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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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Well-being

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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

Moher, D., Liberati, A., Tetzlaff, J., Altman, D. & The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *PLOS Medicine*. 6 (7): e1000097. [The PRISMA Statement](#).

National Assembly Wales (2014). *Social Services and Well-being (Wales) Act 2014*. Available at: [Social Services and Well-being \(Wales\) Act 2014](#).

Well-being

Alkire, S. (2015). Capability Approach and Well-being Measurement for Public Policy. *OPHI Working Paper 94*, Oxford University.

Atkinson, S. (2013). Beyond components of well-being: The effects of relational and situated assemblage. *Topoi*, 32(2), 137-144.

Dolan, P. & Metcalfe, R. (2012). Measuring subjective wellbeing: Recommendations on measures for use by national governments. *Journal of Social Policy*, 41(2), 409-427.

Henderson, L. W. & Knight, T. (2012). Integrating the hedonic and eudemonic perspectives to more comprehensively understand wellbeing and pathways to wellbeing. *International Journal of Wellbeing*, 2(3), 196-221.

Huppert, F. & Timothy, T. (2013). Flourishing Across Europe: Application of a New Conceptual Framework for Defining Well-Being. *Social Indicators Research*, 110, pp. 837-861

Ruggeri, K., Garcia-Garzon, E., Maguire, A., Matz, S. & Huppert, F. (2020). Well-being is more than happiness and life satisfaction: a multidimensional analysis of 21 countries in Health and *Quality of Life Outcomes*, 18.

Selwyn, J., Wood, M. & Newman, T. (2017). Looked after children and young people in England: Developing measures of subjective well-being. *Child Indicators Research*, 10(2), 363-380.

Sen, S. (2009). *Ideas of Justice*. Oxford. Oxford University Press.

Prevention and Early Intervention

Abrams, T., Man, M. & McLeod, R. (2019). Building Connections Fund: Guidance on co-design and community spaces. London. NPC.

Allen, K. & Glasby, J. (2010). The (Multi-)Billion Dollar Question: Embedding Prevention and Rehabilitation in English Health and Social Care. *Journal of Integrated Care*. 18 (4): 26-35.

Bedford, S. & Harper, A. (2018). Sustainable social care: What role for community business? London. The New Economics Foundation.

Clark, P. (2019). Problems of Today and Tomorrow': Prevention and the National Health Service in the 1970s. *Social History of Medicine*, 33(3), 981-1000.

Curry, N. (2006). Preventative Social Care: Is it Cost Effective? King's Fund. Available at: [Preventative Social Care: Is it Cost Effective? King's Fund](#).

Emerson, E., Hatton, C. & Robertson, J. (2011). Prevention and Social Care for Adults with Learning Disabilities. A Scoping Review. School for Social Care Research. Available at: [Prevention and Social Care for Adults with Learning Disabilities. A Scoping Review. School for Social Care Research](#).

- Gough, I. (2013). The Political Economy of Prevention. *British Journal of Political Science*, 45(2), 307-327.
- Hull, D., Davies, T. & Swersky, A. (2016). The Community Business Market in 2016. Research Institute Report No. 4. Power to Change. Available at: [The Community Business Market in 2016](#).
- Kerslake, A. (2011). Investing in prevention for older people at the health and social care interface. Oxford. Institute of Public Care, Oxford Brookes University.
- Knapp, M., Bauer, A., Perkins, M. & Snell, T. (2012). Building community capital in social care: is there an economic case? *Community Development Journal*, 48(2), 313-331.
- Marczak, J., Wistow, G. & Fernandez, J. (2019). Evaluating Social Care Prevention in England: Challenges and Opportunities. *Journal of Long-Term Care*, (2019), 206–217.
- Miller, R. & Whitehead, C. (2015). Inside out and down: Community based approaches to social care prevention in a time of austerity. University of Birmingham. Available at: [Inside out and down: Community based approaches to social care prevention in a time of austerity](#).
- Shapiro, V.B., Hawkins, D.J., Oesterle, S., Monahan, K.C., Brown, E.C. & Arthur, M.W. (2013). Variation in the Effect of Communities That Care on Community Adoption of a Scientific Approach to Prevention. *Journal of Social Work Research*, 4(3).
- Tew, J., Duggal, S., Carr, S., Ercolani, M., Glasby, J., Kinghorn, P., Miller, R., Newbigging, K., Tanner, D. & Afentou, N. (2019). Implementing the Care Act 2014: Building social resources to prevent, reduce or delay needs for care and support in adult social care in England. University of Birmingham for the Department of Health and Social Care.
- Warin, M., Zivkovic, T., Moore, V., Ward, P. & Jones, M. (2015). Short horizons and obesity futures: Disjunctures between public health interventions and everyday temporalities. *Social Science & Medicine*, 128, 309-315.

Co-production

- Bradley, E. (2015). Carers and co-production: Enabling expertise through experience? *Mental Health Review Journal*, 20(4), 232–241.
- Budge, G., Mitchell, A., Rampling, T., Down, P. & Bridge Collective (2019). “It kind of fosters a culture of interdependence”: a participatory appraisal study exploring participants' experiences of the democratic processes of a peer-led organisation. *Journal of Community & Applied Social Psychology*, 29(3), 178-192.
- Denbighshire Voluntary Services Council (2018). Sustainable Funding: Small is Beautiful (and Wise). Summary of Wales School for Social Care Research event. Available at: [Sustainable Funding: Small is Beautiful \(and Wise\)](#).
- Doran, P. & Buffel, T. (2018). Translating Research into Action: involving older people in co-producing knowledge about age-friendly neighbourhood interventions. *Working with Older People*, 22(1), 39-47.
- Dougall, D., Lewis, M. & Ross, S. (2018). Transformational Change in Health and Care: Reports from the Field. London: The King's Fund.
- Dunér, A., Bjälkebring, P. & Johansson, B. (2019). Autonomy, Choice, and Control for Older Users of Home Care Services: Current Developments in Swedish Eldercare. *Journal of Social Service Research*, 45(1), 129-141.
- Ellis, R. (2017). Heritage and Stigma. Co-producing and communicating the histories of mental health and learning disability. *Medical Humanities*, 43, 92-98.

- Flinders, M. & Wood, M. (2018). Ethnographic insights into competing forms of co-production: A case study of the politics of street trees in a northern English city. *Social Policy Administration*, 53, 279-294.
- Ford, S.B. Bowyer, T. & Morgan, P. (2015). The experience of compulsory treatment: the implications for recovery-orientated practice? *Mental Health and Social Inclusion*, 19(3), 126-132.
- Freeman, L.R., Waldman, M., Storey, J., Williams, M., Griffiths, C., Hopkins, K., Beer, E. & Davies, J. (2016). Working towards co-production in rehabilitation and recovery services. *Journal of Mental Health Training, Education and Practice*, 11(4), 197-207.
- Gale, N., Brown, P. & Sidhu, M. (2018). Co-production in the epidemiological clinic: A decentred analysis of the tensions in community based, client-facing risk work. *Social Policy Administration*, 53, 203-218.
- Gunasekara, I., Patterson, S., & Scott, J.G. (2017). What makes an excellent mental health doctor? A response integrating the experiences and views of service users with critical reflections of psychiatrists. *Health and Social Care in the Community*, 25(6), 1752-1762.
- Harlock, J. (2014). From outcomes-based commissioning to social value? Implications for performance managing the third sector. Third Sector Research Centre, Working Paper series 123.
- Keinhans, R. (2017). False promises of co-production in neighbourhood regeneration: the case of Dutch community enterprises. *Public Management Review*, 19(10), 1500-1518
- Lowe, T. & Plimmer, D. (2019). Exploring the new world: Practical insights for funding, commissioning, and managing in complexity. Collaborate For Social Change.
- Maurits, E.E.M., de Veer, A.J.E., Groenewegen, P.P. & Francke, A.L. (2018). Attractiveness of people centred and integrated Dutch home care: a nationwide survey among nurses. *Health and Social Care in the Community*, 26(4), 523-531.
- McCarry, M., Larkins, C., Berry, V., Radford, L. & Stanley, N. (2018). The Potential for Co-production in Developing Violence against Women Services in Wales. *Social Policy & Society*, 17(2), 193-208.
- Meerkerk, I., Kleinhans, R. & Molenveld, A. (2018). Exploring the durability of community enterprises: A qualitative comparative analysis. *Public Administration*, 96(4), 651-667.
- Milson, S.G. (2018). Engagement of older people in Wales – how Cymru Older People’s Alliance is forging a new direction. *Working with Older People*, 22(2), 69-75.
- Miller, E. & Barrie, K. (2016). Personal outcomes: Learning from the Meaningful and Measurable project: Strengthening links between identity, action and decision-making. Healthcare Improvement Scotland.
- Munroe, E. (2011). The Munroe Review of Child Protection: Final Report. London, The Stationery Office.
- Nandram, S. & Koster, N. (2014). Organizational innovation and integrated care: lessons from Buurtzorg. *International Journal of Integrated Care*, 2(4), 174-184.
- O’Leary, P., Tsui, M.S. & Gillian, R. (2012). The boundaries of the social work relationship revisited: towards a connected, inclusive and dynamic conceptualisation. *British Journal of Social Work*, 43(1), 135-153.
- Parry-Jones, B. & Soulsby, J. (2001). Needs-led assessment: the challenges and the reality. *Health and Care in the Community*, 9(6), 414-28.
- Patterson, M., Nolan, M., Rick, J., Brown, J., Adams, R. & Musson, G. (2011). From Metrics to Meaning: Culture Change and Quality of Acute Hospital Care for Older People. National Institute for Health Research Service Delivery and Organisation Programme.

Pearson, C., Watson, N. & Manji, K. (2017). Changing the culture of social care in Scotland: Has a shift to personalization brought about transformative change? *Social Policy Administration*, 52(3), 662-676.

Pilgrim, D. (2018). Co-production and involuntary psychiatric settings. *Mental Health Review Journal*, 23(4), 269-279.

Sanders, K.Y. (2006). Overprotection and lowered expectations of persons with disabilities: The unforeseen consequences. *Work*, 27(2), 181-188.

Schlappa, H. & Imani, Y. (2012). *Leadership and Structure in the Co-production of Public Services*. Conference Paper. Paper presented at the annual conference of the British Academy of Management Public Management and Governance Track, 11th – 13th September 2012.

Smale, G., Tuson, G., Biehal, N. & Marsh, P. (1993). Empowerment, assessment, care management and the skilled worker. National Institute for Social Work Practice and Development Exchange, London: HMSO.

Thom, K. & Burnside, D. (2018). Sharing power in criminal justice: The potential of co-production for offenders experiencing mental health and addictions in New Zealand. *International Journal of Mental Health Nursing*, 27, 1258-1265.

Vaeggemose, U., Ankersen, P.V, Aagaard, J. & Burau, V. (2017). Co-production of community mental health services: Organising the interplay between public services and civil society in Denmark. *Health and Social Care in the Community*, 26, 122-130.

Voorberg, W., Tummers, L., Jilke, S. & Bekkers, V. (2018). Financial Rewards Do Not Stimulate Coproduction: Evidence from Two Experiments. *Public Administration Review*, 78(6), 964-873.

Vrangbaek, K., Elling Scheel, C. & Kriegbaum, M. (2018). Voluntary associations and co-production of health promoting activities for older adults: Experiences and policy lessons from Denmark. *Health Policy*, 122, 1255-1259.

Weaver, B. (2018). Co-production, governance, and practice: The dynamics and effects of User Voice Prison Councils. *Social Policy Administration*, 53, 249-264.

Wharne, S. (2015). Shared dilemmas, choice, and autonomy in the management of psychosis: a phenomenological analysis. *Mental Health Review Journal*, 20(4), 256 – 266.

Multi-agency

Cilliers, P. (1998). Complexity and Postmodernism. Understanding complex systems. London, Routledge.

Fernandez, J.L., McGuire, A. & Raikou, M. (2018). Hospital coordination and integration with social care in England: The effect on post-operative lengths of stay. *Journal of Health Economics*, (61) 233-243.

King's Fund (2019). Integrated Care: Our work on joined up health and care services. Available at: [Integrated Care](#).

King's Fund (2013). Making Integrated Care happen at scale and pace. Lessons from experience. Available at: [Making Integrated Care happen at scale and pace. Lessons from experience](#).

Leichsenring, K., Rodrigues, R., Winkelmann, J. & Falk, K. (2016). Integrated Care, Competition and Choice - Removing barriers to care coordination in the context of market-oriented governance in Germany and Sweden. *International Journal of Integrated Care*, 16(6), 1-8.

Peckover, S., & Golding, B. (2017). Domestic abuse and safeguarding children: critical issues for multi-agency working. *Child Abuse Review*. 26, 40-50.

Preiser, R. (2016). *Critical Complexity: Collected Essays*. De Gruyter Inc.

World Health Organisation (2018). Person centred care. Available at: [Person centred care](#).

Voice and control

Brogan, P., Hasson, F. & McIlfratrick, S. (2018). Shared decision-making at the end of life: a focus group study exploring the perceptions and experiences of multi-disciplinary healthcare professionals working in the home setting. *Palliative Medicine*, 32(1), 123-132.

Callaghan, L. & Towers, A.M. (2014). Feeling in control: comparing older people's experiences in different care settings. *Ageing & Society*, 34, 1427-1451.

Darby, J., Williamson, T., Logan, P. & Gladman, J. (2017). Comprehensive geriatric assessment on an acute medical unit: a qualitative study of older people's and informal carer's perspectives of the care and treatment received. *Clinical Rehabilitation*, 31(1), 126-134.

Department of Health (2015). *Voice, choice and control: How registered nurses, care and support staff in the care sector can support people to achieve these aims*. Available at: [Voice, choice and control](#).

Dunér, A., Bjalkebring, P. & Johansson, B. (2019). Autonomy, choice and control for older users of home care services: current developments in Swedish eldercare. *Journal of Social Service Research*, 45(1), 129-141.

Eades, S. (2018). Impact evaluation of an independent mental health advocacy (IMHA) service in a high secure hospital: a co-produced survey measuring self-reported changes to patient self-determination. *Mental Health & Social Inclusion*, 22(1), 53-60.

Ewing, G., Austin, L. & Grande, G. (2016). The role of the Carer Support Needs Assessment Tool in palliative home care: a qualitative study of practitioners' perspectives of its impact and mechanisms of action. *Palliative Medicine*, 30(4), 392-400.

Galiatsatos, P., Gurley, A. & Hale, W.D. (2017). Policy and advocacy for informal caregivers: how state policy influenced a community initiative. *Journal of Public Health Policy*, 38(4), 503-508.

Glennidinning, C., Mitchell, W. & Brooks, J. (2015). Ambiguity in practice? Carers' roles in personalised social care in England. *Health and Social Care in the Community*, 23(1), 23-32.

Hamilton, L.G., Mesa, S., Hayward, E., Price, R. & Bright, G. (2017). "There's a lot of places I'd like to go and things I'd like to do": the daily living experiences of adults with mild to moderate intellectual disabilities during a time of personalised social care reform in the United Kingdom. *Disability & Society*, 32(3), 287-307.

Hanga, K., DiNitto, D.M., Wilken, J.P. & Leppi, L. (2017). A person-centred approach in initial rehabilitation needs assessment: experiences of persons with disabilities. *European Journal of Disability Research*, 11, 251-266.

Gridley, K., Brooks, J. & Glennidinning, C. (2014). Good practice in social care: the views of people with severe and complex needs and those who support them. *Health and Social Care in the Community*, 22(6), 588-597.

Havlicek, J., Curry, A. & Villalpando, F. (2018). Youth participation in foster youth advisory boards: perspectives of facilitators. *Children and Youth Services Review*, 84, 255-270.

Keyes, S.E., Webber, S.H. & Beveridge, K. (2015). Empowerment through care: Using dialogue between the social model of disability and an ethic of care to redraw boundaries of independence and partnership between disabled people and services. *ALTER, European Journal of Disability Research*, 9, 236-248.

Larkin, M. (2015). Developing the knowledge base about carers and personalisation: contributions made by an exploration of carers' perspectives on personal budgets and the carer-service user relationship. *Health and Social Care in the Community*, 23(1), 33-41.

- McCarter, S.P., Tariman, J.D., Spawn, N., Mehmeti, E., Bishop-Royse, J., Garcia, I., Hartle, L. & Szubski, K. (2016). Barriers and promoters to participation in the era of shared treatment decision-making. *Western Journal of Nursing Research*, 38(10), 1282-1297.
- McNeilly, P., Macdonald, G. & Kelly, B. (2018). The participation of parents of disabled children and young people in health and social care decisions. *Child: Care, Health & Development*, 43, 839-846.
- Morris, J.N., Declercq, A., Hirdes, J.P., Finne-Soveri, H., Fries, B.E., James, M.L., Geffen, L., Kehyayan, V., Saks, K., Szczerbinska, K. & Topinkova, E. (2017). Hearing the voice of the resident in long-term care facilities – an internationally based approach to assessing quality of life. *Journal of the American Medical Directors Association*, 19(3), 207-215.
- Rand, S. & Malley, J. (2014). Carers' quality of life and experiences of adult social care support in England. *Health and Social Care in the Community*, 22(4), 375-385.
- Reindl, R.S., Waltz, M. & Schippers, A. (2016). Personalisation, self-advocacy and inclusion: an evaluation of parent-initiated supported living schemes for people with intellectual disabilities and developmental disabilities in the Netherlands. *Journal of Intellectual Disabilities*, 20(2), 121-136.
- Seddon, D. & Robinson, C. (2015). Carer assessment: continuing tensions and dilemmas for social care practice. *Health and Social Care in the Community*, 23(1), 14-22.
- Singleton, B.E. & Fry, G. (2015). Citizen carer: carer's allowance and conceptualisations of UK citizenship. *Journal of Social Policy*, 44(3), 549-566.
- Skills for Care (2018). Using conversations to assess and plan people's care and support: the principles of conversational assessment. *Skills for Care*. Available at: [Using conversations to assess and plan people's care and support](#).
- Tideman, M. & Svensson, O. (2015). Young people with intellectual disability – the role of self-advocacy in a transformed Swedish welfare system. *International Journal of Qualitative Studies on Health and Well-being*, 10(1), 1-8.
- Tucker, S., Hargreaves, C., Roberts, A., Anderson, I., Shaw, J. & Challis, D. (2018). Social care in prison: emerging practice arrangements consequent upon the introduction of the 2014 Care Act. *British Journal of Social Work*, 48, 1627-1644.
- Vamstad, J. (2016). Exit, voice and indifference – older people as consumers of Swedish home care services. *Ageing & Society*, 36, 2163-2181.
- Washburn, A.M. & Grossman, M. (2017). Being with a person in our care: person-centred social work practice that is authentically person-centred. *Journal of Gerontological Social Work*, 60(5), 408-423.
- Watts, J.H. & Cavaye, J. (2018). Being a former carer: impacts on health and well-being. *Illness, Crisis & Loss*, 26(4), 330-345.

Economic and financial

- Bauer, A., Knapp, M., Wistow, G., Perkins, M., King, D. & Valentina, I. (2017). Costs and economic consequences of a help-at-home scheme for older people in England. *Health and Social Care in the Community*, 25(2), 780-789.
- Brilleman, S., Purdy, S., Salisbury, C., Windmeijer, F., Gravelle, H. & Hollinghurst, S. (2013). Implications of comorbidity for UK primary care costs: a retrospective observational study. *British Journal of General Practice*, 63(609), 274-282.
- Byrne-Maguire, I. (2017). Active Ageing - Implementing integrated care for falls prevention and bone health at scale. *International Journal of Integrated Care*, 17(5) pp. 1-8.

- Edwards, R.T., Charles, J.M., Thomas, S. et al. (2014). A national Programme Budgeting and Marginal Analysis (PBMA) of health improvement spending across Wales: disinvestment and reinvestment across the life course. *BMC Public Health*, 14, 837.
- Frick, K.D. & Krunch, J.L. (2008). Understanding cost-effectiveness research applied to social work. *Social Work and Public Health*, 23(6) 7-21.
- Goddard, M., Kasteridis, P., Jacobs, R., Santos, R. & Mason, A. (2016). Bridging the gap: the impact of quality of primary care on duration of hospital stay for people with dementia. *Journal of Integrated Care*. pp. 15-25.
- Knapp, M. (2013). *Prevention: wrestling with new economic realities*. *Tizard learning disability review*, 18(4), 186-191.
- Landeiro, F., Leal, J. & Gray, A.M. (2016). The impact of social isolation on delayed hospital discharges of older hip fracture patients and associated costs. *Osteoporosis International*, 27, 737.
- Marsh, K., Phillips, C., Fordham, R., Bertranou, E. & Hale, J. (2012). Estimating cost-effectiveness in public health: a summary of modelling and valuation methods, *Health Economics Review*, 2(1), 1-6.
- Mitchell, P., Husbands, S., Byford, S., Kinghorn, P., Bailey, C., Peters, T. & Coast, J. (2021). Challenges in developing capability measures for children and young people for use in the economic evaluation of health and care interventions *Health Economics*, 30, 1990-2003.
- Rutter, M. & Quinn, D. (1984). Parental psychiatric disorder: Effects on children. *Psychol Medicine*, 14(4), 853-880.
- Sanders, T., Grove, A., Selway, S., Hampshire, S. & Goyder, E. (2017). Incorporation of health economic modelling tool into public health commissioning: Evidence in use in a politicised context. *Social Science and Medicine*, 186, 122-129.
- Stein, K. V., Evers, S., Rutten-van Molken, M., Paulus, A. & Tsiachristas, A. (2016). Kicking off the Special Interest Group Health Economics in Integrated Care – key questions and actions to move research forward. *International Journal of Integrated Care*, 16(6).
- Teresi, J.A, Ocepek-Welikson, K., Toner, J.A., Kleinman, M., Ramirez, M., Eimicke, J.P., Gurland, B.J. & Siu, A. (2017). Methodological issues in measuring subjective well-being and quality-of-life: Applications to assessment of affect in older, chronically and cognitively impaired, ethnically diverse groups using the Feeling Tone Questionnaire. *Applied Research in Quality of Life*, 12(2) 251-288.

Service users and carers

- All Wales People First (2020). The Effect of the Coronavirus Pandemic on People with Learning Disabilities Across Wales. Phase Two – Amber. Available at: [he Effect of the Coronavirus Pandemic on People with Learning Disabilities Across Wales](#).
- Alzheimer's Society Cymru (2018). Welsh Speakers' Dementia Care. Available at: [Welsh Speakers' Dementia Care](#).
- Burrows et al. (2021). Voices of Carers during the COVID-19 Pandemic: Messages for the future of unpaid caring in Wales. Cardiff University. Available at: [Voices of Carers during the COVID-19 Pandemic](#).
- Carers UK (2021). State of Caring 2021. A snapshot of unpaid care in the UK. Available at: [A snapshot of unpaid care in the UK](#).
- Carers Wales (2022). Wales Carer Summit, 2022 Report. Available at: [Wales Carer Summit, 2022 Report](#).

Carers Wales (2020a). COVID-19 Briefing: Impact on Unpaid Carers in Wales. Policy briefing. Available at: [COVID-19 Briefing: Impact on Unpaid Carers in Wales](#).

Carers Wales (2020b). Track the Act: Briefing 5. Monitoring the 4th year of implementation of the Social Services and Well-being (Wales) Act 2014. Available at: [Track the Act: Briefing 5](#).

Carers Wales (2019a). State of Caring 2019. Available at: [State of Caring 2019](#).

Carers Wales (2019b). Track the Act: Briefing 4. Monitoring the 3rd year of implementation of the Social Services and Well-being (Wales) Act 2014. Available at: [Track the Act: Briefing 4](#).

Carers Week (2022). Make caring visible, valued, and supported. Carers Week 2022 report. Available at: [Make caring visible, valued, and supported](#).

Children's Commissioner for Wales (2021). The Right Way. A children's rights approach for social care in Wales. Available at: [The Right Way. A children's rights approach for social care in Wales](#).

Children's Commissioner for Wales (2020). Coronavirus and Me: Understanding how disabled children and young people have experienced the pandemic in Wales. Available at: [Coronavirus and Me: Understanding how disabled children and young people have experienced the pandemic in Wales](#).

Children's Commissioner for Wales (2020). No Wrong Door: bringing services together to meet children's needs. Available at: [No Wrong Door](#).

Children's Commissioner for Wales (2018a). 'Don't hold back': Transitions to adulthood for young people with learning disabilities. Available at: [Don't hold back](#).

Children's Commissioner for Wales (2018b). Hidden Ambitions. Wales' commitment to young people leaving care. Available at: [Hidden Ambitions](#).

Children's Commissioner for Wales (2018c). Hidden Ambitions. One year on: A follow-up report on local authorities' progress and good practice in supporting care leavers. Available at: [Hidden Ambitions. One year on](#)

Cooke, K., Iredale, R., Williams, R. & Wooding, N. (2019a). Measuring the Mountain: What Really Matters in Social Care to Individuals in Wales. Final Report. University of South Wales. Available at: [Measuring the Mountain](#).

Foster, D. (2021). Locked out: liberating disabled people's lives and rights in Wales beyond COVID-19. Welsh Government. Available at: [Locked out](#).

Harries, S. & Bryer, N. (2021). Evaluation of More Than Just Words..., the follow-on strategic framework for Welsh language services in health, social services and social care, 2016-2019: Final Report. Cardiff: Welsh Government, GSR report number 55/2021. Available at: [Evaluation of More Than Just Words](#).

Iredale, R. & Cooke, K. (2020a). Understanding what matters in social care: experiences of care and support services and being an unpaid carer in Wales. Final Report. University of South Wales. Available at: [Understanding what matters in social care](#).

National Assembly for Wales. Health, Social Care and Sport Committee (2019). Caring for our future: An enquiry into the impact of the Social Services and Well-being (Wales) Act 2014 in relation to carers. Available at: [Caring for our future](#).

Older People's Commissioner for Wales (2021). State of the Nation: 2021. Available at: [State of the Nation: 2021](#).

Older People's Commissioner for Wales (2020a). Leave no-one behind. Action for an age-friendly recovery. Available at: [Leave no-one behind](#).

Older People's Commissioner for Wales (2020b). Care Home Voices. A snapshot of life in care homes in Wales during Covid-19. Available at: [Care Home Voices](#).

Older People's Commissioner for Wales (2019). State of the Nation. An overview of growing older in Wales. Available at: [State of the Nation](#).

Roberts, L., Rees, A., Mannay, D., Bayfield, H., Corliss, C., Diaz, C. & Vaughan, R. (2021). Corporate parenting in a pandemic: Considering the delivery and receipt of support to care leavers in Wales during Covid-19. Children and Youth Services Review, 128.

Templeton, F., Mitchell, D. & Luff, R. (2021). Review of evidence relating to unpaid carers' needs assessments in Wales. Social Care Institute for Excellence. Available at: [Review of evidence relating to unpaid carers' needs assessments in Wales](#).

Welsh Government (2021a). Strategy for unpaid carers. Available at: [Strategy for unpaid carers](#).

Welsh Government (2021b). Social Services activity: April 2020 to March 2021. Available at: [Social Services activity: April 2020 to March 2021](#).

Williams, S. N. (2022). Public attitudes to social care in Wales following the COVID-19 pandemic. [Public attitudes to social care in Wales following the COVID-19 pandemic](#).

11. Reference list B – Additional publications cited in the Technical Report

Well-being

- Anthony, R., Moore, G., Page, N., Hewitt, G., Murphy, S. & Melendez-Torres, G.J. (2022). Measurement invariance of the short Warwick-Edinburgh Mental Wellbeing Scale and latent mean differences (SWEMWBS) in young people by current care status. *Quality of Life Research*, 31, 205–213.
- Azizan, N. & Mahmud, Z. (2018). Determinants of Subjective Well-Being: A Systematic Review. *Environment-Behaviour Proceedings*, 3(7), 135-141.
- Bache, I. & Reardon, L. (2013). An idea whose time has come? Explaining the rise of well-being in British politics. *Political Studies*, 61(4), 898-914.
- Ben-Arieh, A. & Frønes, I. (2011). Taxonomy for child well-being indicators: A framework for the analysis of the well-being of children. *Childhood*, 18(4), 460-476.
- Bowling, A. (2010). Do older and younger people differ in their reported well-being? A national survey of adults in Britain. *Family Practice*, 28(2), 145-155.
- Bradshaw, J., Keung, A., Rees, G. & Goswami, H. (2011). Children's subjective well-being: International comparative perspectives. *Children and Youth Services Review*, 33(4), 548-556.
- Charles, S. T. & Carstensen, L. L. (2010). Social and emotional aging. *Annual Review of Psychology*, 61, 383-409.
- Cordis-Bright (2021). Brief 3: Supporting children from BAMER groups with mental health and wellbeing needs. Final Report. Barnardo's Available at: [Supporting children from BAMER groups](#) .
- Cunningham, N., Cunningham, T. & Robertson, J. (2019). Understanding and Measuring the Wellbeing of Carers of People With Dementia. *The Gerontologist*, 59(5), 552-564.
- D'Acci, L. (2011). Measuring well-being and progress. *Social Indicators Research*, 104(1), 47-65.
- Domínguez-Serrano, M., del Moral-Espín, L. & Gálvez Muñoz, L. (2019). A well-being of their own: Children's perspectives of well-being from the capabilities approach. *Childhood*, 26(1), 22-38.
- Dronavalli, M. & Thompson, S.C. (2015). A systematic review of measurement tools of health and well-being for evaluating community-based interventions. *Journal of Epidemiol Community Health*, 69(8), 805-815.
- Easterlin (1974). "Does Economic Growth Improve the Human Lot? Some Empirical Evidence" (PDF). In Paul A. David; Melvin W. Reder (eds.). *Nations and Households in Economic Growth: Essays in Honor of Moses Abramovitz*. New York: Academic Press, Inc.
- Eckersley, R. (2011). A new narrative of young people's health and well-being. *Journal of Youth Studies*, 14(5), 627-638.
- Fabian, M. (2018). A Theory of Subjective Wellbeing. PhD Thesis: The Australian National University.
- Fancourt, D. & Steptoe, A. (2018). Community group membership and multidimensional subjective well-being in older age. *Epidemiol Community Health*, 72(5), 376-382.
- Forgeard, M. J., Jayawickreme, E., Kern, M. L. & Seligman, M. E. (2011). Doing the right thing: Measuring well-being for public policy. *International Journal of Well-being*, 1(1).
- Frijters, P. & Beatton, T. (2012). The mystery of the U-shaped relationship between happiness and age. *Journal of Economic Behaviour & Organization*, 82(2-3), 525-542.

- Hardoon, D., Hey, N. & Brunetti, S. (2020). Wellbeing evidence at the heart of policy. What Works for Wellbeing. Available at: [What Works for Wellbeing](#).
- Hart, C. S. & Brando, N. (2018). A capability approach to children's well-being, agency and participatory rights in education. *European Journal of Education*, 53(3), 293-309.
- Jivraj, S. & Nazroo, J. (2014). Determinants of socioeconomic inequalities in subjective well-being in later life: A cross-country comparison in England and the USA. *Quality of Life Research*, 23(9), 2545-2558.
- Kassenboehmer, S. C. & Schmidt, C. M. (2011). Beyond GDP and back: what is the value-added by additional components of welfare measurement?. *Ruhr Economic Paper*, (239).
- Kenny, C. (2011). Bentham from the Crypt Once More: Politicians in Pursuit of Happiness (No. id: 4332).
- Ku, P. W., Fox, K. R. & Chen, L. J. (2016). Leisure-time physical activity, sedentary behaviours and subjective well-being in older adults: An eight-year longitudinal research. *Social Indicators Research*, 127(3), 1349-1361.
- Layard, R. (2010). Measuring Subjective Well-Being. *Science*, 327, 534-535.
- Litwin, H. & Stoeckel, K. J. (2013). Social networks and subjective wellbeing among older Europeans: does age make a difference?. *Ageing & Society*, 33(7), 1263-1281.
- Long, S. J., Evans, R. E., Fletcher, A., Hewitt, G., Murphy, S., Young, H. & Moore, G. F. (2017). Comparison of substance use, subjective well-being and interpersonal relationships among young people in foster care and private households: A cross sectional analysis of the School Health Research Network survey in Wales. *BMJ Open*, 7(2), 1–10.
- Martyr, A., Nelis, S. M., Quinn, C., Wu, Y. T., Lamont, R. A., Henderson, C., & Morris, R. G. (2018). Living well with dementia: a systematic review and correlational meta-analysis of factors associated with quality of life, well-being and life satisfaction in people with dementia. *Psychological Medicine*, 48(13), 2130-2139.
- McLellan, R. & Steward, S. (2015). Measuring children and young people's well-being in the school context. *Cambridge Journal of Education*, 45(3), 307-332.
- Mogul, E., Kallitsoglou, A, Essau, C. & Castro-Kemp, S. (2022). Caregiver-Reported Changes in the Socioemotional Wellbeing and Daily Habits of Children With Special Educational Needs During the First COVID-19 National Lockdown in the United Kingdom. *Frontiers in Education*. Available at: [Changes in the Socioemotional Wellbeing and Daily Habits](#) .
- Moreno, A. & Vicente-Virseda, J. A. (2016). Family Situation, Social Protection, and Well-being of Older Adults from an European Comparative Perspective. *Research on Ageing and Social Policy*, 4(2), 96-127.
- Muffels, R. & Headey, B. (2013). Capabilities and choices: Do they make Sen'se for understanding objective and subjective well-being? An empirical test of Sen's capability framework on German and British panel data. *Social Indicators Research*, 110(3), 1159-1185.
- National Assembly for Wales Commission (2017) Communities First – Lessons Learnt. Cardiff: Equality, Local Government and Communities Committee.
- O'Connor, R.C., Wetherall, K., Cleare, S., McClelland, H., Melson, A.J., Niedzwiedz, C.L., O'Carroll, R.E., O'Connor, D.B., Platt, S., Scowcroft, E., Watson., B, Zortea, T., Ferguson, E. & Robb, K.A. (2021). Mental health and well-being during the COVID-19 pandemic: longitudinal analyses of adults in the UK COVID-19 Mental Health & Wellbeing study. *British Journal of Psychiatry*, 218(6), 326-333.

- Peasgood, T., Carlton, J. & Brazier, J. (2019). A Qualitative Study of the Views of Health and Social Care Decision-Makers on the Role of Wellbeing in Resource Allocation Decisions in the UK. *Economies*, 7(1), 1-13.
- Peterson, C., Park, N. & Seligman, M. E. (2005). Orientations to happiness and life satisfaction: The full life versus the empty life. *Journal of Happiness Studies*, 6(1), 25-41.
- Petty, S., Griffiths, A., Coleston, D.M. & Dening, T. (2020). Improving emotional well-being for hospital-based patients with dementia. *Quality in Ageing and Older Adults*, 22(1), 56-67.
- Pillai, N. (2013). "All's well that ends well!" subjective well-being: an epistemic enquiry.
- Pinto, S., Fumincelli, L., Mazzo, A., Caldeira, S. & Martins, J.C. (2017). Comfort, well-being and quality of life: Discussion of the differences and similarities among the concepts. *Porto Biomed* 2(1):6-12.
- Robison, O.M.E.F., Inglis, G. & Egan, J. (2020). The health, well-being and future opportunities of young carers: a population approach. *Public Health*. 185,139-143.
- Ryder, R., Edwards, A. & Clements, K. (2017). Measuring the wellbeing of children in care. Views from the frontline and opportunities for change. National Children's Bureau. Available at: [Measuring the wellbeing of children in care](#).
- Sabolova, K., Birdsey, N., Stuart-Hamilton, I. & Cousins, A. (2020). A cross-cultural exploration of children's perceptions of wellbeing: Understanding protective and risk factors. *Children and Youth Services Review*, 110.
- Salvador-Carulla, L., Lucas-Carrasco, R., Ayuso-Mateos, J.L. & Miret, M. (2014). Use of the terms "Well-being" and "Quality of Life" in health sciences: A conceptual framework. *The European Journal of Psychiatry*. 28, 50-65.
- Selwyn, J. & Briheim-Crookall, L. (2017). Our Lives, Our Care: Looked after children's views on their well-being. Available at: [Our Lives, Our Care](#).
- Sen, A. (1987). *The Standard of Living*. (Hawthorne G). Cambridge: Cambridge University Press.
- Shukla, M. (2022). A network analysis of adolescent mental well-being during the coronavirus pandemic: Evidence for cross-cultural differences in central features. *Personality and Individual Differences*, 186, 1-7.
- Siedlecki, K. L., Salthouse, T. A., Oishi, S. & Jeswani, S. (2014). The relationship between social support and subjective well-being across age. *Social Indicators Research*, 117(2), 561-576.
- Simone, P. M. & Haas, A. L. (2013). Frailty, leisure activity and functional status in older adults: Relationship with subjective wellbeing. *Clinical Gerontologist*, 36(4), 275-293.
- Stephoe, A., Deaton, A. & Stone, A. A. (2015). Subjective wellbeing, health, and ageing. *The Lancet*, 385(9968), 640-648.
- Street, M. (2020). Theorising child well-being: Towards a framework for analysing Early Childhood Education policy in England. *Journal of Early Childhood Research*, 19(2), 211-224.
- Stutzer, A. & Frey, B. S. (2012). Recent developments in the economics of happiness: A selective overview. *Recent Developments in the Economics of Happiness: A Selective Overview*. IZA Discussion Paper, (7078).
- Taylor, D. (2011). Wellbeing and welfare: A psychosocial analysis of being well and doing well enough. *Journal of Social Policy*, 40(4), 777-794.
- Thevenon, O., Clarke, C., Dirwan, G. & Fluchtmann, J. (2021). *Measuring what matters for child well-being and policies*. OECD Publishing.

- Trecartin, S. M. & Cummings, S. M. (2018). Systematic review of the physical home environment and the relationship to psychological well-being among community-dwelling older adults. *Journal of Gerontological Social Work*, 61(5), 567-582.
- Ulloa, B. F. L., Møller, V. & Sousa-Poza, A. (2013). How does subjective well-being evolve with age? A literature review. *Journal of Population Ageing*, 6(3), 227-246.
- UNICEF (2009). Manual for the measurement of indicators for children in formal care. Available at: [Measurement of indicators for children in formal care](#).
- van der Deijl, W. (2017). Are measures of well-being philosophically adequate?. *Philosophy of the Social Sciences*, 47(3), 209-234.
- Vanhoutte, B. (2014). The multidimensional structure of subjective well-being in later life. *Journal of Population Ageing*, 7(1), 1-20.
- Vincent, S. & Jopling, M. (2018). The health and well-being of children and young people who are looked after: findings from a face-to-face survey in Glasgow. *Health and Social Care in the Community*, 26(2), 182–190.
- Welsh Centre for Public Policy (2021). Evidence briefing paper: Well-Being and Equalities. Available at: [Well-Being and Equalities](#).
- Welsh Centre for Public Policy (2021). Evidence briefing paper: Well-being and the impacts of Covid-19 and Brexit. Available at: [Well-being and the impacts of Covid-19 and Brexit](#).
- Welsh Centre for Public Policy (2021). Evidence briefing paper: Cultural Well-Being. Available at: [Cultural Well-Being](#).
- Welsh Government (2016). Social Services: The national outcomes framework for people who need care and support and carers who need support.
- Welsh Government (2014). Well-being statement for people who need care and support and carers who need support. Available at: [Well-being statement for people who need care and carers](#).
- What works wellbeing (2020). Rapid Evidence Assessment of Wellbeing Impact Evaluations using ONS4 Personal Wellbeing Measures. Solutions for Public Health. Available at: [Assessment of Wellbeing Impact Evaluations](#).
- World Health Organisation (2001). International classification of functioning, disability and health. Geneva. Available at: [International classification of functioning, disability and health](#).
- Wu, Y.T., Nelis, S., Quinn, C., Martyr, A., Jones, I., Victor, C., Knapp, M., Henderson, C., Hindle, J., Jones, R., Kopelman, M., Morris, R., Pickett, J., Rusted, J., Thom, J., Litherland, R., Matthews, F. & Clare, L. (2020). Factors associated with self- and informant ratings of quality of life, well-being and life satisfaction in people with mild-to-moderate dementia: results from the Improving the experience of Dementia and Enhancing Active Life programme. *Age and Ageing*, 49, 446-452.

Prevention and Early Intervention

- Abendstern, M., Hughes, J., Clarkson, P., Tucker, S. & Challis D. (2012). Exploring the Contribution of Self-Assessment to Preventative Services in Social Care. *British Journal of Social Work*, 44, p.729-746.
- Allen, K. & Miller, R. (2012). Prevention services, social care, and older people: much discussed but little researched? NIHR School for Social Care Research: London. Available at: [Prevention services, social care, and older people](#).
- Chambers, D., Cantrell, A. & Booth, A. (2021). Recognition of risk and prevention in safeguarding of children and young people: a mapping review and component analysis of service development interventions aimed at health and social care professionals. *BMC Health Services Research*, 21, 1241.

Community Catalysts (2017). Releasing Somerset's Capacity to Care. Community micro-providers in Somerset: The impact and outcomes of the Community Catalysts project. Available at: [Releasing Somerset's Capacity to Care](#).

Cohen, A. (2013). The Cohen Interviews: Clare Winnicott (nee BRITTON) – Interview no 24, Edited by Tim Cook and Harry Marsh. Available at: [The Cohen Interviews](#).

Co-operatives UK (2017). Owing our Care: Investigating the development of multi-stakeholder co-operative social care in the UK. Co-operative Care Forum, East of England Co-operative, Wales Co-operative Centre. Available at: [Owing our Care](#).

Department for Communities and Local Government (2009). Guidance for local authorities on how to mainstream community cohesion into other services. Available at: [Guidance for local authorities on how to mainstream community cohesion into other services](#).

West, D. & Verity, F. (2018). Practising Sociological Social Work. Macmillan Press.

Foot, J. & Hopkins, T. (2010). A glass half-full: how an asset approach can improve community health and well-being. Improvement and Development Agency. Available at: [A glass half-full](#).

Health Education England, Skills for Health, and Skill for Care (2017). Person-Centred Approaches: Empowering people in their lives and communities to enable an upgrade in prevention, wellbeing, health, care and support. A core skills education and training framework. Available at: [Person-Centred Approaches](#).

Institute of Public Care (2011). ADASS Eastern region. Investing in prevention for older people at the health and social care interface. Oxford Brookes University. Available at: [Investing in prevention for older people](#).

Kern, R. & Holman, A. (2017). Mobilising Communities. Insights on Community Action for Health and Wellbeing. Nesta. Available at: [Mobilising Communities](#).

Marczak, J., Fernandez, J.L., Manthorpe, J., Brimblecombe, N., Moriarty, J., Knapp, M. & Snell, T. (2021). How have the Care Act 2014 ambitions to support carers translated into local practice? Findings from a process evaluation study of local stakeholders' perceptions of Care Act implementation. *Health and Social Care in the Community*, 30(5), 1711-1720.

McClellan, S., Ismail, S., Powell, J., Jones, M., Kimberlee, R., Bird, E. & Shaw, P. (2019). Systematic review of community business related approaches to health and social care. Power to Change. Available at: [Systematic review of community business related approaches to health and social care](#).

Miller, R., Allen, K., Mangan, C. & Glasby, J. (2013). Singing from the same hymn sheet? Commissioning of preventative services from the third sector. *Journal of Integrated Care*, 21(5), 288-299.

Miller, R., Mangan, C. & Allen, K. (2013). Older people's prevention services: Comparing perspectives of local authorities and the third sector. London: NIHR School for Social Care Research.

Miller, R., Williams, I., Allen, K. & Glasby, J. (2014). Evidence, insight, or intuition? Investment decisions in the commissioning of prevention services for older people. *Journal of Care Services Management*, 7(4), 119-127.

Munoz, S., Steiner, A. & Farmer, J. (2014). Processes of community-led social enterprise development: learning from the rural context. *Community Development Journal*, 50(3), 479-493.

Obbia, P., Graham, C., Duffy, R. & Gobbens, R. (2019). Preventing frailty in older people: An exploration of primary care professionals' experiences. *International Journal of Older People and Nursing*, 15, 1-13.

- O'Rourke, G., Lloyd, L., Bezzina, A., Cameron, A. & Jessiman, T. (2021). Supporting Older Co-Resident Carers of Older People – The Impact of Care Act Implementation in Four Local Authorities in England. *Social Policy & Society*, 20(3), 371-384.
- Poppe, M., Mansour, H., Rapaport, P., Palomo, M., Burton, A., Morgan-Trimmer, S., Carter, C., Roche, M., Higgs, P., Walker, Z., Aguirre, E., Bass, N., Huntley, J., Wenborn, J. & Cooper, C. (2020). "Falling through the cracks"; Stakeholders' views around the concept and diagnosis of mild cognitive impairment and their understanding of dementia prevention. *International Journal of Geriatric Psychiatry*, 35, 1349-1357.
- Richards, L., Vascott, D., Blandon, C. & Manger, L. (2018). Factors that contribute to community business success. Power to Change Research Institute Report No. 13. Available at: [Factors that contribute to community business success.](#)
- National Collaborating Centre for the Determinants of Health (nd). Let's talk moving upstream. Available at: [Let's talk moving upstream.](#)
- Richards, L., Vascott, D., Blandon, C. & Manger, L. (2018). What works: Successful community hubs. Power to Change Research Institute Report No. 14. Available at: [What works: Successful community hubs.](#)
- Richards, L., Vascott, D., Blandon, C. & Manger, L. (2018). What works: Successful health and wellbeing community businesses. Power to Change Research Institute Report No. 14. Available at: [What works: Successful health and wellbeing community businesses.](#)
- Skills for Social Care (2019). Prevention in social care: where are we now? Available at: [Prevention in social care: where are we now.](#)
- Smith, N. & Barnes, M. (2013). New jobs old roles – working for prevention in a whole-system model of health and social care for older people. *Health and Social Care in the Community*, 21(1), 79-87.
- Social Care Institute for Excellence (2019). Scaling up community-based models of care in Northern Ireland. SCIE highlights no.6. Available at: [Scaling up community-based models of care](#)
- Social Care Institute for Excellence (2021). Prevention in social care, SCIE Briefing. Available at: [Prevention in social care, SCIE Briefing.](#)
- Think Local Act Personal (2016). Engaging and Empowering Communities: Our shared commitment and call to action. Available at: [Engaging and Empowering Communities.](#)
- Verity, F., Richards, J., Read, S & Wallace, S. (2022). Towards a contemporary social care 'prevention narrative' of principled complexity: An integrative literature review. *Health & Social Care in the Community*, 30(1), 51-66.
- Voluntary Organisations Disability Group (2019). Above and Beyond: How voluntary sector providers add value to communities. Available at: [Above and Beyond: How voluntary sector providers add value to communities.](#)
- Waid, J., Cho, M. & Marsalis, S. (2022). Mental health targets in child maltreatment prevention programs: A systematic review of randomized trials. *Children and Youth Services Review*, 136.
- Wales Cooperative Centre (2011). Social enterprise in the service of the public. An exploration of the benefits and barriers for social enterprises in designing and delivering public services in Wales. CM International and Rocket Science. Available at: [Social enterprise in the service of the public.](#)
- Wilding, J. & Barton, M. (2009). Evaluation of the Strengthening Families, Strengthening Communities Programme 2005/6 and 2006/7. Race Equality Foundation. Available at: https://researchplusnfk.files.wordpress.com/2014/06/sfsc-full-report-january-2009_0.pdf.

Co-production

- Aabe, N., Fox, F., Rai, D. & Redwood, S. (2019). Inside, outside, and in-between: The process and impact of co-producing knowledge about autism in a UK Somali community. *Health Expectations*, 22, 752-760.
- Armstrong, A., Cansdale, M., Collis, A.R., Collis, B.E., Rice, S. & Walmsley, J. (2019). What makes a good self-advocacy project? The added value of co-production in *Disability and Society*, 34(7-8), 1289-1311.
- Allen, K., Needham, C., Hall, K. & Tanner, D. (2018). Participatory research meets validated outcome measures: Tensions in the co-production of social care evaluation. *Social Policy Administration*, 53(2), 311-325.
- Andrews, N., Gabbay, J., le May, A., Miller, E., O'Neill, M. & Petch, A. (2015). Developing Evidence-Enriched Practice In Health And Social Care With Older People. Joseph Rowntree Foundation. Available at: [Developing Evidence-Enriched Practice In Health And Social Care](#).
- Andrews, N., Driffield, D. & Poole, V. (2009). All Together Now: A collaborative and relationship-centred approach to improving assessment and care management with older people in Swansea. *Quality in Ageing*, 10(3), 12-23.
- Askheim, O.P., Christensen, K., Fluge, S. & Guldvik, I. (2016). User participation in the Norwegian Welfare Context: an Analysis of Policy Discourses. *Journal of Social Policy*, 46(3), 583-601.
- Baines, R.L. (2018). Patient and public involvement in the design, administration and evaluation of patient feedback tools, an example in psychiatry: a systematic review and critical interpretative synthesis. *Journal of Health Services Research and Policy*, 24(2), 130-142.
- Beresford, P. (2013). *Beyond the Usual Suspects, Shaping Our Lives*. Available at: [Beyond the Usual Suspects, Shaping Our Lives](#).
- Bester, K., McGlade, A. & Darragh, E. (2021). Is co-production working well in recovery colleges? Emergent themes from a systematic narrative review. *The Journal of Mental Health Training, Education and Practice*, 17(1), 48-60.
- Bianchi, C., Bovaird, T. & Loeffler, E. (2017). Applying a Dynamic Performance Management Framework to Wicked Issues: How Coproduction Helps to Transform Young People's Services in Surrey County Council, UK. *International Journal of Public Administration*, 40(10).
- Bovaird, T. & Loeffler, E. (2014). Bringing the power of the citizen into local public services – An evidence review, Cardiff: Welsh Government. Available at: [Bringing the power of the citizen into local public services](#).
- Bovaird, T., Van Ryzin, G.G., Loeffler, E. & Parrado, S. (2014). Activating Citizens to Participate In Collective Co-Production of Public Services. *Journal of Social Policy*, 44(1), 1-23.
- Bovaird, T. & Loeffler, E. (2012). From Engagement to Co-production: The Contribution of Users and Communities to Outcomes and Public Value. *Voluntas*, 23, 11, pp. 1119-1138.
- Clarke C., Wilkinson, H., Keady, J. & Gibb, C. (2011). *Risk and Dementia Care*. London: Jessica Kingsley.
- Compton, L., Wilkinson, P. & Lawn, L. (2017). North West Surrey's locality hubs – delivering integrated care. *International Journal of Integrated Care*, 17(5), pp. 1-8.
- Connolly, J., Munro, A., MacGillivray, S., Mulherin, T., Toma, M., Gray, N. & Anderson, J. (2022). The Leadership of Co-Production in Health and Social Care Integration in Scotland: A Qualitative Study. *Journal of Social Policy*, 1-20.
- Cree, L., Brooks, H.L., Berzins, K., Fraser, C., Lovell, K. & Bee, P. (2015). Carers' experiences of involvement in care planning: a qualitative exploration of the facilitators and barriers to engagement with mental health services. *BMC Psychiatry*, 15, 208.

- Curran, T., Jones, M., Ferguson, S., Reed, M., Lawrence, A., Cull, N. & Stabb, M. (2021). Disabled young people's hopes and dreams in a rapidly changing society: a co-production peer research study. *Disability & Society*, 36(4), 561-578.
- Dent, N. (2019). Appreciating collaborative service improvement – a case study on using appreciative inquiry methodology in co-production in mental health. *Mental Health and Social Inclusion*, 23(3), 105-111.
- Dewa, L., Lawrence-Jones, A., Crandell, C., Jaques, J., Pickles, K., Lavelle, M., Pappa, S. & Aylin, P. (2019). Reflections, impact, and recommendations of a co-produced qualitative study with young people who have experience of mental health difficulties. *Health Expectations*, 24(1), 134-146.
- Dodd, E., Ismail, S. & Christopher, G. (2022). Nostalgic conversations: The co-production of an intervention package for people living with dementia and their spouse. *Dementia*, 21(2), 489-502.
- Eoyang, G. & Oakden, J. (2016). Adaptive Evaluation: A synergy between complexity theory and evaluation practice. *Emergence: Complexity and Organization*, 18(3-4).
- Escobar, O. (2011). Public Dialogue and Deliberation: A communication perspective for public engagement practitioners. *Beacons for Public Engagement*. Available at: [Public Dialogue and DeliberationPublic Dialogue and DeliberationPublic Dialogue and Deliberation](#).
- Fang, Q., Fisher, K. & Li, B. (2021). How can coproduction help to deliver culturally responsive disability support? A case study from Australia. *Health and Social Care in the Community*, 29, 396-404.
- Faulkner, A., Carr, S., Gould, D., Khisa, C., Hafford-Letchfield, T., Cohen, R., Megele, C. & Holley, J. (2020). "Dignity and respect": An example of service user leadership and co-production in mental health research. *Health Expectations*, 24, 10-19.
- Fledderus, J., Brandsen, T. & Honingh, M. (2014). Restoring Trust Through the Co-Production of Public Services: A theoretical elaboration. *Public Management Review*, 16(3), 424-443.
- Fusco, F., Marsillo, M. & Guglielmetti, C. (2020). Co-production in health policy and management: a comprehensive bibliometric review. *BMC Health Services Research*, 20, 504.
- Greenhalgh, T., Howick, J. & Maskrey, N. (2014). Evidence based medicine: a movement in crisis? *British Medical Journal*, 348.
- Gunasekara, I., Patterson, S. & Scott, J.G. (2017). 'What makes an excellent mental health doctor?' A response integrating the experiences and views of service users with critical reflections of psychiatrists. *Health and Social Care in the Community*, 25(6), 1752-1762.
- Hall, B.L. & Tandon, R. (2017). Decolonization of knowledge, epistemicide, participatory research and higher education. *Research for All*, 1(1), 6–19.
- Hall, B.L. & Tandon, R. (2017). Participatory research: Where have we been, where are we going? – A dialogue. *Research for All*, 1(2), 365-74.
- Hartworth, C., Simpson, D. & Attewell, H. (2020). Coproduction, participation, and empowerment: A participatory evaluation of a young care leavers project in prison. *Probation Journal*, 68(1), 107-115
- Harris, M. & Boyle, D. (2009). *The Challenge of Co-production*, London: New Economics Foundation.
- Heron, G. & Steckley, L. (2020). Digital storytelling using co-production with vulnerable young people. *Journal of Social Work*, 20(4), 411-430.
- Hill, L., Brandeau, G., Truelove, E. & Lineback, K. (2014). *Collective Genius: The Art and Practice of Leading Innovation*, Boston: Harvard Business School Publishing.

- Huss, E. (2018). Arts as a Methodology for Connecting between Micro and Macro Knowledge in Social Work: Examples of Impoverished Bedouin Women's Images in Israel. *British Journal of Social Work*, 48(1), 73-87.
- Masterson, D., Joseffson, K.A., Robert, G., Nylander, E. & Kjellstrom, S. (2021). Mapping definitions of co-production and co-design in health and social care: A systematic scoping review providing lessons for the future. *Health Expectations*, 25(3), 902-913.
- McGregor, J., Repper, J. & Brown, H. (2014). 'The college is so different from anything I have done'. A study of the characteristics of Nottingham recovery college. *Journal of Mental Health Training, Education and Practice*, 9(1), 3-15.
- Park, S. (2020). Beyond patient-centred care: a conceptual framework of co-production mechanisms with vulnerable groups in health and social service settings. *Public Management Review*, 22(3), 452-474.
- Patton, S., McGlade, A. & Elliott, J. (2021). Does training in co-production lead to any real change in practice? Reflections from practitioners in Northern Ireland: Managing Community Care. *Journal of Integrated Care*, 29(2), 141-152.
- Percy-Smith, B. & Dalrymple, J. (2018). Stories from journeys to the edge of care: Challenges for children and family services. *Children and Youth Services Review*, 94, 216-224.
- Pritchard, R., Bhavsar, S., Campbell-Morris, P., Modi, P., Nugent, M. & Hughes, J. (2021). Lessons from the field: The role of agility in a coproduction project encompassing the COVID-19 pandemic. *Health Expectations*, 25, 499-505.
- Jalonen, H., Puustinen, A. & Raisio, H. (2012). The hidden side of co-production: When self-organisation fails and emergence overtakes. Conference Paper: Transatlantic Dialogue on Transitions in Governance, Nijmegen, The Netherlands.
- Warsen, R., Nederhand, J., Hans Klijn, E., Grotenbreg, S. & Koppenjan, J. (2018). What makes public-private partnerships work? Survey research into the outcomes and the quality of cooperation in PPPs. *Public Management Review*, 20(8), 1165-1185.
- Sancino, A. & Jacklin-Jarvis, C. (2016). Co-production and Inter-organisational Collaboration in the Provision of Public Services: A Critical Discussion. In Fugini, M. (2016). *Co-Production in the Public Sector*, Springer.
- Sicilia, M., Guarini, E., Sancino, A., Andreani, M. & Ruffini, R. (2016). Public services management and co-production in multi-level governance. *International Review of Administrative Sciences*, 82(1), 8-27.
- Steiner, A., McMillan, C. & O'Connor, C. (2022). Investigating the contribution of community empowerment policies to successful coproduction - evidence from Scotland. *Public Management Review*.
- Van Der Graaf, P., Cheetham, M., Redgate, S., Humble, C. & Adamson, A. (2021). Co-production in local government: process, codification and capacity building of new knowledge in collective reflection spaces. Workshops findings from a UK mixed methods study. *Health Research Policy & Systems*, 19(1), 1-13.
- Voorberg, W.H., Bekkers, V. J. J. M. & Tummers, L.G. (2015). A Systematic Review of Co-Creation and Co-Production: Embarking on the social innovation journey. *Public Management Review*, 17(9), 1333-1357.
- Wilton, C. (2021). Coproduction and partnership with people and communities. *BMJ Leader*, 5, 79-82.

Multi-agency

- Alderwick, H., Hutchings, A., Briggs, A. & Mays, N. (2021). The impacts of collaboration between local health care and non-health care organizations and factors shaping how they work: a systematic review of reviews. *BMC Public Health*, 21, 753.
- Alter, C. & Hage, J. (1993). Organizations working together. Newbury Park, Ca. Sage Publications.
- Abendstern, M., Rowan, J., Loynes, N., Hughes, J., Sutcliffe, C., Axelsson, D.R. & Axelsson SB. (2006). Integration and collaboration in public health—a conceptual framework. *International Journal of Health Plan Management*, 21(1), 75-88.
- Baginsky, M. & Manthorpe, J. (2021). Multiagency working between children's social care and schools during COVID-19: case study experiences from English local authorities and international reflections. *Journal of Integrated Care*, 30(2), 134-145.
- Barber, K. & Wallace, C. (2012). 'Happily independent' – configuring the Gwent frailty support and wellbeing worker. *Journal of Integrated Care*, 20(5), 308-321.
- Beacon, A. (2015). Practice-integrated care teams – learning for a better future. *Journal of Integrated Care*, 23(2), 74-87.
- Benson, J. K. (1975). The interorganisational network as a political economy. *Administrative Science Quarterly*, 20(2), 229–249.
- Bhaumik, S., Watson, J., Barrett, M., Raju, B., Burton, T. & Forte, J. (2011). Transition for Teenagers with Intellectual Disability: Carers' Perspectives. *Journal of Practice in Intellectual Disabilities*, 8(1), 53-61.
- Boon, H., Verhoef, M., O'Hara, D. & Findlay, B. (2004). From parallel practice to integrative health care: a conceptual framework. *BMC Health Services Research*, 1,4 (1), 15.
- Carlsson-Wall, M., Krause, K. & Lind, J. (2011). The interdependencies of intra- and inter-organisational controls and work practices—The case of domestic care of the elderly. *Management Accounting Research*, 22, 313-329.
- Challis, D. (2016). Care coordination for adults and older people: The role and contribution of the non-statutory sector. *Journal of Integrated Care*, 24(5/6), 271-281.
- Cheminais, R. (2009). Effective multi-agency partnerships: putting every child matters into practice. Los Angeles, London: SAGE.
- Cheng, S.M. & Catallo, C. (2020), Conceptual framework: factors enabling collaborative healthcare and social services integration. *Journal of Integrated Care*, 28(3), 215-229.
- Christensen, J.H., Block, P., Moller, S.R., Sogaard, C.P., Klinker, C.D., Aagaard-Hansen, J. & Bentsen, P. (2018). Health in All local Policies: Lessons learned on intersectoral collaboration in a community-based health promotion network in Denmark. *International Journal of Health Plan Management*, 34(1), 216-231.
- Citrin, D. et al (2018). Developing and deploying a community healthcare worker-driven, digitally enabled integrated care system for municipalities in rural Nepal. *Healthcare*, 6(3), 197-204.
- Collaborate Foundation (2018). *The State of Collaboration: How ready are we to work together*. Available at: [The State of Collaboration](#).
- Compton, L., Wilkinson, P. & Lawn, L. (2017) North West Surrey's locality hubs – delivering integrated care. *International Journal of Integrated Care*, 17(5), pp. 1-8.
- Connolly, J., Barnes, J., Guerra, J. & Pyper, R. (2020). The facilitators of interagency working in the context of European public services reform. *Contemporary Social Science*, 15(5), 533-547.
- Crocker, H. & Kelly, L., Harlock, J., Fitzpatrick, R. & Peters, M. (2020). Measuring the benefits of the integration of health and social care: qualitative interviews with professional stakeholders and patient representatives. *BMC Health Services Research*, 20, 515.
- Czypionka, T., Kraus, M., Reiss, M., Baltaxe, E., Roca, J., Ruths, S., Stokes, J., Struckmann, V., Hacek, R.T., Zemlenyi, A., Hoedemakers, M. & Rutten-van Molken, M. (2020). The patient at the centre: evidence from 17 European integrated care programmes for persons with complex needs. *BMC Health Services*, 20,1102.

- De Guinea, A.O. (2011). The Level Paradox of E-Collaboration: Dangers and Solutions. *International Journal of e-collaboration* 7(4), 1-21.
- De Ridder, R., Bourgeois, J., Van den Bogaert, S. & Van der Brempt, I. (2017). Implementing integrated Care in Belgium: a nationwide mobilization. *International Journal of Integrated Care*, 17(5), 1-8.
- Deloitte Centre for Health Solutions (2019). The transition to integrated care: Population health management in England. Available at: [The transition to integrated care](#).
- Dickinson, H. & Neal, C. (2011). Single Point of Access to Third Sector Services: The Conwy Collaborative Approach. *Journal of Integrated Care*, 19:2.
- Drysdale, C. (2017). Integrated care in practice. *International Journal of Integrated Care*, 17(5), 1-8.
- Dubuc, Nicole et al. (2016). Development of a Computerized Integrated-Care-Pathway System to Support People-Centred and Integrated Care: Usefulness of the Participatory Design Method. *International Journal of Integrated Care*, 16(6), 1-8.
- Erens, B., Wistow, G., Mays, N., Manacorda, T., Douglas, N., Mournier-Jack, S. & Duran, M.A. (2019). Can health and social care integration make long-term progress? Findings from key informant surveys of the integration Pioneers in England. *Journal of Integrated Care*, 28(1),14-26.
- Hansson, J. et al. (2010). Coordination in networks for improved mental health service, in *International Journal of Integrated Care*, 10, 25.
- Henttonen, K., Lahikainen, K. & Jauhiainen, T. (2016). Governance Mechanisms in Multi-Party Non-Profit Collaboration. *Public Organisation Review*, 16, 1-16.
- Hebert, R. (2015). Evaluation of the Implementation of PRISMA, a Coordination-Type Integrated Service Delivery System for Frail Older People in Québec. *Journal of Integrated Care*, 16:6.
- Henderson, L., Bain, H, Allan, E. & Kennedy, C. (2020). Integrated health and social care in the community: A critical integrative review of the experiences and well-being needs of service users and their families. *Health and Social Care in the Community*, 29, 1145-1168.
- Holding, E., Blank, L., Crowder, M. & Goyder, E. (2020). Bridging the gap between the home and the hospital: a qualitative study of partnership working across housing, health and social care. *Journal of Interprofessional Care*, 34(4), 493-499.
- Hummell, E., Venning, A., Foster, M., Fisher, K. & Kuipers, P. (2020). A rapid review of barriers and enablers of organisational collaboration: Identifying challenges in disability reform. Australia in *Australian Journal of Social Issues*, 00, 1-17.
- Huxham, C. & Vangen, S. (2005). Managing to collaborate. The theory and practice of collaborative advantage. Abingdon, Routledge.
- Hopwood, A.G. (1974). Accounting and Human Behaviour. Haymarket Publishing: London.
- Karlsson, F., Frostenson, M., Prenekert, F., Kolkowska, E. & Helin, S. (2017). Inter-organisational information sharing in the public sector: A longitudinal case study on the reshaping of success factors. *Government Information Quarterly*, 34, 567-577.
- Keeling, D., Rigby, M. & Carroll, A. (2017). Assessing National Practice and Preparedness for Integrated Care Delivery Ireland. *International Journal of Integrated Care*, 17(5), 1-8.
- Kodner, D.L. & Spreeuwenberg, C. (2002). Integrated Care: meaning, logic, applications, and implications - a discussion paper. *International Journal of Integrated Care*, 2(4).
- Meng, L., Yong, O. & Cameron, A. (2019) What is the relevance of policy transfer and policy translation in integrated care development? *Journal of Integrated Care*, 27(1), 5-14.
- Lalani, M. & Marshall, M. (2020). Co-location, an enabler for service integration? Lessons from an evaluation of integrated community care teams in East London. *Health and Social Care in the Community*, 30, 388-396
- Lennox-Chhugani, N. & Crossely, K. (2017) Readiness Assessment Tool: Strengthening Implementation of Integrated Care. *International Journal of Integrated Care*, 17(5), 1-8.
- Leutz, W N. (1999). Five laws for integrating Medical and Social Services: Lessons from the United States and the United Kingdom. *The Millbank Quarterly*, 77(1), 77- 110.

- Leutz, W.N. (2005). Reflections on Integrating Medical and Social Care: Five Laws Revisited. *Journal of Integrated Care*, 13(5), 3-12.
- Levine, S. & White, P. E. (1962). Exchange as a conceptual framework for the study of interorganizational relationships. *Administrative Science Quarterly*, 5(4), 583–601.
- Lintz, G. (2016). A Conceptual Framework for Analysing Intermunicipal Cooperation on the Environment. *Regional Studies*, 50(6), 956-970.
- Lyon, F. (2013). Social Innovation, co-operation, and competition: inter-organisational relations for social enterprises in the delivery of public services. In Nicolls, A. & Murdock, A. (2012). *Social Innovation*, Palgrave Macmillan.
- Mayntz R. & Scharpf F. W. (1995) Der Ansatz des akteurzentrierten Institutionalismus, in Mayntz R. and Scharpf F. W. (Eds) *Steuerung und Selbstorganisation in staatsnahen Sektoren*, 39–72. Campus, Frankfurt/Main.
- MacAdam M. (2015). PRISMA: Program of Research to Integrate the Services for the Maintenance of Autonomy. A system-level integration model in Quebec. *Journal of Integrated Care*, 15, 08.
- Montoya, L.A., Montoya, I. & Sanchez Gonzalez, O.D. (2013). Lessons from collaborative governance and socio-biology theories for reinforced sustained cooperation: a government food security case study. *Public Health*, 129(7), 916-931.
- New Philanthropy Capital (2018). Tapping the Potential: Lessons from the Richmond Group's practical collaborative work in Somerset, NPC report for the Richmond Group of Charities. Available at: [Tapping the Potential](#).
- Nicolaisen, A. (2016). Implementing integrated care in a fragmented health care system. *International Journal of Integrated Care*, 16(6), 1-8.
- Nolte, I.M., Martin, E.C. & Boenigk, S. (2012) Cross-sectoral Coordination of Disaster Relief. *Public Management Review*, 707-730.
- Nuffield Trust (2011). What is Integrated Care. An overview of integrated care in the NHS. Available at: [What is Integrated Care](#).
- Roy, M., Lavoie-Trudeau, E., Roy, M.A., Clapperton, I., Courturier, Y., Lane, J., Bibeau, L., Ouellette, M., Benkhalti, M. & Camden, C. (2020). Barriers and Facilitators to Implementing Community Outreach Work, and Inter-professional Collaboration with Regional Partners. *Journal of Community Health*, 45(5), 979-986.
- Rozansky, D., Johnston, L., Dussin, L., King, E. & Hunter, T. (2017). Developing an integration scorecard: A model for understanding and measuring progress towards health and social care integration. Social Care Institute for Excellence. Available: [Developing an integration scorecard](#).
- Sarquella, E., Henderson, D., Faba, M., Mead, E., Solanes, P., Plaza, A. & Contel, J.C. (2016). Health and Social integrated care in practice. Local Partnerships in action. *International Journal of Integrated Care*, 16(5), 1-8.
- Scharpf F. W. (1997). *Games Real Actors Play. Actor-Centred Institutionalism in Policy Research*. Westview, Boulder, CO.
- Scott, V.C., Kenworthy, T., Godly-Reynolds., E, Bastien., G, Scaccia, J., McMickens, C., Rachel, S., Cooper, S., Wrenn, G. & Wandersman, A. (2017). The Readiness for Integrated Care Questionnaire (RICQ): An instrument to assess readiness to integrate behavioural health and primary care. *American Journal of Orthopsychiatry*, 87(5).
- Shorrocks, S., McManus., M. & Kirby, S. (2020). Practitioner perspectives of multi-agency safeguarding hubs (MASH). *The Journal of Adult Protection*, 22(1), 9-20.
- Solomon, M. (2019). Becoming comfortable with chaos: making collaborative multi-agency working work. *Emotional and Behavioural Difficulties*, 24(4), 391-404.
- Southby, K. & Gamsu, M. (2017). Factors affecting general practice collaboration with voluntary and community sector organisations. *Health & Social Care In The Community*, 26(3), 360-369.
- Talbot, L., Fuggle, P., Foyston, Z. & Lawson, K. (2020). Delivering an Integrated Adolescent Multi-Agency Specialist Service to Families with Adolescents at Risk of Care: Outcomes and Learning from the First Ten Years. *British Journal of Social Work*, 50, 1531-1550.

- Tong, C., Franke, T., Larcombe, K. & Sims-Gould, J. (2018). Fostering Inter-Agency Collaboration for the Delivery of Community-Based Services for Older Adults. *British Journal of Social Work*, 48, 390-411.
- Tsartsara, S. (2016). What are the regional governance structures at early stages of Integrated Care design and management in a LMIC Region under economic crisis? *International Journal of Integrated Care*, 16(6), 1-8.
- Tsais, P. (2009). The Social Processes of Interorganizational Collaboration and Conflict in Nonprofit Organizations. *Nonprofit Management & Leadership*, 20(1), 5-21.
- Tsutsui, T., Higashino, S. & Otaga, M. (2017). Development of quality indicator for adult day services towards promoting the community-based integrated care system in Japan. *International Journal of Integrated Care*, 17(5), 1-8,
- Turnhout, S., Feliksdal, D. & Minkman, M. (2016). Citizens as partners in integrated care. *International Journal of Integrated Care*, 16(6), A296, 1-8.
- Wain, L.M. (2020). Does integrated health and care in the community deliver its vision? A workforce perspective. *Journal of Integrated Care*, 29(2), 170-184.
- Warsen, R., Nederhand, J., Klijn, E.H., Grotenbreg, S. & Koppenjan, J. (2018). What makes public-private partnerships work? Survey research into the outcomes and the quality of cooperation in PPPs. *Public Management Review*, 20(8), 1165-1185.
- Van Raak, A., Mur-Veeman, I., Hardy, B., Steenbergen, M. & Paulus, A., (2003). Integrated Care in Europe. Description and comparison of integrated care in six EU countries. Maarssen, Elsevier Gezondheidszorg.
- Van der Meer-Kooistra, J. & Scapens, R., (2008). The governance of lateral relationships between and within organizations. *Management Accounting Research*, 19, 365–384.
- Warner, M. & Gould, N., (2009). Integrating Health in all policies at the local level: Using network governance to create virtual reorganization by design. In: Kickbusch, I., (ed.) Policy Innovation for Health. New York, Springer 125-163
- Weinberg, L., Zatlil, A. & Shea, N. (2009). Removing Barriers to Educating Children in Foster Care Through Interagency Collaboration: A Seven County Multiple-Case Study. *Child Welfare*, 88(4).
- Willcocks, S, and Conway, T. (2020). The shift to collaborative working and integration in the English NHS: developing shared leadership in primary care networks. *Journal of Integrated Care*, 30(1), 28-41.
- World Health Organisation (2016). Person centred care. Available at: [Person centred care](#).
- Worsley, J., Rotherham, C. & Corcoran, R. (2021). "Traditionally you would be passing them from pillar to post": an evaluation exploring the Life Rooms model of partnership working. *BMC Health Services Research*, 21(1), 1-17.
- Yang, T.-M, & Maxwell, T. A. (2011). Information-sharing in public organizations: A literature review of interpersonal, intra-organizational and inter-organizational success factors. *Government Information Quarterly*, 28(2), 164–175.

Voice and control

- Aktin, C. & Kroese, B.S. (2021). Exploring the experiences of independent advocates and parents with intellectual disabilities, following their involvement in child protection proceedings. *Disability & Society*. doi: 10.1080/09687599.2021.1881884.
- Biziewska, D. & Palattiyil, G. (2022). Promoting human rights or increasing expectations? Effects of Self-Directed Support on the realisation of human rights in Scotland, in *Disability & Society*. doi: 10.1080/09687599.2021.1994370.
- Boumans, J., Boekel, L., Verbiest, M., Baan, C. & Luijkx, K. (2022). Exploring how residential care facilities can enhance the autonomy of people with dementia and improve informal care in *Dementia*, 21(1), 136-152.
- Buzanko, C. (2017). Understanding parents' experiences of their child's assessment process. *Child Care in Practice*, 24(3), 304-316.

- Chapman, A. (2020). Person-centred care in Northern Ireland: learning from the experiences of adult social care users in *Journal of Integrated Care*, 29(3) 242-253
- Chester, H., Clarkson, P., Davies, L., Sutcliffe, C., Davies, S., Feast, A., Hughes, J., Challis, D. & Home Support in Dementia (HOST-D) Programme Management Group (2018). People with dementia and carer preferences for home support services in early-stage dementia. *Aging & Mental Health*, 22(2), 270-279.
- Clifford, A., Standen, P.J. & Jones, J. (2018). "I don't want to take any risks even if it's gonna mean this service-user is gonna be happier": a thematic analysis of community support staff perspectives on delivering Transforming Care. *Journal of Applied Research in Intellectual Disabilities*, 31(6), 1209-1218.
- Cranley, L., Slaughter, S., Caspar, S., Heisey, M., Huang, M., Killackey, T. & McGilton, K. (2019). Strategies to facilitate shared decision-making in long-term care in *International Journal of Older People Nursing*, 15.
- Davies, N., Livingston, W., Owen, O. & Huxley, P. (2016). Social care legislation as an act of integration. *Journal of Integrated Care*, 26(3), 139-149.
- Dhillon, S., Wilkins, S., Stewart, D. & Law, M. (2016). Understanding advocacy in action: a qualitative study. *British Journal of Occupational Therapy*, 79(6), 345-352.
- Dixon, J., Laing, J. & Valentine, C. (2020). A human rights approach to advocacy for people with dementia: A review of current provision in England and Wales in *Dementia*, 19(2), 221-236
- Forrester-Jones, R. (2021). Older carers of people with learning disabilities: their experiences with local authority assessment processes and personnel. *Learning Disability Review*, 26(2), 105-113.
- Greig, R. (2015). Commentary on: Can self-advocacy impact upon culture? *Tizard Learning Disability Review*, 20(2), 77-79.
- Hayes, D., Edbrooke-Childs, J., Town, R., Wolpert, M. & Midgley, N. (2019). Barriers and facilitators to shared decision making in child and youth mental health: clinician perspectives using the Theoretical Domains Framework. *European Child & Adolescent Psychiatry*, 28, 655-666.
- Health Research & Educational Trust (2016). Engaging patients and communities in the community health needs assessment process. Available at: [Engaging patients and communities in the community health needs assessment process](#).
- Health and Social Care Alliance Scotland and Self-Directed Support Scotland (2020). My support my choice: Black and minority ethnic people's experiences of self-directed support and social care: thematic report. Available at: [My support my choice: Black and minority ethnic people's experiences of self-directed support and social care](#).
- Health and Social Care Alliance Scotland and Self-Directed Support Scotland (2020). People's Experiences of Self-directed Support and Social Care in Scotland. Available at: [People's Experiences of Self-directed Support and Social Care in Scotland](#).
- Jordan, A., Joseph-Williams, N., Edwards, A., Holland-Hart, D. & Wood, F. (2019). 'I'd Like to Have More of a Say Because It's My Body': Adolescents' Perceptions Around Barriers and Facilitators to Shared Decision-Making. *Journal of Adolescent Health*, 65, 633-642.
- Larkin, M., Henwood, M. & Milne, A. (2019). Carer-related research and knowledge: findings from a scoping review. *Health and Social Care in the Community*, 27, 55-67.
- Liverpool, S., Pereira, B., Hayes, D., Wolpert, M. & Edbrooke-Childs, J. (2019). A scoping review and assessment of essential elements of shared decision-making of parent-involved interventions in child and adolescent mental health. *European Child & Adolescent Psychiatry*, 30, 1319-1338.

- Lonbay, S.P. (2018). "These are vulnerable people who don't have a voice": exploring constructions of vulnerability and ageing in the context of safeguarding older people. *British Journal of Social Work*, 48, 1033-1051.
- Lonbay, S.P. & Brandon, T. (2017). Renegotiating power in adult safeguarding: the role of advocacy. *The Journal of Adult Protection*, 19(2), 78-91.
- Moilanen, T., Suhonen, R. & Kangasniemi, M. (2020.) Nursing support for older people's autonomy in residential care: An integrative review in *International Journal of Older People Nursing*, 17, pp. 1-16.
- Montgomery, L., Davidson, G., Bernie, K., McKendry, L., Newton, L.A, Webb, P. & Wood, L. (2021). Getting our voice heard: empowering people with a learning disability to influence adult safeguarding policy: empowering people with a learning disability to influence adult safeguarding policy. *The Journal of Adult Protection*, 23(6), 384-396.
- Montgomery, L., Hanlon, D. & Armstrong, C. (2017). 10,000 Voices: service users' experiences of adult safeguarding. *The Journal of Adult Protection*, 19(5), 236-246.
- Newbigging, K., Ridley, J. & Sadd, J. (2021). Realising the right to equal recognition for disabled people: commissioning statutory advocacy in England in *Disability & Society*, 36 (3) 420-442.
- Nilsen, E.R., Hollister, B., Soderhamn, U. & Dale, B. (2021). What matters to older adults? Exploring person-centred care during and after transitions between hospital and home. *Journal of Clinical Nursing*, 31, 569-581.
- National Development Team for Inclusion (2020). Valuing voices in Wales: protecting rights through the pandemic and beyond. Available at: [Valuing voices in Wales](#).
- Nurmatov, U.B., Foster, C., Bezeczky, Z., Owen, J., El-Banna, A., Mann, M., Petrou, S., Kemp, A., Scourfield, J., Forrester, D. & Turley, R. (2021). Impact of shared decision-making family meetings on children's out-of-home care, family empowerment and satisfaction. What Works for Children Social Care. Available at: [What Works for Children Social Care](#).
- O'Connor, L. & Leonard, K. (2014). Decision-making in children and families social work: the practitioner's voice. *British Journal of Social Work*, 44(7), 1805-1822.
- O'Mahony, C., Burns, K., Parkes, A. & Shore, C. (2016). Representation and participation in child care proceedings: what about the voice of the parents? *Journal of Social Welfare and Family Law*, 38(3), 302-322.
- O'Rourke, G. (2021). Supporting Older Co-Resident Carers of Older People – The Impact of Care Act Implementation in Four Local Authorities in England in *Social Policy & Society*, 20(3), 371-384.
- O'Rourke, G. (2016). Older people, personalisation, and self: an alternative to the consumerist paradigm in social care. *Ageing & Society*, 36, 1008-1030.
- Patients Association (2020). Shared decision making: shared reality or insider jargon? Available at: [Shared decision making](#).
- Pavlo, A.J., O'Connell, M., Olsen, S., Snyder, M.K. & Davidson, L. (2019). Missing ingredients in shared decision-making? *Psychiatric Quarterly*, 90(2), 333-338.
- Pearl, R., Williams, H., Williams, L., Brown, K., Brown, B., Hollington, L., Gruffydd, M., Jones, R., Yorke, S. & Statham, G. (2018). Service user and carer feedback: simply pass/fail or a genuine learning tool? *Social Work Education*, 37(5), 553-564.
- Pocock, L., MacKichan, F., Deibel, F., Mills, A. & Wye, L. (2021). Stories from the fourth age: autonomy and the lives of older care home residents. *Ageing & Society*, 41, 1637-1650.
- Rouse, L., Tilley, E. Walmsley, J. and Picken, S. (2020). Filling the Gaps: The role of self-advocacy groups in supporting the health and wellbeing of people with learning disabilities throughout the pandemic. The Open University. Available at: [Filling the Gaps](#)

- Rutherford, A.C. & Bu, F. (2017). Issues with the measurement of informal care in social surveys: evidence from the English Longitudinal Study of Ageing. *Ageing & Society*, 38(12), 2541-2559.
- Ryan, C. & Quinlan, E. (2018). Whoever shouts the loudest: listening to parents of children with disabilities. *Journal of Applied Research in Intellectual Disabilities*, 31(52), 203-214.
- Sherwood-Johnson, F. (2016). Independent advocacy in adult support and protection work. *The Journal of Adult Protection*, 18(2), 109-118.
- Stafford, L., Harkin, J, Rolfe, A, Burton, J. & Morley, C. (2021). Why having a voice is important to children who are involved in family support services in *Child Abuse and Neglect*, 115.
- Symonds, J., Miles, C, Steel, M, Porter, S. & Williams, V. (2020). Making person-centred assessments in *Journal of Social Work*, 20(4), 431-447.
- Templeton, F., Mitchell, D. & Luff, R. (2021). Review of evidence relating to unpaid carers' needs assessments in Wales. Social Care Institute for Excellence.
- Tilley, E., Strnadova, I., Danker, J., Walmsley, J. & Loblinzk, J. (2019). The impact of self-advocacy organizations on the subjective well-being of people with intellectual disabilities: A systematic review of the literature. *Journal of Applied Research in Intellectual Disabilities*, 33, 1151-1165.
- Vadapalli, D.K. (2017). Citizen review panels in child protection: misunderstood, neglected, and underutilized. *Children and Youth Services Review*, 79, 539-346.
- Webber, M., Reidy, H., Ansari, D., Stevens, M. & Morris, D. (2015). Enhancing social networks: a qualitative study of health and social care practice in UK mental health services. *Health and Social Care in the Community*, 23(3), 180-189.
- What Works for Children's Social Care (2019). Shared decision-making meetings programme theory published by What Works for Children's Social Care. Available at: [Shared decision-making meetings programme theory](#).
- Wright, A.C. & Taylor, S. (2014). Advocacy by parents of young children with special needs: activities, processes, and perceived effectiveness. *Journal of Social Service Research*, 40(5), 591-605.

Economic and financial

- Burrows, A. & Gannon, K. (2013). An evaluation of health and well-being checks for unpaid carers. *Journal of Integrated Care*, 21(3), 148-156.
- Dhanji, N., Brouwer, W., Donaldson, C., Wittenberg, E. & Al-Janabi, H. (2021). Estimating an exchange-rate between care-related and health-related quality of life outcomes for economic evaluation: An application of the wellbeing valuation method. *Health Economics*, 30, 2847-2857
- El-Banna, A., Petrou, S., Yiu, H.H.E., Daher, S., Forrester, D., Scourfield, J., Wilkins, D., Evans, R., Turley, R. & Wallace, S. (2021). Systematic review of economic evaluations of children's social care interventions. *Children and Youth Services Review*, 121.
- Frew, E. & Breheny, K. (2019). Methods for public health economic evaluation: A Delphi survey of decision makers in English and Welsh local government. *Health Economics*, 28, 1052-1063.
- Godfrey, M. (2001). Prevention: developing a framework for conceptualizing and evaluating outcomes of preventive services for older people. *Health and Social Care in the Community*, 9(2), 89 –99.
- Knapp, M., Lemmi, V. & Romeo R. (2012). Dementia care costs and outcomes: a systematic review *International Journal of Geriatric Psychiatry*, 6, 551-561.

Le, L.K.D., Esturas, A.C., Mihalopoulos, C., Chiotelis, O., Bucholc, J., Chatterton, M.L. & Engel, L. (2021) Cost-effectiveness evidence of mental health prevention and promotion interventions: A systematic review of economic evaluations. *PLOS Medicine*, Open Access.

Pelone, F., Jacklin, P., Francis, J. & Purchase, B. (2021). Health economic evaluations of interventions for supporting adult carers in the UK: a systematic review from the NICE Guideline. *International Psychogeriatrics*, 1-14.

Picco, L., Achilla, E., Abidin, E., Chong, S., Vaingankar, J., McCrone, P., Chua, H., Heng, D., Magadi, H., Ng, L., Prince, M. & Subramaniam, M. (2016). Economic burden of multimorbidity among older adults: impact on healthcare and societal costs. *BMC Health Services Research* 16(1).

Rahja, M., Nguyen, K.H., Laver, K., Clemson, L., Crotty, M. & Comans, T. (2019). Implementing an evidence-based dementia care program in the Australian health context: A cost–benefit analysis. *Health and Social Care in the Community*, 28, 2013-2024.

Rutschmann, C. (2017). Care at home for elderly – lessons learnt from the Swiss Red Cross “Integrated Home Care” in Eastern Europe/CIS. *International Journal of Integrated Care*, 17 (5).

Skills for Care (2019). The value of adult social care in England: Why it has never been more important to understand the economic benefits of adult social care to individuals and society. Available at: [The value of adult social care in England](#).

Teresi, J.A., Ocepek-Welikson, K., Toner, J.A., Kleinman, M., Ramirez, M., Eimicke, J.P, Gurland, B.J. & Siu, A. (2017). Methodological issues in measuring subjective well-being and quality-of-life: Applications to assessment of affect in older, chronically and cognitively impaired, ethnically diverse groups using the Feeling Tone Questionnaire. *Applied Research in Quality of Life*, 12(2) 251-288

Visram, S., Walton, N., Akhter, N., Lewis, S. & Lister, G. (2020). Assessing the value for money of an integrated health and wellbeing service in the UK. *Social Science and Medicine*, 245.

Wansink, H.J et al., (2016). Cost-effectiveness of preventive case management for parents with a mental illness: a randomized controlled trial from three economic perspectives. *BMC Health Services Research*, 16, 228.

Wistow, G., Perkins, M., Knapp. M., Bauer, A. & Bonin, E.M. (2016). Circles of Support and personalization: Exploring the economic case. *Journal of Intellectual Disabilities*, 20(2), 194–207.

Service user and carers

Carers Wales (n.d). Track the Act. Available at: [Track the Act](#).

Cooke, K. & Iredale, R. (2019b). Measuring the Mountain: What Really Matters in Social Care to Individuals in Wales? Report of a Citizens’ Jury. Available at: [Measuring the Mountain](#).

Iredale, R. & Cooke, K. (2020b). Doing what really matters in social care in Wales: how can we make it happen together? Report of an Online Citizen’s Jury. Available at: [Doing what really matters in social care in Wales](#).

Welsh Government (2020). Social Services and Well-being (Wales) Act 2014. Code of practice in relation to the performance and improvement of social services in Wales. Available at: [Code of practice in relation to the performance and improvement of social services in Wales](#).