals with the same client and/or family, often requiring information sharing, coordination of service provision and joint visiting and/or assessment. Another context is the formal strategic arrangements between local partner agencies'* (Peckover & Golding, 2017: 41).
- 6.5 In this chapter we first of all offer an understanding of the many definitions of the terms used in the Act to describe how we work together. We attempt to show the relationship between them (through their characteristics) and how multi-agency working fits in the continuum between parallel working and integration.
- 6.6 To do this, we acknowledge that a complex world of working together is developed through the interaction of relationships where the individual service user (local level) influences the context of the family, carer which in turn influences knowledge and change in care organisations (Cilliers, 1998; Preiser, 2016).
- 6.7 Considering the complexity of the whole system helps us to consider these domains whilst also identifying and understanding the success factors and challenges, mechanisms and processes required to work together to meet the aims of the Act.
- 6.8 Key messages from this literature review are:

- Terms are often used interchangeably but have common characteristics and success factors.
- Building equal relationships with common language and purpose, culture (trust, honesty, reciprocity), managing expectations, permissions and processes are key although can be resource (including time) intensive.
- Working together across agencies is challenging but it provides opportunity to problem solve by sharing each other's knowledge and skills, so benefitting individuals, families, and communities.
- There is a gap in the multiagency literature on the views and experiences of the individual, but especially family and carers and the workforce as the literature focusses mainly on care organisations, policy, and governance.
- Integrated care has mainly focussed on health service delivery until recent years where it is now moving towards health and social care integration.
- Not one study has sought to identify the success factors of a country's workforce working towards multiagency working.

7. Voice and control

Mark Llewellyn, Roiyah Saltus, Heulwen Blackmore, Sion Tetlow, Zoe Williams and Sarah Wallace

7.1 In respect of the concept of ‘voice’ and ‘control’, the Act provides no formal definition. There are fragments of definitions within different Parts of the Act, and the Codes of Practice. For example, Part 6 of the Act provides a number of key statements which are useful proxies to be considered in lieu of formal definitions, and in addition, the Code of Practice for Part 2 draws from the National Outcomes Framework in identifying key aspects of what it means to exercise ‘voice’ and ‘control’:

- *A right to be heard as an individual...to have control over their daily lives;*
- *My voice is heard and listened to;*
- *I speak for myself and contribute to the decisions that affect my life or have someone who can do it for me.*

7.2 Our working definition of voice and control is therefore based on having one’s voice heard and listened to as a basic right, having control over daily life by contributing to decisions and, if needed, receiving support to be heard.

7.3 Perhaps tellingly, on the whole, the published literature also does not provide clear definitions of the terms ‘voice’ and ‘control’ (Vamstad, 2016; Bamford and Bruce, Quereshi et al, Gabriel and Bowling, Quereshi and Henwood, all cited by Callaghan et al., 2014). What the literature reveals is the fact that terms such as voice and control are defined in various ways, with proxy terms often used interchangeably leading to conceptual overlap.

7.4 While most of the literature available does not explicitly use or define the terms ‘voice’ or ‘control’, a number of similar or related concepts have been defined within the literature e.g., person-centred care (Washburn and Grossman, 2017), empowerment (Keyes et al., 2015), participation (Havlicek et al., 2018), self-determination (Eades, 2018), personalisation (Department of Health 2015; Glenndinning et al., 2015) and shared decision-making (Brogan et al., 2018).

7.5 The review of the literature around voice and control can be understood under the following broad categories.

Individuals

7.6 The review explores how drives to increase voice and control manifest and impact on the lives of individuals, with a focus on those requiring support and care provision. The findings covered a range of population groups, with literature revealing the context of particular groupings including social care setting, for example where older people had more/less voice and control (Callaghan et al., 2014; Vamstad, 2016; Darby et al., 2017; Dunér et al., 2019).

7.7 Issues like quality of life (Reindl et al., 2016; Morris et al., 2017), self-advocacy (Tideman & Svensson 2015; Hamilton et al., 2017), and the voice of people with intellectual disabilities were captured.

7.8 The findings in this section include:

- the complexity of implementing voice and control principles across different care settings;
- the importance of advocacy and self-advocacy in creating a sense of voice and control for service users;
- the challenges in sharing control across the organisation and service user in different social care settings; and
- the challenges involved in implementing voice and control principles with different service user demographics.

Carers

7.9 This centred on the issues in the literature around how voice and control is enhanced or diminished for carers (Rand and Malley, 2014; Glendinning et al., 2015; McNeilly et al., 2018; Watts & Cavaye, 2018). Given the focus of this in the Act, the challenges of assessment tools and processes (Seddon & Robinson, 2015; Ewing et al., 2016) and of resources and budgets (Glendinning et al., 2015; Larkin, 2015; Galiatsatos et al., 2017; Singleton & Fry, 2019) are positioned as key factors shaping how the voice and control of carers may be enhanced or limited.

7.10 The key messages from this section of the literature review are:

- the need to find the appropriate balance between notions of citizenship and having greater financial control;
- the challenges of having control over finances in giving carers and cared-for individuals voice and control; and
- the importance of quality social care practice in empowering carers to gain a sense of voice and control.

Workforce

7.11 The review also examined voice and control and the workforce across social care settings. It explored policy and practice in supporting staff, barriers and enablers in fostering empowerment, and shared control and decision making (Gridley et al., 2014; Keyes et al., 2015; McCarter et al., 2016; Brogan, 2018), in both the development of person-centred care (Gridley et al., 2014; Hanga et al., 2017; Washburn & Grossman, 2017; Dunér et al., 2019) and advocacy (Eades, 2018).

7.12 The key messages that came from this section are:

- the importance of person-centred approaches in fostering voice and control principles for service users;
- the challenges inherent in implementing policy informed by voice and control principles; and
- the importance of the relationship between practitioner and service user in creating a good sense of voice and control for service users.

Organisations

7.13 The final section of the review focused on the role of care and health organisations and voice and control. The literature focuses on one key area, assessment, and the ways in

which assessment of care (Darby et al., 2017; Hanga et al., 2017) and self-assessment (Keyes et al., 2015), and approaches to the assessment process (Skills for Care, 2018), impacts voice and control principles and practices for care organisations (Seddon & Robinson, 2015; Tucker et al., 2018).

7.14 The key findings were that:

- there are challenges in instilling voice and control principles in health and social care assessments; and
- person centred practice and conversational approaches can provide a good platform for voice and control principles to be implemented in social care.

Enablers and barriers

7.15 Overall, the voice and control literature review highlighted a number of barriers and enablers that can hinder or assist individuals who are receiving care and support to have greater input into their care (voice) and a greater say over what happens (control).

7.16 *Enablers*

- Advocacy and self-advocacy in creating a sense of voice and control for service users;
- Quality social care practice is giving carers a sense of voice and control;
- Person-centred approaches in fostering voice and control principles for service users;
- Relationships between practitioner and service user in creating conditions for voice and control to be effective; and
- Person-centred and conversational approaches to social care practice.

7.17 *Barriers*

- Lack of clear definition in the literature as to what voice and control means;
- Complexity of applying voice and control principles in different social care settings;
- Sharing control between the organisation and service user in different social care settings;
- Complexity of implementing voice and control principles with different service user groups, e.g., older people with dementia, or young children.

8. Financial and economic implications

Ceri Phillips, Malcolm Prowle, Sion Tetlow and Zoe Williams

- 8.1 This section of the literature review has considered the economic implications of specific interventions across a variety of social care settings, as well as the range of models employed to assess the costs incurred and benefits generated in different social and health care contexts.
- 8.2 Some of the key messages are organised into three main sections:
- Methodological issues when considering the financial and economic implications of policy ;
 - Economic and financial analysis of interventions versus usual care;
 - Exploring strategies for reducing government social care spending.

Methodological issues when considering the financial and economic implications of policy

- 8.3 This section explores literature around methodological issues that occur when considering the financial and economic implications of policy.

Key messages:

- The difficulties of measuring improvements in well-being, in an objective manner, although a number of approaches are available (Frick & Kunz, 2008);
- The complexity of assessing 'cost-effectiveness' of health and social care services in conjunction with quality-of-life indicators (Frick & Kunz, 2008; Teresi et al., 2017);
- The difficulties of attributing improvements in well-being to the direct impact of the SSWBA, as opposed to other factors;
- Little is known about measuring improvements in use of resources as a consequence of integrated care, partly due to the fact that adequate methods are lacking, partly due to a failure to include economic evaluation in the design, planning, and implementation of integrated care (Stein et al., 2016);
- The availability and challenges of using different tools and models to evaluate the economic health of specific services (Sanders et al., 2017);
- The development of specific capability measures for measuring economic outcomes of interventions designed for children and young people (Mitchell et al., 2021); Capability measures are an alternative to standard mental health and well-being assessments (e.g. the EQ5D) which is 'argued to offer a richer evaluative space than the current approach which (1) limits the focus to specific health functioning, and (2) focuses only on what a person actually does, without consideration of whether they are able to do it, even if they may choose not to do so' (Mitchell et al, 2021);
- For modelling tools interventions to be successful, they should be co-produced by designers of the intervention and the users themselves (Sanders et al., 2017);
- To help capture all the costs and benefits relevant to the assessment of public health interventions, Marsh et al. (2012) proposes 1) the trend of modelling approaches that better capture the effects of public health interventions needs to continue with

economists considering a broader range of modelling techniques, facilitated by better data on behavioural outcomes 2) the use of 'valuation paradigms' which include the capabilities approach and the subjective well-being approach.

Economic and financial analysis of interventions versus usual care

8.4 This section explores literature comparing economic and financial analysis of specific interventions versus usual care.

Key messages:

- Specific interventions can have positive impacts on outcomes and cost-effectiveness for social care organisations, for example, Bauer (2016);
- Certain interventions may be more expensive in the short term, but may offset further costs downstream in the longer term (see PBCM intervention) (Rutter & Quinton, 1984);
- Caution should be applied to the use of interventions that have limited amounts of research and evaluation literature supporting their use.

Exploring strategies for reducing Government social care spending

8.5 This section explores strategies for increasing capacity over a variety of social and health care settings.

Key messages:

- Challenges and complexities of using 'cost-effectiveness' models in different social and health care contexts (Edwards et al., 2014);
- Long term, preventative strategies may increase capacity (Byrne-Maguire, 2017);
- Improving the problem of social isolation amongst older patients, and undertaking an annual dementia review for dementia patients could have the potential to reduce delays in hospital discharge (Landeiro et al., 2015; Goddard et al., 2016);
- There is much debate about the difference in resource implications of co or multi-morbidity compared to just a single morbidity (Brilleman et al., 2013);
- The distribution of costs and benefits associated with the SSWBA may not be distributed evenly over different parts of Welsh society (age, sex, location etc.).

9. Service user and carer experiences under the Act

Sarah Wallace

- 9.1 This chapter focusses on social care service users and carers and their experiences under the Act, both before and after the COVID-19 pandemic. It draws almost explicitly upon grey literature from Wales and papers and reports published between 2018-2022, which was the focus of this review. It reports on subgroups of service users and carers most relevant to our study, i.e., children and young people (CYP), adults and older people, disabled and learning-disabled people, and Welsh language speakers.
- 9.2 Under the Act, a social care service user is defined as an adult or child in need of care and support, and a carer is defined as a person who provides or intends to provide unpaid care to an adult or disabled child. The Act sets out the equal rights of carers to an assessment of their needs as those they provide care for, and if assessed as having an eligible need, local authorities have a duty to plan for and meet those needs by putting in place a 'Carer's Support Plan' (Welsh Government, 2021a; Carers Wales, 2022).

Overview

- 9.3 The new Performance and Improvement Framework for social services, introduced on 1st April 2020, provided a set of metrics to be collected under the 'Measuring Activity and Performance' section (Welsh Government, 2021b).
- 9.4 The most recent data from these metrics for the period 1st April 2020 to 31st March 2021³ show that in terms of service users and carers in Wales:

Service users

- 149,591 contacts were received by statutory social services for information, advice and assistance (IAA) services for adults.
- 73,658 new assessments were completed for adults.
- 176,408 contacts were received by statutory social services for IAA services for children.
- 47,950 new assessments were completed for children.
- As of the 31st March 2021, 46,585 adults had a care and support plan, of which 11% had a care and support plan supported using a Direct Payment, and there were 18,827 children with a care and support plan, of which 7% had a care and support plan supported using a Direct Payment.

Carers

- 6,841 contacts were received by statutory social services from adults or professionals contacting the IAA service on their behalf.
- 6,683 new assessments were completed for adult carers.

³ This is the first time data for the metrics have been collected and reported on. Quality issues broadly relate to missing data and inconsistencies in the way that data is reported between local authorities. For adults (including adult carers), data for 21 out of 43 metrics have been published. Additional data items on safeguarding have also been published. For children (including young carers), data for 23 out of 69 metrics have been published. For more information, refer to the [quality statement](#).

- 1,163 contacts were received by statutory social services from young carers or professionals contacting the IAA service on their behalf.
- 806 new assessments were completed for young carers.
- As of the 31st March 2021, 2,116 adult carers had a support plan. No specific details relating to the number of young carers with a care and support plan were provided.

9.5 According to the 2011 census, there are over 370,000 carers in Wales with approximately 30,000 carers under the age of 25 years⁴. Further, in the UK, Wales has the highest proportion of older carers, carers under 18 years, and carers providing more than 50 hours of care a week (Welsh Government, 2021a). Other sources highlight that post-March 2020, the number of carers in Wales increased significantly to an estimated 683,000 (Carers Wales, 2020b), whilst more recent estimates put the numbers of carers in Wales as 584,134 (Carers Week, 2022).

National perspectives

- 9.6 *Measuring the Mountain* (MtM) (Cooke et al., 2019a; Iredale & Cooke, 2020a) collected nearly 1,000 stories from service users and carers from across Wales. Findings from the first phase of MtM highlighted the immensely varied experiences of individuals and carers and underlined the complexity of their lives, and of delivering social care services (Cooke et al., 2019a). The evidence suggested a need for co-production to be better understood and embedded within citizens' and carers' interactions with social care and that 'people need to be viewed as partners in social care delivery' (p.79); a feature further emphasised in phase two of MtM.
- 9.7 Across both phases, negative stories and difficulties experienced included, having to fight for support, feeling judged when accessing care and support, confusing and complex systems, having to seek out information rather than being provided it, and needing to fit in with service provision. By contrast, those with positive experiences gave examples of inclusive, balanced decision-making, and asset-based meaningful exchanges with social care professionals, facilitated by thorough and reliable communication, and flexible approaches.
- 9.8 In drawing their conclusions, Iredale & Cooke (2020a) noted that 'in some cases, the principles of the *Social Services and Well-being (Wales) Act 2014* can be seen prominently and keep with the aspirations of the Act. In others, they are missing, and people's experiences are at best poor, and at worst damaging' (p.91)⁵.
- 9.9 The COVID-19 pandemic has served to exacerbate existing challenges within the social care sector in Wales. Exploring public attitudes to social care in Wales, Williams (2022) found that COVID-19 was widely felt to have caused significant strain on social care, as well as health, and was a commonly cited reason amongst survey respondents as to why those 'who felt they needed care did not or could not access it during the past two years' (p.4). It also identified that four in ten of those who felt that they or someone in their household/close family needed social care during the past two years did not receive or

⁴ [Welsh residents by hours of care and local authority](#)– awaiting publication of 2021 census figures.

⁵ [Welsh Government \(2022\). Measuring the Mountain: response to 2020 recommendations.](#)

make use of it. As well as COVID-19, other reasons included a lack of availability or staff shortages, and the ‘application or access processes being too complex’ (p.2). Within focus groups held as part of the same study, participants urged the need for more consistency in the social care received, more personalised care, better integration between health and social care, and more investment in social care.

Service users

Children and Young People (CYP)

- 9.10 Findings from the *Right Way Social Care Project* identified that CYP receiving support, want to be seen as individuals, to be listened to, and understood (Children’s Commissioner for Wales (CCW, 2021). The findings also highlighted the importance of communication and confidentiality for CYP when interacting with supporting adults. Key messages included forming trusting relationships, getting good quality information, getting feedback on what has been done with their views and having a broad range of rights upheld, including privacy, information, and a right to family life.
- 9.11 CYP with complex needs – e.g., those experiencing distress with mental health, emotional well-being, and behavioural issues – have been found to be waiting too long to receive support, with experiences of being ‘bounced’ between services who cannot reach an agreement about who is responsible for their care (CCW, 2020).
- 9.12 Similarly, learning disabled CYP transitioning to adult services ‘too often’ face a complicated and stressful experience (CCW, 2020). In earlier work undertaken by the CCW (2018a), key messages from young people (YP) and their families included a lack of opportunities for YP to be involved in planning and decision-making, with planning too often done ‘about them’ rather than ‘with them’, variation in provision e.g., services ‘having different ways’ (p.4) of transferring to adult services, and expectations that learning disabled YP will slot into services that already exist. Further, the crucial role and reliance on parents and their need for support and recognition was also highlighted. Where YP and their families reported good experiences of transition, they had been involved; were clear about the process; felt well supported by a keyworker, lead professional or dedicated transition service; and often had access to a youth-centred provision that helped young people prepare for adulthood and expand their social and community networks.
- 9.13 Whilst recognising there are ‘promising’ and good examples of work with these specific CYP groups in regions of Wales, including early help panels, and that all regions now have specific multi-agency groups to consider the needs of CYP, the report concluded that more is needed, that regions need to do more to learn from each other, and that particularly for learning disabled CYP, ‘in some regions little has changed on the ground’ (CCW, 2020).
- 9.14 Previous work by CCW emphasised the importance that CYP leaving care have an ‘equal chance to be the best they can be as they approach adulthood’ (CCW, 2018b). Whilst good progress had been made amongst local authorities in Wales, CCW (2018c) acknowledged that further progress was still required in some areas. Specific examples included a lack of clarity on how education, social services, and housing are working together within each local authority area to support care leavers, and the importance of clear, accessible information being available to care leavers. In addition, it identified that clarity is also required within services as to care leavers’ entitlement to grants and funding within the LA as this can pose challenges for those working with care leavers.

- 9.15 *The Coronavirus and Me* survey (CCW, 2020) aimed to find out how CYP experienced the pandemic in Wales and responses from CYP reporting disability were compared with CYP reporting no disability. Disabled CYP were significantly more likely to say that the closure of a business or service was having a big impact on how they felt. Examples provided included the cancellation of hospital appointments, and respite support being withdrawn. Results also highlighted that disabled CYP were significantly more likely to comment about the negative impact of the pandemic on their mental health.
- 9.16 Roberts et al. (2021) considered corporate parenting in a pandemic and the delivery and receipt of support to care leavers during COVID-19. Findings illustrated aspects of ‘good’ corporate parenting of which underpinning features were professionals who recognised their corporate parenting responsibilities, were pro-active in contacting YP, understood their needs and situations, and were willing and able to respond meaningfully. Relationships were central to YP’s reflections and they appreciated professionals who showed interest and concern for their well-being and conveyed to them that they were available and reliable. Yet, for other YP, corporate parenting support was perceived as unavailable, unhelpful and/or uncaring, with evidence of disconnect between professionals’ reporting of practice and YP’s experiences.

Older people

- 9.17 *State of the Nation* (Older People’s Commissioner for Wales (OPCW), 2019) drew on a range of data sources including: primary data collected on behalf of the Commissioner via polling by ICM Direct and organisational data provided directly to the Commissioner’s office by Local Police Forces in Wales and Welsh Government Departments, publicly available datasets (e.g., National Survey for Wales, Labour Force Survey) and data published on the Welsh Government website or available via StatsWales.com; Official Statistics collated and published by the Office for National Statistics (ONS); and reports and literature published by a range of public, private, academic and third sector organisations. Findings illustrated that despite many older people feeling in control of their lives and able to do the things that mattered to them, stark inequalities existed within the older population in Wales. Many older people struggled, or were unable, to make their voices heard, often feeling powerless when proposals were made that would affect their lives (OPCW, 2019).
- 9.18 In terms of the impact of COVID-19 on older people and the significant challenges faced by health and social care services, the OPCW (2020a) referred to the need for ‘urgent change’ (p.10). For example, this included the need for social care to have parity with the NHS, more investment in services, and support to enable healthy ageing. Further, it included the voices of older people needing to be heard, to be at the heart of decision-making, and adopting a truly person-centred approach to support older people.
- 9.19 COVID-19 restrictions meant that many older people were unable to participate in activities that supported their health and well-being, fully engage with their communities, or access the healthcare services and support they needed, all to the detriment of their physical and mental health (OPCW, 2021). The report found that pressures on health and social care systems meant that for some, domiciliary care was withdrawn, leading to older people becoming increasingly reliant on family and friends to provide some of this support, either as new carers or adding to their existing caring responsibilities.

9.20 Issues highlighted for care home residents during COVID-19 included access to health services (particularly GP visits), the effect of a lack of support on their physical health as well as the impact of the pandemic on their quality of life and mental health and well-being (OPCW, 2020b). As such, ‘the pandemic period has shown that the rights of older people living in care homes are not always upheld and respected and action is needed to strengthen and promote the rights of residents’ (OPCW, 2021, p.14).

Disabled and learning-disabled people

9.21 The Disability Equality Forum’s COVID-19 Impact Report (Foster, 2021) brings together the results of an intensive enquiry into disabled people’s experiences during the pandemic. In relation to the Act, the enquiry highlighted the detrimental impact on disabled people’s rights to independent living⁶, and that the key principles of ‘Voice, Choice and Control’ had been seriously eroded (inaccessible information and poor consultation during COVID-19). Many essential services were withdrawn or reduced, often at short notice and there were experiences of being unable to access information and essential long-term healthcare. COVID-19 significantly impacted disabled people’s physical and mental health and well-being (e.g., increased anxiety, isolation) with individuals experiencing a loss of power, voice, choice, and citizenship, which impacted their day-to-day living.

9.22 Additionally, those living alone and in institutions were particularly vulnerable. Deaf older adults and those experiencing hearing loss were also identified as potentially being at greater risk of negative COVID-19 outcomes, related to poor access to public information, inaccessible support (telephone service), inadequate provision of interpreters, and a ‘serious lack of information in BSL’ (Foster, 2021, p.48).

9.23 All Wales People First (2020) members experienced very sporadic contact with and from social services during lockdown, with some having regular contact and ‘check-ins’, and others receiving occasional calls, or no contact at all. However, positives and potential long-term change were demonstrated; in some areas, members were reported to begin to question their level of need for day centre services and felt more confident and comfortable in staying home and interacting with others through digital channels and accessing the local community.

Welsh Language Speakers

9.24 With 28% of fluent Welsh speakers over 65 years old, ensuring that individuals can use the language of their choice should be of vital importance when planning health and social care services (OPCW, 2021). Similarly, Alzheimer’s Society Cymru (2018) emphasised the relevant language considerations for dementia care, key policy and legislative developments, and that Welsh language provision is an important part of people’s health and care package, particularly for children, vulnerable individuals and people living with dementia. However, the organisation found that the needs of Welsh speakers living with dementia were often not met. It also found that care in Welsh was often not available without people having to ask for it. Whilst recognising good practice at a local level and that

⁶ Schedule 12 part 2 of the Coronavirus Act which suspended key duties under the SSWBA

awareness of the Welsh language and the *Active Offer*⁷ at a strategic level had improved, awareness and understanding had not filtered down into practice with inconsistencies identified in the availability of tools, diagnostic tests, and assessments in Welsh and very few examples of the needs of Welsh-speaking service users being fully met.

- 9.25 *More Than Just Words* (Welsh Government, 2019) has provided strategic direction and guidance enabling the health, social care and social services sector in Wales to increase and strengthen its Welsh language service provision (Harries & Bryer, 2021). Whilst evidence indicates that *More Than Just Words* has successfully raised awareness of the importance of Welsh language service provision not only as a right or a choice, but also as an essential need for many Welsh speaking service users, less progress appears to have been achieved across most settings in relation to delivering the *Active Offer*. In comparison to health, greater traction with the strategic aims of the framework are highlighted within social care. Nonetheless, the authors findings indicate that a lack of parity persists between Welsh and English language provision across many areas of the sector and that at the operational planning level the challenge of changing culture and mindset has been greater.

Carers

- 9.26 The Act aims to strengthen the rights and improve services for carers; yet evidence indicates the Act ‘is not having the desired impact’ (National Assembly for Wales, 2019, p.10⁸). Whilst the pandemic has exacerbated the experiences of carers and intensified pressures within the health and social care sector, even before COVID-19, the Act was not working for carers (Carers Wales, 2020b), and there was a need to provide better support for carers (Cooke et al., 2019a). Additional support cited as being required for carers included increased financial support, and greater investment in care and support services to enable carers to have a break from their caring role (Carers Week, 2022).

Pre-COVID-19

- 9.27 The National Assembly for Wales (2019) inquiry on the impact of the Act in relation to carers of all ages in Wales, focussed specifically on assessments of need; provision of support, including respite care; provision of information, advice, and assistance; and information collected by LAs and health boards on carers and their needs. The inquiry found from evidence received by the committee, that the Act was ‘broadly supported, but expressed disappointment both in the way that the Act has been implemented and the way it has been resourced’ (p.17). The inquiry also found that improvements for carers under the Act were ‘patchy’ (p.15), and that most carers lacked awareness of the Act itself, and their rights under the Act, particularly regarding their right to a carer’s needs assessment. For young and young adult carers, a lack of recognition existed amongst public services and inconsistencies to assessments and support were raised. Findings also referred to carers having to ‘fight’ for services, and the impact on their own health and well-being due

⁷ Providing a service in Welsh without someone having to ask for it. The Welsh language should be as visible as the English language: [Active Offer](#)

⁸ Evidence cited by the National Assembly for Wales refers to Carers Wales (2018), Care Inspectorate Wales (2017), and the former Older People’s Commissioner, Sarah Rochira, p.10).

to services such as respite lacking flexibility, being of variable quality, and difficult to access.

- 9.28 Carers Wales (2019a) called for system reform to ensure carers are properly supported. Survey findings revealed that carers were experiencing loneliness and social isolation, financial pressures, and were facing their own health problems due to their caring role. In terms of carers' assessments, 28% had received an assessment or a review of their assessment in the previous 12 months. Most carers who had received an assessment/review in the previous year felt that their needs were not given sufficient consideration.
- 9.29 Findings from Carers Wales (2019b) *Track the Act Briefing 4* reinforce the importance of carers receiving timely and appropriate advice, enabling carers to remain resilient and preventing them from requiring more formal support. Yet, of those who had received a carer's assessment, most had asked for one themselves, rather than being offered one, and in terms of support, '57% of carers advised they did not receive any support' (p.14). Findings from *Track the Act 5* carers survey echoed those of *Track the Act 4*: many carers (85%) had not had a needs assessment in the year before March 2020, and 72% had not received or been offered an assessment since the introduction of the Act (Carers Wales, 2020b). Findings from *Track the Act 5* also indicated a lack of awareness of carer needs assessments, with more than 41% of carers who had not heard about needs assessments before completing the survey.

Post-COVID-19

- 9.30 Post Covid-19 estimates of the number of carers in Wales vary but all agree a significant increase (see 9.5). Many of these additional carers are described as 'hidden carers' who do not recognise or identify themselves as a carer, which has a detrimental impact in terms of access to information, advice, and support (Carers Wales, 2020b). A central tenet of the evidence collected by Carers Wales (2020b) referred to the isolation and loneliness experienced by carers during the pandemic due to restrictions and shielding which 'stripped away carers' support networks' (p.2). Findings describe a 'lack of systemic recognition' (p.3) for carers and their role during lockdown.
- 9.31 With regards to support and services, barriers reported to accessing services included a lack of awareness of services and sources of support for carers in their local community or feeling that the services available to them did not meet their needs or the needs of the person they care for (Carers UK, 2021). Closed or reduced provision required carers to provide more care with less support, reducing their ability to take breaks from caring. Furthermore, comparing survey findings from Carers Wales (2019a), the number of carers who had received a carer's needs assessment reduced (from 28% to 21%). Regarding their own health, most carers reported their physical and mental health had deteriorated during the pandemic.
- 9.32 Templeton et al. (2021), identified an absence of literature centred on young carers' needs assessments with most evidence identified relating to adult carers, and little evidence in relation to COVID-19 and assessment processes, but rather more general information about support for carers. Challenges to accessing assessments included carers and/or professionals/services not identifying as carers, confusion surrounding terminology, a lack of timely information or advice, confusion around where to access support, delays in

accessing assessments or not meeting the criteria for support, language barriers, sensory impairments, and limited internet access. Specific groups identified as being more at risk of not accessing information included people caring for children with additional support needs, carers not in employment and/or seeking employment, young carers, and carers of people living with dementia. Enablers included highly trained staff (knowledge, attitudes, and importance of carers feeling heard and treated with respect during the assessment process), well-designed online resources, and carers groups (peer support). Notably, the role of the third sector was essential in identifying and providing information and support to carers.

- 9.33 Burrows et al. (2021) further highlight the pressures faced by carers during COVID-19. Whilst the pandemic had enabled some carers to feel they were ‘stepping off the treadmill’ (p.5), allowing them more time to relax with the person cared-for, many carers’ stress, anxiety and isolation were exacerbated. Examples provided include closure of provision, being cut-off from sources of support such as friends and family, increased time spent pursuing services, and increased financial worries. However, features such as online access to carers groups and the rapid adaptation of young adult carers support groups were appreciated and supported well-being. Nevertheless, the authors concluded that, despite carers being central to care planning, they continue to suffer detriment to their own well-being because of their caring responsibilities. Further, the Act and the Welsh Government Carers Strategy (2021a) have not produced the required changes in approaches to working with and supporting carers by health and social care services.
- 9.34 During the Carers Wales (2022) summit, carers expressed frustration, anger and upset that the pandemic had worsened an already precarious situation and that the past two years had been challenging on several levels. Key themes included the need for improvements in carers accessing and benefitting from their rights within the Act, improvements in the recognition and understanding of the role of carers, greater respect for the knowledge and experience carers have, improvements in meaningful communication with and involvement of carers across statutory services, and improvements in service provision to support carers to care safely and confidently.

Key messages

- 9.35 This section has presented what the literature says on the experiences of subgroups of service users (i.e., CYP, adults and older people, disabled and learning-disabled people and Welsh language speakers) and carers under the Act.
- 9.36 Findings highlight a breadth and variation of experiences amongst service users and carers in receipt of care and support. The review has identified many of the features that service users and carers value e.g., trusting relationships, provision of timely information and advice, meaningful communication, and the importance of including people in the delivery of their care and support.
- 9.37 Yet, whilst there are examples of good practice and good experiences, overall, the evidence included within the review reveals many challenges and issues affecting service users and carers; and access to good provision is not consistent. For example, despite a right to an assessment under the Act, carers experience difficulties in obtaining an assessment and are often not routinely offered one, and discrepancies persist in the consistency of assessments being offered by different local authorities.

9.38 COVID-19 has exacerbated existing difficulties for both individuals and health and social care delivery and there remains some distance to realise the aspirations of the Act for all service users and carers.

10. Reference list A – publications cited in this report

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